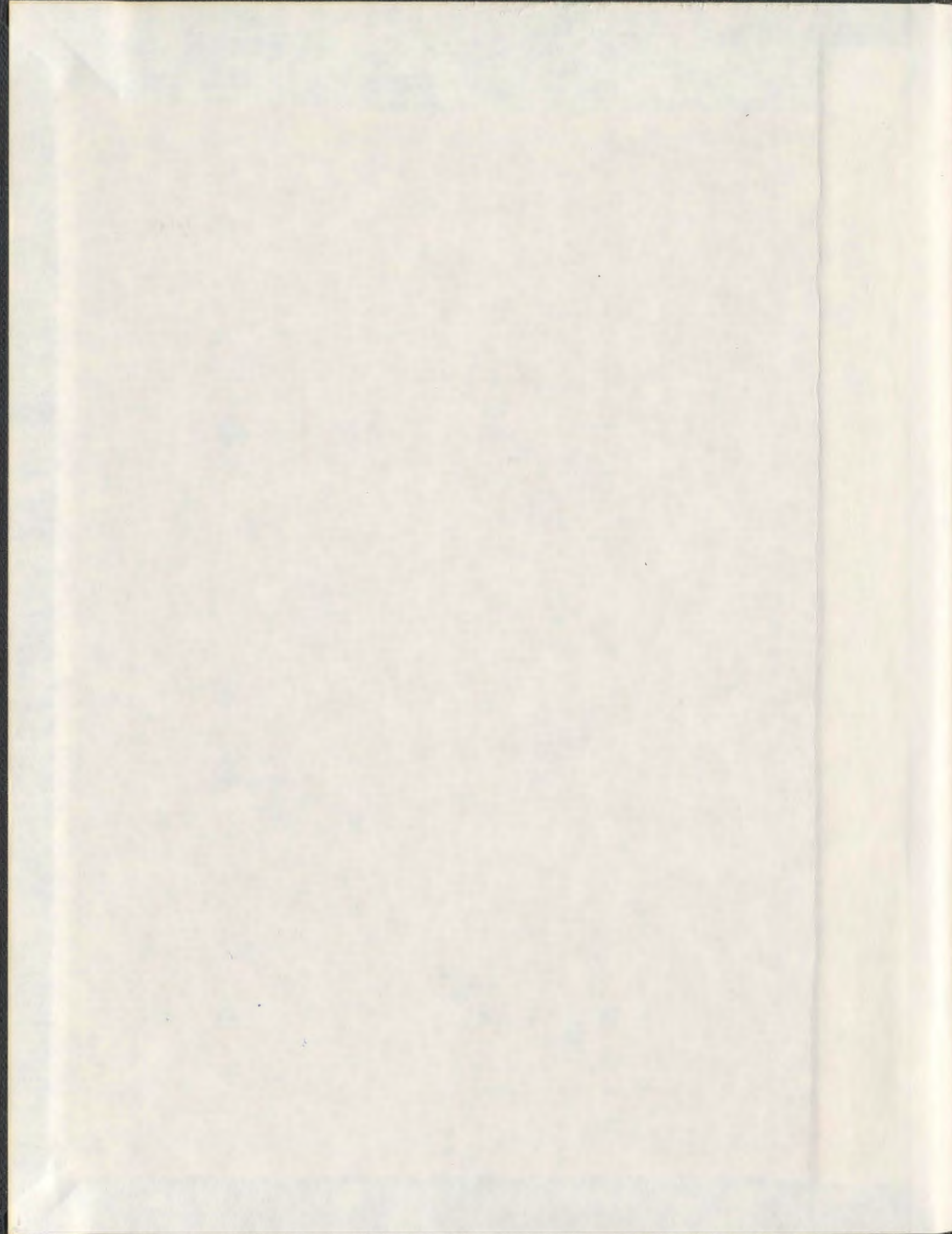


A SHOT IN THE DARK:  
LAY PERCEPTION OF INOCULATIONS AND  
ANTI-VACCINATION DISCOURSE

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A Shot in the Dark:  
Lay Perception of Inoculations and  
Anti-Vaccination Discourse

By  
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## **Abstract**

In spite of the success of the childhood inoculation movement, questions about vaccines have increasingly been an object of concern for Canadians. This thesis explores vernacular beliefs and practices that surround decisions **not** to vaccinate, with the primary aim of providing concrete recommendations for improving inoculation promotion programs. Ideally health education programs are community based, involve collaborative partnerships between communities, researchers, and service providers, and make use of local concerns. Understanding health choices is dependent on exploring the variety of cultural issues and influences that constitute risk for the communities and individuals in question. Risk categories and risk perception are multifaceted, culture bound, personal, and political. Through the use of ethnographic, media, and narrative analysis, this thesis explores the vernacular explanatory models used in inoculation decision-making. The purpose of this research is targeted at the creation of public health education programs and promotional materials which respond to patients' real fears, real understandings of risk, real concerns, and real doubts. Exploring the nature of inoculation distrust and miscommunication, this work isolates areas which require better public health communication and greater cultural sensitivity in the handling of inoculation programs. It also suggests guidelines for physician interaction with inoculation resistant patients.

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## Chapter One

### Introduction

In spite of the success of the childhood inoculation movement, questions about vaccines have increasingly been an object of concern for Canadians. In a recent telephone survey concerning vaccines, 61.7% of Canadians were reluctant to dismiss anti-vaccination arguments (Ritvo et al. 2003). Recent research and media coverage also shows that parents are increasingly choosing **not** to vaccinate their children. One study of nearly 1,500 doctors indicated that 93% of paediatricians and 60% of family physicians had seen at least one patient who refused a vaccination for his or her child (Freed et al. 2004). In a 2003 study of reasons for choosing **not** to vaccinate, Ritvo et al. argued that most parents lacked sufficient knowledge of how vaccinations work (Ritvo et al. 2003). Factors isolated by other researchers include: religious or philosophical objections, fear of government control in areas of personal choice, concern about safety and/or efficacy, beliefs that vaccine-preventable diseases do **not** pose a serious health risk, and belief that vaccines are not “natural” (Health Canada 1996).

Nevertheless, the evidence in favour of vaccination is very strong if one examines the recent inoculation history of countries such as Great Britain, Sweden, and Japan. A decline in the numbers of children vaccinated in these countries has had immediate effects. In Great Britain, over 10,000 cases of pertussis and thirty-six deaths were reported following a decrease in vaccination rates in 1974-1978 (Health Canada 1996). In Japan, which had a vaccination rate of 70% in 1974 before dropping to 20%-40% in 1979, there was an increase from 393 cases of pertussis to 13,000 cases in that period. In



Sweden, the incidence rate rose from 700 cases of pertussis per 100,000 children in 1981 to 3,200 cases per 100,000 children in 1985 due to a decrease in vaccinations (Health Canada 1996). These studies, taken as a group, present a powerful argument for the need to understand reasons for vaccination reluctance.

This research will explore vernacular beliefs and practices that surround decisions **not** to vaccinate, with the primary aim of providing concrete recommendations for improving inoculation promotion programs. This project is consistent with a number of studies which apply vernacular health belief research to health education and health promotion policy. These studies use as their central premise the notion that health education must be based on community understandings of risk, and that such understandings require ethnographic investigation (Goldstein 2004; O'Connor 1995; Hufford 1997; Brady 2001). Goldstein notes, "Culturally sensitive health education must adapt itself to existing beliefs, attitudes and practices within a community rather than expect that the community will change to fit the educational program" (2004: 56). Ideally, health education programs are community-based; involve collaborative partnerships between communities, researchers, and service providers; and make use of local concerns. Understanding health choices is dependent on exploring the variety of cultural concerns and influences that constitute risk for the communities and individuals in question. Risk categories and risk perception are multifaceted, culture bound, personal, and political. As Sobo notes, research on risk perception suggests that the meanings associated with a given risk affect how individuals "personalize, internalize, and apply to themselves the information they receive about that risk" (1995: 3). Through the use of

ethnography, media, Internet, and narrative analysis, I will explore the vernacular explanatory models used in inoculation decision-making. Many of the studies mentioned above touch on reasons why patients decide not to vaccinate. This research, however, does not take the analysis far enough. The majority of knowledge, belief, and behaviour studies on inoculation decision-making are based on survey style self-report. As has been shown consistently with health risks taken in relation to AIDS, smoking, breast examinations, and pap tests, risk perception is not easily accessed through survey methods but requires the greater ethnographic and qualitative study that a folklorist can provide. Powell and Leiss state, "Problems in communicating about risk originate primarily in the marked differences that exist between the two languages used to describe our experience with risks: the scientific and statistical language with experts on one hand and the intuitively grounded language of the public on the other" (1997: 26). In order to even begin to understand this language, ethnographic and research skills are necessary.

The literature used in this study comes from a variety of sources. Using a similar model to that of John Dorst's in *The Written Suburb*, I will consider the texts that the medical field provides for itself, mainly found in medical journals. In this research, the concept of "compliance" in medical texts is key. Although medical journals are necessarily demonstrative of the beliefs of the entire group, they are important to consider because they set the standards for what the group *should* believe. Medical journals provide a model for professionals in the field and, since most are limited in time, the journals often function as dogma until the next study comes along. In addition, medical



journals provide an example of the acceptable terminology and language of this group, which proves invaluable in the ethnographic process.

Media, such as newspapers, television news shows, and radio news shows, have also been used as sources of health information for the lay public. Oftentimes, especially in the case of vaccines, this information is frightening. Although the lay public does not accept everything they read and see as being true, the media frequently functions as an important source of information. For example, on January 24, 2006, Oprah Winfrey hosted a show on avian flu. Immediately after this show, CNN also had a special on avian flu. Subsequently, the Internet was flooded with questions and discussion about the flu. The next day, my Folklore 1000<sup>1</sup> students could talk of nothing else, and it seemed that people everywhere were talking about the avian flu, regardless of whether or not they agreed with what they saw on Oprah, CNN, or the Internet.

I will also consider Internet sources in my research. Recent research and polls have found that anywhere between 40%-80% of adults with Internet access use the Internet to find health information (Baker et al. 2003; Horrigan and Rainie 2002; Fox, Rainie, Horrigan, et al. 2000; Brodie, Flournoy, Altman, et al. 2000; Taylor et al. 2003; Taylor 2002; Taylor 2001). Medical professionals identified in my survey estimate that at least 60% of their patients make decisions based on health information found on the Internet. While it should not be assumed that the public believes everything that they read on the Internet, it is important to consider Internet sources and explore the quality and content of information found in those texts. The Internet, however, is not a single entity,

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<sup>1</sup> Folklore 1000 is the Introduction to Folklore class at Memorial University.

but rather consists of various communication methods within the same medium. The differences between websites versus forums and other types of Web 2.0 technology<sup>2</sup> are important since websites tend to remain static while forums form dialogues for further public communication. Static sites may create a “standardization of texts” as Smith suggests happened with broadsides and chapbooks in the seventeenth, eighteenth, and nineteenth centuries and to some extent to legends in the media (Smith 1992: 66). Although even these static websites can and do change over time, they do not evolve with the same rapidity as dialogical forms of communication where information can be changed, added to, or modified within a matter of seconds.

Finally, I conducted ethnographic research through the use of surveys and personal interviews, which have been outline in the appendix. In most cases, my informants were found by one of two methods: a survey which I distributed in Folklore 1000 classes and posted on the Internet, or by word of mouth. I found that word of mouth was the most effective method of finding informants and quickly discovered that one informant would provide the names of several others. I relied on my social networks in the area as my primary source, but I also contacted people previously unknown to me on the recommendation of acquaintances via email. In addition, I contacted key figures in the region: Dr. Rick Cooper, Chief of Paediatrics; Dr. David Allison, Medical Officer of Health, Eastern Health; Dr. Jim Connor, John Clinch Professor of Medical Humanities and History of Medicine; Dr. Molly Graham, Homeopath; Dr. Roy West, Honorary Research Professor, Division of Community Health; Dr. Keith Cassell, former president

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<sup>2</sup> Web 2.0 technologies refer to sites where communication is facilitated among users. It involves, but is not limited to, social networking sites, forums, video exchange sites, and blogs.



of the Newfoundland Chiropractic Association, as well as a variety of others. While many did not respond to my queries, the above-mentioned were integral participants in providing information and informants. Throughout my research, I gave several lectures, including talks for the Community Health Program and Paediatric Grand Rounds. Many of the attendees from these lectures introduced themselves and became informants as well.

Although attempts were made to make this research province-wide, survey response was poor from Labrador and Central Newfoundland, with only two and three respondents, respectively. Informants from regions in Western Newfoundland (15), the Northern Peninsula (5), and the South Coast (5) were more responsive; however, the majority of informants (37) came from the Avalon Region. Informants tended to live in St. John's, but approximately 46% were originally from areas in Newfoundland other than St. John's. Additionally, the majority (66%) of the health care professionals I interviewed were not originally from the region. Of parents and other informants who were not medical professionals, 30% were not originally from Newfoundland, which included twenty-five people who were born in countries outside of North America. All informants have lived or are currently living in Newfoundland and Labrador. Fifteen of those surveyed indicated that they currently live elsewhere, but were originally from the province and have strong ties to the area.

Vaccination choice is a sensitive topic. During the course of my research, I found an overwhelming reluctance in my informants to participate in recorded interviews, in spite of the desire to be part of the study. In these instances, I took field notes, and in

situations when I wished to directly quote my informants, I contacted them at a later date to recheck and seek approval to quote them as their statements appeared in my notes. All informants were asked to fill out a survey, even if they were not originally identified as informants through the survey. Interviews lasted anywhere from twenty minutes to hours, and approximately forty percent of informants were contacted more than once. The interviews took place in a variety of locations by the choice of the informant, since many felt uncomfortable discussing their opinions in public and because approximately half of the informants had young children. Informants were also reluctant to sign the consent forms, in spite of the precautions I took to conceal their identity. Those unwilling to sign their consent (approximately 63% of those interviewed) were happy to contribute but wanted no evidence of their contribution – primarily due to fear of social consequences. In these cases, I received verbal consent and/or encouraged the participant to sign using a pseudonym. Although over half of my informants consented to using their real names, I chose to leave their names out. Instead, I have described the informants after their quotes by stating if they self-identified as a lay person, medical professional, or wished for another label. Since this research is intricately tied to parental decision-making, I thought it would be useful to indicate if an informant had children. The date of all interviews is also listed.

My informants came from a variety of backgrounds and educational levels, and included many medical professionals, parents, and advanced degree holders. Approximately 85% of my informants had some university education, which was not intentional, but rather a testament to the socioeconomic range of this issue. However, I



would not go so far as to say that my informants were all middle or upper class. Many informants are, what I have termed, the “educated poor,” meaning that these participants were highly educated, but typically in the early years of their education and careers. The majority of my informants fell into this category and typically involved one or both parents pursuing advanced degrees while raising a family. While it is probable that these participants will eventually reach a higher socioeconomic status, they are currently living in economically challenging conditions – sometimes by choice.

Among those surveyed, 46% claimed to work in a health related field or considered themselves to be more knowledgeable than average concerning medical issues. Later interviews determined that eight of the sixty-seven interviewed placed themselves in this category because of personal experience or informal education, typically due to research in fields related to medicine or an established relationship, such as marriage, to a person in the medical field. It is interesting to note that all who claimed informal medical knowledge firmly placed themselves in the lay category unless they had a degree or worked in a medical field. Eighteen percent of those surveyed claimed to be alternative care practitioners or knowledgeable about alternative medicine. Later interviews indicated chiropractors were unsure whether they fit the criteria of “alternative care”, with approximately 25% placing themselves into the alternative care category, while the rest claimed medical professional status. Three chiropractors interviewed admitted that they placed themselves in both. Approximately 10% of medical and nursing students indicated that they were not entirely comfortable with being placed in the category of “medical professional”, although they indicated they had more knowledge

than the lay public. Those interviewed have been listed as students; however, I am not certain as to the status of those who only responded by survey.

To date, I have collected 637 survey responses, 343 of which were collected online. Sixty-seven interviews were conducted, not all of which appear in this work. I investigated over 500 websites, online forums, and message boards, and watched hundreds of hours of videos on both anti- and pro-vaccination topics. I quickly discovered that my topic was extensive and that my approach would have to exclude some information for purposes of length and clarity. All vaccination issues which did not focus on childhood inoculations were noted but are not discussed extensively in this thesis. However, topics, such as pet vaccinations and narratives from travellers who received vaccines, are rich areas of research which deserve further study.

The choice of Internet sites to use in this study was primarily based on sites which appeared first in a Google search. I chose this technique since it was the method used by approximately eighty percent of my lay informants. Morahan-Martin's study indicates that this is a common practice, reporting that the majority of internet health seekers do not go beyond the first two pages of results (2004: 499-500). Additionally, I considered websites suggested by informants, although the majority of these were present in my initial search perimeters.

In the past, much of the literature presents two standpoints on vaccination: pro-vaccination or anti-vaccination. While these terms remain accurate, I have found that there is an additional group which has often been neglected. I have termed this group "vaccine safety activists" as they do not adhere strictly to either viewpoint, but rather



prefer to base their vaccine choices on a case-by-case basis. Many of those who in the past have been considered anti-vaccinationists actually fall under the category of vaccine safety advocates since they support the development of safer vaccines over the choice of eliminated vaccination. Members of this group may support some vaccination, but not all vaccines. For example, many in this group vaccinate their children for all diseases except chicken pox because they believe that it is better to get the disease (and life-long immunity) rather than avoid what they consider a relatively harmless disease. Parents who prefer to space out their MMR (Measles, Mumps, and Rubella) vaccines in lieu of receiving a single combined vaccine may also fall under the categorization of “vaccine safety advocates.”

## **Objectives**

This research is organized around the following four objectives:

1. Working with a sampling of individuals who have chosen to inoculate, a similar group who have chosen **not** to inoculate, and a sampling of paediatricians, chiropractors, and public health nurses, this study will use in-depth risk-perception collecting methodologies devised through a strategic combination of face-to-face interviews and narrative analysis to explore the “explanatory models” (Kleinman 1980) of vaccination use found within the lay public and similarly within the professional community. Although lay models of health and illness tend to differ from biomedical models, this does not necessarily lead to the conclusion that physicians, medical researchers, or medical health educators hold

strictly to a single shared viewpoint. One of the central strategies of vernacular health research is what David Hufford has termed “methodological symmetry”, a methodology based on the theoretical premise that the same questions must be applied to medicine as are applied to the lay community (Hufford 1997).

Methodical symmetry frequently reveals complex perspectives encountered in both communities.

2. Due to the role currently played by the Internet in providing health information to the lay community, this study will explore the message of Internet anti-vaccination groups and the impact of those messages on the lay public. Recent North American studies have shown that 66% of adults use the Internet and that currently 80% of adults who are online use the Internet to find health information (Taylor 2002). According to Wolfe et al., of these 80%, 52% of people report that “almost all” or “most” of the information they find is credible (Wolfe et al. 2002: 3245). Anti-vaccination websites are most popular in areas such as the United States, Australia, New Zealand, the United Kingdom, and Canada (Nasir 2000: 732). One study, which reviewed 722 anti-vaccination websites, found that 100% of these sites claim that vaccines cause idiopathic illness, 95% claim that adverse vaccine reactions are underreported, and 91% reported that vaccine policy is motivated by profit (Wolfe et al. 2002: 3246-3247). Medical professionals are acutely aware of information found on the Internet (Chatterjee 2003, Nasir 2000, Schmidt and Ernst 2003, Wolfe et al. 2002) and of the existence of the anti-vaccination movement itself (Andre 2001; Andre 2003; Baker et al. 2003; Bigham

and Hoefer 2001; Chen et al. 2001; Cookson 2001; Ernst 2002; Gangarosa et al. 1998; Gellin et al. 2000; Poland and Jacobson 2001; Spier 2001). Nevertheless, many of the suggested solutions, such as further education of the public (Poland and Jacobson 2001; Spier 2001), are non-specific and offer no concrete recommendations (Ernst 2002; Chatterjee 2003; Nasir 2000). Clearly the use of health information on the Internet has created a new kind of medical consumer in North America, one who has access to an abundance of information and ideas (Goldstein 2008). Lay readers of Internet health materials are not, however, simply passive receptors of the information they contain (Goldstein 2000; Goldstein 2004). The means by which members of the lay community access Internet information and how they process that information is crucial to understanding vernacular health decision-making related to the reception of anti-vaccination messages.

3. It is central in a study of this type to explore the interchange between the news media and the beliefs of the general population. As Powell and Leiss note, "Society as well as nature abhors a vacuum...events reported in the media (some of them alarming) become the substantial basis of the public framing of ...risks" (1997:31-32). Rumours and medical legends related to ineffective vaccines, "cash cow" vaccines developed to fill the pockets of pharmaceutical companies, deadly side effects, and conspiracy theories appear regularly in the media (and on the Internet). The post-September 11<sup>th</sup> media representation related to the smallpox vaccine created a degree of concern and distrust around issues of vaccine safety,



efficaciousness, and production. More recent scares, such as the Avian Flu Virus and Severe Acute Respiratory Syndrome (SARS), have further contributed to these issues. The media treatment of such issues is often mentioned in expressions of concern related to medical distrust, and when legend and rumour propagated by the media take the place of medical information, perceptions of risk can escalate. The goal of this thesis involves not just an analysis of media handling of vaccination issues but also lay retention and interpretation of media discussions.

4. This research is targeted at the creation of public health education programs and promotional materials which respond to patients' real fears, real understandings of risk, real concerns, and real doubts. This thesis will also explore the nature of inoculation distrust and miscommunication, and will isolate areas which require better public health communication and greater cultural sensitivity in the handling of inoculation programs.

The Newfoundland research environment is an ideal context for this study, a subject which will be further discussed in Chapter Two. Inoculation statistics in Newfoundland and Labrador are currently high, and inoculation programs have had a great amount of success; nevertheless, conversations encountered throughout this project indicate a growing public concern about the efficacy and long-term impact of vaccination. These conversations, combined with evidence of a growing rumour-based movement, indicates the importance of exploring lay health beliefs surrounding this issue.



## **Chapter Construction**

This thesis begins with a brief introduction to the materials, including methodology, and an outline of the objectives of this research. Chapter Two is an historical look at Newfoundland, including the history of inoculation and how public reaction to inoculation has differed here as compared to other areas. Also included is a brief look at the history of provincial medical care, the past and current climate of health and inoculations, and issues related to how the current “crisis in health care” affects inoculation information programs.

The ways in which the lay public demonstrates and communicates their beliefs is the topic of Chapter Three. After a discussion of the presentation forms of folklore used, the ways in which the lay public obtains, interprets, and uses the health information is discussed. Vaccination narratives are presented and communicated in a variety of ways through the use of traditional narratives and beliefs, and a consideration of the forms used to communicate these narratives, such as word of mouth, the Internet, and broadcast media is crucial to this study. In this chapter, I consider the use and dissemination of information on the Internet (the manner in which the public accesses, uses, and processes health information) as well as the types of sources used, including the health information of major organizations, personal websites, email, list serves, and media representation.

Included in Chapter Four is a discussion of the content of vaccine narratives told by the lay public, including the history and logic behind conspiracy thinking. These stories, which come from a variety of sources, frequently involve tales of warning and terror concerning “hot lots” (lots of vaccine with more adverse affects than normal),

MMR (Measles, Mumps, and Rubella Vaccine) and Autism, SIDS (Sudden Infant Death Syndrome), and the personal experience narratives of parents. These types of narratives are grouped into themes, and the belief content of each type of narrative is considered with contamination as a key theme.

Vaccination narratives from the medical field are the main topic of Chapter Five, with consideration given to the ethical issues of vaccination. Multiple cases exist where parents are accused of abuse, but claim that the damage to their children was caused by vaccination. A local legend concerning "the doctor from Toronto" who calls child protection services on parents who refuse to vaccinate is discussed, as are the functions of these legends. The ethics of informed consent and the use of legend as a method of intimidation are also considered.

Chapter Six examines the vernacular traditions that affect notions of risk and reactions to inoculations. The role of the scientific community, the media, and the public in risk perception are discussed, as well as how all of these opposing systems can lead to medical distrust and decisions not to inoculate.

Finally, I offer ethnographically-based suggestions for improvements to health education campaigns which attempt to respond to the real concerns of the lay public in Chapter Seven.

## **Chapter Two**

### **History of Inoculation and Immunization**

In order to understand the reliance on and opposition to vaccines, one must consider the history of inoculation and immunization both within the province and more generally in medical history. Although these two words, inoculation and immunization, are often used interchangeably, the processes differ. Inoculation was historically used to describe the process of conveying immunity to smallpox through the introduction of a similar disease to the body, typically through scratching the skin or inserting material into the nose (also known as variolation). Immunization, which can be active or passive and/or natural or artificial, generally refers to the introduction of a vaccine in order to elicit a response (Benjamini et al. 2000: 431). However, since the process of inoculation is rarely used in North America today, these words (along with the term vaccination) have become interchangeable. For that reason, I will use inoculation, immunization, and vaccination to describe the process of vaccination, and I will use the phrase “the process of inoculation” to describe the method used by the literal definition of inoculation. These terms are not without fault, especially when considering the history of the anti-vaccination movement, which will be discussed later.

#### **Early Inoculation**

Intentional exposure to diseases as a way of creating immunity to other illnesses is thought to have begun in China in 590 A.D.; however, some believe it was probably practiced before then (Lattanzi and Rappuoli 2004: 4). This process, which is called



variolation, used the dried pustules from an infected person which were ground and placed in the nose of an uninfected person. This was the only known way of preventing smallpox (Link 2005: 11). Most early inoculations (including the first vaccine) were strictly for smallpox, which was a horrible disease:

....the first sign of smallpox was a nonspecific bodily reaction of fever and pain. Four days later, fluid-filled pox erupted through the skin and in the mouth and throat. The pox made it excruciatingly painful to swallow, and pox-covered flesh stank like rotting meat. In the worst cases, people died before the pox even erupted, their bodies turning purple from blood vessels rupturing beneath the skin—or they suffered for weeks before dying, the eruptions of pox so massive that they all ran together, layers of skin peeling from the body. The mortality of these epidemics varied from episode to episode, but sometimes reached 30 per-cent [sic] or more, a fearsome toll. In persons who survived, the eruption of pox would taper off, with scabs forming after fifteen to twenty days. The disease left some survivors blinded by pox-scarred corneas, caused many pregnant women to miscarry, rendered some men sterile, and disfigured them all. (Gronim 2006: 248-249)

Very little is written on vaccination between 590 and 17<sup>th</sup> century. However, it is believed that the tradition of “pox parties” was in common practice in the 1700s. A “pox party” is a method of spreading communicable diseases which are primarily non-threatening (most commonly chicken pox) under the guise of a “party” in which healthy children visit the home of an infected child in order to become infected themselves. This practice is not as cruel as it sounds, since the belief is that a disease such as chicken pox is easier on younger children than children who are older, and exposure frequently produces lifelong immunity. Chicken “pox parties” continue to be used today and even made an appearance on an episode of *The Simpsons* (Millhouse of Sand and Fog 1703 F72828 SI-1619 Original air date 25/9/05) and recent news reports have indicated that “flu parties” are becoming more common, much to the chagrin of health care



professionals (Ubelacker 2009). Although pox parties were not common in Newfoundland they did occur occasionally (Goldstein 2009), as it was commonly thought to be better to expose everyone in a household to chicken pox at the same time. This was rarely done in a party format, however, but rather through natural patterns of contagion (Andersen et al. 1998: 107).

Historically, another method which involved scratching the arm and rubbing of liquid from a smallpox pustule, became popular and reached Constantinople by 1679 (Behbehani 1983: 455-509). The first well-known documentation of an English account of variolation is from Lady Mary Wortley Montague in 1718 in which she describes the scratch method used in Turkey. Lady Montague attended an event similar to a pox party; however, at this party children were variolated, including Lady Montague's own children (Link 2005: 11-12). Some believe Lady Montague's story received more notice than other inoculation stories since her "uncommon beauty" had been destroyed by scarring caused by smallpox.

The first instance of two British individuals to be inoculated was in 1716. They were the sons of Mr. Heffernan, the secretary to the British ambassador in Turkey. Before this, Dr. Edward Tarry was said to have seen over 4,000 people inoculated in Turkey, and it was reported that the children of the French Consul in Syria had also undergone this procedure (Link 2005: 11-12). Reports concerning the process of inoculation had been made to the English Royal Society by Emanuele Timoni, who was the physician to the British ambassador in Constantinople, and Jacob Pylarini, who was a member of the Venetian Consul in Smyrna (Lattanzi and Rappuoli 2004: 4). Variolation was a common

practice by this time in many regions of Asia, Africa, and the Balkans; however, it was relatively unheard of in Western Europe until the 18<sup>th</sup> century (Risse 1999: 396).

At this time there was opposition to the smallpox variolation, including a dispute in the United States which began in 1721 between Cotton Mather, Zabdiel Boylston, and Dr. William Douglass over whether or not the people of Boston should be inoculated.<sup>3</sup> Up to four percent of those inoculated could develop a severe or fatal form of the disease; however, since smallpox had a 20-30 percent fatality rate, some (but not all) perceived this as an acceptable risk (Lattanzi and Rappuoli 2004: 4).

Variolation was first used in Canada in Quebec in 1765 by James Latham, a British military surgeon. Latham variolated over 300 people in the first year, including members of elite families in Quebec City and another 200 people in Montréal without fatality. He used this technique on over 1,250 people before leaving the area in 1770 (Tunis 1982: 264-278). However, since vaccination programs were not always consistent, endemic smallpox was still present in Canada until 1946:

Concerted vaccination campaigns were successful in eliminating endemic smallpox from Canada by 1946, 26 years later than from Norway, Sweden, Denmark and Holland. Nova Scotia had a suspected case in 1949, evidently brought by a visitor from the United States; with rigid quarantine the disease did not spread. The final, laboratory-confirmed case in Canada, in 1962, involved the 15-year-old son of a Canadian missionary who returned to Toronto by air from Brazil. (McIntyre and Houston 1999: 1546)

The process of variolation varies little from the method used by Edward Jenner in 1796 (Henderson 1997: 236) when he observed that milkmaids who contracted a similar

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<sup>3</sup> For additional information, see John D. Blake's "The Inoculation Controversy in Boston: 1721-1722" and Maxine van de Wetering's "A Reconsideration of the Inoculation Controversy".



disease, known as cowpox, seemed immune to smallpox. Jenner used a different technique than those before him. He lacerated patients and placed cowpox from an infected person on their skin as was common practice, but he also vaccinated through the use of injection. Jenner's first patient, James Phipps, did come down with a case of cowpox; however, after his forty-eight day recovery he was injected and found to be immune to smallpox (Andre 2003: 593; Lattanzi and Rappuoli 2004: 4). Jenner's accomplishment and the smallpox/cowpox connection continue to have a major influence on medicine. The term "vaccine" comes from the Latin word for cow ("vacca") a term which was introduced by Louis Pasteur in 1881 (Andre 2003: 593), who added a more scientific element to the process through the idea that infectious diseases are caused by micro-organisms (Lattanzi and Rappuoli 2004: 4). Pasteur later applied this idea to his invention of the rabies vaccine that he successfully used on Joseph Meister in 1885, who had been bitten by a rabid dog (Lattanzi and Rappuoli 2004: 4-5). Roux, a worker in Pasteur's lab, found that the bacteria that caused disease could be weakened (a process known as attenuation), thereby making the risk of catching the actual disease much lower (Benjamini 2000: 433).

The basic principle behind vaccination is remarkably similar to principles behind homeopathy. In the case of homeopathy, which uses the law of similars, a substance is used that invokes a similar reaction to the symptoms of the disease. In the case of vaccination, either a small part of the disease or a condition similar to the disease (such as cowpox for smallpox) is put into the body (through the process of variolation in the past and vaccination in the present). Once this outside enemy is introduced to the body, the



body's natural defences attack this disease and destroy it. However, after this is over, the body keeps a memory of the disease so that it can be more easily recognized in the future to quicken its destruction. This process is known as immunization because it is believed that the body is now better prepared to defend itself from the same disease.

Another key concept for understanding vaccination is "herd immunity", the type of immunity which occurs when the vaccinated population provides immunity to unvaccinated individuals. In medical literature, this is accomplished by vaccinating the majority of individuals, which reduces the overall amount of disease in the population, making person-to-person spread of the disease unlikely. This decreases the risk overall in the population, especially for those unable to receive vaccines or those who, for whatever reason, did not have an immunological response to the vaccine (John and Samuel 2000; Anderson 1992).

### **History of Medical Care and Vaccination in Newfoundland**

The medical history of a region is crucial to understanding the perception of medical authority and the cultural memory of an area. This research focuses primarily on the island portion of the province of Newfoundland and Labrador. A comprehensive understanding of the conditions faced by those in Newfoundland before 1832 does not really exist due to the shifting and isolated population and Newfoundland's status as a colony (Baker and Pitt 1984: 1). In the eighteenth century, a significant portion of the population only lived on the island during the fishing season; the off-season population in 1713 was believed to be fewer than 1,000. However, the year-round population did

increase. By 1785 it was just over 10,000, and by 1830 it was estimated to be around 60,000 year-round residents (Baker and Pitt 1984: 1-2). Due to its isolation and poverty, health care in Newfoundland has always been problematic. Not only is Newfoundland isolated from other regions by geographical location, but it is also isolated in terms of rural communities. In the past, most of the population was scattered along the coastlines, and there were few roads on the interior of the island. Although roads were built post-confederation<sup>4</sup> and some smaller communities were resettled to more populated areas (a topic of much debate still today), many communities still remained isolated from major medical centres, especially in the winter months. Even today in St. John's, it is quite common to be either from the St. John's area or from "out around the bay," a term which is sometimes further qualified by town names or bays, but is often meant as "anywhere outside of the St. John's area."

The little that is known concerning early health conditions in Newfoundland comes primarily from accounts of early settlers, missionaries, ship surgeons, naval officers, and governors (Baker and Pitt 1984: 2). Historically, St. John's primarily functioned as a port city with a changing population. Today the port is less active than in years past (predominantly due to the Cod Moratorium of 1992), and the population, although dynamic due to the university, still tends to be primarily people from Newfoundland. As with most port cities, St. John's has been no stranger to infectious disease. Numerous epidemics have broken out in the region, including cholera,

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<sup>4</sup> Newfoundland became the tenth province to enter Canadian Confederation in 1949.

diphtheria, influenza, and tuberculosis. The majority of these diseases were complicated by poor living conditions and the general poverty of the region.

One theory is that these epidemics were primarily due to poverty and poor living conditions. Handcock states that, "It has been generally concluded from the primitive diet, the lack of formal education or any kind of public health laws, services or agencies, that Newfoundland had a high infant mortality rate, a high maternal morbidity rate and a high overall death rate in proportion to the small but growing population" (1979: 7). It is also believed that the cold climate, lack of farmable land, and consequent poor diet are the reasons why colonists such as George Calvert abandoned Ferryland, Newfoundland in 1629 for more temperate climates (Sheppard and Miller Pitt 1994). Newfoundland's harsh conditions were also mentioned in *Qvod libets Lately Come Over from New Britaniola* in 1628 by Robert Hayman in the verse "Yet scuruy (sic) Death stalks here with theeuish (sic) pace, Knocks one down here, two in another place" (G.T. Cell 1969: 86 as quoted in Sheppard and Miller Pitt 1994).

Nutrition has frequently been a problem throughout Newfoundland's history. Although actual starvation was not extremely common, many other conditions related to malnutrition were widespread. Ailments such as "listlessness, apathy, weight loss or inadequate growth, poor digestion and constipation, and cosmetic disfigurements such as staring hair<sup>5</sup>, pallid or roughened skin, skin rashes and boils" (Sheppard and Miller Pitt 1994) were frequently seen, and symptoms such as anaemia, bone deficiencies, hair and tooth loss, blindness, dementia, and haemorrhaging were prevalent. Diseases and

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<sup>5</sup> This condition is used to describe hair that is lacklustre, coarse, or dry (Crellin 1994).



disorders such as scurvy, pellagra<sup>6</sup>, rickets<sup>7</sup>, beriberi<sup>8</sup>, and xerophthalmia<sup>9</sup> were not uncommon (Crellin 1994: 12-14; Sheppard and Miller Pitt 1994). Due to these diseases and symptoms, other diseases and disorders were also likely. For example, still births and infant mortality were higher than normal, and illnesses such as tuberculosis and pneumonia were more common due to the long term effects of malnutrition on the body (Crellin 1994 12-14; Sheppard and Miller Pitt 1994).

### **John Clinch and Edward Jenner**

Perhaps the most interesting aspect of the medical history of Newfoundland is the work of John Clinch. Clinch, one of twins, fathered by Thomas Clinch, was born on January 9, 1749 and entered in the parish register of the Anglican Church in Cirencester, England. Very little is known about John Clinch's early life, other than that he and Edward Jenner attended school together under Reverend Dr. Washbourn in Cirencester, Gloucestershire and John Hunter in London (McIntyre and Houston 1999: 1543-1548). Much more is known about Clinch after his arrival as a medical practitioner in Bonavista in 1775 at the request of George Kemp, a deacon and merchant who wished to provide medical care to the fishermen of Poole, Dorset while they were working in Newfoundland (Davies 1970). After leaving Twillingate, Clinch went on to Trinity in 1783, where he was so respected as a doctor and spiritual adviser that he was asked to be

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<sup>6</sup> A disease caused by a deficiency of niacin in the diet, characterized by skin changes, severe nerve dysfunction, mental symptoms, and diarrhoea.

<sup>7</sup> A disease of childhood, characterized by softening of the bones as a result of inadequate intake of vitamin D and insufficient exposure to sunlight, also associated with impaired calcium and phosphorus metabolism.

<sup>8</sup> Beriberi is a disease of the peripheral nerves caused by a vitamin B1 deficiency.

<sup>9</sup> Abnormal dryness of the eyeball as a result of a vitamin A deficiency.

named rector. In order to fulfill this duty, Clinch went back to England in 1787 to study divinity. He again returned to Newfoundland in 1789, where he was soon joined by Edward Jenner's nephew, George C. Jenner. Clinch had secured a religious position in Harbour Grace for George C. Jenner, which Edward Jenner discusses in a letter to Clinch, dated February 7, 1789:

George has at length left us to take leave of his friends elsewhere before he departs to your snowy shores. Your offer was in every respect so liberal that it would have been unjust in me to have said anything to have damped his ardour for catching at so good an opportunity of improving his fortune. As a medical character we shall one day or another see him shine. (Jenner 1789)

George Jenner stayed in Newfoundland until 1798 when he returned to England to help his uncle. Clinch married Hannah Hart of English Harbour in 1784. The couple had eight children, seven sons and one daughter. Clinch's friendship with Jenner is not only evident from the many letters between the two but also from the name of Clinch's first born son, Edward Jenner Clinch, born January 1, 1786. It is reported that Clinch made another trip to England in 1787 to become ordained by the Bishop of London (Davies 1970). He then returned to Trinity where he would serve both as medical doctor and minister for over 30 years until his death in 1819. Clinch also served in other capacities as did many educated men at the time. In August of 1800 he was appointed by the Governor as Judge of Surrogate Court of the Island and Receiver of the Greenwich Hospital Dues. In his lifetime he also served as a Poor Law Commissioner, Justice of the Peace, land surveyor, and collector of customs (Davies 1970). Clinch was one of the founders of the Masonic Lodge in Trinity and became their first Master. In addition to all of these duties, Clinch



also compiled a glossary of 112 Beothuck terms (Clinch 1888), one of three in existence (Davies 1970).

Clinch's relationship to Jenner played a significant role in the history of vaccination in Newfoundland and North America. Although the history evidence is patchy, Jenner and Clinch clearly shared medical information. Perhaps the most interesting item that Jenner sent to Clinch was a copy of his book describing methods of vaccination. A copy of this original text with the inscription "for the Rev. John Clinch From his affectionate friend the author" exists in the Boston Medical Library (Davies 1970). We know that Clinch requested information concerning Jenner's discovery on December 1, 1796 in a letter in which Clinch wrote: "I am obliged to you for what you say respecting your late discovery. Why not send me a sketch of your idea in print?" (Clinch 1/12/1796). Since this letter is dated only six months after Jenner's first vaccination on James Phipps, one can only assume this is the discovery that Clinch is inquiring about. Although there is no documentation as to when Clinch actually began his vaccination program in Trinity, it must have been between early 1797<sup>10</sup> and July 15, 1800. We can assume this later date because of a letter from Jenner to Clinch which states,

My pursuit, Thank God! Is constantly making those advances which increase my fame, and will certainly add to the stock of human happiness by eradicating one of the greatest of its miseries. Lest the threads sent you by George should not take effect<sup>11</sup>, I have enclosed a bit more, newly impregnated with the cow-pox virus; use it like a smallpox thread, but

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<sup>10</sup> This assumes Clinch sent his letter right away and Jenner responded quickly; however, it is hard to estimate how long it took a letter or package to cross the Atlantic. With the popularity of St. John's port, it is possible that the letter arrived sooner; however, with the winter months, one cannot be sure.

<sup>11</sup> The tissue would have been transported by drying it onto threads or glass.



small as it is, divide it into portions, that you may multiply your chances of infection. Wet it before insertion, or rather moisten it. (Jenner 1800)

Also in this letter, Jenner mentions, "My acquaintance with your Governor commenced from my having inoculated his infant daughter, I hope you have got my books on this subject." These two sections show that Jenner had already sent threads of the virus to be used for vaccination (a later letter states that the threads sent by George C. Jenner did work) and that he had already sent books to Clinch on the subject. Even though Jenner's book was published in 1798, it is possible that he had already discussed the matter with Clinch in other letters which may have been lost. Considering the closeness of their friendship and the frequency of their letters, it would be hard to believe that Jenner had not already discussed vaccination with Clinch and possibly sent strands to be used for vaccination before Jenner's book had been published. Even if Clinch had not attempted vaccination until after the publication of Jenner's book, one can guess that Clinch would have received one of the first copies of this book (possibly with smallpox strands) as early as 1798.

We know that by the end of 1801 Clinch vaccinated 700 people (Davies 1970). There is also documentation from Dr. John McCurdy, a surgeon in St. John's, who in a letter dated October 2, 1800 mentions his plans to set out with Clinch the following day to vaccinate the people of Portugal Cove.

More information on the historic event of the first vaccination in North America comes from a much later letter to Jenner which was published in the *Medical and Physical Journal* in May 1801 in which Clinch writes:

The threads you sent me produced the desired effect, which proved a happy circumstance for this harbour. After inoculating my own family, I availed myself of the opportunity, whilst the smallpox was making its ravages at St. John's, of visiting that place. Encouraged by your representation, and in order to establish the fact of the cowpox being an absolute preventative of the smallpox, I put my nephew Joseph Hart to the most rigid test by inoculating him with active-variolous matter and exposing him to a contagious atmosphere, but without its producing in either instance the smallest effect on the system. This single case excited the astonishment of every person without whose knowledge it came; and most of those who had not previously gone through the smallpox were eager to shield themselves against that dreadful malady by adopting the Vaccine Inoculation. (Clinch 1801 as quoted in Davies 1970)

Later, in the same letter, Clinch mentions:

Shortly, after my return to this place (Trinity), the smallpox was imported in a vessel from Quebec. One of her crew died of it. Fortunately for the inhabitants of Trinity, most of them had been inoculated with the cowpox and were thereby prepared to resist the influence of the smallpox. Several of my cowpox patients attended this man during his illness, but escaped the infection of his disease. (Clinch 1801 as quoted in Davies 1970)

Clinch also mentions in a letter dated January 25, 1802,

I will hasten to tell you the general result of my practice in the vaccine disease in the Island of Newfoundland. I informed you in a former letter that the matter sent me by your nephew produced the effect completely, although from the date it was kept full four months.

I began by inoculating my own children and went on with the salutary work till I have inoculated 700 persons of all ages and description; many opportunities soon offered at St. John's (where the smallpox was making great ravages) which afforded convincing proofs of the safety of the practice to the inhabitants and servant in Trinity Bay; they saw (at first, with astonishment) that those who had gone through the Jennerian inoculation, were inoculated with the smallpox, and exposed to the infection without the least inconvenience; and I hope it will every day become more and more extensive, as nothing can be more certain, than that it will annihilate the worst and most dreadful of all disorders, the smallpox. (Clinch 1802 as quoted in Davies 1970)



The story of Clinch's vaccination was also documented in an article in the *Evening Telegram* dated February 4, 1922 contributed by Canon Lockyer:

I have always known that vaccination for smallpox was introduced in Newfoundland by Reverend John Clinch, surgeon, and that it was used by him for the first time on a boy in Trinity, but I had forgotten the details. A few days ago, however, I found a letter from a grandson of Rev. John Clinch to me, some 25 years ago, in which he mentioned what he had heard his father say, as follows: "Dr. Jenner and Rev. John Clinch were personal friends, and when he (Dr. Jenner) had discovered a vaccine for smallpox he wrote to Dr. Clinch about it and at the same time he sent him some quills of the vaccine, soon after, a severe epidemic of smallpox broke out in Trinity, and I think in St. John's too. He wanted to vaccinate the people but they were afraid of it. His favourite nephew, a lad of 17, offered himself to be put to the severest test he could think of. Dr. Clinch vaccinated him and put him in bed with a man dying of confluent smallpox, and the lad took no hurt. Then the people flocked to be vaccinated and the epidemic was arrested. After that, the doctor had no trouble to introduce it generally, and the people were intensely grateful. I think this act was even more heroic of the man than of the boy, for if the boy had succumbed he certainly could never have forgiven himself. The boy he vaccinated was Joseph Hart of English Harbour, a nephew of Mrs. Clinch who was Hannah Hart of English Harbour. (Lockyer, Canon.<sup>12</sup> *Evening Telegram*, February 4, 1922)

Clinch also states that he owes a large debt to Dr. McCurdy, whose "zeal and exertion" helped the vaccine reach many areas of Newfoundland. Clinch continued his work in Newfoundland, but suffered a stroke in 1818 and later died on November 22, 1819 at the age of 71. He was buried under the altar at the first St. Paul's Church in Trinity (later his memorial was moved into the churchyard)<sup>13</sup> (Guttridge 2000).

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<sup>12</sup> Lockyer's letter also mentions that people were afraid of vaccination, but does not elaborate on why. I have not been able to locate any other sources which describe Newfoundlanders' reactions to vaccination during this time period.

<sup>13</sup> It is unfortunate to note that outside of the medical community, none of my informants knew about Clinch and his role in vaccination. Additionally, little has been written on Clinch, even though he might be the first vaccinator in North America.



## **Public Health, Infectious Disease, and Healthcare in Newfoundland, 1814 to Present**

The first civilian hospital in Newfoundland, which was named the Newfoundland Hospital or the Riverhead Hospital but was later called the St. John's Hospital, was not opened in St. John's until 1814 (Baker and Pitt 1984: 3). It has been described as:

.... a welfare institution designed for the poor, the homeless and the chronically ill; its purpose was not so much to benefit the sick as it was to protect the public at large. It housed the insane, blind, crippled, aged, alcoholic and syphilitic, and victims of accidents, as well as poor people suffering from prolonged bouts of rheumatism, dysentery, bronchitis, pleurisy, and heart and kidney ailments, from St. John's and other parts of the Island. (O'Brien 1994)

Before this, the majority of health care was done by naval surgeons, although there were a few civilian doctors in the St. John's area. In the outports, most of the medical care was handled by clergymen, such as John Clinch. Due to the isolation of regions of the island, the vast majority of health care remained community-based, relying primarily on household cures, midwives, and other healers, such as blood-stoppers and those who could cure warts. In St. John's, however, the majority of health matters came under the public domain after 1832 when the colony gained self-governing status (Crellin 1994; Baker and Pitt 1984: 1). This is not to say that community-based health care ceased to exist, even after the increase in hospitals in the area. Both health systems existed side-by-side and continue to do so today. O'Brien states:

Public health, or preventative medicine, traditionally was the responsibility of the state, while acute medicine normally was provided by the private sector. But in Newfoundland this was not the case, for the Newfoundland government had since the last century been involved in the provision of medical and hospital services. It owned and operated the General Hospital and allied health institutions in St. John's; it provided the voluntary hospitals of the I.G.A., the Moravians and the Salvation

Army with government subsidies for the treatment of indigents; it subsidized hospitals at Grand Bank and Twillingate in a similar manner; it operated the Labrador Medical Service; it provided those who did have money to pay for their own medical care with doctors' services (O'Brien 1994).

The majority of the public health initiatives developed at this time were in response to infectious diseases. Newfoundland had seen more than its share of epidemics, including epidemics of cholera, diphtheria, and tuberculosis (Sheppard and Miller Pitt 1994). A report on the health conditions in Newfoundland by William Carson, M.D., which was made in January 1830, listed the greatest concerns to be contagious disease, especially in the port city of St. John's. Carson also estimated the death rate in 1830 to be around one in every sixty-two people and he mentioned that vaccination was widely practiced in St. John's (Sheppard and Miller Pitt 1994).

In 1833, one of the many cholera epidemics warranted a Quarantine Act. This act, which discussed how quarantine should be conducted, included the establishment of a board of health and street cleaning (3 Wm. IV, c.1). This act was extended for another year due to an additional epidemic; however, in later years no quarantine could be called because the legislature was not in session at the time. Because of this, the act was later made permanent in 1843, and the governor could issue quarantines by act of proclamation (6 Vic., c 71). However, there were no further quarantines called in the 1830s and 1840s since all of the epidemics at the time were already present in Newfoundland, such as in 1837 and 1838 when typhus ravaged Newfoundland and 1843 when smallpox was common. In the smallpox case mentioned above, free vaccinations were given to the public (Sheppard and Miller Pitt 1994).



In 1832, there was a threat of Asiatic cholera. Acting governor Richard Tucker, under the direction of 13 outport doctors, had Dr. William Carson write a pamphlet on how to recognize and treat the disease. This pamphlet was given to “responsible persons”<sup>14</sup> along with a supply of drugs (“calomel, rhubarb, jalap, castor oil, carbonated soda, senna, mustard, laudanum, aromatic spirit of ammonia, hartshorn and armed clyster pipes” – none of which are actually useful in the treatment of cholera) (O’Brien 1994). After this incident, medical chests were given to people thought to be responsible (O’Brien 1994).

As a part of the effort to prevent epidemics, vaccinations were made mandatory. On April 23, 1849, the government passed a law which forbid the use of smallpox inoculation among patients and instead made a smallpox vaccine available to the public:

*Be it therefore enacted*, by the Governor, Council and Assembly, in Legislative Session convened, that from and after the passing of this Act, the Governor, for the time being, is authorized from time to time, as occasion may require, to procure, or cause to be procured, from some Vaccination Institution in London, such quantity of Vaccine Matter as may be sufficient to supply the Stipendiary Justices of the Peace, or others engaged in the relief of the Poor in the several Outport Districts of this Colony, for the Vaccination of all Persons resident with the same: and that such Vaccine Matter shall be distributed under such rules and regulations as the Governor and Council may make and issue for that purpose; and that the said Stipendiary Justices, and other engaged in relief of the Poor, shall conform to all such rules and regulations, and cause the same to be strictly observed within their respective Districts, and shall transmit, when and so often, and in the manner required, a report to the Governor of the number of Persons successfully Vaccinated in their respective Districts aforesaid. (Newfoundland Acts of the Legislative, 12<sup>th</sup> Victoria, 1849)

In addition, this Act also states that:

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<sup>14</sup> There is no description of the process to determine if someone was responsible or not.



....any Person who shall....produce or attempt to produce, in any Person, by Inoculation with Variolous Matter, or by willful exposure to Variolous Matter, or to any Matter, Article, or Thing impregnated with Variolous Matter, or willfully, by any means whatsoever, produce the disease of Small Pox in any Person in this Colony, shall be liable to be proceeded against and convicted summarily before two or more Justices of the Peace, and for every such offense shall, upon conviction, be imprisoned in the common Gaol for any term not exceeding One Month. (Newfoundland Acts of the Legislative, 12<sup>th</sup> Victoria, 1849)

This vaccine was mandatory whenever the governor issued a vaccination proclamation, and penalties were enforced for those who refused to vaccinate (Newfoundland Acts of the Legislative, 12<sup>th</sup> Victoria, 1849). At this time, the city of St. John's also began to build additional sewers, drains, and wells; however, funds were insufficient for a major project. The need for better sanitation was made evident in July of 1854 when the city was once again quarantined due to a cholera epidemic, later known as "The Year of Cholera". At this time new drains were built, residents were forbidden to throw garbage in the streets, and people were hired to collect night soil (Sheppard and Miller Pitt 1994). Several deaths were reported in August, but the worst of the epidemic was still to come. In the months of October, November and December, eighty-eight of the two hundred and twelve patients who were admitted to the hospital died. The death toll was estimated to be around 500; however, the epidemic stayed in the St. John's region and did not spread to other parts of the island.

While some public health measures were taken after this epidemic, it unfortunately took yet another epidemic, this time of diphtheria, for St. John's to find an alternate water source. The 1859-60 diphtheria epidemic spread from the Burin peninsula to the St. John's region, killing over 1,000 people (primarily children). In 1863 after

overcoming many financial obstacles, the city began to use Windsor Lake (originally known as Twenty Mile Pond) as an alternate source of water. This also meant that a new sanitation system had to be built; however, this system again needed to be more extensive and was replaced from 1889-92 (Sheppard and Miller Pitt 1994).

A new quarantine act in 1886 enabled the Board of Health to remove a person suffering from an infectious disease from their dwelling and take them to the hospital. At this time, many people did not want to go to the hospital because of the numbers of deaths which occurred there. This act, however, made both the reporting and the removal of a sick person mandatory if a medical practitioner certified the transition (Sheppard and Miller Pitt 1994). Later in 1886, St. John's was once again threatened by a cholera epidemic; however, they were able to avoid it at this time<sup>15</sup> (Sheppard and Miller Pitt 1994). In 1887, the medical practitioners of St. John's organized themselves into a medical society in order to regulate the fees paid and discuss the health problems of the province. Before this, patients provided an annual fee; however, after this society was developed, patients were to pay per visit for both the visit and the medicines used (Sheppard and Miller Pitt 1994).

On April 24, 1871 the governor was given the right to declare smallpox vaccination mandatory whenever they saw fit and appoint vaccinators. Dr. Thomas Howley was made the official smallpox vaccinator. This Act also stated:

In the case of the refusal of any person or perons [sic] so called on the Vaccinator may, and hereby is empowered, to summon such person or persons, or, in the case of Children, the Parents or persons aforesaid, before a Justice of the Peace, and in a summary way sue, and if necessary

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<sup>15</sup> There is no documented description of the method used to avoid this epidemic.



recover by distress, a fine not exceeding Two Dollars for such refusal unless the person so summoned can shew [sic] satisfactory cause, as regards the health of such person or child, why such should not be Vaccinated, or should be exempted under the provisions of the Act, the burden of proof being with the person so summoned; the said fine shall go to the Receiver General for the use of this Colony and the purpose of this Act. (Newfoundland Acts of the Legislative, 34<sup>th</sup> Victoria, 1871)

Also at this time, a military hospital on Forest Road in St. John's was converted into a civilian hospital, which would become known by 1880 as the General Hospital. With this change, the Riverhead Hospital was used for typhoid fever, and St. George's Hospital, formerly a military building on Signal Hill, was employed as a lazaretto for those who came into port with infectious disease. This hospital was converted into a barracks in the mid-1840s, but was switched back into a hospital during the smallpox outbreak of 1871 (Candow 1980: 1). This hospital's use varied throughout the years, and it was typically utilized for outbreaks, quarantines, and when the other hospitals were overcrowded (Candow 1980: 1-2). Two people, collectively known as the medical health officers, declared persons to be quarantined. These officers were paid a salary by the local government (Sheppard and Miller Pitt 1994).

Again, due to previous epidemics, in 1879 yet another public health act was passed, this time to provide St. John's with sanitary inspection. The Sanitation Department, which consisted of four workers and one supervisor, was required to make daily health checks and were authorized to enter areas thought to be of concern to public health and safety. They were also put in charge of various other sanitation issues, including the containment of animals (Sheppard and Miller Pitt 1994).



In 1880, the smallpox vaccination was again made mandatory by the Prevention of Small Pox Act which took a firm position on non-compliance, including fines not to exceed two dollars and imprisonment which was to last no longer than a week. In addition, those who refused vaccination could be fined at every refusal; however, if they could give just cause, it was possible for the judge to rule in their favour. However, the burden of proof fell to the non-vaccinator, similar to the previous act nine years earlier (Acts of the General Assembly of Newfoundland, 43<sup>rd</sup> Victoria, 1880). Even though I conducted a thorough search, I was unable to find any records which showed that anyone had been fined or imprisoned for this offence. However, records from this time are rare due to the damage caused by The Great Fire of 1892. I was also unable to find any evidence that anti-vaccination pamphlets arrived in the St. John's region.

In 1888, St. John's experienced yet another diphtheria epidemic, which lasted until 1892 in the outports. In 1888, 273 cases were found in St. John's, with sixty-seven deaths; however, the worst was to come the following year when over 1,881 cases were reported with 350 deaths. Later years did not have as many fatalities, with 1890 reporting 133 deaths and 1891 reporting 140 deaths in the St. John's area. Due to this outbreak, the Board of Health was involved in the passage of an act that forced those experiencing an illness to come forward. Many residents kept their illnesses a secret due to fear that they would be stigmatized, especially in the workplace (Sheppard and Miller Pitt 1994). In addition to this legislation, the 1889 Public Health Act could now send medical professionals into houses with infectious disease with a penalty to those who might interfere and a penalty to any doctor who did not report the disease. Also included in this

act was the appointment of one of the medical health officers to the case of infectious disease (52 Vic., c. 13). Dr. Philip T. Hubert was the first appointed to this position; however, his appointment lasted only slightly more than a year since he himself died of diphtheria (Sheppard and Miller Pitt 1994). Another officer was not appointed immediately, and the Public Board of Health disbanded in April of 1892 (Sheppard and Miller Pitt 1994).

In Newfoundland, as elsewhere in the nineteenth century, there was very little that could distinguish a professional doctor from a non-professional one. Surgical procedures were one of the few ways that professionals could distinguish themselves from other practitioners. However, late in the 1800s this began to change, with the development of germ theory, antiseptic surgery, and the identification of the microscopic organisms that were responsible for a number of infectious diseases: "Doctors came to understand that diseases were specific; they were beginning to understand how infection could be prevented and were capable of performing a wide range of new surgical procedures" (O'Brien 1994).

One of the most significant events of this time was the Great Fire of 1892, which nearly destroyed St. John's for the third time<sup>16</sup> (Cuff 1994). However, in spite of the fire, public health concerns were still being addressed. Daniel W. Prowse<sup>17</sup> was elected to the position of Public Health Officer on September 7, 1892. Although he was successful in the prevention of infectious disease epidemics, he would be most remembered for his

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<sup>16</sup>Two other disastrous fires also occurred in 1817 and 1846 in St. John's.

<sup>17</sup> Prowse was also a lawyer, judge, and historian. He is the author of the first complete history of Newfoundland.



insistence that a new hospital be built, as St. George's had been destroyed in the fire. Another barrack on Signal Hill had been used as a hospital, which was more commonly known as The Fever Hospital, The Diphtheria Hospital, or the Fever and Diphtheria Hospital since these were the most common ailments treated. It was later referred to as The Signal Hill Fever Hospital<sup>18</sup> (Candow 1980: 3). Prowse's Hospital was built, only to be destroyed by fire in 1911. There were no outbreaks of smallpox at this time, and the building became known as "Prowse's Folly" (Sheppard and Miller Pitt 1994). However, there has been some debate in this story. According to Candow, the hospital was built for the purposes of containing cholera threats from ships. If a ship arriving in Newfoundland was found to have cholera aboard, infected persons would land near Chain Rock in The Narrows and be taken up to the hospital. A road was built in this location after a previous incident in 1854 when cholera patients were allowed to walk through the city to reach Signal Hill (*Evening Telegram*, September 17, 1892: 4). Prowse's Hospital was never meant to be in constant use, a fact which has escaped some of the public's (and historians') attention (*Evening Telegram*, September 10, 1892:4). The hospital itself was used twice, in 1899 and 1903, for smallpox patients, which is perhaps the origin of the idea that it was originally built for smallpox (Candow 1980:5).

In 1893, the first diphtheria anti-toxin was used in Newfoundland (Sheppard and Miller Pitt 1994), and efforts were made to professionalize the medical and dental practices in Newfoundland through the "Act to Regulate the Practice of Medicine and Surgery in this Colony" (56 Vic. c. 12; 56 Vic., c. 13) which "established the

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<sup>18</sup> This hospital was also the location of Guglielmo Marconi's first transoceanic wireless message. He received it in the unoccupied fever end of the hospital (*Evening Telegram*, December 9, 1901. 4).



Newfoundland Medical Board, the profession's official regulatory and licensing body, consisting of seven members: three appointed by the Governor-in-Council, two by the Medical Society of St. John's, two by the Conception Bay Medical Society" (O'Brien 1994). However, a grandfather clause was brought in which stated that any Newfoundland resident who had practised for five or more years in a single area could be licensed, regardless of formal medical training. People who had practiced for less than five years could also be licensed if the Board found them to be "reasonable competent and fit," and someone with "a reasonable amount of competency" could practice in an areas where no other practitioners lived. Another section of this Act allowed for the practice of midwifery by women who had worked for five consecutive years and were "adept" (56 Vic. c. 12). O'Brien states:

Between January 1, 1894 and January 20, 1896, 61 medical men (no women) were registered under the Act. Of the 51 who had university degrees and/or diplomas, roughly half had medical degrees from American medical schools; the others had qualified in Scotland, Canada, Ireland and England. The remaining 10 were registered under Section 37, the grandfather clause. Fourteen of the 61 were registered as practising in St. John's, four in Harbour Grace, three in the Bay of Islands, two each in Bay Roberts, Trinity, Twillingate and Little Bay. The remaining 32 practised singly in communities around the coast. Thus, in 1895, based on a population estimate of 210,000, the doctor-to-population ratio was 1:3,442, a dismal ratio by the standards of the day. (O'Brien 1994)

In spite of this Act, many people continued to practice both folk medicine and the medicine they read about or witnessed medical professionals use (O'Brien 1994). One could even buy "medical kits" from James Dobie's Chemical Establishment and T. McMurdo and Company in St. John's (*Royal Gazette*, Dec. 15, 1914). Women were also known to provide health care, either for their families or for the community at large

(O'Brien 1994). In addition to these various forms of health care, "patent medicines" were also widely used. These "medicines" promised cures for almost every ailment (including infectious disease) and were produced by local pharmacies well into the early twentieth century. In fact, in 1930 it was estimated that Newfoundlanders spent over \$250,000 on patent medicines (O'Brien 1994; Crellin 1994: 15). Folk remedies were also used to offer immunity, even after vaccinations were readily available. "Passing through", where children were passed through the limbs of a dogberry tree to offer good health and immunity to diseases such as smallpox and measles, for example, was a common practice (Crellin 1994: 197), although not mentioned by any of my informants.

In 1896, the doctors of Newfoundland attended their first convention in Whitbourne, Newfoundland to discuss the medical issues of the area and set fees for services (Sheppard and Miller Pitt 1994). Previous to this, in 1869, there were fifteen doctors in the St. John's area, making the doctor-to-population ratio 1:1,923. In 1891, the ratio was down to 1:2,119, which means the ratio for Newfoundland as a whole was only 1:3,259 (O'Brien 1994). The following year, a new organization, the Department of Charities, was put in control of public health, quarantines, and the legislation of the Board of Health (Sheppard and Miller Pitt 1994). As a part of this new development, another wing was added to the hospital, and the property of the legally insane and their trials were brought under legislation (60 Vic., c. 15).

In 1905, the office of Medical Health Officer was finally made permanent when the salary for this office was split between the government and St. John's Municipal Council. The first person to be appointed in this capacity was Dr. Robert Almon Brehm



(Sheppard and Miller Pitt 1994). The following year, a fever hospital and laboratory were made to assist Dr. Brehm in his tasks (Sheppard and Miller Pitt 1994). In this time period (late 1800s to early 1900s), advances were also being made in the access to health care in outport communities, including Dr. Wilfred Grenfell's work in establishing cottage hospitals and access to health care in outport Newfoundland and Labrador (Sheppard and Miller Pitt 1994).

In 1910, the first hospital was opened outside of St. John's in Grand Falls, and the St. John Ambulance Association was begun. Governor Sir William MacGregor, a promoter of public health and a physician in his own right, had many concerns about the health care situation in both Newfoundland and Labrador. MacGregor criticized the government for not doing more in both areas after a visit to Labrador in 1905. In 1908, he chaired a committee concerning the prevalence of tuberculosis in the area where he suggested a variety of solutions ranging from better health care in outport regions including the education of mothers on childcare, better sanitation, a pure water supply, and the development of a Department of Health and Education. The immediate result of this meeting was the development of the Association for the Prevention of Consumption (APC). The organization grew rapidly and benefited from help from the Teachers' Association, who took it upon themselves to educate people in the outport regions about tuberculosis (Sheppard and Miller Pitt 1994).

Because of the increased interest in health due to the anti-tuberculosis movement, MacGregor was able to persuade the People's Party Administration to appoint a royal commission into the health conditions of Newfoundland and Labrador in 1909. The



report stated that the biggest concern in the area was tuberculosis and that education in schools was the best way to reach people. The report also mentioned the high infant mortality in the area, which was partially blamed on the lack of milk and mothers who did not know how to properly take care of their children, especially concerning their food and fresh water needs. The document suggested that a better method of obtaining vital statistical information was needed so that the number of tuberculosis patients and their location could be tracked. Also mentioned was the need for better sanitation, nutrition, ventilation, and water supplies. The statement also recommended the development of more sanatoriums but was unclear on how to solve the issue of funding (Sheppard and Miller Pitt 1994).

Within the next decade, many of these suggestions were incorporated. In 1910, improvements were made on the sewage and water situation, a nurse was hired for the purpose of tuberculosis education, and a temporary camp was set up for women with tuberculosis in the summer months at Mundy Pond. This camp proved to be a success, and the government decided that a new permanent structure was needed (Sheppard and Miller Pitt 1994). The Signal Hill Fever Hospital, although it did still receive the occasional small pox patient, was utilized as a tuberculosis hospital (Candow 1980: 3). This hospital, although it was not well sheltered, was thought to be acceptable because of the "absence of dust and smoke, and pure air" ("Report of the Commission Appointed by the Government to Deal with and Report upon the Subject of Public Health in the Colony of Newfoundland, 1910: 5). In 1912, the government had passed legislation to build sanatoriums; however, the outbreak of World War I quickly put an end to these plans.

After the war, the situation became even more severe with servicemen returning home with tuberculosis. In 1916, the Jensen camp, which was privately funded, was launched. Later that year, the government sponsored the Escasoni Hospital, which was located on a house and farm. Another farm was purchased the next year to be used as a sanatorium which grew in size over the years and eventually became the main tuberculosis hospital after the closing of the Escasoni Hospital in 1920 and the Jensen Camp in 1921 (Sheppard and Miller Pitt 1994). The Signal Hill Hospital reopened once again for cases of smallpox and quarantines (Candow 1980: 4).

Other types of infectious disease were also treated at this time. In 1916, a special facility was used for servicemen with measles. A small house was acquired on Topsail Road known as Donovan's Hospital, and another larger house was used as a Military Infectious Disease Hospital until 1920 (Sheppard and Miller Pitt 1994). Newfoundland was also devastated by an outbreak of the Spanish Influenza in 1918. The disease is believed to have arrived via a steamer with three infected people. Within two weeks, the disease had spread throughout St. John's and the outports. However, no population was hit as hard as Labrador. At the end of the epidemic, sixty-two people in St. John's had died and hundreds died in the outports (Sheppard and Miller Pitt 1994); but, 10% of the population of Labrador perished (compared to 0.1% of the population of Newfoundland). In one location in Labrador, Okak, 85% of the population was killed by the Spanish flu (Sheppard and Miller Pitt 1994).

The 1920s saw even more work in the improvement of health conditions of Newfoundland and Labrador. A children's hospital was opened (although it closed a few



months later due to financial difficulties and a ward of the general hospital was dedicated to children later that year), more nurses were placed in outport areas, an act was passed in 1920 allowing midwifery (11 Geo. V, c. 18), and legislation was passed concerning venereal diseases (12 Geo. V, c. 14). Many hospitals also opened at this time, including two new private hospitals in the St. John's area (St. Clare's and the Salvation Army Maternity Hospital) and smaller hospitals in Twillingate, Corner Brook, and Buchans.

In 1929, a major study was done by the Royal Commission of Inquiry which investigated public health concerns in the region. One of the results of the investigation was the development of the Board of Health as a separate entity from the Commission of Charities. The new Board of Health was responsible for the inspection of water, sanitation, and food; infectious disease control; the treatment of the sick (including the insane); and the health of schoolchildren (22 Geo. V, c. 12). However, even though a cottage health system was suggested at this time, the funding for the inception of this plan was not available until 1935. Also in this year, the first of the hospital ships, the M.V. Lady Anderson, was used to reach those areas only accessible by boat (Sheppard and Miller Pitt 1994).

Due to the establishment of American bases in the region during World War II, Newfoundland found itself in a better economic situation (Sheppard and Miller Pitt 1994). In 1941, the government took control of the Grand Bank Hospital, turning it into a cottage hospital and creating several other cottage hospitals in other areas. A new wing was added to the St. John's General Hospital, and renovations were made to the St. John's Hospital for Mental and Nervous Diseases (the former Asylum for Lunatics). In 1945, the



Division of Child Welfare was created, which became responsible for adoptions, foster homes, childcare and protection, and services to unwed mothers. Shortly before this a nutritional survey of the regional diet was conducted, and the population was shown to be nutritionally deficient in a variety of ways in spite of the increased economy due to American bases (Sheppard and Miller Pitt 1994).

After the war ended, the military hospitals built by the Americans were taken over and converted into hospitals for the public. Construction for a new tuberculosis hospital was established in 1947 in Corner Brook and finished in 1951. It was noted that this addition finally meant that there were enough beds for all the tuberculosis patients in the region (Rowe 1985: 416). Also in 1947, another ship was purchased to be used for tuberculosis patients. This ship, the Christmas Seal, was equipped with X-ray machines and staff who were able to educate the public. The first regional office of the Health Inspection Division of the Department of Public Health and Welfare was established in Corner Brook in 1949.

After much debate and a very close vote, the province of Newfoundland and Labrador became a part of Canada in 1949. Confederation with Canada provided some opportunities for the new province. Federal funds flowed into Newfoundland and Labrador via the Federal Government's Department of Health and Welfare with the goal of bringing the province closer to the Canadian standard of living. The Newfoundland Department of Health and Welfare was begun and put in charge of the medical needs of the population. Outport areas also benefited from Old Age Pensions and Canada Family Allowances, which brought much needed income to these regions, enabling the

population to purchase more diverse foodstuffs. The hospital system continued to grow at this time, with fourteen hospitals built from 1949-1980. Additional improvements included: the renovation and extension of other hospitals in the region, the establishment of air ambulances, the addition of four more hospital ships, and medical coverage under Medical Care Plan (MCP). In later years, medical and nursing schools were established in the province (Sheppard and Miller Pitt 1994).

However, not everyone was happy with some of the changes Confederation brought to the province. In particular, there was much debate concerning the resettlement program. This program, which aimed to move people into centralized hubs which would provide better job opportunities, was not always successful. Many of the people who moved voluntarily found that there was a lack of jobs in their new area or had trouble adjusting to the new lifestyle. Others, who refused to move at first, were told that services to their areas would be discontinued, which forced many people to move.

The current population of Newfoundland is 512, 509 (as of the April 2006 census, Statistics Canada) with 182,485 located in the St. John's Metropolitan Area (Newfoundland and Labrador Statistics Agency). Medical care in the province to the present day is government controlled. However, despite the great advances made in providing health care to residents of Newfoundland and Labrador, there are still many problems. In spite of both the medical and nursing schools, the province still lacks health care workers, especially doctors and nurses. One of the reasons cited by medical professionals for leaving the area is because they can receive higher wages for the same work. Medical technology in the area is good; however, some advanced medical

treatments and diagnostic testing are not available, and those requiring such medical services must leave the province. Wait times on diagnostic testing and non-emergent surgeries are long (typically 6 months for non-emergent CT scans and years for certain procedures), and many people must travel to the St. John's area for various testing and treatments.

With the increase in income and varieties of food, diseases and conditions associated with over-nourishment are now common in the province. Over-nourishment is a common problem in areas which have been historically undernourished (Sheppard and Miller Pitt 1994). Newfoundlanders and Labradorians have been noted to be the most overweight of all Canadians and have a high risk of diseases associated with obesity, such as heart disease, high blood pressure and diabetes (Sheppard and Miller Pitt 1994).

Even today, the evidence of past infectious diseases is present both in narratives and visibly in the population. For example, there are visible survivors of polio who suffer from post-polio syndrome, and stories about "The San" (The Sanatorium, one of the largest tuberculosis hospitals from 1910-1972) are still common in all regions of the province.

At the turn of the millennium, Newfoundland started to be referred to as a "genetic goldmine" (Staples 2000: 117) because the island portion of the province has an isolated gene pool. Approximately 95% of the population can trace their ancestry back to the first twenty thousand people who settled the area. This fact, coupled with the "Texas



vampire” incident<sup>19</sup> where the results of genetic testing for arrhythmogenic right ventricular cardiomyopathy (ARVC)<sup>20</sup> were not shared with the participants or their doctors, has made the ethics of genetic testing important to the island (Goldstein 2004: 15). Because of concerns about ethical research, I have found that many people in Newfoundland are reluctant to participate in medical research, both clinical and ethnographic.

### **Jenner and the Anti-Vaccination Movement**

The anti-vaccination movement is not a recent development, there has been an anti-vaccination movement as long as there have been vaccines. Jenner himself had many critics and received harsh reviews, including a cartoon thought to be drawn by James Gillray in 1802 which depicts Jenner vaccinating people who later develop cow-like characteristics (Howard 2003: 22). Jenner’s critics also extended into the medical world and included Dr. Walter Hadwen, M.D., who felt that smallpox outbreaks had more to do with unsanitary conditions than with vaccination. Dr. Hadwen, often celebrated as one of the first people to promote vegetarianism and an anti-vivisectionist, might also be considered one of the first animal rights protesters. According to his granddaughter, Eulalie Rodenhurst, he first became a vegetarian as a bet with a colleague who told him he could not survive for six months without eating meat. Hadwen did survive and was

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<sup>19</sup> This incident involved a group of researchers from Texas who came to Newfoundland to study ARVC, but did not share the results of their findings. The “vampire” reference is due to the collection of blood for genetic testing. For more information, please see Diane Goldstein’s *Once Upon a Virus*.

<sup>20</sup> A genetic condition which is characterized by an irregular heartbeat coupled with degenerative condition where heart muscle is slowly replaced by fibrous scar tissue and fat which typically happens in the right ventricle (Memorial University Health Sciences 2004).

later quoted in a letter stating, "For my part I am quite satisfied with my trial of vegetarianism, and it would take more than moral power to persuade me once again to make my stomach a graveyard for the purpose of burying dead bodies in!" (Rodenhurst 1984). Hadwen was just as passionate when discussing his views on vaccination. With lectures with titles such as "Dare Doctors Think?" and "The Fraud of Vaccination," Hadwen's speeches bordered on scathing, often degrading others and picturing them as fools. He was also fond of making the assumption that if doctors only thought about vaccination, they would understand why it was wrong. He was once quoted as saying, "I once believed in Jenner; I once believed in Pasteur. I believed in vaccination. I believed in vivisection. But I changed my views as the result of hard thinking. I belong to the new fashion and not to the old, antiquated fashion of my medical opponents" (Rodenhurst 1984). Hadwen also believed that the only reason vaccination was used was because it was profitable, an idea we can still see in today's anti-vaccination movement. It is no wonder that Jenner often complained about Hadwen and others, dubbing those opposed to vaccination as "anti-vacks" (Howard 2003: 22). Jenner had many other critics, such as Edgar Crookshank, Charles Creighton, and William Collins, all medical doctors. Interestingly enough, even though Jenner understood the power of the press, he never used it. Instead, the anti-vaccinationists harnessed this power, publishing frequently in the *Medical Observer* starting in February of 1806 (Howard 2003: 22). Jenner was also featured in anti-vaccination demonstrations and hung in effigy (Durbach 2005: 50-51).

Later critics of Jenner attack his character as well as his methodology. They argued that Jenner's methods were "based on superstition," that his degree from St.



Andrews University in Scotland was purchased, that his credentials as a medical doctor have been challenged, and even that his early observations on cuckoos were said to be based on conjecture. Some even detail the amounts of money Jenner received for his discovery as problematic since “Jenner’s social circle, however, did include very influential friends. In 1802, the Pitt government awarded him £10,000. Another £20,000 followed in 1807” (Pead 2003: 2104). Pead goes on to state that:

Jenner is rightly celebrated as the scientist whose cautious investigations, published works, and prolific correspondence brought vaccination to the notice of the world. However, his endeavours generated much controversy. He was the victim of satiric ridicule in the popular press, and many eminent members of the medical profession were politically opposed to Jenner. (Pead 2003:2104)

Perhaps the most troubling aspect of Jenner’s work is the claim that Benjamin Jesty, a Dorset farmer, performed vaccinations twenty-two years earlier (Pead 2003: 2104). Although Jesty himself never sought out to discredit Jenner, he was invited to speak by the Vaccine Pock Institute in London. Pead mentions the details of this meeting stating:

In 1805, Jesty accepted a formal invitation to attend the Original Vaccine Pock Institute in London. This visit was organised by Pearson, probably as a political slight against the Royal Jennerian Society. Jesty saw no reason to dress differently in London than he did in the country. Members of the Institute were much amused by his old fashioned appearance. Robert, the eldest son (by then 28 years old), also made the trip to London and agreed to be inoculated with smallpox again to prove that he still had immunity. Although Benjamin Jesty’s only experience of life was that of a farmer in a rural community, Jesty had based his experiment on a plausible hypothesis formed from his personal observations and experience—evident from the report of the officers of the Institute in 1805. (Pead 2003: 2107)



Pead feels that Jesty should be given some credit for being the first vaccinator. He defends Jesty's actions by comparing them to Jenner's, stating:

Why should it be inappropriate to equate the simplicity of Jesty's homespun logic with the rationale of Jenner's studied deduction? There is much common thinking in their approach, but Jesty did not have support from luminaries such as John Hunter, who was Jenner's mentor and friend. However, the practical applications of their respective ideas differed greatly. Jesty was convinced enough that he was prepared to attempt a true vaccination—ie [sic], from the cow—on those he held most dear. Jenner ignored the potential risks of person-to person transfer, but was careful to prove this technique on the children of other parents before immunising his own son, Robert. Jenner was mistaken in his belief that cowpox was derived from horses, and did not vaccinate directly with bovine cowpox until 1798. Both men were unable to explain how cowpox protected against smallpox. Jenner's publications and extensive correspondence encouraged widespread adoption of the vaccination technique. Jesty was unable to do the same because he did not have scientific training or professional credentials. Jenner saw the means to eliminate a pestilence. Jesty's only motivation was the wellbeing of his family, but his courageous initiative contrasts favourably with Jenner's protracted indecision. Jesty was not a member of the medical community, which should command our admiration, not our prejudice. We have dignified the doctor with greatness. Why dismiss the farmer as reckless? (Pead 2003: 2107-2108)

Jenner was and continues to be attacked both as a person, but also as a medical doctor and researcher. Although there are some who herald his initiative (an idea attributed to his mentor, John Hunter – “Do not think, try”) as heroic, others comment on the bravado and lack of concern for his patients. Many feel that Jenner rushed into trying his vaccine without the benefit of real medical knowledge or research. Unlike today, where such bravado in research is considered unethical, the only true test was to use human subjects as a means of determining efficacy. One has to remember at this time that many of the tools used in epidemiology were not yet available and germ theory had not entered the arena.

Regarding medical thought at the time, Colin R. Howard asserts that doctors were not ready for Jenner's vaccination:

Unsympathetic to the contagion theory, it was difficult for the authorities of the day to accept, let alone understand, the significance of his findings. The implication was that, not only was the disease of smallpox specifically the result of contact with an infectious agent, but that a contagion of cattle was sufficiently similar to confer protection in humans. In the absence of knowledge of germ theory, the initial reaction of the education and public alike was that transfer of animal matter may be necessary but was definitely undesirable. (Howard 2003: 22)

This coupled with a lack of quality control, a lack of standardization of the lymph used<sup>21</sup>, and Jenner's insistence that immunity was life-long, troubled the pro-vaccination movement from its inception (Howard 2003: 22); however, vaccination was often used in debates over professionalism in the Victorian Era (Durbach 2005: 24-25) and is still seen as one of the greatest advances made in medicine.

### **The History of the Anti-Vaccination Movement, 1798-early 1900s**

To date, no one has done a complete history of the anti-vaccination movement. While certain time periods and locations have been covered, there are many gaps in the timeline of the movement. As mentioned previously, Jenner encountered many who were against vaccination. Not only was Jenner attacked personally, but he was also attacked by organizations; such as the Anti-Vaccination Society, which was established in 1798, and the London Society of the Abolition of Compulsory Vaccination, which was established in 1800. The reasons for these attacks varied by society, but included the following ideas:

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<sup>21</sup> Lymph was often found to be inactive or contaminated with erysipelas, hepatitis B, and syphilis (Henderson 1997: 235-245).



vaccination was against God's will; the human body could be contaminated by using animal materials; mandatory vaccines are a violation of civil liberties; and the vaccine was ineffective. Although there have been changes in medical technology, many of the arguments at the forefront of the current anti-vaccination movement are remarkably similar to these early concerns.

Following Jenner's presentation to the Royal London Society in 1796, widespread vaccination was begun in the early 1800s. By this time, Jenner was already under attack from those who opposed vaccination and those in the medical profession who did not believe in Jenner's ideas or theories. However, some cite the beginning of the movement as 1854 when John Gibbs published his sixty-four page pamphlet "Our Medical Liberties," which made the beliefs of the movement both public and readily available (Spier 2001: S81). This pamphlet was written in response to the Compulsory Vaccine Acts of 1853 in Britain. This act, founded on an earlier act in 1840 which provided free vaccinations to the poor and outlawed variolation, made vaccination compulsory for all infants under the age of three months. It also imposed fines and imprisonment on those who did not comply (Wolfe et al. 2002: 430). The act was greeted by riots in Ipswich, Henley, Mitford, and other towns (Wolfe et al. 2002: 430). The situation worsened when the act was expanded in 1861: fines became cumulative and the age of mandatory vaccination was raised to 14 years (Wolfe et al. 2002: 430). The Act was changed again in 1867, adding jail time for those who did not vaccinate (Spier 2001). *The Anti-Vaccinator*, a weekly publication begun in 1869, heralded those in prison to be heroes. Spier claims that two new concerns came to the front at this time:



By this time the thrust of the anti-vaccine arguments had radically changed tack. Two new targets came into view. The first was that the autonomy of the individual was impugned in that they were forced into receiving material into their arms that was foreign and potentially the cause of a disease. And, secondly, the law was being brought into disrepute because people who had not committed a crime (a positive act that hurt or disadvantaged another person in the society) were found guilty for having not done something. (2001: S81)

All along, the idea of injecting something foreign into the body was forefront in opposition to vaccination (which is clearly demonstrated by Gillray's cartoon, mentioned earlier).. The concept that one could be arrested for the refusal to comply, however, may not be as new as Spier thought, especially since most areas already had quarantine acts in place and one could be arrested for the omission of information, such as reporting ones own illness or the illnesses of another person. Spier also later argues that vaccination challenged the right of the parents to make decisions for their children. This is an issue that is still debated today.

It should also be mentioned that vaccination at this time was a disfiguring process which was frequently painful and left scars (Colgrove 2004: 356). The disfigurement and pain caused by vaccination was likely a contributing factor to vaccination reluctance. Even today, the mild pain associated with vaccination disturbed approximately twenty-five percent of my informants, even though they knew the process was necessary.

### **Conscientious Objection and Anti-Vaccination Organizations**

Conscientious objection was, and continues to be, one of the most persuasive and difficult objections to vaccination:

The final argument in this vein may be adduced from the contention that it was improper and a profanity for any individual to interfere between a person's conscience and God. This latter argument was so powerful that much parliamentary time was taken up in determining just how a person might present the argument from conscience as a valid reason for not having a child vaccinated. (Spier 2001: S82)

Since most laws decreed that if there was just cause given to refuse a vaccination the charges would be dropped, many people attempted (and do to this day) to prove that vaccination is not the right choice for them, often citing religious or medical reasons. Today, in some states in the United States, a parent can object medically, religiously, or philosophically to a vaccination; however, as it was in England at this time, the burden of proof falls on the parents.

There were many anti-vaccination leagues formed throughout the years, including the National Anti-Vaccination League (originally the Leicester Anti-Vaccination League) (Swales 1992), which began in England in 1896, and the Anti-Vaccination Society of America, which began in 1879 after a visit from William Tebb, a British anti-vaccinationist. Shortly following the development of this society in the United States, others followed, including The New England Anti-Compulsory Vaccination League in 1882 and the Anti-Vaccination League of New York City in 1885.

Journals also flourished, such as *The Anti-Vaccinator* mentioned above, *The National Anti-Compulsory Vaccination Reporter* (1874) and the *Vaccination Inquirer* (1879) (Wolfe et al. 2002: 430-431). This trend continues even today with both the formation of organizations and websites which display vaccine safety messages. Such messages encourage parents to make informed decisions concerning vaccination. Current organizations include Vaccination Liberation (USA), VRAN (Vaccination Risk



Awareness Network in Canada), AVN (Australian Vaccination Network), and many others. The majority of these organizations focus on the need for parents to make informed decisions, with anti-vaccine information available. Many sites, such as the National Vaccine Information Center, also provide online newsletters.

The anti-vaccination movement prompted official inquiries over the years, and continuous re-definition of the right to abstain. Smallpox vaccination of infants was made compulsory in England through a series of laws passed in 1853, 1867, and 1871 (Durbach 2005: 59). In 1885 a Royal Commission was begun in response to a massive anti-vaccination demonstration in Leicester that attracted over 100,000 people (Wolfe et al. 2002: 430-431; Swales 1992: 1021). This commission sat for seven years to investigate grievances and hear evidence from both sides. Their report, which came out in 1896, stated that vaccination was effective; however, they did recommend dismissal of the cumulative penalties. A new Vaccination Act in 1898 introduced a conscientious clause and introduced the concept of a "conscientious objector"<sup>22</sup> (Wolfe et al. 2002: 431; Swales 1992: 1021; Durbach 2005: 58). By the end of 1898, over 200,000 certificates indicating the status of conscientious objector were given in England (Durbach 2005: 58). After 1907, when an amendment was added to the law making it easier to receive this status, exemption status rose to 25% of all births (Durbach 2005: 58). However, the matter of who could conscientiously object became an issue, perhaps because most of

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<sup>22</sup> Although the term was used before this by the anti-vaccinationists who used this phrase to describe how the issue played on their conscience, this concept was also used before this concerning oaths and compulsory education. See Durbach 2002.



those seeking exemption were of the working classes and/or women (Durbach 2005: 58-59):

For those who could not afford the services of a private sanctioned physician, vaccination was performed by state-paid vaccinators at public stations. At vaccination stations, vaccine matter was transferred directly from one child to another, and with it, parents routinely complained, a variety of other diseases. The arm to arm method thus provoked profound fears of blood pollution and bodily contamination. (Durbach 2005: 58)

This movement, however, was not only amongst the working classes. Middle class people also opposed vaccination, emphasizing:

....civil liberties and the sanctity of the home, adding anti-vaccinationism to an "Old Liberal" and libertarian agenda of personal rights. While workers shared this commitment, they also maintained their right in particular to control over their own and their children's bodies. They did not, however, claim this as a universal human right. Rather, they reasoned that this privilege derived from their English citizenship. (Durbach 2005: 58)

This concept of "good citizenship" was used by both pro-vaccinators and anti-vaccinators, albeit in very different ways. At this time in England, the pro-vaccinators felt that it was their duty as good citizens to be vaccinated in order to protect other citizens from disease. Anti-vaccinators felt that they were good citizens and a part of good citizenship was respecting the rights of other citizens, including their rights over their own bodies and the bodies of their children (Durbach 2005: 60-61). The anti-vaccination movement also became linked to a variety of other movements including women's issues, worker's movements, anti-vivisection organizations, and vegetarianism.<sup>23</sup> Much like today, anti-vaccinators were thought of as "anti-everything cranks" (Durbach 2005: 42).

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<sup>23</sup> For more information, please see Durbach 2002.

However, some members of the anti-vaccination movement encouraged parents to refrain from receiving exemption. In Leicester in 1934, there were only 95 vaccinations and 3,438 certificates of exemption in a population of 200,000 (Swales 1992: 1020). Many anti-vaccinationists felt that the certificates of exemption “insult the objector by converting him into a licensed law-breaker” (*Vaccination Inquirer* 1 Feb 1908: 194). They argued that the certificate itself would brand the possessor, causing him or her to feel stigmatized (Durbach 2005: 67).

The Leicester Anti-Vaccination League (later the National Anti-Vaccination League) was formed to protest the Act of 1867 which made vaccination mandatory. While the movement was grounded in religion, civil liberty was the concept that drove the faction (Swales 1992: 1019). William Johnson was the first to be imprisoned for refusal to vaccinate, but by 1889 over 6,000 were prosecuted, resulting in 64 people being imprisoned and 3,000 fines received (Swales 1992: 1019). Also interesting to note is the “Leicester Method” of treating smallpox, which was first described in Mr. J.T. Biggs’s book (Biggs 1912). This method involved the strict quarantine and disinfection of the premises, which may have kept smallpox cases in the region negligible (Swales 1992: 1019).

At this time, there were continuing problems in England over the concept of a conscientious objector since the term itself had never been defined (Durbach 2005: 71). Since the decision was up to the magistrate in the region, the definition of conscience was up for negotiation. Many objectors were caught in circular reasoning while others were told outright that their objection was not conscientious (Durbach 2002: 71). The



magistrates' own judgement often came into play with matters concerning certificates of objection, and one magistrate was even quoted as saying that he "conscientiously objected to giving out certificates of exemption" (Minutes of home secretary *The Lancet* 1898: 953). Durbach states:

Magistrates who refused to grant certificates, and who acted instead according to their conscience, often did so precisely because they felt that working people lacked intelligence and thus could not possibly make conscientious choices themselves. They often explicitly made assumptions about a person's claims to conscience based on the individual's class and gender. As in prosecutions for non-compliance, working people felt they were unfairly treated by the new conscience clause and dismissed as genuinely conscientious precisely because of their social status (Durbach 2002: 184).<sup>24</sup>

This attitude towards the working class is demonstrated in the following poem, which was written about a father who objects to vaccination:

I conscientiously object  
To the vaccinatin' of my kid;  
In vaccination as a check  
I don't berlieve, 'an never did  
I do berlieve it's bin imposed  
The workin' classes to annoy;  
And that is w'y I ain't disposed  
To try it on my girl – or boy.  
I says girl or boy becos  
I don't know if it's he or she  
But my old woman 'ere is poz  
That it's a girl – so let it be.  
But wot she called I couldn't say;  
I know my wife is called the same,  
I think it's Rose, or Kate, or May,  
Or Poll, or Sue or some such name.  
I ain't quite certain w'er we live,  
W'en she was born, I couldn't tell;  
I didn't come up 'ere to give

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<sup>24</sup> For more information on issues of vaccination and social status, please see Durbach 2000, Durbach 2002, and Durbach 2005.



'Er blooming pedigrees as well.  
If you want facks you'll 'ave ter go  
And arst my missus, I expeck,  
But for meself, I only know,  
I conscientiously object.

(Author Unknown. Blackburn Standard (24  
September 1898), LSHTM/AM, vol 51, 26  
as quoted in Durbach 2005)

There were also problems with economic discrimination in the Acts. As Durbach states:

The Acts themselves also discriminated economically against working people. The fine for non-compliance was 20s plus court costs which could range anywhere from one penny to one pound. For the working class these penalties were more than trifling, considering that it was not uncommon for a working man to earn between 15 and 20s a week. The Vaccination Officer's Birth Books for Enfield in the 1880s and 1890s reveal that most defaulters were factory operatives or journeymen labourers whose salaries could not have accommodated such a hefty penalty, and who could not have afforded to miss a day of work to appear in court. Even if one could pay the fine the first time, the cat and mouse nature of the 1867 and 1871 Acts, which allowed for repeated fining for non-compliance, meant penalties could be repeated almost indefinitely for each child, forcing penniless parents into prison. (Durbach 2000: 53)

Household and property auctions were also commonly used to pay the fines of those who refused to pay or could not pay, and often these sales could turn into political acts or even violent ones:

The most contentious site for both anti-vaccinationists and the police who monitored them was the distraint sale. If one could not afford to pay the fine for non-compliance with the Vaccination Act, or simply chose not to, one's goods could be seized and sold at auction to raise funds. Distraint sales provided a perfect opportunity for protest, and anti-vaccinationists took full advantage of this by using these auctions as meeting sites. When an anti-vaccinationist's goods were distrained the local anti-vaccination league mobilized its members and supporters to demonstrate at the sale by placarding the town with incendiary posters. Their goal was to prevent the auction from taking place, or to purchase the goods themselves. (Durbach 2000: 56)

Anti-vaccinationists rallied against these attitudes in three main ways: by seeking support from those sympathetic to anti-vaccination, by using the law to their advantage, and by lobbying the Home Office (Durbach 2005: 74). However, in some areas, magistrates were giving out exemptions to almost everyone who applied (Durbach 2005: 75). Objectors were advised to stick with the strict letter of the law and only reply in certain ways (Durbach 2005: 75-76). Durbach goes on to state:

Concerned with promoting equality under the law, in 1904 and 1906 the Home Office issued memoranda in an attempt to encourage greater uniformity among magistrates as to the evaluation of conscientious objectors. The issue at stake, the Home Office maintained, was whether the applicant had a 'honest conscientious belief' that vaccination would be, as the act stated 'prejudicial [sic] to the health of the child' whether or not this position was 'reasonably founded'. Conscientious objectors, the Home Office insisted, did not require a doctor's certificate stating the child was unfit for vaccination. Their knowledge or ignorance on medical, sanitary, or statistical matters was equally irrelevant. Indeed, neither the intelligence or the education of the applicant was supposed to be under scrutiny. The key point of the clarification was that the magistrate did not himself have to agree with the applicant's position, as long as the declaration was sincere. (Durbach 2005: 76)

It seems that the conscientious objector clause caused more problems than it solved, especially with struggles concerning who could be considered "conscientious" and those who refused to even be counted as a conscientious objector due to the stigmatization associated with the status.

Later years brought more lobbying for the appeal of the Vaccination Acts; however, all the efforts of the anti-vaccinationists were met with compromise, including making exemptions easier to obtain. These new acts no longer required the satisfaction of a magistrate in obtaining a certificate. While this helped the cause of the working class and gave "him or her" the satisfaction of being able to make their own decisions, it was



the absence of the “her” in this statement which became the new issue. Prior to this time, the term used had been “parent” implying either mother or father. However, with this latest act, the custodian of the child was the only one who could claim exemption, and the father was considered to be the primary custodian. Although custodianship was much debated, it was left to local courts to decide who the custodian was. Many conservatives felt that the father alone could be the custodian, while anti-vaccinationists felt that since it was the mother who was typically responsible to vaccinate the child in the first place, that she should also be able to object to the vaccination of the child. It was argued that women should be able to object since it would mean a day’s work if the father was forced to object instead. It was also argued by some (including anti-vaccinationist John Burns) that women were not able to make a rational decision such as this, especially after the birth of a child. The concept that women were too emotional to be able to reason and, thus, unable to conscientiously object was a view held by many, both pro- and anti-vaccinationists alike. In 1907, the term “parent” was again used; however, there was still much debate as to exactly who was the parent of a child (Durbach 2005: 78-82).

In the 1900s, anti-vaccinators felt that there was more evidence against vaccination than for it. The main piece of evidence was the idea that improvements in sanitation decreased the number of smallpox cases and that those areas which had the lowest incidents of vaccination also had the lowest incidents of small pox (Spier 2001: S82). Many anti-vaccination and vaccine safety advocates believed that increasing the cleanliness of an affected area was the first route to a cure and that no other medical interventions were needed.



### **Forced Vaccination**

A decrease in incidents of smallpox also contributed to a decrease in uptake of the vaccine. In the United States, 1893-1894 and 1901-1902 brought serious smallpox epidemics to Brooklyn and New York. While many voluntarily took the vaccine, there were a number who had not been vaccinated. Colgrove states:

In the last decades of the nineteenth century, public attitudes towards smallpox ran toward an ambivalent mixture of complacency and dread. Although it had once been one of the world's most devastating diseases, it had long ceased to be a major source of sickness or death in the United States and elsewhere in the Western world. Years of relative freedom from the disease – due, many argued to the success of vaccination – had engendered considerable indifference in the public and many physicians could no longer accurately diagnose it in its early stages, often mistaking it for measles or chicken pox. (Colgrove 2004: 351-352)

The Health Departments in both regions began a door-to-door campaign.

Although the region never had a compulsory vaccination law in place, those who went door-to-door made it seem as if vaccination was mandatory and that there was no choice in the matter (Colgrove 2004: 351). Vaccination was seen as one of many things that the “common people” needed the assistance of the educated people to understand (Colgrove 2004: 357). This paternalistic attitude is clearly seen in this statement made in a Brooklyn Health Department report which described tenement residents as “so indifferent to vaccination, that they accumulate the material upon which contagious disease feeds and spreads, and are a constant source of anxiety unless specially supervised. As a rule, their habits are careless, and they have no dread of smallpox, its suppression among them is at all times difficult” (Annual Report. Brooklyn. 1886: 10).

It was not long before people began to protest concerning not only the vaccinations, but also the quarantines which were enforced, sometimes with the only reason being the refusal of a vaccination (Colgrove 2004: 359-361). This problem was seen as racist and classist since the areas which received the majority of the attention were the immigrant and poorest communities. Vaccines were also brought into the workplace where many feared termination if they refused the vaccination (Colgrove 2004: 363) and later into schools (Colgrove 2004: 364). It was in schools, however, that both rich and poor alike were vaccinated. This caused much distress in the schools of Boston's elite since the girls were required to receive their vaccination scar in a place that would be visible, spoiling the beauty of a debutante in a sleeveless ball gown (Colgrove 2004: 364). After protests from parents, the vaccination site was changed and female doctors were brought in to confirm the girls' vaccination status.

In addition to more individual protests, a group of homeopathic doctors formed the Brooklyn Anti-Vaccination League in April of 1894. Not only did this league lobby for the repeal of many vaccination laws, they also accused the Board of Health of hiding the cause of death in cases where vaccinations were fatal. These accusations led to additional court cases which were crucial to later rulings on the extent of public health's powers (Colgrove 2004: 364-365).<sup>25</sup>

The early 1900s also brought the last smallpox epidemic to Boston, where yet another mandatory vaccination campaign was carried out. In this case, vaccinators came door to door, and people who refused had to pay a fine of \$5 or spend 15 days in jail. The

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<sup>25</sup> For more information concerning details on the court cases, please see Colgrove 2004.



situation became much more violent when the Board of Health developed “virus squads” who were sent to vaccinate those who lived in rooming houses in the poorer areas (Albert, Ostheimer, and Breman 2001: 376). The scene was described in the *Boston Herald*:

Every imaginable threat from civil suits to cold-blooded murder when they got an opportunity to commit it, was made by the writhing, cursing, struggling tramps who were operated upon, and a lot of them had to be held down in their cots, one big policeman sitting on their legs, and another on their heads, while the third held the arms, bared for the doctors. (*Boston Herald* February 12, 1902: 10)

Boston’s Anti-Compulsory Vaccination League fought back. They felt that compulsory vaccination was a violation of civil liberties (Albert, Ostheimer, and Breman 2001: 376) and that “from the standpoint of free citizenship no government should forcibly inflict on any individual enjoying all other rights of the nation, a disease loathsome in its origin, and not free from danger to life, and with, at all events, impairment of bodily health, at least of a temporary nature” (Albert, Ostheimer, and Breman 2001: 376). These events led to a piece of legislation which was proposed in January of 1902. However, after hearing from a number of experts from both sides of the argument (including doctors), the compulsory vaccination bill was upheld (Albert, Ostheimer, and Breman 2001: 376), although it did specify it was for the protection of the public, not an individual:

This epidemic led to a landmark legal case on the constitutionality of compulsory vaccination. In *Jacobson v. Massachusetts*, a citizen challenged a Massachusetts law that allowed the Cambridge Board of Health to fine him for refusing revaccination. Jacobson argued that the law opposed ‘the inherent right of every freeman to care for his own body and health in such a way as to him seems best. In 1905, the U.S. Supreme Court voted seven to two in favour of the state, ruling that although the



state could not pass laws requiring vaccination in order to protect an individual, it could do so to protect the public in the case of a dangerous communicable disease. (Albert, Ostheimer, and Breman 2001: 376-377)

In the same year in Boston, the chairman of the Boston Board of Health, Durgin, stated:

If there are among the adult and leading members of the antivaccinationists [sic] any who would like an opportunity to show the people their sincerity in what they profess, I will make arrangements by which that belief may be tested and the effect of such exhibition of faith, by exposure to smallpox without vaccination, be made clear. (*Boston Globe* November 26, 1901. 4)

Dr. Immanuel Pfeiffer took Durgin up on his challenge, visiting Gallop's Island's smallpox hospital. Pfeiffer, who believed that healthy people were not at risk for smallpox (a belief not held by those in the anti-vaccination movement) visited the hospital with Dr. Paul Carson. *The Boston Globe* even reported that Carson suggested Pfeiffer actually smell the odour of a patient's breath while there, just to ensure he was infected (*Boston Globe* February 10, 1902: 1, 4). Health officers later visited Pfeiffer's home to find him seriously ill; however, even after claims that he would die, Pfeiffer did survive (Albert, Ostheimer, and Breman 2001: 377). Durgin went on to state that no one who received the vaccine had contracted smallpox while at the hospital. However, the anti-vaccination activists had already condemned Pfeiffer and challenged Durgin's morals since he let someone who was not vaccinated be in close contact with those suffering from the illness. Durgin was also challenged by the town of Bedford who had threatened to sue the city for negligence since no restrictions were placed on Pfeiffer after the exposure (Albert, Ostheimer, and Breman 2001: 377). Years after these incidents,

anti-vaccinationists continued to be vocal in the region and were even mentioned by a Health Department report in 1926 (Albert, Ostheimer, and Breman 2001: 378).

### **Canada and the Anti-Vaccination Movement**

Resistance to vaccination was also an issue in Canada, especially Ontario, beginning in 1900. Although vaccination was widespread, it was not always consistent. Following the Montreal Smallpox Epidemic of 1885-1886, the government of Ontario passed a Vaccination Act, requiring parents to have children vaccinated within three months of birth and every seven years following. This act also allowed a municipality to order a general vaccination if faced with an epidemic and allowed school boards to require a vaccination certificate if they so wished (Arnup 1992: 160). It was because of such a by-law that Canada saw its first anti-vaccination league, The Canadian Anti-Vaccination League, which was begun on January 18, 1900 (Arnup 1992: 160-161). This league, which modeled itself on its British counterparts, set out to repeal all compulsory vaccination laws (Arnup 1992: 161). This was considered to be a mass movement, which was mentioned daily in Toronto newspapers, and although it only had a few hundred members, it was supported by thousands in the area (Arnup 1992: 161).

Although the league was not initially successful with the repeal of compulsory vaccination, it again returned to the Toronto Board of Education with a petition of over five thousand signatures in 1906 (Arnup 1992: 161). A vote of ten to two removed the need for a certificate in the school district (Arnup 1992: 161). As did their counterparts in Britain and the United States, the League argued that the best method of preventing



smallpox was sanitary conditions and isolation. Also similar to their counterparts in other regions, the League felt that the method of vaccination was unsanitary and made it possible for the spread of other forms of infectious disease (Arnup 1992: 161-162). This argument, once again, had some validity. MacDougall noted:

The lymph that was used to immunize the individual was occasionally contaminated with streptococcal or other organisms, and quite frequently inactive. The ivory points which were used to scarify were not always cleaned from person to person. Of equal importance was the tendency of recently vaccinated people to contaminate their wounds through ineffective bandaging or improper cleaning. All these potential hazards led some citizens to avoid vaccination because they were afraid of getting an infection and being unable to work. (MacDougall 1990: 122)

Even though the quality of the lymph had improved by this time, the fears of the public were unchanged. The public was affected by horror stories of others, which were frequently published in the *Toronto Daily Star*, such as the following:

Never in my life had I witnessed such suffering anywhere as among the little ones through inoculation. Mother after mother [bared] the arms of their little ones to show me the vicious, ulcerous sores, so large a silver half dollar would drop into them, and deep, nearly to the bone. I am not easily affected, but this made my heart ache and I shudder to-day when I recall their suffering. (A. Love. "Vaccination in Aurora" *Toronto Daily Star*, 3 March 1906. 20)

Anti-vaccinationists in Canada also felt that compulsory vaccination was a violation of their civil liberties. Problems of class were also addressed, especially noted was that the lower classes and immigrants were vaccinated while those in the upper and middle classes would avoid vaccination (Arnup 1992: 162-163). This was mentioned by Dr. Alexander M. Ross, founder of the Toronto Anti-Vaccination League, in a letter to the *Toronto News*:



Compulsory vaccination is never attempted on the so-called better classes. It is the poor wives and children of laboring men; it is the clerks in the stores and operatives in factories and workshops; it is the working men and women that are threatened and driven by the hirelings of the infamous compulsory vaccination law. (Dr. Alexander M. Ross, *Toronto News*. 20 October 1888, quoted in MacDougall 1990: 122)

Anti-vaccinationists received a great deal of media support at this time. The editors at *Saturday Night* stated that compulsory vaccination was “a sham” and that “The doctors and their families, the members of the School Board, the teachers as well as the pupils, in schools separate and private, as well as public, all should be required to pull up their sleeves and contract sore arms” (*Saturday Night* 19, 10 March 1906: 1). *The Star* also stated that doctors needed to actively defend and prove that vaccination was effective:

Medical science does not rest, like geometry, on self-evident propositions. It rests upon experience. It is not stationary, but progressive. It has abandoned modes of treatment as well established as vaccination, and taken up new ones. If, therefore, medical scientists wish the people to retain their faith in vaccination, they must keep them constantly supplied with facts and arguments, and must be ready to meet the opposition, not angrily, but patiently. (“Vaccination” *Toronto Daily Star*. 7 March 1906. 6.)

The Ontario Board of Health responded by issuing an advertising campaign, including pamphlets, outlining the importance of vaccination. However, during and after World War I, many concerns arose regarding public health, especially the spread of infectious disease, which led to the Vaccination Act of 1914 in Ontario (Arnup 1992: 164-165). This act, although virtually unnoticed at the time, made smallpox vaccination mandatory and required all students to be inoculated. It was not until 1919 after a minor outbreak of smallpox that Hastings, Toronto’s Medical Health Officer, called for a general

vaccination. When City Council's vote was split down the middle and no vaccinations were carried out, Hastings began a mass inoculation of students, threatening expulsions for those who did not comply (Arnup 1992: 165). The campaign itself was poorly executed, and Mayor Church called an emergency meeting declaring that Hastings needed to justify himself. Hastings made the argument that vaccination worked during the war; however, the council felt that it was not the vaccination, but the execution and compulsion that was the issue (Arnup 1992: 165). The vaccinations continued, under the guidance of doctors in the local schools, but parents began to complain about the procedure and stated that some children had been inoculated a second time even after officials had been told about their prior vaccination (Arnup 1992: 165). The Anti-Vaccination League also began to address the issue publicly, except this time the Board of Health responded sooner. Their responses, however, were not serious or scientific and instead resorted to calling anti-vaccinators names such as "ignoramuses" ("Says Antis Not Public Spirited" *Toronto World*. 19 December 1919. 11). Although the anti-vaccinators did respond, it is interesting to note that unlike many other anti-vaccination campaigns<sup>26</sup>, this one was peaceful (Arnup 1992: 168). The League (which after 1920 was known as the Anti-Vaccination and Medical Liberty League of Canada) was never able to repeal the Act or gain conscientious objector status before smallpox was eradicated (Arnup 1992: 168). However, the residents of the region did not forget these

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<sup>26</sup> Many other anti-vaccination rallies in Montreal, the United States, and England did turn violent. For more information on the Montreal riots, please see Bliss 1991; please see Leavitt 1982 for information on Milwaukee, and Durbach 2000 for issues in England.



matters and mounted yet another even stronger anti-vaccination campaign in the 1980s against the DPT (diphtheria, pertussis, tetanus) vaccine (Arnup 1992: 168-170).

### **Historic Legal Proceedings**

Important to discuss, primarily due to its legal implications, is the case of *Jacobsen v. Massachusetts* which began on March 15, 1902 when the Reverend Henning Jacobsen refused to be vaccinated after the Cambridge Board of Health issued a vaccination order following an outbreak of smallpox (Parmet, Goodman, Farber 2005: 652). Jacobsen had objected to vaccination because he felt it was harmful; however, he was still fined five dollars and lost all following appeals, including one to the United States Supreme Court, who ruled that Cambridge, Massachusetts had the right to make smallpox vaccinations mandatory. The Court also stated that compulsory vaccination was not a violation of an individual's right, but that states may limit the liberty of individuals in order to protect the public health of the community (Parmet, Goodman, Farber 2005: 652-653). This ruling is important due to the upholding of this law in cases against mandatory vaccination; it set a precedent for future court cases, both in the United States as well as other countries.

### **Vaccine Disasters**

In addition to the above-mentioned incidents and concerns, the efficacy and safety of vaccines has always been forefront. Many times, the anti-vaccination movement itself has gained strength by unfortunate events whereby a vaccine has been life-threatening.



There have been many instances of vaccines which were thought to be safe proving to be deadly, especially in the case of killed vaccines, and throughout the history of vaccination, there have been disasters in the manufacturing and distribution of vaccines. On a secondary level, vaccines can be injected incorrectly, causing symptoms although typically nothing more than a bruise or swollen muscle that is warm to the touch. Throughout the history of vaccination, we also see problems with diseases which are seen to be related to the vaccine itself. Autism, Sudden Infant Death Syndrome, allergies, and many other diseases and conditions have been linked either to the makeup of the vaccine itself or the manufacturing and storage of the vaccine. While I will discuss these incidents in later chapters, I will now focus on vaccine incidents which both the medical community and their critics have agreed caused idiopathic illnesses. Events such as these, especially when acknowledged by all sides, increase uncertainty in vaccination.

The first incident occurred in 1800, after Benjamin Waterhouse vaccinated the town of Marblehead, Massachusetts, which was relatively smallpox free, using strains given to him by Edward Jenner. Within the course of a few months, there was a smallpox epidemic that killed sixty-eight residents. It appears that the strains used were virulent, and instead of protecting the town from smallpox, the end result was an epidemic (Tucker 2001: 26-27; Link 2005: 23-37).

Much later, in 1901, there was another incident with the diphtheria vaccine in St. Louis, Missouri. At the time, the vaccine was made using the serum of horses that had been injected with the diphtheria toxin. The horse that would produce the most anti-bodies was the one most utilized. In this case, the horse's name was Jim; however, it was

found that Jim also carried tetanus and, for an unknown reason, the batch distributed was not tested for toxicity. Twenty children were infected, and fourteen of those twenty died of lockjaw (Offit 2005a: 58-59; Link 2005: 23-37).

Again the diphtheria vaccine was to blame in 1919 in Dallas, Texas. At this time, the diphtheria toxin was mixed with antitoxin, which was a very delicate balance to maintain. In this case, over three hundred children were injected before it was discovered that the balance was incorrect. One hundred and twenty children reported a reaction, which included burning at the site of the injection and horrible pain and swelling at the injection site, which later caused a massive edema until the skin ruptured. Following this, those injected experienced high fevers, vomiting, and later heart failure and paralysis. Ten children died, and those who lived had a very long recovery time (Bewley 1924; Park and Schroder 1928; Link 2005: 23-37). Later in 1948, in Kyoto, Japan, a similar incident occurred due to toxins not fully neutralized. In this case, 15,000 people were injected with 606 becoming ill. In the end sixty-eight people died (Wake 2005; Link 2005: 23-37).

Once again, with diphtheria, this time in Bundaberg, Queensland, Australia in 1928, the vaccine was found to be contaminated with staph bacteria. Twenty-one children were infected and twelve died. An incident similar to this happened with Yellow Fever in 1942, where US army personnel were given yellow fever vaccinations, only to later find they were infected with hepatitis. Fifty-one thousand people were hospitalized, one hundred and fifty died, at least twenty-four survivors developed liver cancer, and an undeterminable number developed cirrhosis (Coote 2005; Link 2005: 23-37).



Perhaps the worst of the disasters happened in the 1950s after the release of the polio vaccine, a much anticipated event. However, as Offit explains:

Two weeks after the release of the vaccine, on April 26, the director of the Laboratory of Biologics Control, William Workman, received a series of telephone calls about five children in California who had become paralyzed after receiving polio vaccine. In each case, paralysis occurred in the arm that was inoculated, and in each case, the vaccine had been made by Cutter Laboratories. Cutter's vaccine was immediately recalled, but 380,000 doses had already been administered — mostly to healthy first- and second-graders. (2005b: 1411)

The lab was required to recall its vaccines since two production pools (around 120,000 doses) were thought to contain the live polio virus (Offit 2005b: 1411):

Among the children who had received vaccine from these pools, abortive polio (characterized by headache, stiff neck, fever, and muscle weakness) developed in 40,000; 51 were permanently paralyzed; and 5 died. Cutter's vaccine also started a polio epidemic: 113 people in the children's families or communities were paralyzed, and 5 died. It was one of the worst pharmaceutical disasters in U.S. history. (Nathanson and Langmuir 1963: 29)

This disaster resulted in a series of legal cases, the first of which came two years later and was filed on behalf of Anne Gottsdanker, who was five years old. Cutter was sued both for negligence and breach of implied warranty since the labelling stated that the virus was "inactivated":

The jury was shown two pieces of evidence that determined the verdict: all five companies had difficulties in completely inactivating poliovirus, and Wyeth Laboratories also produced one lot of vaccine that paralyzed and killed several children in the Northeast. The jury found that Cutter Laboratories was not negligent but was guilty of breaching an implied warranty. (Offit 2005b: 1411)

This ruling meant that a company could be found liable for their products without being negligent in the production and design (Offit 2005b: 1411).



There was also an incident in the 1960s involving the measles vaccine. Two vaccines for measles were released at the same time; one was a live measles vaccine, the other a dead measles vaccine. Unfortunately, the dead vaccine was shown to be ineffective, and those who were injected with it were unprotected from the disease within a year. Even worse than this, many of those injected came down with atypical measles and had extreme reactions to the live vaccine. The killed vaccine was quickly taken off of the market, and cases of atypical measles dropped (Evans and Kaslow 1997: 520; Link 2005: 23-37).

“Flugate,” as the incident was later dubbed, began when a soldier at Fort Dix reported flu-like symptoms and then later died after attending a march. A few others also came down with mild, flu-like symptoms, although there were no other fatalities. A panic ensued, and it was dubbed the next 1918 flu epidemic. Pressure was placed on manufacturers to produce large quantities of flu vaccines; however, the first two million doses had to be thrown out since they were made with the wrong strain. Later doses were linked to the deaths of three elderly people in Pittsburgh, who died within hours of receiving the vaccine. Pennsylvania and several other states suspended the program, in spite of President Ford’s effort and T.V. appearance in which he and his family received their flu vaccines. By this time, the “epidemic” had become a joke (and was thus nicknamed “Flugate”); however, there were incidents a month later which ended the laughter. Reports of people with neurological conditions after receiving their flu vaccine began to pour in, and a real panic ensued. Many people contracted Guillain-Barre Syndrome (GBS), which required them to be ventilated until recovery. Although no one

died from this incident, many became increasingly wary of flu vaccinations (Canadian Broadcasting Company 1986; Link 2005: 23-37).

Other events, such as the recall (and re-release) of the rotavirus vaccine and the vaccine for Lyme disease, also elicited suspicion. In addition to these examples, there have been many other possible vaccine disasters. As I mentioned earlier, I have only recounted those incidents which both the medical community and vaccine safety activists have agreed upon. In later chapters, I will explore other incidents which have been the subject of controversy, including the SV40 virus, Autism and the MMR vaccine, and a variety of other vaccine safety events.

Although very little has been written on the history of anti-vaccination, it is not surprising to note that places which have had a large number of vaccination disasters tend to have the strongest anti-vaccination movements. Currently, England, Japan, and many Scandinavian countries have the lowest rates of vaccination, closely followed by the United States, Canada, and Australia. Other countries where vaccination rates are thought to be low (however, this is uncertain due to a lack of documentation) are areas such as Africa and India where stories of vaccination mishaps and contemporary legends concerning the link between HIV and the polio vaccine are prevalent.

Even the medical community has admitted that the anti-vaccination issue is not an easy one, as noted by Wolfe et al. in *The Journal of the American Medical Association*:

Vaccination is unique among de facto mandatory requirements in the modern era, requiring individuals to accept the injections of a medicine or medicinal agent into their bodies, and it has provoked a spirited opposition. This opposition began with the first vaccinations, has not ceased, and probably never will. From this realization arises a difficult issue: how should the mainstream medical authorities approach the anti-

vaccination movement? A passive reaction could be construed as endangering the health of society, whereas a heavy handed approach can threaten the values of individual liberty and freedom of expression that we cherish. This creative tension will not leave us and cannot be cured by force alone. (Wolfe et al. 2002: 432)

Clearly vaccination is a much debated issue with a complex history. It is also obvious that the medical community as well as the lay community would benefit from an open discussion on this topic, which this dissertation hopes to provide in the upcoming chapters.



### **Chapter Three**

## **Folkloric Content in Lay Vaccine Narratives**

This chapter considers the content of lay vaccine narratives as a way to understand health belief. Understanding the logic and beliefs of the lay public is the first step towards better communication between the medical field and the public; however, it should be noted that the beliefs expressed here may differ not only from region to region, but also from person to person. This consideration of content is not meant to serve as a list of all possible beliefs, but rather as examples of the vaccination beliefs found in this research.

Belief in folklore studies can be a complicated topic to discuss since belief itself is an element frequently found in other forms of folklore. Historically, belief has been linked to superstition and has been studied in condemnation of those who hold the beliefs with little thought given to their context. Perhaps the best way to discuss belief is terms of traditions of belief and disbelief (Hufford 1982). Hufford's work on belief indicates that both belief and disbelief are traditional, and people tend to either believe or not believe in something because it is acceptable to do so (Hufford 1982). However, as Hufford points out, disregarding something because it is traditionally disregarded constitutes a logical error since it excludes an entire group of theories *a priori*. If we assume that a vaccine narrative (pro-vaccination or anti-vaccination) is not true based only on our traditions of belief or disbelief, then we suffer from such a fallacy since we have already automatically disregarded some of the possibilities based on our own beliefs. Hufford succinctly re-examines this concept in the statement, "What I know, I

know, what you know, you only believe...." (1982: 47). By considering both the traditions of belief and disbelief in vaccine narratives, one can assure that both systems of belief are honoured and can attempt to eliminate personal biases. Additionally, there is a distinction between what is believed and what people will admit they believe; someone could be either for or against vaccination, but may not acknowledge these beliefs. In both the pro-vaccination and anti-vaccination arguments we see that the traditions of disbelief of each group are offered as indisputable facts, demonstrating that both groups are using the same rhetorical strategies.

The following subcategories outline major types of content and messages intrinsic to vaccination and anti-vaccination debates. While the majority of the materials discussed here are associated with lay perspectives, a clear distinction between vernacular perceptions and medical positions cannot be made. Although clearly lay models of health and illness tend to differ from biomedical models, it does not follow that physicians, medical researchers, or health educators hold strictly to medical models (Goldstein 2004: 70). As noted by Lock (1982) in relation to gynaecological understandings of menopause, practicing physicians' views are often based on a melding of folk as well as textbook concepts. As such, biomedical perspectives are rarely solely biomedical, just as vernacular perspectives are rarely solely traditional. Among my informants I found medical professionals who were anti-vaccination in their personal lives, but who told their patients to vaccinate. I interviewed chiropractors who were pro-vaccination, public health nurses who were anti-vaccination, and even a few parents who claimed pro-vaccination status with some friends and anti-vaccination beliefs with others. Over half of

my informants confessed conflict in their own beliefs because they were taught to believe one way, but felt the evidence was in favour of the opposing viewpoint. Additionally, nearly forty percent of informants, including health care professionals, reported changing their views after having children of their own.

### **Contamination Legends**

Contamination legends fall into five categories: 1) vaccines that cause the disease they are supposed to prevent, 2) vaccines that cause additional diseases, 3) chemicals and other “unnatural” ingredients, 4) natural ingredients that do not belong in vaccines, and 5) improperly stored vaccines. Additionally, there are some narratives that indicate the intentional placement of disease-causing agents.

#### **Vaccines That Cause the Diseases They Are Supposed to Prevent**

The concept that a vaccine can cause the disease it was supposed to prevent is not far-fetched, especially considering the Cutter Incident (see Chapter Two). There have been vaccine disasters that have infected both single patients and communities at large, at times with an atypical version of the very disease it was supposed to prevent. Although current testing methods are thorough and more stringently followed than in the past, the possibility persists that the vaccine itself can cause the disease. This rarely happens, since many of those who might contract the disease (for example, those who are immuno-compromised) are not given the injection. Currently, there are very few live or killed strains of any disease contained in vaccines, so the likelihood of a vaccine causing an



illness is highly unlikely. However, these stories remain common, especially in the case of the flu vaccine.

An online poll<sup>27</sup> on uptake of the flu vaccination administrated by SurveyCentral.com showed that of those who responded, 42% said they had never received the flu shot (and would not be getting one in the future), 20% said that the flu shot had made them sick, and 25% disagreed that the flu shot caused any concerns. One person commented:

It seems that most people here haven't gotten a flu shot. I have been sick more times in the past year than I have in my entire life and I was considering getting a flu shot although I have never had one before. I have decided against it based on this survey. Thanks for your input. (Survey Central 2007)

Even though this was an unofficial online poll, it clearly made the difference in at least one person's decision to vaccinate.

The most common narrative content states that the flu vaccine has the ability to cause the flu, which is something that nearly all of my informants reported:

I remember when I was staying up North, it was a fly-in community, and they wanted everyone to get a flu shot. Well, I didn't and mom didn't and there were a few others who didn't either, including the nurse, but everyone else got it. A few weeks later everyone had a horrible flu. It was so bad people were being flown to hospitals. But those of us who didn't get the shot, well, we didn't get the flu either. I think that shot actually caused the flu. (Interview with lay person. January 18, 2004)

This interview demonstrates the lay logic used to understand this particular situation based on observed epidemiological patterns, although most medical professionals would

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<sup>27</sup> This was an unofficial poll, produced by a member of the forum. The poll was small with only fifty-one participants; however, it was widely cited on a variety of anti-vaccination website due to the large number of comments left by participants. Polls such as these, which rely on lay authority, are considered by anti-vaccinationists to be more unbiased since they are perceived as random and without ulterior motives.

disagree with the conclusion. Another informant felt that even though they did not suffer as much as the previously mentioned community, they were also affected by their flu shot. One informant stated: "The last time I had the flu shot, well, I just felt terrible afterwards. I ended up in bed for two days with flu-like symptoms. I might not have even gotten the flu, but I still got sick from the shot. I'm not doing that again!" (Interview with lay person. November 28, 2007).

Of the health professionals I spoke with, many were divided on the issue. Their knowledge of the medical literature told them that it would not cause flu-like symptoms, but their actual experience varied, and over half of them reported that they themselves experienced flu symptoms. A medical practitioner's experience of flu symptoms, with the knowledge that they could not be caused by the flu shot, may be an excellent place to begin to understand risk perception, even if symptoms are less extreme than the actual flu:

Most people really don't get the full-blown flu. You don't just feel a little sick; you literally can't get out of bed. THAT'S the flu. What they have is a cold. A lot of people don't know the difference. Trust me, a little bit of achiness and tiredness is nothing in comparison. (Interview with medical professional. October 5, 2007)

In this case, the medical professional perceived the problem to be both the awareness of illness and the understanding of how the vaccines works.

There are many incidents where people contracted the very disease they were trying to prevent, as occurred in the Cutter Incident (see Chapter Two). It is not unreasonable to assume that this could happen again. Even with strict production



guidelines and more accurate testing, there is always the possibility that the virus will not be properly treated or that an atypical strain might result.

### **Vaccines That Cause Additional Diseases**

Claims that vaccines cause diseases or conditions beyond the diseases they are supposed to prevent, such as autism, allergies, and SIDS, are also common in narratives of vaccination concerns.

Although the majority of flu shot narratives address the idea that it causes the flu, it has also been known to trigger other illnesses, such as Guillain-Barré Syndrome<sup>28</sup> (GBS) as shown from this personal experience narrative found on the Internet on the website for Think Twice Global Vaccine Institute<sup>29</sup>:

I had a flu shot in November, and by December I became weak and continued to get weaker until I collapsed in my bedroom and was taken to the hospital. I was surrounded with intravenous lines, a feeding tube, bladder catheter, and tracheotomy for the ventilator. I was helpless, totally paralyzed with Guillain-Barre syndrome. I had a blood infection, pneumonia, a fever of 107.9 degrees, and blood pressure of 44 over zero. My wife was told to make arrangements for a post-mortem. I was in ICU for three weeks and then transferred to a rehabilitation center. Three months later I was released to come home because I could ambulate approximately 100 feet with a walker. I continued rehabilitation as an outpatient for the next three months until I could walk with hand crutches.

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<sup>28</sup> Guillain-Barré Syndrome is a disorder in which the immune system attacks the peripheral nervous system. Symptoms include varying degrees of weakness or tingling sensations in the legs, which may spread to the arms and upper body. These symptoms can increase in intensity until the muscles cannot be used at all and the patient is almost totally paralyzed. (National Institute of Neurological Disorders and Stroke 2009).

<sup>29</sup> The Think Twice website was mentioned by slightly over half of my informants and ranks high among internet searches. Think Twice does not make any claims to medical authority and admits that some of the information presented conflicts with other information on the website. This site promotes that parents carefully consider all options, recommends the use of pro-vaccination websites, and encourages parents to speak to medical professionals. Think Twice is also associated with New Atlantean Press and sells books and nutritional supplements.



Today I need a cane. I was not forewarned of any possible hazard when they gave me the flu shot. (Think Twice Global Vaccine Institute 2007)

Many people also believe that the flu shot causes other illnesses as well:

My husband had a flu shot in January and experienced swelling in his axilla that night, probably the lymph nodes. After that, he became weak and chilled all the time, with a dry cough. During the next two months, the coughing, weakness and chills persisted, and by the end of the second month he was vomiting. His doctor did several tests until one showed acute kidney failure. He was diagnosed with Goodpasture's syndrome. This condition causes an abnormal amount of antibodies in the blood, causing them to attack the kidneys and lungs. The treatment is immune suppressive therapy. Isn't that ironic. It seems that the flu shot that is supposed to build up immunity caused his to work too hard and didn't know when to shut down. Needless to say, the doctors refuse to admit that the flu shot caused this. He has been unable to work, gets tired, and is at increased risk of catching a virus due to drug therapy (Think Twice Global Vaccine Institute 2007)

One informant that I interviewed found that her child had contracted the mumps shortly after receiving his vaccination:

One I remember particularly he had for mumps. And he did get mumps and all one side and I phoned to let the public health know that he had mumps and they said "How do you know? Did you take him to a doctor?" and I didn't take him to a doctor, but I do know a doctor (she laughs)<sup>30</sup>, I do have a Merck manual. I have seen mumps growing up and recently because people aren't always vaccinated for mumps and also a couple friends of mine are nurses and they saw it and they said "he definitely got the mumps." (Interview with lay person with children. July 25, 2007)

Her son also contracted the measles and chicken pox after his vaccinations. She eventually stopped vaccinating him, and he did not have any additional incidents of common childhood diseases.

Another concern of parents is Sudden Infant Death Syndrome (SIDS). To this day, no one is entirely sure what causes SIDS and in fact SIDS is defined by its

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<sup>30</sup> Her laughter is because her husband is a doctor.

unexplained nature. Health Canada<sup>31</sup> describes this condition as “....the unexpected death of an apparently healthy infant that remains unexplained after a complete post-mortem investigation, which includes an autopsy, death scene investigation and review of the medical history” (Health Canada 2001). They also state that:

- The rate of SIDS is highest between 2-4 months old.
- 90-95 per cent of SIDS cases occur before the age of 6 months.
- There appears to be no suffering.
- SIDS is the leading cause of death in Canada for infants between the age of one month and one year, claiming the lives of 3 babies every week.
- SIDS strikes one in every 2,000 liveborn babies in Canada. (Health Canada. 2001)

Health Canada does not address the belief that there is a link between vaccines and SIDS.

However, the Centers for Disease Control<sup>32</sup> (CDC) does tackle this matter:

How do we know that some SIDS deaths are not due to vaccines?  
This issue has been studied for many years, and several lines of evidence reassure us about the safety of vaccines.

- A study using Vaccine Safety Datalink (VSD) data, which included children who were covered by a health maintenance organization (HMO) health plan, found no association between immunization and deaths in young children. The study investigated deaths in children one month to 7 years of age between 1991 and 1995. Data were analyzed by comparing vaccination histories for each vaccine during the week and month prior to the date of death for each child. Five hundred and seventeen deaths occurred between 1991–1995, most (59%) during the first year of life. Of these deaths, the results did not show an association between immunizations and childhood deaths.
- The Vaccine Adverse Event Reporting System (VAERS) also monitors the safety of vaccines.

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<sup>31</sup> Health Canada’s website offers authoritative medical information in French and English, and links to other official medical sites.

<sup>32</sup> The Centers for Disease Control is based in the United States, but is frequently used worldwide for authoritative medical information.



- Studies that looked at the age distribution and seasonality of deaths reported to VAERS, SIDS and VAERS reports following DTP vaccination, and SIDS and VAERS reports following hepatitis B vaccination found no association between SIDS and vaccination.
- The Food and Drug Administration (FDA) carefully investigates all deaths following vaccination that are reported to VAERS. Between 1990 and 1992, the FDA and the Institute of Medicine (IOM) reviewed 208 deaths reported to VAERS. Only one death was believed to have resulted from a vaccine: a 28-year-old woman who died from Guillain-Barré syndrome after tetanus vaccination. The IOM concluded that the vast majority of deaths reported to VAERS are coincidental and not causally related to vaccination. (Centers for Disease Control. 2007. [http://www.cdc.gov/od/science/iso/concerns/archive/sids\\_faq.htm](http://www.cdc.gov/od/science/iso/concerns/archive/sids_faq.htm))

Many vaccine safety advocates have stated that the public does not know the whole story, especially since the CDC has not provided a link to the sources of this information. There are many conflicting viewpoints when it comes to which symptoms and events are relevant and which are not, as seen in this quote reported as coming from the *Journal of Pediatrics*<sup>33</sup>, referenced on an anti-vaccination website:

Post mortems on cot death babies indicate asphyxia, which can be due to the level of poisons being just that little bit too high for these individuals' immature immune systems to mount a defence of the strength and sustained period of time required to deal with them. Adding to the difficulty in dealing with the large load of poisons is the fact that these poisons interfere with the activities of the immune system itself, and thus weaken its ability to eliminate any poisons. In the younger babies the battle is more often lost within hours or a few days from the injection. In the older babies they more often hold out longer and only lose the battle after a few weeks or longer (J Pediatrics 1982). (Vaccine Information Services: Who Do You Trust, Nature or Man?)

Other studies, including those from countries outside of North America, have been used as proof of a connection between vaccines and SIDS. Since these studies do

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<sup>33</sup> I could neither confirm nor deny this reference as it is incomplete, however, searches with the terms "cot death", "Journal Pediatrics", and "1982" did not produce any results.



not have a link to North American vaccine manufacturing companies, they are often seen as being unbiased in a way that a North American study cannot be, and the studies are often summarized on anti-vaccination sites, such as this one, called Whale<sup>34</sup>:

Delay of DPT immunization until 2 years of age in Japan has resulted in a dramatic decline in adverse side effects. In the period of 1970-1974, when DPT vaccination was begun at 3 to 5 months of age, the Japanese national compensation system paid out claims for 57 permanent severe damage vaccine cases, and 37 deaths. During the ensuing six year period 1975-1980, when DPT injections were delayed to 24 months of age, severe reactions from the vaccine were reduced to a total of eight with three deaths. This represents an 85 to 90 percent reduction in severe cases of damage and death. (Obomsawin 2007)

Some parents feel the medical community is attempting to cover up the vaccine/SIDS link. The following personal experience narrative was encountered on the anti-vaccination website, Whale:

I set about trying to discover exactly what apparent data in relation to my children had been used in these papers. Initially I tried 'locally' to obtain records in relation to my children; I then discovered that records in relation to my children '**could not be found**'. These included GP, Health Visitor, Clinic, Midwifery and Birth, Vaccination, Hospital admission, Outpatient and Ambulance records. With regard to Post Mortem records, all that was available was a brief 2 page Official Coroners Record for each child, which gave scant details and a cause of death as SIDS for both children. I knew that there had to be a Post Mortem File in relation to each child which obviously contained specific details of my children's Post Mortems i.e. tests carried out, date and time of PM, samples taken etc. It later was confirmed that my children's Post Mortem Files '**could also not be found**'. There were 40+ SIDS deaths in my city area (including my own children) these 40+ deaths occurred within a total of 2 years. For a population of approx 250.000 this appeared to be a high incidence. In fact this is documented by a GP as being 'a significant blip'.

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<sup>34</sup> Whale is a vernacular website offering a host of alternative medical therapies and conspiracy theories. It was mentioned by over fifty percent of my informants and frequently appears in Google searches on vaccination.

I discovered that all 40+ SIDS victims Post Mortem Files apparently also 'could not be found'. It was clear that Post Mortem samples and organs were retained from many of these SIDS victims (including my own). Though why this happened, what was being tested for and the results of these tests apparently 'were not available' or 'could not be found'.

Given the 'research' being carried out in my area by SIDS researchers I find it impossible to believe records in relation to 40+ children apparently have simply '**disappeared**'.

.....My own child died within 36 hours of having his vaccines. My first child died approx 2 weeks after vaccines. I know of one other family (in my own city) whose child died within 24 hours of having vaccines. The parents were convinced that their child died as a result of the vaccines and actually told the pathologist when he gave the cause of death as SIDS that they thought there had been a 'cover up'.

I have recently had released to me vaccination records for my children, (records that have taken over 5+ years to get released, records whose very existence was denied 5+ years ago) these say that I gave permission for my child to have his vaccines 2 weeks after he died! Why would I give permission for a dead child to have vaccines? There are other worrying discrepancies. I find it interesting that the majority of deaths within my own area occurred on or around the time of vaccines being due. I understand that one 'batch' of these vaccines would have been enough to vaccinate the children of my own city. (Blakemore-Brown 2007)

Others feel that the Vaccine Adverse Event Reporting System's database (VAERS)<sup>35</sup> is incomplete and that many cases of vaccine reactions are underreported. In some instances, cases which should have been reported were never reported at all. All sides have agreed that since VAERS is a passive system (vaccine reactions must be reported by medical professionals or parents), it is not perfect. Vaccine safety advocates feel that many events that are vaccine reactions are not reported by the medical

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<sup>35</sup> The Vaccine Adverse Event Reporting System is a joint program run by the Centers for Disease Control (CDC) and the Food and Drug Administration (FDA). It is used as a safety surveillance program to collect information about side effect and adverse reactions. The information found on this database is available to the public (Centers for Disease Control and Food and Drug Administration 2009).



community and are instead given a different label (such as SIDS), while many in the medical community feel that parents are reporting reactions to the VAERS system which have not been caused by vaccines. Overall, the system is perceived to have many faults:

The passive Vaccine Adverse Events Reporting System [VAERS] is not a reliable means of identifying problems which have resulted from vaccinations. Even the FDA admits that only approximately one in ten doctors reports reactions. Though they are required by law to do so, they can rationalize their failure as being due to the fact that any health problem was not due to the vaccine, in their opinion. That opinion might be heavily influenced by their own reluctance to admit that they may have done something to harm a patient, or by a fear of being sued. (Vaccinations: You Decide!<sup>36</sup> 2007)

The majority of my informants did not have detailed information on which vaccines could cause SIDS, but 28% of them had heard that there was a link between SIDS and vaccination. Most of them were familiar with the sleeping positions recommended by public health officials and seemed to possess a general overall understanding of SIDS. One frequently reported comment was that it was hard for some to accept that a baby could just die of unknown causes:

I just don't buy it. I'm not saying I know what it is, but I just don't buy that a baby can die and in this day and age they don't know why. That just doesn't make any sense to me. I'm not saying there's a big conspiracy or that it's the doctor's fault or anything, but it seems to me that they should know what's going on. Babies just don't die of nothing. (Interview with lay person with children. June 20, 2007)

Of course, this is the very reason why medical professionals often feel that their patients are not informed, as one informant states:

People just don't understand that we still don't know it all. We don't have a cure for the common cold and prevention is as simple as washing your

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<sup>36</sup> Vaccinations: You Decide! is a vernacular anti-vaccination website run by a woman who chooses not to disclose her name. She does have links to her educational background which includes a Ph.D., ABD.



hands, but no one believes that. Sometimes people just die. It happens all the time to the elderly. But people can't accept that it can happen to infants as well. But it does. Sometimes people and babies just die and we really don't know why. (Interview with medical professional with children. November 24, 2006)

Although those involved with vaccine safety know that vaccines are not infallible, many of them still cling to the hope that there is a cure or a way of avoiding childhood illnesses. It is extremely rare to come across any vaccine safety site which does not offer alternatives to biomedical vaccination. This indicates that those involved in this movement are aware of the dangers of these illnesses and that they are actively searching for a way to avoid them. They simply do not choose vaccination as their means of doing so.

### **Chemicals and Other "Unnatural" Ingredients**

The actual contents of the vaccine itself, especially in the case of preservatives, is a widely debated issue. Ingredients such as thimerosal, formaldehyde, mercury, and others, are frequently linked to the causation of the diseases mentioned in the previous section. All of these ingredients, regardless of whether or not they have been linked to an actual disease, are to blame since they are considered not "natural." In this instance, natural means something which is not commonly associated with the body and/or is not produced in nature. Many sites, such as the one run by Dr. Mercola<sup>37</sup>, a physician who does not support immunization, offer information including the following ingredient list:

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<sup>37</sup> Dr. Mercola's website offers alternative health advice and frequently appears on Google searches for vaccination topics. He also has an electronic newsletter.

Do you want any of the following vaccine constituents in YOUR bloodstream?

- Ethylene glycol (antifreeze)
- Phenol, also known as carbolic acid (this is used as a disinfectant, dye)
- Formaldehyde, a known cancer-causing agent
- Aluminium, which is associated with Alzheimer's disease and seizures and also cancer producing in laboratory mice (it is used as an additive to promote antibody response)
- Thimerosal (a mercury disinfectant/preservative) can result in brain injury and autoimmune disease
- Neomycin and Streptomycin (used as antibiotics) have caused allergic reaction in some people. (Mercola 2001)

Approximately twenty-five percent of the vaccine safety websites found listed a variety of ingredients in vaccines, most of which are not disputed by the medical community. Frequently the argument made by the medical community is that these chemicals are harmless in small quantities; however vaccine safety activists question this:

If you are tempted to assume that these poisons would only be in harmless quantities in vaccines, note:

- 1) There is **no** safe level for some of these poisons, such as formaldehyde and mercury, even if one of them was consumed or injected on its own.
- 2) Even if the quantity of any given ingredient was within a safe level, remember that a large number of these are being taken in all at once, which can lead to the accumulative toxicity being much higher.
- 3) Poisons such as formaldehyde and mercury are well known to have a sensitizing effect on the body, i.e. they cause increased susceptibility to any foreign substance that it might encounter at the same time or in the future.
- 4) Even the manufacturers admit to a large list of adverse effects of vaccines, including even death. (Vaccine Information Services: Who Do You Trust, Nature or Man? 2007)

Other websites list each ingredient in greater detail, such as the following from the Vaccination Information Services website:



Formaldehyde:  
(Used in vaccines as a tissue fixative)

Aust. National Research Council: Fewer than 20% but perhaps more than 10% of the general population may be susceptible to formaldehyde and may react acutely at any exposure level. More hazardous than most chemicals in 5 out of 12 ranking systems, on at least 8 federal regulatory lists, ranked as one of the most hazardous compounds (worst 10%) to ecosystems and human health (Environmental Defense Fund).  
It is not safe at ANY level.

National Academy of Science:  
There is no population threshold for irritation effects.

National Research Council:  
Fewer than 20% but perhaps more than 10% of the general population may be susceptible to formaldehyde and may react acutely at any exposure level.

Formaldehyde is oxidised to formic acid which leads to acidosis and nerve damage. Acidosis can be described as a condition in which the acidity of the body tissues and fluids is abnormally high. The liver and the kidneys may also be damaged.

Other effects:

Eye; nasal; throat and pulmonary irritation; acute sense of smell; alters tissue proteins; anaemia; antibodies formation; apathy; blindness; blood in urine; blurred vision; body aches; bronchial spasms; bronchitis; burns nasal and throat; cardiac impairment; palpitations and arrhythmias; central nervous system depression; changes in higher cognitive functions; chemical sensitivity; chest pains and tightness; chronic vaginitis; colds; coma; conjunctivitis; constipation; convulsions; corneal erosion; cough; death; destruction of red blood cells; depression; dermatitis; diarrhoea; difficulty concentrating; disorientation; dizziness; ear aches; eczema; emotional upsets; ethmoid polyps; fatigue; fecula bleeding; foetal asphyxiation (and they don't know what could cause SIDS?); flu-like or cold like illness; frequent urination with pain; gastritis; gastrointestinal inflammation; headaches; haemolytic anaemia; haemolytic haematuria; hoarseness; hyperactive airway disease; hyperactivity; hypomenstrual syndrome; immune system sensitiser; impaired (short) attention span; impaired capacity to attain attention; inability or difficulty swallowing; inability to recall words and names; inconsistent IQ profiles; inflammatory diseases of the reproductive organs; intestinal pain; intrinsic asthma;



irritability; jaundice; joint pain; aches and swelling; kidney pain; laryngeal spasm; loss of memory; loss of sense of smell; loss of taste; malaise; menstrual and testicular pain; menstrual irregularities; metallic taste; muscle spasms and cramps; nasal congestions; crusting and mucosae inflammation; nausea; nosebleeds; numbness and tingling of the forearms and finger tips; pale, clammy skin; partial laryngeal paralysis; pneumonia; post nasal drip; pulmonary oedema; reduced body temperature; retarded speech pattern; ringing or tingling in the ear; schizophrenic-type symptoms; sensitivity to sound; shock; short term memory loss; shortness of breath; skin lesions; sneezing; sore throat; spacey feeling; speaking difficulty; sterility; swollen glands; tearing; thirst; tracheitis; tracheobronchitis; vertigo; vomiting blood; vomiting; wheezing.

References; C. Wilson; Chronic Exposure and Human Health (1993), McFarland & Company taken from Our Toxic Times Feb 1997 pgs 18 & 19. (Vaccine Information Services: Who Do You Trust, Nature or Man? 2007)

Extensive lists of reactions, such as the one above, are often used to demonstrate the affects of using “unnatural” ingredients in the body.

The arguments over the use of “natural” vs. “unnatural” ingredients can be confusing since what counts as which is a matter of perception. Local medical professionals have complained about this confusion of vaccine ingredients, including one I interviewed:

Some people just don't get it. They want all natural, but natural doesn't always mean safe. And chemical doesn't always mean that it's bad for you. We're made up of chemicals, aren't we? (Interview with medical professional. March 13, 2007)

However, one of the arguments made by more than half of my informants concerns the use of natural products and how they can be better for you:

I know it may sound sort of corny, but I figure that if God didn't make it, it's probably not something I should have. Sure, God made some poisonous plants but some of those in small doses are good for you. And they all serve some sort of purpose. It just makes sense to me. If God didn't make it, then maybe it didn't need to be made. I'd rather they

looked in nature, in what we already have, for a solution. And once they find it, stick with it! Stop making chemical forms of something we already have out there. (Interview with lay person. May 7, 2007)

As one medical doctor I interviewed stated: "Everyone wants natural, but what they don't realize is that natural isn't regulated. You don't know how much you're taking. When they figure it out chemically, well, then we know for sure" (Interview with medical professional. December 6, 2007). The regulation of herbal and other natural products did concern many of my informants; however, they mentioned that all of their products came from reliable, well-tested facilities. As one informant stated, "It's not like they came from Wal-Mart! I wouldn't use that stuff even in an emergency. I don't know where it came from" (Interview with lay person. May 7, 2007).

It is evident that this issue is problematic, especially when combined with current social and environmental concerns. My research has shown that some medical professionals, primarily doctors, also feel that the increase in environmental awareness and environmental movements has resulted in the desire for more natural products over synthetically created ones. The physicians I interviewed seemed to have mixed feelings on the effect of environmental movements; most supported aspects of environmentalism, but did not feel it fit into the current state of medicine. Multiple informants even joked that medicine, with all of its disposable instruments, was the environment's worst enemy.

### ***MMR and Autism***

The medical community and most national organizations, such as the CDC (Centers for Disease Control) in the United States and Health Canada, have done studies



showing that thimerosal, a common “unnatural” additive in vaccines, does not increase the risk of autism in children in a statistically significant way (Centers for Disease Control 2007). However, these studies do not relieve the public’s fear of the MMR/Autism connection. The number and variety of anti-vaccination websites which specifically deal with MMR on the Internet is astounding.<sup>38</sup> The information contained on these sites varies from practical advice on discussing vaccinations with your family doctor to how to properly line your child’s room with aluminium foil to “cure” autism. These websites are so widespread that major health organizations, such as the World Health Organization (WHO), the Centers for Disease Control (CDC) and Health Canada, contain information on their websites to answer questions related to the connection. Health Canada has gone as far as to issue a statement on the amounts of thimerosal in vaccines in Canada (Health Canada 2003). Health Canada also lists answers to common questions concerning vaccination, including an entry which discusses Andrew Wakefield specifically:

**12. Can measles vaccine or MMR vaccine cause autism or other kinds of brain damage?**

In 1998, a British physician named Dr. Andrew Wakefield described 12 children whom he claimed had a new and unique form of bowel disease. Most of the children also were said to have autism, although that diagnosis was not confirmed. Dr. Wakefield claimed that symptoms of autism in these children developed soon after immunization with MMR vaccine. Dr. Wakefield proposed the following theory in which he linked measles vaccine and autism:

1. MMR vaccine may produce damage to the bowel;
2. The bowel damage leads to either

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<sup>38</sup> A Google search produced 49,600 hits in 0.35 seconds on June 17, 2009.



- impaired absorption of vitamins or micronutrients, or
- an increase in intestinal permeability to protein,

3. Either state leads to the formation of antibodies (antibodies that attack tissues in the body) that damage the brain.

**There is NO scientific evidence to support Dr. Wakefield's theory.**  
(Health Canada. 2002 emphasis in original).

The explicit debunking of Dr. Wakefield's theory by Health Canada demonstrates recognition of the popularity of the theory in popular and vernacular culture. Regardless, many vaccines have become thimerosal-free in recent years, but statements concerning removal are often not enough for many vaccine safety activists such as Dr. Mercola:

Many will say that thimerosal [sic] is not in the vaccines any more. Well last summer Congress "strongly recommended" that the Pharmaceutical Company take the thimerosal [sic] out of vaccines....it was not mandated; simply recommended. The drug companies were not told to take the existing lots off the market. The recommendations only applies to new product line manufacture. An unknown amount of vaccine was/is still on the shelves.

Now the twist:

Yes, the new vaccines are supposed to be thimerosal-free, but I'm not sure that they are. In addition, it is unknown when you get a vaccination if you are getting a "new lot" or an "old lot." It is unknown exactly when the new thimerosal-free vaccines went into effect and were available in the market. In addition, if you were vaccinated with an old lot, or vaccinated previous to last summer, you got a dose of the mercury.

NOW the "big marketing push" for vaccines, in 6 color glossy is "this vaccine is THIMEROSAL-FREE!!!!" ....as if they had no idea before last summer that mercury was a problem. And, in response to "YOUR CONCERNS (even tho [sic] unfounded), oh faithful followers, we are making a new, and safe vaccine." (Mercola 2001)

The MMR/Autism link was by far the most well-known anti-vaccination belief among all of my informants. Eighty-one percent of those I interviewed in the lay

community had heard of it overall, and all of those I interviewed with some medical training and/or parents knew about it. It is the most widely publicized of all of the anti-vaccination narratives. Part of its popularity may also come from the support it has received from celebrities. For example, Robert F. Kennedy, Jr. spoke out numerous times concerning the link between autism and MMR and is affiliated with the website [putchildrenfirst.org](http://putchildrenfirst.org) (Kennedy Jr. 2005), and Jenny McCarthy first began to discuss her child's autism on Oprah (Airdate: September 18, 2007). McCarthy later started her own website, Generation Rescue, and has posted a variety of videos there.

The information concerning the MMR/Autism link is frequently confusing. Doctors and pro-vaccine organizations have declared these vaccines to be safe (Centers for Disease Control), but statements such as the following have a strong Internet presence:

The recognition that some children could be exposed to a cumulative level of mercury over the first six months of life that exceeds one of the federal guidelines on methyl mercury now requires a weighing of two different types of risks when vaccinating infants. On the one hand, there is the known serious risk of diseases and deaths caused by failure to immunize our infants against vaccine-preventable infectious diseases; on the other, there is the unknown and probably much smaller risk, if any, of neuro-developmental effects posed by exposure to thimerosal. The large risks of not vaccinating children far outweigh the unknown and probably much smaller risk, if any, of cumulative exposure to thimerosal-containing vaccines over the first six months of life. Nevertheless, because any potential risk is of concern, the Public Health Service, the American Academy of Pediatrics, and vaccine manufacturers agree that thimerosal-containing vaccines should be removed as soon as possible. Similar conclusions were reached this year in a meeting attended by European regulatory agencies, the European vaccine manufacturers, and the US FDA which examined the use of thimerosal-containing vaccines produced or sold in European countries. (Joint Statement of The American Academy of Pediatrics and the Public Health Service 1999)



The thimerosal issue seems a matter of common sense for many in the lay public. If you put too much of any one substance into a human being, there will be an effect. If that substance is known to be harmful, it can only be assumed that harm will come to the person who is given the substance. Many websites also express concern over the sensitising affects of mercury and other vaccine ingredients, believing these to be the cause of ailments such as allergies and other diseases.

The MMR/Autism link does demonstrate the power of legend, rumour, and belief. Even though medical research proves there is no link between thimerosal and autism, thimerosal was still removed from many vaccines in response to these narratives, showing that anti-vaccination belief can affect policy and influence research.

#### **“Natural” Ingredients That Should Not Be in Vaccines**

Although ingredients that occur naturally are more acceptable to those involved in the vaccine safety movement, they may not be perceived as suitable if they are alleged to be atypical or against the norm of what should be put into the body. Using herbal or plant materials is often seen as preferable, while the use of maggots or bee stings may be deemed as not ideal, but better than their biomedical counterparts. Certain prescriptions, such as the use of Premarin for menopause (which was made of pregnant mare urine), was disconcerting to some, but still considered better than a chemical substance. However, there are certain substances, although naturally occurring, which fall completely out of this category, such as monkey kidneys or DNA, aborted foetuses, or any materials made from animal substances for those opposed to this treatment of



animals. Even chicken egg embryonic materials can induce allergic reactions or be less than desirable to those opposed to animal testing or the eating of animals. One anti-vaccination site clearly states these substances are used in vaccines:

Vaccines are also grown and strained through animal or human tissue like monkey kidney tissue, chicken embryo, embryonic guinea pig cells, calf serum, and human diploid cells (the dissected organs of aborted human fetuses as in the case of rubella, hepatitis A, and chickenpox vaccines). (Day 2000)

However, Health Canada states the following on their website:

No vaccine contains human blood or serum. Trace amounts of human albumin (a protein fractionated from whole blood) are used as a stabilizer in rabies vaccine and other vaccines. No vaccine contains animal or human cells. (Health Canada 2002)

The CDC has a much more comprehensive list of six pages in PDF format (see Appendix Two), which clearly states the ingredients in various vaccine. For example:

Human Diploid Tissue Culture MRC-5	Hepatitis A ( <i>Havrix</i> , <i>Vaqta</i> ), Hepatitis A – Hepatitis B ( <i>Twinrix</i> ), Polio Virus inactivated ( <i>Polovax</i> ), Rabies ( <i>Imovax</i> ), Varicella ( <i>Varivax</i> )
Human Diploid Tissue Culture WI-38	Rubella ( <i>Meruvax II</i> ), combination vaccines containing it, Varicella ( <i>Varivax</i> )
Monkey kidney tissue culture, Vero (Vervet or African Green Monkeys)	DTaP-Hep B-IPV (polio virus component <i>Pediarix</i> ), Polio virus inactivated ( <i>Ipol</i> )
Mouse brain	Japanese encephalitis ( <i>JE-Vax</i> )

(Centers for Disease Control 2007 “Vaccine Ingredients”)

As far as I have been able to deduce there are some differences between American and Canadian vaccines, both in their production and ingredients. However, I was not able to find any reliable information, even on the vaccine manufacturers’ websites. Health

Canada assures Canadians that their vaccines are thimerosal free, but does not address many of the concerns mentioned by informants.

Parents have had a passionate response to this as well, as is demonstrated through these examples I found on an open online message board. One parent responded online to a public board that she felt the Canadian system was better since it was not as interested in profit as the American health system:

Yes you are right on this, however it also means that even when I was on the Health Canada websites they had a strong bias that vaccines were good....This is Health Canada's propaganda, they will only show you one side. Just like doctors get kickbacks for prescribing even when they shouldn't and Nestle exploits early infancy with formula samples against the WHO code. Both formula and prescriptions are necessary HOWEVER sometimes I think the means in which we come by them are not always good. (Kids in Victoria<sup>39</sup>)

Another parent also commented that many of the medical professionals themselves are often unaware of what is found in vaccines:

The nurses and doctors DO NOT KNOW 100% of the ingredients found in the vaccines - they are given one set of ingredients that are for public disclosure, however, due to GMP & MRA programmes that Health Canada participates in, the vaccine manufacturer's are protected from having to share proprietary secrets with the general public (including nurses & doctors). (Kids in Victoria)

Although I have not found any vaccine legends concerning whole bodies or animals found in the production of vaccines themselves, Domowitz offers variants of the legend which include the motif "human flesh eaten unwillingly".<sup>40</sup> This motif includes narratives about entire bodies and/or human body parts in vats, and variants on both the contents and the containers of the above examples, such as cremated remains eaten unwittingly, a

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<sup>39</sup> Kids in Victoria is a vernacular parenting website which offers an open forum.

<sup>40</sup> Motif X21 (Thompson 1935).



mouse found in a Coke bottle, bodies in barrels of alcohol which have already been drunk, and dead cats in a barrel of cider (Domowitz 1979: 86-89). Previously mentioned narratives state that human or animal parts are used in the production of vaccines; however, the greater fear is human foetuses in vaccines, an injectable form of cannibalism. At this time, there are still vaccines on the market which use human diploid cells harvested from human foetuses. Although there has been research done to remove human foetuses from the production of vaccines, their use has proven to be one of the safest ways to produce the vaccine since other materials, such as other species or chemicals, may have negative effects on humans (Life Canada 2007).

Catholic organizations have spoken out against the use of foetuses, but they do not necessarily condemn the use of vaccines. The Catholic Medical Association released the following via their website:

....the Catholic Medical Association makes the following recommendations to ensure that vaccines produced in ethically acceptable ways (hereinafter referred to as "alternative vaccines") are made available as soon as possible.

- 1) When alternative vaccines are available, they must be used in place of those produced by immoral means.
- 2) When no alternative vaccines are available "it is right [permissible] to abstain from using these vaccines if it can be done without causing children and indirectly the population as a whole, to undergo significant risks to their health" ("Moral Reflections on Vaccines Prepared from Cells Derived from Aborted Human Foetuses" Pontifical Academy for Life, June 2005). In forming their consciences, parents should be aware that there is no absolute guarantee that an unvaccinated child will not expose a non immune pregnant woman to risk of infection with rubella.
- 3) When no alternative vaccines are available, it must be reaffirmed that the use of vaccines whose production is connected with acts of procured aborting is lawful "on a temporary basis" and "insomuch as is necessary" ("Moral Reflections on Vaccines Prepared from Cells Derived from Aborted Human Foetuses" Pontifical Academy



for Life, June 2005) to avoid significant risk to the health of an individual or community.

- 4) When no alternative vaccines are available there is a "moral duty to continue to fight and to employ every lawful means ("Moral Reflections on Vaccines Prepared from Cells Derived from Aborted Human Foetuses" Pontifical Academy for Life, June 2005) to pressure the pharmaceutical industry, government authorities and national health systems to make ethical alternatives available. Immediate action should include petitioning the FDA to allow for licensing and importation of safe and effective ethical alternative vaccine such as Takahashi (rubella) and Aimmugen (Hepatitis A). In addition, we encourage accurate labelling and informed consent for the use of all vaccines derived from cell lines connected with acts of procured abortion. (Catholic Medical Association 2005)

In addition to the many concerns over the use of human foetuses, there is also apprehension over the use of human materials in general and their ability to revert back to their former state, specifically that an inactivated vaccine may become virulent again:

The viruses against which the vaccine is supposed to protect are frequently said to be "killed", "inactivated" or "attenuated". This is a myth. The main method used to inactivate viruses is treatment with formaldehyde, whose effectiveness is only limited, and even then only temporary - once the brew is injected into the body and disperses, it is documented in orthodox medical literature that these "killed" viruses can revert to their former virulence. (Vaccine Information Services: Who Do You Trust, Nature or Man? 2007)

Cases such as these were prevalent throughout vaccine history, as demonstrated in 1950's during the Cutter Incident (discussed in Chapter Two), which shows that these fears are not unfounded. I was surprised to find that less than fifteen percent of my informants had not heard that vaccines contained human materials or that they had heard that information and immediately dismissed it as false. One informant stated, "Yeah, I heard that once, but there's no way there's dead babies in vaccines. They wouldn't, no, they couldn't do that. People would freak out. That has to be an urban legend" (Interview with lay person with

children. May 14, 2007). My informant thought that the issue of abortion was too volatile and believed that there were laws in place preventing the use of aborted fetuses. The same informant believed other legends and conspiracy theories previously mentioned, which have been denied by the medical profession. This is intriguing since it demonstrates how belief structures are not accepted whole and can vary significantly from person to person.

As previously mentioned, the use of animal tissues, such as embryonic chicken material and monkey fluids, concerns the public. For those allergic to eggs, the risk of disease is easier to accept. However, there are other diseases associated with the use of animal tissues which are not so easy to classify, such as SV40:

Some of these (animal viruses) can be particularly alien to the human body. The most frequently documented and publicised example is the monkey virus SV40. This is harmless in monkeys, but inject it into a human and it can cause cancer – in the brain (tumours), bone (e.g. multiple myeloma), lungs (mesothelioma) and lymphoid tissue (lymphoma). It has appeared in people born in the last 20 years (The Journal of Infectious Diseases, Sep 1999;180:884-887)<sup>41</sup>, long after the manufacturer claimed to have "cleaned up" the polio vaccine in which it was found. Such cases include the late Alexander Horwin, both of whose parents tested negative for SV40, therefore recent cases cannot just be blamed on inheritance from parents who received the vaccine (see [www.ouralexander.org](http://www.ouralexander.org)). (Vaccine Information Services: Who Do You Trust, Nature or Man? 2007)

SV40 has been the subject of debate over the years and has found its way from the Internet and conspiracy groups into books and the media. Believed to be a virus from monkeys (SV stands for "Simian Virus"), it is thought to be highly contagious and almost impossible to eliminate from labs. Additionally, it spreads in a manner similar to

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<sup>41</sup> The article referenced here is Butel, Janet S., Amy S. Arrington, Connie Wong, John A. Lednicky, and Milton J. Finegold. 1999. Molecular Evidence of Simian Virus 40 Infections in Children. The Journal of Infectious Disease 180: 3. 884-887.



HIV/AIDS (through human bodily fluids) and is said to increase its infection in the population by three percent every year (Bookchin and Schumacher 2005: XVI). Although the medical community recognizes this virus, they have maintained that it is harmless to humans (Centers for Disease Control 2007 "Polio and Cancer").

The CDC has issued statements on SV40, but these statements can be confusing to the public. The CDC admits the polio vaccine was contaminated with SV40; but states that this is not the only way to be infected:

Receiving contaminated vaccine is not the only way to become infected with SV40. Data suggest that SV40 has infected a small percentage of the human population independently of the polio vaccine. A study of German medical students found that 12% had SV40 antibodies in 1952, before the introduction of the polio vaccine (Geissler et al., 1985). Moreover, SV40 has been identified in people born in the 1980s and 1990s, well after the elimination of SV40 contamination from polio vaccines. This has led some to consider that the virus may spread from person-to-person. Some laboratory workers may have been exposed to SV40 (Horvath, 1965). It is not known whether people who live in countries with wild rhesus monkeys also could be exposed to SV40. Exactly how SV40 is transmitted among humans and how common it is among people in the U.S. population are unknown. (Centers for Disease Control. "Polio and Cancer")

The CDC also questions the clarity of the link between SV40 and certain types of cancer:

SV40 is known to cause tumors in rodents. Have research studies found an association between SV40 and cancer in humans?

Yes. An association has been found between SV40 and certain types of cancer in humans. However, though the virus or its DNA have been found in certain types of cancer, it has not been determined that SV40 causes these cancers. Finding that two events are "associated" is not the same as establishing that one event caused the other.

SV40 was linked with mesothelioma after tumors developed in hamsters that were injected with SV40 into the lungs, heart and abdomen (Cicala et al., 1993). Mesotheliomas are rare cancers usually located in the lining of the lungs in humans and are associated with asbestos exposure. SV40 has



been found in 47% to 83% of human mesothelioma tumors (Carbone 1999). In addition, reports have documented an association between SV40 and brain and bone tumors (Jasani 2001).

Two recent studies also found an association between SV40 and non-Hodgkin's lymphoma (Shivapurkar et al., 2002; Vilchez et al., 2002). These studies identified the virus in 42 to 43 percent of non-Hodgkin's tumors, while finding no SV40 in tissue from healthy study volunteers. Lymphoma is a general word for cancers that develop in the lymphatic system – the tissues and organs that produce, store and carry white blood cells that fight infection and other diseases. Hodgkin's disease is one type of lymphoma; all others are called non-Hodgkin's lymphoma. Lymphomas account for about 5 percent of all cases of cancer in this country. (Centers for Disease Control. "Polio and Cancer")

Vaccine safety activists, including Barbara Loe Fisher<sup>42</sup>, have found it strange that the CDC refuses to acknowledge a link, and have questioned their reasoning and research:

Today, there are scientists associated with the US government who continue to deny that SV40 causes human cancer or that SV40 associated cancers have had any effect on cancer rates since the early 1960's. However, highly credentialed non-government scientists in multiple labs around the world continue to identify SV40 in human brain and lung cancers of children and adults and are finding that SV40 is also associated with bone cancers and Non-Hodgkin's Lymphomas. The majority of these independent scientists have concluded that, yes, SV40 does cause human cancers. And in a report published in 2001, the Institute of Medicine Immunization Safety Review Committee stated that "in light of the biological evidence supporting the theory that SV40 contamination of polio vaccines could contribute to human cancers, the Committee recommends continued public health attention in the form of policy analysis, communication and targeted biological research. (Fisher 2003)

During the course of my research, I was fortunate to interview someone who was intimately involved with SV40 research and currently lives in Newfoundland. While

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<sup>42</sup> Barbara Loe Fisher is the co-founder and president of the National Vaccine Information Center (NVIC) and is a well-respected member of the vaccine safety community. She is frequently asked to report and testify on a variety of vaccination topics.

living in Britain, he both worked in the public health laboratories as well as Glaxo. He recounts his personal experience working with SV40 in the 1960s and 1970s:

....I actually was involved in identifying SV40 in the monkey kidney cells that we were using to grow, but what we tried to do of course was to monitor each patch of cells and before they were used for vaccine use to if a patch of cells had a Simian virus in it, then it was never used for it. But the trouble was in the very early days, nobody recognized that SV40 was there. Okay, and so that was one problem and then that was well in Britain Oral polio vaccine, the Glaxo vaccine, was the first one to be licensed in 1963. And I would say that unless you know, and I am trying to remember the exact date, some time in the late '60s, depending on country, and the late '60s or early '70s, they went over to using human diploid cells for growing polio vaccine and so of course that did away with the risk absolutely at that point of time. But I would have said from 1964 onwards at least Glaxo, we were picking up most batches of cells which were contaminated with SV40. That probably was an absolute and so there was still the risk there, like it wasn't an easy virus to identify. There were other simian viruses, monkey viruses particularly SV5.... which was much easier to identify, you see many viruses when they are in cells have a particular what this cool Cytopathic effect on the cell. And changes the shape of the cell or creates vacuoles within the cell or whatever and if you see that happening in the cells and you know the cells are contaminated with a virus. Equally in the early days, these days we are really using far different techniques but in the early days when we were trying to isolate the virus from a human being we inoculate the specimen in the cells and then look for typical changes to the cells, let the virus remain okay. And so that was the way that we were attempting to pick up SV40 in the early days. And so as to say there was no doubt that some of the very early batches of vaccine, we didn't know whether SV40 was there or not and probably was in the public carried through into the vaccine because unlike kill polio vaccine with oral polio vaccine, obviously there was no virus in activation process because we were using a live virus. (Interview with medical professional. January 17, 2008)

My informant did not feel that this was a problem since time has proven SV40 is not harmful to humans:

And you know I think that there is no doubt on quite a number of people apply for those numbers may be, may have been given SV40 virus in oral polio vaccine in those very early days. But I think the real issue is here we are now over 40 years down the road and as you know there has been a



number of studies to look at whether the rates of cancer for instance are higher in people who had those early batches of vaccine compared with other people and there has been well there has been no evidence which has been detected and so at least you know from the point of view of reading the book<sup>43</sup>, you know he almost implies so there would be large very large increase in lung cancer....But. I think we are past it by now. I think you know we have passed that, there is no doubt it was a huge natural experiment but I think we are past the risk point of view and the other thought point of view from the public. The other message from the public point of view is that, this is were it comes around to your research is that from 1970 roughly onwards it definitely is a myth because the vaccine was no longer made in monkey kidney cells anyway.

Author: Okay and so there won't be even a possibility at that point. Yes I still remember the book also said that, it talked a lot about how it spread and that SV40 can be spread through, you know, similar to the way that AIDS has spread through human saliva and I wasn't sure of that.

Informant: I don't think there has been ever been any conclusive evidence of human to human spread of SV40. Many viruses as you probably know are relatively species specific and so something which may cause, while another virus very dangerous virus, another monkey viruses I think Simian B virus which is a Herpes virus and it causes like hepatic like lesions in monkeys, but just as Herpes virus causes Herpes in humans. But, Simian B virus is lethal to humans. We had unfortunately, not during my time but, Glaxo, two monkey handlers who were bitten by monkeys with Simian B and both died. But that is just; I am just using that as an example that a virus in one species does not necessarily do the same thing in another. (Interview with medical professional. January 17, 2008)

As my informant has stated, many viruses have different results in other species. He believes SV40 to be an example of a virus that does not affect humans. He also points out that this is true with laboratory studies using animals:

I think there is no doubt that SV40 is antigenic. I did some experiments when I was at Glaxo injecting SV40 into laboratory animals and can certainly cause cancers in the laboratory animals with SV40. But, on the other hand then it is a huge jump to say that it will cause cancer in

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<sup>43</sup> The book he is referring to is *The Virus and the Vaccine: Contaminated Vaccine, Deadly Cancers, and Government Neglect* by Debbie Bookchin and Jim Schumacher.



humans. Because there are a number of things which will cause cancer in laboratory animals.

Author: And you are talking about different species again, too.

Informant: It is different species but also you have got the viral load that is necessary in a small animal you might need much less virus than you do in a big animal. (Interview with medical professional. January 17, 2008)

My informant states that SV40 is not a threat to humans, merely another virus which has no effect on the population. He also feels that SV40 was not something that anyone tried to hide, just something that was told to the public, then exploited by a journalist.

Other forms of contamination which are linked to the use of animal materials exist, but are less common than SV40, as seen in this newspaper series:

The British vaccine manufacturer Medeva has a horrendous record of contamination and blunders. In 2000, the FDA found that Medeva was making vaccines in conditions of filth, resulting in contaminated products. Medeva had been illegally using bovine medium to culture its polio vaccines, then lied about it. Medeva also used the blood of a Creutzfeldt-Jakob victim (mad cow) to manufacture 83,000 doses of polio vaccine used for (against?) Irish children. Nevertheless, the FDA allowed the USA to accept Medeva's flu vaccine (Fluvirin) for the year 2000. (London Observer Series 2000)

A common fear of the lay public is that the animal elements in vaccines cannot be filtered out, thus causing potential unwanted exposure to animal materials. Although some protest this issue from an animal rights standpoint, the majority are simply concerned with a foreign material being placed in the body. Their fears are often not linked to a specific illness or condition, just to the general idea that there is something unknown in their body.

I was surprised to find that very few of my informants had heard of SV40, perhaps because many of them did not question the need for the polio vaccine. I found

that while people questioned MMR, the flu shot, the chicken pox vaccines, and hepatitis, they did not question the polio vaccine. Perhaps the ravages of polio are still too recent in cultural memory for it to be questioned.

### **Improperly Stored Vaccines**

The concept that a vaccine is safe until the moment it is stored improperly is also of concern to parents, who are aware that certain chemicals change composition if there is a change in their environment. One parent remarked: "I know wine changes if it's not stored properly, why would a vaccine be any different? I mean, why would they put those warnings on the bottles about which temperature to store the vaccine at if it didn't matter?" (Interview with lay person with children. November 6, 2007). Research indicates that it is for purposes of efficacy that vaccines must be stored properly:

Vaccine susceptibility to loss of potency from out-of range temperatures depends on several factors including the presence of an adjuvant in the vaccine, whether the vaccine is live or inactivated, and whether the vaccine preparation is liquid or lyophilized. Vaccines can be categorized as heat-sensitive or freeze-sensitive. Heat-sensitive vaccines include live attenuated vaccines that are stable at freezing temperatures but lose potency after exposure to temperatures above the recommended range. Freeze-sensitive vaccines contain aluminum adjuvants and irreversibly lose potency when exposed to freezing temperatures. Freeze-sensitive vaccines require storage at 2 to 8°C and can lose potency even without visible signs that freezing has occurred. Storing freeze-sensitive vaccines above the recommended temperature range results in a more predictable and gradual loss in potency. Storage-temperature ranges for vaccines can be found in the package inserts, the Red Book, the general recommendations, and from the CDC. (Pickering, Wallace, et al. 2006. 1738-1739)

A few of my informants (less than ten percent) mentioned that the efficacy of the vaccine can change or that the chemical composition can change to cause disease. Informants



were also non-specific about the types of disease it could cause, mentioning only that they had heard the breakdown in chemicals could causes diseases related to unnatural substances in the body.

The fear of certain chemical breakdowns has lead to conspiracies about vaccine “hot lots” on the Internet. “Hot lot” is the nickname given to a group of vaccines with the same lot numbers that cause a high number of adverse reactions. These hot lots are often not reported. Even when there is a large number of adverse reactions from a vaccine reported, the FDA (Federal Drug Administration in the United States) does not remove these vaccines from circulation, since there is no way of knowing for sure if the reaction was caused by the vaccine or some other source (Fisher “Hot Lots”, Offit et al. 2003). The majority of my informants (approximately seventy percent) were not aware of the term “hot lots” and had not thought to look into the lot numbers of vaccine batches. One informant mentioned that she did ask in advance for the lot numbers on her child’s vaccines and was told it would not be possible for her to have that information. Even though the information was offered to her after the vaccination, she was upset since the vaccine had already been given and she could no longer check the lot number to see if it was safe.<sup>44</sup> Another informant, who was present at the time, told us not to worry, she was sure that if there ever was a bad batch of vaccines, everyone would know about it quickly, since this information would be “spread around the island faster than any Internet connection” (Interview with lay person. November 6, 2007).

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<sup>44</sup> This informant asked not to be quoted directly, but consented and approved of the use of her story and my version of it.

### Characteristics of Contamination Legends

Contamination legends have the following characteristics, according to Susan Domowitz: 1) Pre-packaged food is bought or food is ordered from a fast-food or ethnic restaurant, 2) A horrifying or disgusting substance is found in the food, usually after some of it has been consumed, 3). The substance is usually a part of a human being or animal, 4) Evidence is produced either for or against the truth of the reported incident (1979: 86). If we consider these characteristics, we see a similar pattern in vaccine contamination legends:

1. Many of the vaccines come "from away" (i.e., they are not made here and/or are made by unknown people);
2. The vaccine is given and later on found to contain something it was not supposed to, typically either a disease (most of which come from our close contact with animals) or;
3. An unknown substance such as a chemical or animal part such as egg embryo or monkey kidney, foetus and;
4. Finally, the issue is widely debated on the Internet as well as other places.

Legend scholars have observed that in both contemporary legends (in general) and contamination legends (specifically) most of the victims tend to be female. This has been associated most commonly with the idea that women are perceived to be more vulnerable to attack than their male counterparts (deVos 1996: 136). As Fine mentions, these legends also serve to remind women of their "traditional role":

Female victims eating at fast-food restaurants also symbolize the loss of traditional values that tell women to stay at home and prepare the meals for the family. She, by neglecting her traditional (and proper) role, helps to destroy the family by transferring control from the home to "amoral profit-making corporations". According to the legends, therefore, she deserves to be appropriately punished! (1980: 222-223)



Although it would be presumptuous to assume that this is the only reason why this legend exists (especially given that women tend to be in charge of family health), vaccine legends certainly function as a warning to parents to make sure they know what they are giving their children. It reminds them that they need to be vigilant and that they have an additional responsibility in their lives. However, it would be short-sighted to say that there is not an element of guilt involved, especially for working mothers. All of the mothers I interviewed (twenty-seven in total) either directly stated or hinted that child-rearing was hard; they felt others expected a lot from them, or at least more than they expected from their male counterparts. While this may not be the key to the reason why vaccine stories are told, the warning is certainly a contributing factor. Kapferer suggests that, in the case of food contamination legends, there is a neglecting of the "traditional role" of wife and mother, which puts the entire family at risk (Kapferer 1990: 153). Many of the women I spoke with told me that they wished they knew more about vaccines. Often they did not have the time to do the research while raising a child and (sometimes) pursuing a career. These women reported feeling frustrated and guilty about not knowing this information. It was something they felt they should know. They also reported they felt that their mothers and grandmothers did not have the same worries.

As mentioned in Chapter Two, there is a documented fear of human or animal contamination in vaccines, going at least as far back as Gilfroy's cartoon of Jenner from 1802. Western society has very strong ideas about what does and does not belong in the body, things which cross this barrier are feared, which is perhaps why so many people fear doctors, shots, and surgeries. We are used to considering the skin as a barrier which

protects us from the outside world, and we have a long-standing tradition of seeing the body and its defences in a militaristic way (Martin 1995). Since we perceive our body as a defence system, it is only natural to perceive anything that enters the body through the skin as an enemy, or at least perceive it as not being the norm. Mary Douglas noted that the body itself is “a model which can stand for any bounded system. Its boundaries can represent any boundaries which are threatened or precarious” (2002: 142). The entire act of vaccination crosses already established boundaries, which automatically causes suspicion. Additionally, the idea of something foreign, especially an animal, entering the body may be seen as having moral implications and is symbolic of a primeval or sinful nature (Bennett 2005: 11-13). Even more concerning are people, especially women, who allow or prefer animals to contaminate their bodies, which is seen as threatening or going against nature (Whatley and Henken 2001:127-129). In Newfoundland, we see even more specific concepts of purity within the body. Not only does the body need “inner cleanliness” (typically through the use of tonics and laxatives), but it is thought that the blood can become impure as well, causing conditions such as mental illness (Crellin 1994: 22-23).

North American culture is very “personal space” oriented, which is evident from the distance comfortable for conversation to the number of people who typically live in one dwelling. The idea of anything getting that close, especially something which is perceived to be disgusting or unknown, can be terrifying on many levels. This is exacerbated by the idea of such a thing happening to a child, whom parents are expected to protect. The entire process is counter-intuitive to much of what society teaches us.



Contamination narratives are very common, both in the context of vaccination and other aspects of technology, such as food production. This certainly indicates there is a fear and an awareness that vaccination is not fool-proof and that many people are aware of the risks. How people choose to proceed with this information differs; however, all involved are concerned with childhood illnesses and their prevention.

### **Contamination Narratives**

An overarching theme of all of these legends is contamination. As noted above, contamination legends are very common in the canon of contemporary legends, especially legends which concern contaminated food. As far back as the fourteenth century, there were mass poisoning legends blaming Jews for contaminating local wells and causing the Black Death (deVos 1996: 132-133). Mass poisonings are also associated with wartime crimes and sabotage, with the enemy putting shards of glass into food or drink as a method of harming the other side (deVos 1996: 133). Of course, as deVos demonstrates, not all of these legends were false. Public debate over Upton Sinclair's *The Jungle* led to a closer look at slaughterhouses and the beginnings of regulations and inspections of food products (deVos 1996: 133):

Legends about contaminated food reflect some legitimate health concerns. Pre-packaged food with extended shelf life contain substances that, although not dangerous to humans, are not actual sources of nourishment either. Here again, it is people's lack of understanding about the technology of modern food manufacturing that lies behind the anxiety demonstrated in these legends. (deVos 1996: 133)

This is additionally true of contamination legends concerning the use of non-natural materials in vaccines. Like food, there is debate among vaccine safety advocates

as to whether or not these products are safe for humans. Frequently, prolonged exposure is part of the problem. The ingestion or injection of a non-natural substance may be fine if infrequent, but prolonged usage or exposure to chemicals like aspartame or mercury is harmful. An additional concern expressed by approximately half of my lay informants is that since children are so small, they are more sensitive to the dosage:

In his 2002 article published in Pediatrics, Dr. Paul Offit asserts an extrapolated mathematical formula demonstrated that children can be vaccinated with thousands of vaccines without harm. "Each infant would have the theoretical capacity to respond to about 10,000 vaccines at any one time."

It appears that Dr. Offit should undertake a review of human immunology. The idea that 10,000 doses of chemicals, viruses and bacterial bits could uneventfully be deposited into the blood stream of an infant or an adult without consequence defies medical logic. The direct injection of pathogens into the body bypasses the first four lines of immune defense: the skin, the mucous membranes, the intestinal lymphoid tissue and lymphatic neutralization. Unlike the claims of the pharmaceutical companies, the introduction of germs and chemicals into the blood stream does not "trick" the immune system, as claimed by doctors and researchers. **It contaminates it.**

In fact, children are contaminated with up to 51 vaccine antigens by the time they are six months of age. If they receive all doses of all recommended vaccines, including annual flu shots and boosters for MMR and chickenpox, that number skyrockets to 113 by the time that they enter school. And that number doesn't take into account the measurable amounts of formaldehyde, aluminum, calf serum, gelatin and other chemical aliquots injected with each vaccine. (Tenpenny<sup>45</sup> 2002 emphasis in original )

These outside contaminants are also perceived by many of my informants to be in our foods. DeVos mentions another issue concerning preservatives:

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<sup>45</sup> Dr. Tenpenny's website offer alternative medical information as well as books and videos. She is a doctor of osteopathic medicine.



There is also an underlying concern that our emphasis on pre-packaged, fast-food nourishment may be wrong, either morally or nutritionally. 'Food may be contaminated with substances which poison not our physical beings, but which corrupt of social, cultural, and moral identities' (Clements 1991, 42.) Contamination legends reflect modern society's fears of flouting traditional mores about food and about ignoring more recent nutritional guidelines, such as the low-fat diet. (deVos 1996: 133)

Parents reported concerns about everything they put in their child's body – both food and vaccines.

You have to be a supermom these days. I have to know everything they're getting, everything that goes in their mouth and other kid's mouths because of allergies these days. I don't even want to get into the pressure of what needles to give them. I already agonize over everything. They shouldn't have sugar, they can't have honey, that kid is allergic to peanut butter. Feeding them alone is a full time job. Don't even get me started on the needles. (Interview with lay person with children. August 6, 2007)

Parents perceive the pressures of raising children to be different than in the past, they feel that more is expected of them and that they are seen as "bad parents" if they do not know everything about their children. Informants reported feeling frustrated and overwhelmed, and stated that they were told by more experienced parents to question everything people tried to give their children. However, Crellin states that historically mothers in Newfoundland have always expressed concerns over the quality of their families' nutrition, and have stated that they feel overwhelmed by the choice of medicines available (Crellin 1994: 25). This questioning over the ingredients of both food and vaccines is seen as acceptable and appropriate behaviour by other parents and family members, causing my informants who were new parents to feel that they should question everything.

## Conspiracy Thinking

Conspiracy thinking is an important part of vaccination discourse and is articulated in a variety of ways, including through legends, rumours, and gossip. Conspiracy theories have been seen as a separate entity from other forms of folklore, primarily by other disciplines such as psychology; however, it is their content rather than form that makes a conspiracy. Throughout this chapter I will refer to “conspiracy narratives” not to define them as something different from the forms they often take, but rather to address the content. Additionally, I use the term “conspiracy thinking” (Smith 2009; Zonis and Joseph 1994) to describe the belief behind the content of conspiracy narratives.

It should also be noted that conspiracy thinking exists on a spectrum. Movies and other media frequently picture conspiracy theories as outlandish, much in the way that the term “folklore” is used by non-folklorists as a synonym for “falsity.” Campion-Vincent’s definition of conspiracy, which is based on its cognitive attributes, is preferred for this study. She lists the characteristics of conspiracies as follows:

1. A specific agent(s) is named, with a clear motivation.
2. The agent is evil, the outcome is destructive, which is easy to understand—evil results in evil—and not a complicated and probably more accurate explanation of complex events with unintended consequences of multiple intersecting agents and actions.
3. The evil agent has the capacity for some big event—controls important resources, acts united or with powerful allies, does it in secret, and thus nobody stops it.
4. Conspiracies sometimes do happen, and everyone agrees that they have at times.



5. Some learned, respected, prominent people, not just ignorant marginal people, promote the conspiracy theory—they may be self-serving, but they cannot be ignored. (Anthony Oberschall, personal communication with Veronique Campion-Vincent, October 19, 2003 as cited in Campion-Vincent 2005: 104-105)

By using this as the defining features, the variety of conspiracy narratives can be discussed by their attributes rather than opinions of truth or falsity.

Conspiracy thinking has been perceived as irrational; however, Basham notes that it might be just as irrational to assume that no one is conspiring against us as it is to assume that someone is. Basham asserts:

The conspiracy theorist has compelling cause to suspect that today's society suffers a serious and unavoidable prior probability of conspiracy. Conspiracy is all too human. In our personal lives most all of us have encountered the existence of treacherous disloyalties, conspiratorial sexual infidelities, carefully crafted business betrayals, and life-crippling slander that, insidiously, are sometimes never revealed to the victims. (Basham 2003: 271)

It is useful to consider conspiracy thinking from another perspective, offered by Paul Farmer, which he calls the "hermeneutic of generosity". This viewpoint asks that we "proceed as if our informants were themselves experts in a moral reading of the ills that afflict them" (Farmer 1992: 235) as a way to lead us to "an interpretive analysis accountable to history and political economy, the force fields from which the conspiracy theories initially arose" (Farmer 1992: 235). Through the use of the hermeneutic of generosity, one hopes to address the concerns of the lay public and discuss why these narratives are expressed, rather than focusing on their plausibility, which has been the focal point of much of the work done on conspiracy thinking. Turner states:

Those of us who have fielded the calls and emails from journalists know to prepare for several predictable questions. The first is always about the origins, reporters expect rumor scholars to identify the parties who were in the first exchange of the texts and when and where the conversations took place.

Most of their questions focus on plausibility. If they themselves have been taken in by a text, they are likely to ask the rumor scholar to prove it is false, to prove that one had their stomach pumped after eating a Kentucky Fried Rat. If they personally find the rumor ludicrous, they want an explanation for why any logical human being might draw a different conclusion – how could any sane, smart person believe that the government created the HIV virus as part of an experiment in biological warfare? (Turner 2005: 169)

Although Turner is discussing rumour specifically, the content of the form of folklore is the issue, not the specific type. Conspiracy thinking exists within the content, not the genre of folklore.

Following the lead of scholars such as Diane Goldstein, Pat Turner, and Paula Treichler, conspiracy narratives is used in this chapter as a way to understand the vernacular reasoning behind the folklore of vaccination.

### **Conspiracy and Belief**

One reason conspiracy narratives are so attractive is their ability to explain data which is currently without an explanation. Keeley states:

The first and foremost virtue which conspiracy theories exhibit, and which accounts for much of their apparent strength, is the virtue of unified explanation or explanatory reach. According to this virtue, all things being equal, the better theory is the one that provides a unified explanation of more phenomena than competing explanations. Unified explanation is the *sine qua non* of conspiracy theories. Conspiracy theories *always* explain more than competing theories, because by invoking a conspiracy, they can explain *both* the data of the received account *and* the errant data that the received theory fails to explain. (2003: 119 italics original.)



Keeley feels that this is problematic due to the imperfect nature of human interpretation (2003: 120). While Keeley's assessment is reasonable, he does not go far enough, especially when it comes to the assessment of risk. For most folklorists, it does not matter whether or not something is true, it matters that someone *believes* it is true. Conspiracy theorists may try to convince others of their point of view, but their beliefs are not based on beliefs of others or whether the narrative is true. One can also see that the average person does not need to be a conspiracy theorist in order to believe in a conspiracy. It is possible to believe in one or more conspiracy theories without becoming a conspiracy theorist. Perhaps the major difference between a conspiracy theorist and a lay person who believes in a conspiracy is their focus on content and events. A conspiracy theorist may focus on the conspiratorial aspect of the narrative, for example, that the government is attempting to make vaccination mandatory for some evil purpose. The important part for the conspiracy theorist is government control – it may not matter to them what the government is trying to control. A lay person who believes in a conspiracy, however, would focus on the events and content of the narrative – why should vaccines be mandatory and what affect will that have on their lives and decisions? Due to the conspiracy theorists' focus on the conspiracy aspect of the narrative, they may also display other qualities which may distinguish them from a lay person looking at a conspiracy, such as a desire to expand or promote conspiracies, the active seeking of evidence for conspiracies, a philosophical approach to the materials, and/or membership in a group which discusses, uses, or promotes conspiracy thinking.

The narrative structure also differs between the tellers. Conspiracy theorists' narratives tend to be complex, full of detail, and provide evidentiary support, while the lay persons' narratives tend to be shorter and in a structure more closely akin to rumour. Some of the lay conspiracy narratives could be expanded by the teller and often rely on either personal experience narratives or legends, although many of my informants were also able to provide evidence for their claims – typically this evidence was found on the Internet and tended to derive from anti-vaccination websites. Although there is certainly a difference between conspiracy theorists and lay people who believe in conspiracies, there are also those who fall between. This is primarily due to the ambiguity often used in the language of the lay public concerning vaccination narratives. This ambiguity is not uncommon and has been seen in other narratives which focus on belief. As Hufford states:

It appears to allow for a constantly branching process in which hearers interpret what is heard in terms of either their own experiences or what they perceive as a cultural consensus concerning what experiences are possible. This accounts for the apparent homogeneity of meaning and belief within a given tradition which is in considerable contrast to the heterogeneity usually presented to the inquirer who seeks to compare such model representations to the statements and evaluations of individuals who partake of that tradition. It also helps to explain the enormous selectivity of communication which allows a large number of apparently unorthodox belief systems to exist within a broad cultural context, with neither constant conflict nor even general knowledge of each system by outsiders unless the system manages to become in some way fashionable. Of course, this latter possibility occurs with considerable frequency today, and the variety of the material continues to be a source of great surprise – and in some cases chagrin – to those who see themselves as adhering to a general modern consensus. (Hufford 1976: 21)

Vaccine narratives, while traditional, are in an almost constant flux while belief in them waxes and wanes. This belief is not only coloured by personal circumstances, but also by



what beliefs are currently “fashionable” and which expressions of said belief are appropriate.

### **Conspiracy Thinking, Race, and Ethnicity**

Conspiracy thinking can be quite selective in the lay community and has historical roots. This is especially true in medicine, where the belief that certain ethnic and racial groups are given different medicines and vaccines, and where legends that involve elements of racism and matters concerning trust and a lack of information, are rife. For example, approximately thirty percent of my informants believe that some countries receive inferior vaccines from Western nations, especially countries who are perceived to be “undesirable populations” or enemies. Such conspiracy narratives do not require a strong degree of belief, especially since they are coupled with the idea that minority groups receive different medications for certain conditions, something that is currently under debate since some studies have shown that medications work more effectively on different ethnic or racial groups (Bloche 2004: 2035-7N; O’Malley 2005: 291-3; Kingsland 2005: 42-7). Since both groups are receiving different medications, it is not undiscerning to believe that one of these products is better than the other. This use of different medications, conditioned with knowledge about experiments done on minorities in the past (e.g. the Tuskegee Experiment<sup>46</sup>), can lead to a shared conspiratorial thought

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<sup>46</sup> The Tuskegee Experiment was a clinical study of syphilis conducted between 1932 and 1972 in Tuskegee, Alabama by the U.S. Public Health Service. Three hundred and ninety-nine Black males, who were mostly economically challenged, were used for this experiment, which studied the natural progression of untreated syphilis. However researchers did not treat patients for syphilis, even after the validation of penicillin as a cure in the 1940s. For more information on the Tuskegee experiments, please see: Reverby, Susan M. 2009. *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy*. North Carolina:

which is less dramatic in nature. The same types of narratives are also common in HIV/AIDS legends<sup>47</sup>, including those with origins connected to vaccines (Henderson 2004, Cantwell 1992: 1, Mikkelsen 2007).

Waters suggests that conspiracy theories may be indicative of an increase in social or racial relationships and “express deep-running ethnic tensions while they influence the directions of interethnic interaction” (1997: 112). However, there is nothing irrational to these beliefs as Pratt states:

This increasingly common and, it becomes ever more clear, perceptive form of anxiety evident in popular psychology throughout recent U.S. history represents neither silly nor irrational reaction to imagined plots, but a reasonable response to the real-life experiences of real people – disadvantaged, discriminated against, lower-status groups, ethnic minorities, and women. (Pratt 2003: 258)

Conspiracy thinking as a response to the actions of the past may be a rational way of dealing with these actions.

While the issue of race is apparent in many of the HIV/AIDS legends, many of the other legends and conspiracy theories concerning vaccines may have roots elsewhere. Approximately half of my informants with a medical background felt that anti-vaccinationists tend to be middle-class with some university education, but not all anti-vaccinationists fall under this category and anti-vaccination sentiments cannot be entirely localized to a certain group, ethnicity, education level, or class.

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University of North Carolina Press.; Reverby, Susan M. 2000. *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study*. North Carolina: University of North Carolina Press.; Gray, Fred D. 1998. *The Tuskegee Syphilis Study: The Real Story and Beyond*. Montgomery, Alabama: NewSouth Books.; Jones, James H. 1981. *Bad Blood: The Tuskegee Syphilis Experiment*. New York: Free Press.

<sup>47</sup> For more on legends and HIV/AIDS, please see Diane Goldstein's *Once Upon a Virus*.



These concerns with race do bring up a matter which is often mentioned: the link between minority status and a belief in conspiracies. While some studies have noted that conspiracy beliefs are more prevalent in communities which have been exploited (Turner 1993), there are many researchers who argue that this is not the case. Simmons and Parsons' study showed that race was more of a determinant in belief in conspiracy theory than education or socioeconomic status (Simmons and Parsons 2005: 582-598). Donskis concluded that "The conspiracy theory appears as a phenomenon radically opposed to the principle of tolerance" (Donskis 1998: 360), which indicates that there may possibly be an interchange of intolerance involved in conspiracy theory belief. Those who feel victimized might tell stories to relieve or express their feelings of unfairness, but the stories themselves may contribute to greater intolerance from those different from themselves, even if they are the dominant power. Conspiracy thinking in rumour has also been identified as one of the most important contributing factors to violence, prejudice, and discrimination (Knopf 1975), and the 1968 Kerner Commission of Civil Disorders estimated that half of all racial riots were caused or exacerbated by racial rumours (Fine 2005: 3). In addition to this, Goertzel found that people tend to believe more in conspiracy theories which involve their own community. Goertzel states:

Conspiratorial beliefs are useful in monological belief systems since they provide an easy, automatic explanation for any new phenomenon which might threaten the belief system. In a monological belief system, each of the beliefs serves as evidence for each of the other beliefs. The more conspiracies a monological thinker believes in, the more likely he or she is to believe in any new conspiracy theory which may be proposed. Thus African-Americans, who are more likely to be aware of the Tuskegee syphilis conspiracy, are predisposed to believe that AIDS may also be a conspiracy, while this idea may seem absurd to people who are unfamiliar with past medical abuses. (Goertzel 1994: 10-11)

This view seems basic when considering a belief system, a complex entity which does not readily accept any piece of information given (not to mention that the Tuskegee experiments are a fact, as well as an important part of conspiracy theory). It would also be incorrect to assume that just because a person belongs to a group who has been marginalized they will believe in conspiracies.

Within the context of vaccine narratives, we see a high number of individual minority groups who believe that vaccines have been used to cull marginal populations or that the vaccines given to those populations are inferior in quality. Goldstein suggests that this is caused by mistrust of the dominant culture:

Treichler's argument, that the narratives are grounded in resistance to colonialism, refers to a very specific political experience; if broadened, the argument suggests the simple prerequisite of insecurities concerning those in positions of power. As political insecurities increase, conspiracy beliefs seem to also increase, and a decrease should accordingly create fewer such narratives. (Goldstein 2004: 98)

But, as Goldstein demonstrates, this demedicalizes the initial problem:

AIDS conspiracy theories and their attendant elites are not solely about government genocide but also about medicine as warfare, purposeful disinformation, and the withholding of drugs, treatment, and knowledge by those who serve as gatekeepers of life and death. The theories articulate substantial medical distrust, perhaps tied to the Tuskegee experiment, perhaps tied to any number of ethnically scandalous medical and scientific research projects that have been reported in the news years after their damage has been inflicted. (Goldstein 2004: 98)

Medical distrust is a serious issue in Newfoundland and Labrador, even though many members of the population do trust their own doctors, perhaps because those doctors are members of their community. The idea that vaccines come from places other than



Newfoundland exacerbates this issue. Goldstein lists other reasons why Newfoundlanders may experience medical distrust:

Perhaps the distrust is tied to the current consumer/business model of health care, a model that Canadians see as threatening social medicine. Perhaps the distrust is linked to simple professional elitism, particularly in a place where employment has been ravaged by the death of the fishery. The articulated insecurities expressed in the conspiracy theories draw a frightening picture of medical professionals. (Goldstein 2004: 98)

Goldstein mentions that those who have been historically accused often engage in counterblame, which “frames conspiracy belief as defensive, thereby diverting attention away from the more general message of medical distrust” (Goldstein 2004: 95).

Medical distrust is certainly foremost in a consideration of medical conspiracy beliefs if one considers some of the narratives of vaccine reactions. Many of these narratives are very defensive, and in many cases, what parents believe to be a vaccine reaction has been diagnosed as either SIDS or Shaken Baby Syndrome. Both of these conditions place a significant amount of blame on the family of the child and away from the medical establishment. It is not unreasonable to consider that the increase of vaccine conspiracy narratives may have a correlation with the number of accusations of neglect or abuse.

### **Why Are These Stories Appealing?**

Many of the legends reported in the media are consistent with public opinion. Legends reported in the media and other non-oral transmissions of folklore are often treated as less valid. Smith states:

This emphasis on oral, as opposed to written/literary or any other form of transmission, has in the past produced a tendency to disregard the effects of alternative forms of transmission on folklore....In order to avoid this problem, perhaps a better approach is to consider that, in fact, little difference exists between the transmission of a tradition and any other type of communicable information. (Smith 1992: 42) For in the real world, not just a single oral medium of transmission is utilised to communicate folklore, but any available and relevant media is employed. (Smith 1997: 5-14).

If the story does not appeal to the public on some level, then it may not be readily accepted by the public. Even outlandish accounts, however, may serve a purpose and function as a sort of counterphobia which reassures the population that their thoughts and opinions represent the opinion of the general public (Manoff and Schudson 1987: 168). What is reported in the news is not only important because it mirrors public opinion, but also because it can feed into already established fears and prejudices.

In a country like Canada, where medicine is socialized, health and safety are no longer private choices since everyone pays for the illnesses of everyone else. Public pressure to vaccinate can be high since it is an issue both of public health and safety as well as the utilization of the health care system. One of my informants commented on this:

You know how it is. I'm paying for your disease and you pay for mine, so if you aren't taking care of yourself, well, you aren't a team player now, are you? I know it's not PC and all of that, but, well, when I see someone who is overweight, I think, I'm paying for that. I'm paying for their heart disease and if they aren't going to take care of themselves for them, then at least do it for the rest of us. I mean, I'm paying for my own gym membership, right? (Interview with lay person. May 23, 2007)

With this type of pressure, many people are reluctant to comment on their vaccine status or the status of their children because they fear the response.



A more unfortunate result of these news stories is the suggestion that it is the fault of a specific group or person. Stories such as these not only point out the prejudices that others have concerning certain groups, but they also reinforce such beliefs since the news is seen as a credible source of information. In St. John's, many of the international students feel that they have been used as a scapegoat for pestilence and disease:

First it was the TB thing, right? Some international student had TB and the next thing you know, no one wants to sit next to you in class after that. People actually moved when I walked into class and sat down. I know a little about the medical history of Newfoundland and I have a few friends who are med students. They still look for active cases of TB here, you know? TB is in the Newfoundland population, not the international student population. It even turned the international students against each other. Remember that insurance meeting? Where that girl said that our insurance wouldn't have been so expensive if someone hadn't gotten TB? Man, it wasn't their fault. They probably got it from a Newfoundlander. But no, that wasn't on the news. Just that it was an international student. They wouldn't name the person, but they sure named them as an international student. (Interview with lay person. May 17, 2007.)

A similar problem happened when cockroaches were found in one of the residences on campus. Cockroaches are not commonly found in Newfoundland, and many believed that the international students brought them in:

It's just like the cockroaches, right? The international students must have brought them in. The majority of people in that dorm were Canadians, but no, someone couldn't have possibly brought them in from Toronto or something. It had to be the international students. And it was all over the media. Even NTV had it on. They never blamed us personally but they just had to mention that a lot of international students lived in those rezes. (Interview with lay person. May 17, 2007)

Stories such as these, which were reported in the media, can lead to racism or other forms of prejudices.

## **Chapter Four**

### **Genres and Communicative Forms**

Vaccination narratives are presented and communicated in a variety of ways through the use of traditional narratives and beliefs. The most common genres used in vaccination discourse are contemporary legends, rumour, and personal experience narratives, or in some cases, a combination of the three. This chapter will define these terms, discuss the differences in authority they imply, comment on their intertextual nature, and consider the vehicles used to communicate these genres, including word of mouth, the Internet, and broadcast media.

#### **Contemporary Legends**

Contemporary legends are “unsubstantiated narratives with traditional themes and modern motifs that circulate in multiple versions and are told as true or at least possible” (Turner 1993: 5). They may or may not be believed, but are believable, and they are often told by a “friend of a friend” (FOAF). Tellers often change the narrative format of contemporary legends to adapt them to the geographic or cultural environment, a process known as “oikotypification” (Von Sydow 1948). These changes, along with the use of personal names, are often used to add credibility to the story, thus making it more believable (Dorson 1964, Mullen 1978, Brunvand 1981).

An example of an anti-vaccination legend would be the following, which I collected from one of my informants:

So, I heard that MMR causes autism. That's why there's so many kids with autism now, allergies too. There's something in there, an ingredient, I



think it's a preservative, so the vaccine lasts longer. Well anyway, it's doing something to kid's brains, I'm not sure what, and they end up developing autism. It happens pretty quickly as well, usually within a few hours or days of getting the shot. I hadn't heard about it before, not until I had my baby, and all these other mothers and I were talking while waiting for the nurse. Well, these moms knew all about it. One lady had a friend out in Placentia and it happened to her. Her daughter was fine, until she got her MMR needle. Now they need all kinds of assistance and they don't have enough to cover her care and all. I don't know what to think of that. (Lay informant with children. August 17, 2006)

Contemporary legends are characterized by "persistence, pervasiveness, and persuasiveness" (Kapferer 1996: 246). They exist primarily in a conversational forum and do not tend to exhibit definitive texts or formulaic opening and closings (Smith 1998: 493).

## **Rumour**

Contemporary legends are closely akin to rumour, but there are significant differences:

Rumor, like legend, is performed as a believable account. It, too, is highly localized and closely linked to a particular historical period. The notable difference between rumor and legend is that rumor is not always a narrative. The designation "rumor" can also refer to nonnarrative expressions of folk belief. Therefore, the term "rumor" does not describe a specific genre, but rather a hyperactive transmissionary state. If a legend is repeated frequently within a short time period in a circumscribed area, it can be called a "rumor." Even after the disappearance of the "rumor," the potential for the legend to be told remains. (Tangherlini 1998)

Rumour tends to be defined as a "brief, oral, non-narrative statement based on hearsay" (Turner 1993: 4) while the legend is often described as having a stronger and more elaborate narrative component. The tendency to shorten legend forms and embed them in other types of expressions complicates the definition. Because of their intertextuality and

generic blurring, Patricia Turner suggests emphasizing the complementary nature of the two forms rather than their distinctiveness, understanding rumour and legend as part of a clearly related narrative complex (Turner 1993:5). While vaccine belief can be articulated through the use of rumour, it is more commonly expressed in contemporary legends and personal experience narratives. However, some of my informants only knew vaccination rumours. For example, informants reported that they knew that the MMR vaccine caused autism, but they did not recall how they knew that, who told them, or any additional details.

Some rumours associated with vaccination include that childhood vaccinations are used for profit, typically to benefit pharmaceutical companies or the government, and have no known affect on immunity. Additional rumours involve the propensity for certain batches of vaccines to have higher than normal adverse reaction rates.

### **Personal Experience Narratives**

Personal experience narratives are told in the first person, in prose, and typically (but not always) contain non-traditional elements since they focus on the events experienced by the teller (Stahl 1975, 1977, 1985, 1988, 1989). The form, style, and function of the narrative are what make it traditional, as opposed to the content, although many other forms of folklore, such as contemporary legends, have been known to mirror elements of the personal experience narrative (Stahl 1975, 1977, 1985, 1988, 1989). The functions of these stories may vary, but often involve one or more of the following: (1)



entertainment; (2) cautionary tales; and; (3) the presentation of the character or personal values of the storyteller (Stahl 1975, 1977, 1985, 1988, 1989).

This example comes from my informant interviews:

I truly believe that my little girl has autism because of her MMR vaccine. I read all about it on the Internet, other babies with the same story. One day, they're fine. Then they get their needle, then suddenly, out of nowhere, they are diagnosed with autism. Everyone tells me I wrong, but how could I be? There were no signs of autism, of anything, before that needle. (Interview with lay person with children. April 22, 2006).

The internet is an excellent forum for personal experience narratives, as will be discussed later in this chapter.

## **Differences Between These Genres**

The first and most obvious difference between personal experience narratives and legends is that personal experience narratives are events from the teller's life.

Additionally, the truth behind a legend falls more under the believable than the believed.

Paul Smith expands on the motivating factors behind legends:

The purpose of a legend is to report, inform, explain, teach, advise, warn, help, or enlighten. The legend answers unuttered questions of common concerns: What is it? Why is it so? Can this be true? How can such a thing happen? What can be done about it? How can it be avoided or made to happen? And since the legends seeks an answer, its message need not be encased in an artistically constructed and stabilized or conventionalized talelike frame. The ambiguity of feelings, the uncertainty, the hope, and the despair surrounding the message create a specific narrational form and style for the legend and keep the narrated text eternally unfinished, amplifiable, and fragmentary. (Smith 1997)

The idea that the legend is unfinished and amplifiable is similar to personal experience narratives since these stories may be elaborated on or added to as time goes on. Allison mentions:

Few other forms of narrative expression can provide the same depth of revelation of the social life of a community as can the personal experience narratives of its members. As a narrative form, the stories arise out of the experience of their individual performers – and out of a felt need to relate those experiences. Performers develop their own repertoire of narratives, and individual personal experience narratives are readily identifiable by group members as to their “owners”. Like other narrative genres, their form and structure – though it is always relatively loose, especially when compared to genres such as the *Marchen* – may become more polished over time with retelling. Conversely, they arise within the conversation contexts, may be communally constructed within such setting, and may be so closely tied to a given interaction that their text almost disintegrates outside the original setting. (Allison 1997)

Since personal experience narratives tend to have “owners,” there can be reluctance for others to tell the story. In the case of an online posting of the narrative, additional events may colour the original experience; however, any major changes within the story are sure to be noticed by other members of the group. On many forums, editing a previous post is either not an option or frowned upon. A teller might modify a story with additional information, but the text itself will remain as a part of the larger narrative structure. Although arguments could be made that a post can simply be deleted, that does not necessarily mean that members of the group will have forgotten about the text. Even when one posts anonymously on the Internet, there are still consequences for the teller, including exclusion from the group.

Primarily due to their sense of ownership, personal experience narratives at first glance do not appear to exhibit communal nature in the same way as a legend. Since there



is an issue of ownership, others may not feel comfortable telling someone else's story if the original storyteller is present. However, in a venue such as an Internet forum where community members may be distant in spatial location, one can see instances in which "other people's stories" are told by people who know them; for example, this narrative from the internet directly uses information from a personal experience narrative sent via email:

Hey ladies,

I have a friend who just had her second baby on Friday. He was 2 weeks early but over seven pounds and fine at birth and now he is in the NICU. Here is an excerpt from an email from the dad giving us an update on Zachary:

"He aspirated some breast milk into his lungs on Friday night, turned blue, and stopped breathing. They were able to revive him, but he continues to have aspiration pneumonia and spells where the oxygen levels in his blood go down and he stops breathing. They are taking very good care of him, but they are still unsure why this is happening. He could have a seizure disorder or reflux or it could just be the result of the trauma that happened on Friday. He is being evaluated by neonatologists and other specialists and is hopefully being seen by a neurologist today."

I don't know whether he had the Hep B shot or not, but I have to think he probably did since I know that they follow the regular CDC schedule with their first drs. [sic] **Does this sound like a possible Hep B reaction to anyone?** I know I can go look it up myself, but I thought I would get some good responses here.

Thanks and say lots of prayers for this precious little boy. (Café Mom 2008. Emphasis in original)

People post these stories because they have a network of others who may be able to offer some advice, or because their friends are too busy with what is happening to post and ask their friends or family to post for them.

If we consider these narratives from another perspective, using Stahl's viewpoint on personal experience narrative we see that, "...the experiences used as content matter represent a combination of collectivity and individuality. No experience nor experience story can ever be entirely individual" (Stahl 1977: 16). The narratives are affected by other narratives and the cultural climate of the group. The individual's narrative is still their own, influenced by their own experiences and perspectives, but it does not exist inside a vacuum (Stahl 1977: 17). These narratives are vital because, in the same manner as memorates display belief, they also display the attitudes of the teller (Stahl 1977: 22). These attitudes, just as the beliefs which are expressed in legends, are traditional even if they are influenced by the teller's own unique history:

All attitudes are formed through group interaction, but a specific combination of influences is unique to the individual....every individual belongs to any number of "reference groups," and from these groups they acquire shared attitudes which are internalized and perhaps altered slightly as they come into contact with other attitudes integrated into the particular individual's personality. There may even exist conflicting attitudes in the individual's "repertoire" as well as in that of any group to which he belongs. Nevertheless, no attitude itself will exist independently, idiosyncratically: it will always be shared by group members, varying only in the degree of relative importance each individual personality affords it. This degree of importance attached to the attitude will easily display itself in personal narratives, since the attitude is what gives the narrative its meaning; it is the point of the story and therefore is an attitude regarded as important by the teller and presumable by his audience. (Stahl 1977: 22)

When a story "belongs" to an individual, the attitudes expressed by the story can be a part of the group's collective attitudes. Each story which is added to a forum, such as the one above, reinforces those attitudes – even if the story does not specifically belong to the person posting it.



While there are differences between legends and personal experience narratives, one can see that they both express the beliefs and attitudes of the individual and the group. Stahl states, "The traditionality of attitudes is much like the traditionality of themes or motifs or even structured 'function'" (Stahl 1977: 22-23). Personal experience narratives can also be "traditional" in the attitudes they express, and forums where vaccine narratives are posted can provide a history of the shared attitudes of the group.

These stories may also be added to or referenced when others are telling their own vaccination stories, such as this personal experience narrative which was posted after the one above:

That almost sounds like my identical story of when my second child (my son) was born. He was born about 7:30 pm totally fine. The next a.m. [sic] the Dr [sic] was prepping us for an early departure, things were going so well. I know I didn't want him to get his hep B [sic] shot so we refused it right after birth, But I think in a frenzy to get out of there signing papers I guess I signed it (because it says on his discharge papers he got it) Any way they took him to get circumcised and he was away from me for about 45 min [sic] when the Dr. came back in to tell me they couldn't do the circumcision because he turned blue and they had to give him oxygen. He was fine but in the NICU and would stay there for at least 2-3 more days. Then they said they didn't know what happened and thought he aspirated on breast milk. The story never lined up with me. He wasn't nursed before he left, aspirating and turning blue are 2 [sic] totally different things, what was he doing for all that time before the circ [sic]? You mean to tell me out of the blue he just stopped breathing??

Anyway we were devastated. He is 3 1/2 now but shortly after he was home we were seeing signs he wasn't right. We thought he may be autistic. We got help for him and it has been an uphill climb all the way. I researched the hep B [sic] vaccine and I really have no doubt it was that and the doctors were covering their butts. I would ask if and when exactly this baby got the shot. It can be a very dangerous vaccine. I wish your friends the best and hope their child is fine. (Café Mom 2008)

Others stories like these were also posted after the original story, all supporting or sharing similar information and/or expressing sympathy.<sup>48</sup>

Approximately eighty-three percent of my informants knew personal experience narratives from other parents with both positive and negative experiences with vaccines, approximately half of which came from a friend, the friend of a friend, or from the Internet. They were willing to share these narratives with me, although approximately twenty percent mentioned their telling would not be as good as the original narrative. However, if my informant thought the parents would be willing to speak to me and/or if they were accessible to interview, I was given the contact information. In all but one case, the parents were unable or unwilling to be interviewed.<sup>49</sup>

As Paul Smith has mentioned concerning legend:

Culturally, the teller and the audience share a common knowledge of legendry, and the story brought up is based on a shared frame of reference whereby the telling becomes conversational. The proponent who starts a story will be joined by co-proponents who add their information to the telling as the story unfolds. Those present contribute to a communal version, adding their information, making corrections, and expressing their opinions concerning the veracity of the event. (1997: 494)

Even if this format is framed as a personal experience narrative, to a reader who is unacquainted with the teller it is a "friend of a friend" situation, something which is a hallmark of legend. It is also possible that these "unknown" others may report stories as

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<sup>48</sup> The "Choosing Not to Vaccinate" section contains 2401 registered members, although anyone can read the posts (<http://www.cafemom.com/group/4388/>) and there are 88 separate groups who are currently discussing both sides of the vaccination debate (<http://www.cafemom.com/groups/find.php?keyword=vaccination&next=1>).

<sup>49</sup> In this one case, I did obtain the narrative from a mother who believed her child's MMR vaccination caused autism in her son and the narrative of their friend who did not believe there was a correlation. However, my permission to use the mother's story was revoked after the interview as she no longer felt comfortable sharing her narrative.



their own even though they are legend, or report stories they have heard from other sources as being true because the teller trusts the source. As Allison states:

Like legends, they recount an experience of a particular person or group, they follow accepted structural and performance patterns; and they rely on a set of understanding common to the group in their transmission of meaning. Personal experience narratives, like other smaller narrative categorized such as family stories or anecdotes, have a limited circulation and, in certain instances, a limited lifespan. The standardization in form of the personal experience narratives has prompted some researchers, such as Juha Pentikainen and Linda Dégh, to suggest that it is nearly impossible to distinguish between early form of legends and those having roots as personal experience narratives or as narrative accounts told in the first person. (Allison 1997: 636)

Of course, with the Internet, one can see this process extending further and having a longer lifespan than originally suggested. At times it can be impossible to distinguish personal experience narrative from legend, especially when the media or Internet is concerned:

On a broader scale, beyond the unofficial confines, legend events are further relayed to society at large by professional mediators who, like oral narrators, modify and re-create their versions to fit their purposes. Emergent legends are immediately reported in the daily news and the popular press, radio and television; they are topics of talk shows, docudramas, and motion pictures; and they appear in popular science and literary works. The media also reconstructs and updates old legends attached to current social concerns, keeping the public attracted and simultaneously confused about what to believe or what to doubt. On the wings of mass media, the proliferation of the legend is unprecedented; it has become the most viable among the genres of folklore and the most characteristic expression of human concerns in the industrial world. (Smith 1997)

This process is dynamic. A legend may be portrayed as a personal experience narrative, or the actual events of a person's life may be disregarded as mere legend. Regardless,

legends, rumour, and personal experience narratives demonstrate the beliefs and attitudes of the group and are important to consider when exploring the vaccination concerns.

### **Communicative Forms**

There are three main methods used by the public to discover health information outside of what is provided by their physicians: 1) word of mouth, 2) the Internet, and 3) the media. In this section, I will talk about each of these methods, with the greatest attention paid to the Internet and media and their affect on health information. As Smith has noted, "in the real world, not just a single *oral* medium of transmission is utilized to communicated folklore, but *any available and relevant media* is employed" (Smith 1992: 41 emphasis in original). Dégh and Vázsonyi also note that it is impossible to find the origins of legends and it can be difficult to comprehend the intersections between legends and the mass media (1973: 36-37), especially since the mass media may carry a story for a longer period of time than the oral tradition might (1973: 1-54).

#### **Word of Mouth**

Historically, the transmission of folklore was seen as being entirely oral. It was only later on in the study of folkloristics that credence was given to other forms of transmission, such as written and printed documents, video, and the Internet. However, word of mouth is still one of the most utilized modes of transmission, and all of my interviewed informants reported that they had both heard and told vaccination narratives in addition to finding them on the media and Internet. Informants also regarded word of



mouth to be a more reliable source of information, especially in the case of personal experience narratives. Informants reported that since they knew the character of the person telling the narrative, they were viewed as more trustworthy than an unknown source on the Internet. Although the public are often seen as passive recipients of the media, personal experience with news personalities, incorrect news information, and limited information from news sources caused informants to be suspicious of broadcast media information, primarily due to the tendency to sensationalize and the belief that information is withheld.

### **The Internet**

Although reports vary on the exact percentage of Internet usage, one cannot argue with the idea that the Internet is an important part of culture and a means of obtaining information for many. The estimated broadband Internet usage in Canada in 2007 is 81% of households (Internet Usage Worldwide). However, Newfoundland was shown in 2000 as being one of two provinces (New Brunswick being the other) with the lowest Internet usage with an estimated 44% of the population online (Bartlett). It is believed that one of the reasons for this is the extensive rural population in Newfoundland and the lack of high speed Internet connections in rural areas (Public Works and Government Services Canada b). In 2003, Internet usage in Newfoundland from any source was listed as 55.3% of the population. There is no doubt that while Internet usage has increased in the past six years, some rural areas of Newfoundland are still not as well connected as larger cities and towns.

### *How the Public Uses the Internet*

Statistics on Internet use reveal its popularity: reported to be as high as 67% in some studies (Fallows 2005: 1)<sup>50</sup>. We also see that Internet use is no longer dominated by men (Fallows 2005: 1) and that women are now more likely to seek out health information on the Internet than men (82% compared to 75%) (Fox 2005: 1), which has increased since 2002 when 58% of men and 74% of women sought health information online (Fallows 2005: 12). Although both women and men are likely to seek out health information for others, women are more likely to look at information for a child than men: 16% versus 7% (Fox et al. 2000: 20). Statistics also demonstrate that of all of the health information being sought, 16% concerned immunizations in 2005 compared to 13% in 2002 (Fox 2005: 11). This study also shows that people who are college graduates (20%) are somewhat more likely to seek out online information on vaccinations than those with some college (18%) and much more likely than those who are high school graduates (11%) (Fox 2005: 11). Of those who have sought information online, 48% have said that the information they have found has improved the way they take care of themselves, and 55% say that Internet access has improved the way they received medical information (Fox et al. 2000: 3). Of those surveyed, 92% said that the information they found was useful, and 81% said that they learned something new (Fox et al. 2000: 3).<sup>51</sup>

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<sup>50</sup> This number is lower than previous studies mentioned and is specific to the United States.

<sup>51</sup> It should be noted that Fallow's study involved 20,819 participants, primarily from the United States, who were contacted by phone. Fox et al. had 15,381 participants, also primarily from the United States, who were contacted by phone and through an Internet survey. These studies are used because no extensive study of Canadians' use of the internet to find health information has been done to date. Less extensive studies have been conducted; however, these studies only give the percentages of Canadians who use the



Fox et al.'s study also showed something I noticed in my own research: that the majority of people look to the Internet for health information after they have already been to the doctor (2000: 4), not before as concerned many of the doctors in the St. John's area. Some of the reasons mentioned for why a person might look to the Internet for health information include convenience (93%) and the feeling that they can get more health information than from their medical professional (83%) (Fox et al. 2000: 5). Eighty-six percent of health seekers are concerned about the quality of information they have found and are concerned that the information may be unreliable (Fox et al. 2000: 6). Not only are women more likely to seek out health information, they are also more concerned about the reliability of the information than men (Fox et al. 2000: 6).

In her article "Imagined Lay People and Imagined Experts: Women's Use of Health Information on the Internet", Diane Goldstein states:

Little exists in the way of actual qualitative studies exploring how and why women use online health information, how they assess what they find, what harm or benefits the users perceive in their search efforts, and the extent to which lay internet research is used to complement or replace other forms of medical consultation. (2008: 10)

She also notes that the qualitative studies which do exist "indicate to some extent that lay users are conscious of issues of quality and have developed commonsense ways of filtering material" (Goldstein 2008: 34). Her informants reported that finding health information which was not mainstream or "official" was a challenge since many sites simply repeated the same information as other health sites. This is the exact opposite of

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Internet (68%) and Canadians who use the Internet to find health information (58%) (Statistics Canada 2005). The only other information offered is that women tend to use the Internet to find health information more than men (63% vs. 53%) (Statistics Canada 2005).

the beliefs and meta-beliefs described by my medical professional informants who assumed “alternative” or “marginal” viewpoints were more prevalent on the Internet.

### *Why Do People Turn to the Internet for Health Information?*

Although many studies have been done on this topic, the majority have been carried out by health professionals within a context of condemnation, making it difficult to explore the actual motivations of those populations being studied. Morahan-Martin (2004) published a more comprehensive study<sup>52</sup>, which mentions cross-cultural differences, although briefly, and takes into account that many of the studies involve participants researching health topics in which they are not personally invested. This may make their dedication to the project less than if they were searching for a health topic that mattered to them. Morahan-Martin states that “search skills are limited” (499) using data from other studies to demonstrate that searchers use less sophisticated terminology and misspell words and that searchers do not go past the first two pages they find online (2004: 499-500).

A 2002 Pew Study on Internet usage in the United States also mentions that 72% of those polled stated that you can believe all or most of the health information online, and that 69% have not seen wrong or misleading information online (Fox et al. 2000). A Harris Poll study of four different countries (United States, France, Japan, and Germany) found that 70% of those surveyed viewed online information as trustworthy (Taylor and

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<sup>52</sup> Morahan-Martin’s study is a cross-cultural review and critique of how researchers study Internet information, and an analysis of their results.



Leitman 2002: 1-4). Of course, survey method is not always the best way to collect such information.

The Pew Study attempts to portray the typical health seekers' pattern:

In fact, most health seekers go online without a fixed destination in mind. The typical health seeker starts at a search site, not a medical site, and visits two to five sites. She feels reassured by advice that matches what she already knows about a condition and by statements that are repeated at more than one site. She is likely to turn away from sites that are selling something or don't identify the source of the information. And only one third of health seekers who find relevant information online bring it to their doctor for a quality check....About half mostly avoid the kind of search strategies experts recommend. And, although health seekers are generally wary about revealing their identity online or having their activities tracked, only about one in five have checked a site's privacy policy. (Horrigan and Rainie 2002)

However, as Goldstein discusses in her article concerning online menopause support groups, patients are often more interested in information on subjective experience rather than objective experience, something that will be discussed later in this chapter (Goldstein 2000).

### ***The Digital Divide***

The digital divide has been defined as:

....the gap that exists in most countries between those with ready access to the tools of information and communication technologies (ICTs) and the knowledge that they provide access to, and those without such access or skills. Lack of access may be due to socioeconomic factors, geographical factors; educational, attitudinal, and generational factors; or physical disabilities. (Cullen 2006: 7)

Some groups who are especially disadvantaged are "people on low incomes, people with few educational qualifications or with low literacy levels, the unemployed, elderly

people, people in isolated or rural areas, people with disabilities, single parents, and women and girls” with regards to information access (Cullen 2006: 7). This is significant because most of Newfoundland is rural, and in many communities the socioeconomic conditions mentioned above apply. For example, 77% of Internet users in Canada have some university education (Public Works and Social Services Canada b). However, only 39% of males in Newfoundland have some university education (Statistics Canada 2002). Also significant to this study is that women and girls may not have access, since it is women who tend to make the majority of medical decisions for the family (Statistics Canada 2005).

Another issue which comes to light concerning medical information on the Internet is that many of the “good” Internet sites charge for information. Although sites such as Health Canada or the CDC have open access, it is only to the information they provide, not to the corresponding studies or research. If these sites both listed and provided access to their sources, the general public may be more inclined to use them. Statistics on educational levels of both Internet users and anti-vaccination decision-makers suggests that health information site users may wish to access supporting studies.

It is also important to note that most of medical information and studies are located in medical journals, which may only be accessed if one pays for the service or has access to a library which offers a subscription to the service. Information can be restricted based on cost, confidentiality, or the intellectual property rights of the creator (Cullen 2006: 18). However, Cullen argues that this might not always matter in cases where the information can help the public good, specifically in the case of vaccination:



Information, in economic and social terms, also has externalities, or benefits enjoyed by a wider group than those who choose to purchase it. These externalities may be either positive or negative. An example of a positive externality in the field of health information is higher levels of vaccination in society through information given to individuals for their own protection. Vaccination programs are considered to have a very strong public good element, because the incidence of disease, and therefore the individual's exposure to risk, drops as rates of vaccination rise in the community. (Cullen 2006: 18)

While Cullen's approach to the greater good of vaccination is being hotly debated by vaccine safety activists, it does show that there is a "trickle down" effect for information. If the public is not able to access the original research, they are forced to make their decisions based on what others tell them instead of their own assessment of the available information.

#### *What Are the Types of Health Seekers?*

The Pew study identified three types of health seekers: vigilant, concerned, and unconcerned. Vigilant health seekers, which make up 25%, are the most methodological in their search. They tend to use sites whose names they recognize, spend more time looking, and visit more sites. Concerned health seekers make up 25% of all health seekers and are less fastidious than the vigilant health seekers, especially when it comes to verifying information, trusting search engine results, and using the first hits as their sources. Unconcerned health seekers, which make up half of the population of health seekers, are less cautious about their approach to information on the Internet. They tend to spend the least amount of time searching and look at the fewest websites. Additionally,

they are the least likely of all the groups to discuss their findings with physicians (Fox et al. 2000).

Morahan-Martin also noted that two groups of people are more vigilant in their evaluation of health information on the Internet: those with chronic conditions and parents of children under 18. Morahan-Martin's research discovered that parents, who made up approximately forty percent of all health seekers, were more likely to check the sources of the information they had found, and spent more time searching for information (2004: 503). Additionally, they were more likely to "approach search engines deliberately and to read the explanation of the search result" (Morahan-Martin 2004: 503). This, coupled with research showing that those who are more personally invested in searching health topics which have a major impact on their own lives (Morahan-Martin 2004: 504), suggests that it is likely that parents who are making decisions about vaccination may be some of the best seekers of health information on the Internet because those facing major health decisions, especially for children, are likely to be more diligent researchers.

Harris Interactive, which manages one of the longest running opinion polls in North American, found that if a patient has a chronic or serious illness, they are more likely to use the Internet to find health information. Their analysis<sup>53</sup>, which was based on severity of condition and attitudes towards doctors, found that there are four types of patients: accepting (8%), informed (55%), involved (28%), and in control (9%). 'Accepting' patients trust their doctors and do not seek other types of information, while

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<sup>53</sup> This analysis involved data collected via the Internet during January 2002 with 309 participants in the United States, 327 in France, 407 in Germany and 275 in Japan (Taylor and Leitman 2002).



'informed' patients both trust their physicians but also seek out their own information. 'Involved' patients actively seek out information and contribute to their health care, seeing themselves as a part of a team, while 'in control' patients tend to walk in to the doctor's office with a diagnosis and treatment plan before even discussing their condition with their health care professional (Taylor and Leitman 2002: 1-4). We also see this trend in vaccine-related decision making, where the majority of parents tend to be either 'informed' or 'involved'; with the minority falling into the 'accepting' or 'in control' categories.

It could also be argued that those with conditions about which little is known or those who have symptoms which do not match the usual pattern also use the Internet more frequently, especially to interact with others who have the same or similar conditions. This pattern has been seen with cancer survivors (Kitta 2003) and women suffering from menopause (Goldstein 2000) as well as a variety of other conditions. One could speculate that those who have a less than satisfying experience with a health professional are more likely to seek health information, either from the Internet or from other sources. In the case of vaccination, where the exact parameters of what defines a vaccination reaction are in flux, we see some of the same problems. Many of the symptoms of a vaccine reaction are debated online and can vary from a site rash to diagnoses such as autism or death. In addition, methods of dealing with new conditions are debated among the parents of children who have suffered a vaccine reaction.

One of the main reasons why an individual might turn to the Internet for health information instead of a medical care professional is that they do not believe they are

getting all of the relevant information. Health seekers use the Internet to fill in the gaps of their knowledge or address further questions they may have about a condition. Morahan-Martin states:

Many health seekers are seeking information about a specific disease, often before or after visiting a physician. The desire for health information when faced with an illness is hardly surprising. Unfortunately, patients and their families often do not feel that they have adequate information. Harris Interactive asked U.S. health seekers what their most frustrating experiences were before, during or after visiting their physicians. Lack of information ranked high. The most widely cited frustration included "forgetting to ask all my questions when I'm with my doctor," "having to see my doctor in person to ask questions that he or she could answer by telephone or email" (41%), "getting through to someone who could answer my questions: (35%), "finding a new doctor" (30%), and "not having enough time with my doctor" (29%). Most (57%) think the Internet will help reduce or eliminate these frustrations. (2004: 503)

This demonstrates the public's desire not only to have more information, but also to have that information readily available to them.

In some areas, the new technology has created interactive on-line health care, not just on-line health information. It is clear that many health professionals would prefer to keep their interactions face to face, since there may be liability concerns, and because it is difficult to diagnose from a distance. However, for more chronic conditions or regularly prescribed treatments, for follow-ups, refills of regular prescription medications, appointments, and general questions or information, online health care is a possibility. Although online health care has yet to manifest itself in a widespread manner in Newfoundland, HealthLine, a recently established toll-free number that lay people can call and talk to a medical care specialist, has been introduced in the province. Preliminary information indicates that HealthLine received two hundred and ten calls per day between



September 27, 2006 and April 2007 (HealthLine 2007), and interviews and informal discussions have indicated HealthLine is frequently used and popular, especially among first time parents as well as recent and experienced parents without family in the area.

### *The Internet and "Reliable" Information*

Information, both reliable and suspect, travels at increased rates due to the Internet. For example, right after September 11, 2001, commentators took note of the numerous legends and rumours about the attacks (O'Leary 2001, Tyrangiel 2001).

Bratich noted:

While official rumours (health panics, specific warnings about vague new attacks) were spread by mainstream news outlets, popular rumours were attacked by those very outlets. In particular, the Internet was cited as a catalyst for the rapid deployment and wide circulation of unreliable information, the articulation between untrustworthy narratives and this new medium could be made so smoothly because it had already been performed for a few years. (Bratich 2004: 109)

Bratich's article "Trust No One (on the Internet)" is a perfect example of how the Internet has been used as a scapegoat for many years. In Bratich's opinion, it was not only the professional use of the Internet by journalists which contributed to the problem of reliability of Internet sources, but also the way that journalists chose to address conspiracy theories. Bratich begins by telling the story behind the "Dark Alliance" series by news reporter Gary Webb<sup>54</sup>. This series linked a variety of conspiracy theories together, which became known as the CIA-Crack-Contra conspiracy theory. The real problem, from the journalists' perspective, was not only that Webb was widely published

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<sup>54</sup> Webb, an award-winning journalist, wrote these series for the San Jose Mercury News.

on the Internet, but also that he was a journalist himself. Immediately, journalists realized that they had to distance themselves from Webb. Journalists took immediate action, often dismissing Webb's claims without doing any research of their own or waiting for the claims to be dismissed by the government offices attacked in the series (Bratich 2004: 108-113). By this time, conspiracy theories were well-known entities among journalists:

At this historical, premillennial [sic] juncture, the pundits claimed, it has become difficult to distinguish good information from bad, as even conspiracy theories could appear seductively logical and objective...It was harder to reject a conspiracy narrative as "other", when respected journalists—themselves experienced adherents to journalism's truth-telling practices—were its authors. So the object of concern became the Internet, and transgression became not authorship but Internet involvement in the construction and dissemination of conspiracy narratives. (Bratich 2004: 115)

The conspiracy theory itself was considered bad information; however, the idea that it was found on the Internet somehow made it worse since the medium itself was considered to be untrustworthy (Miller 1998; Dean 2000; Bratich 2004: 116). Journalists realized that the Internet was a powerful tool for the dissemination of information, but they needed to establish trust if they wished to use it (Bratich 2004: 119). Anyone can create a webpage which includes any manner of information. In order to make the Internet a useful and trustworthy place, journalists wanted to seek out ways to control it:

In this case, coding the Internet as "out of control" smoothly leads to a conception of it as *needing* control. The wild world of cyberspace (particularly wild because of the unfiltered, even irrational, theories abounding in it) requires professional taming. These protocols would preserve journalism's professional credibility while allowing journalism to synthesize with the emergent technology. Faced with a new development in the amateurization of news and information circulation, and fearing the loss of credibility as a filtering function, this unbridled technology is domesticated through the reaffirmation of reasoned truth-telling protocols of journalistic practice. (Bratich 2004: 120)



In part, this crisis of legitimacy may be due to the perception that the Internet is “wild,” without rules or reason, and it lack ethics and suffers from excess (Markoff 1994; Italiano 1996; Randolph 1996; Rieder 1997; Blumenthal 1997; Shaw 1997, Bratich 2004). Again we see a difference in the types of authority. While some see the limitless potential of the Internet as a source of varying types of information, others see this information as out of control and excessive.

For journalists, controlling the Internet was essential to the survival of the field:

For journalism the development of the Internet was not simply a technological breakthrough in a history of progress. It was also a disruptive force, a threat not only in the usual sense (the hand-wringing sentiment “no one will read print journalism anymore”) but also to the very integrity of journalism as a profession. (Bratich 2004: 120)

One of the tactics used by journalists was to propagate notions about the Internet which were already in place, such as its unreliability:

Journalism problematizes the Internet by attributing certain meanings to it, namely, as a space of untrustworthy uncontrollable information practices and, more important, as the “medium of choice” for conspiracy theories. This problematization of the Internet contributes to ongoing crises and panics of the new medium and adds to the debate around state regulation of cyberspace. (Bratich 2004: 126)

Although many a debate could be had about information control on the Internet, even those who promote free speech and the freedom of press have problems with the information that is available and want to control it. This response mirrors responses to other advancements in communicative technology throughout history.

### *How Does This Affect Patients?*

From the results of various studies, it seems that the more health information a person has, the more positive that individual feels (Eysenbach and Köhler 2002: 577<sup>55</sup>). Ninety-two percent of cancer patients report that finding health information online made them feel more empowered (Eysenbach and Köhler 2002: 575). Other studies indicate that finding health information online seems to have a significant impact, either positive or negative. The 2002 Pew Study in the United States found that only 31% of health seekers reported that the health information they found online had no impact on their decisions, while 16% said it had a major impact and 52% said it had a minor impact (Fox et al. 2000). This health information affected health seekers in a variety of ways, 44% said the Internet information affected their decision on how to treat an illness or condition, and 38% said it led them to ask new questions of the health care provider or seek a second opinion. In addition to empowering the patients, 34% changed their approach to maintain their own health or the health of others due to the information they found, 30% changed their attitudes about diet, exercise, and stress, and 25% changed the way they coped with a chronic illness or pain management. Lastly, 17% said the information they found influenced their decision to see a health care professional (Fox et al. 2000).

Conversely, some negative feelings were also reported. Twenty-seven percent mentioned that the information they found confused them about the right course of

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<sup>55</sup> Eysenbach and Köhler 's study included a total of 21 Internet users, located in Germany, who attended three focus group sessions. Seventeen of these participants were given a series of health questions and observed in a laboratory setting while retrieving health information from the web; this was followed by in-depth interviews (Eysenbach and Köhler 2002).



treatment, 76% said the information they found made them aware of conflicting evidence, and 31% reported that the amount of information was overwhelming (Fox et al. 2000). It is difficult to say that being aware of conflicting evidence has a negative affect; however, it is certain that it can cause internal conflict.

Overall, it does appear that the Internet provides support and a positive influence on those who use it. Health seekers feel more empowered, tend to discuss their conditions more, and report that only 2% have not discussed the information they found with their doctors because they believed the physician would not listen (Fox et al. 2000). Most people (47%) tend to reject sites which are too commercial or appear to be selling something (Fox, et al. 2000). Forty-two percent may reject a site if they cannot find an author or source, and 37% may reject the site if they cannot determine the last time the site was updated (Fox et al. 2000). The Internet, especially online forums, seem to function as a modern day locus for the mass protests seen in the past, and as a place to debate what information is true and what is false.

My informants commented in a similar manner. Approximately fifty percent reported (without being questioned) that they found the amount of information on the Internet to be overwhelming, but they were still glad to have Internet information. Additionally, approximately sixty-five percent of those interviewed reported that even after receiving information from their doctor, they still went to the Internet to corroborate information, find support from others with the condition, and to answer any additional questions. Perhaps the most interesting trend was that approximately half of the medical professionals and students that I interviewed expressed their distain over internet

information, even though approximately eighty percent of them admitted to searching on the internet for health information.

These sites can also become intensely personal for those who use them, especially for those who see them as a form of resistance. As Goldstein noted concerning women suffering from menopause, "As settings for the lay discussion of health issues, the lists become not only sites of support but also of resistance to medical authority" (Goldstein 2000: 313). The same can certainly be said for vaccine safety sites. These sites see themselves as the only alternative to the "misinformation" that is prominent and at least some of my informants agree.

It is extremely important to note that health information seekers do not accept the information that they find blindly. As previously mentioned, the more invested a person is in the health information they are seeking, the more likely they are to find better information. Also as previously mentioned, those seeking health information for children tend to be better educated and more dedicated to their search, indicating that the information they find is better researched than it might be in other situations. However, the information they value can be vastly different than the information that others value since it is frequently based on subjective rather than objective experience (Goldstein 2000).

Goldstein identified numerous issues of the vernacular creation of health theory in her study involving Internet posts of menopausal women, which relates directly to the example of anti-vaccination websites and online groups.



Goldstein argues that in Internet health communities “the absence of medical authority allows for the creation of authority based on experience rather than based on ‘objective’ information” (2000: 315). From the information given on vaccine safety websites, it is easy to see that those who have children who suffered from a vaccine reaction are considered to be the primary voices of authority, closely followed by health professionals who reject vaccination. Health professionals, however, who have personal experience with a vaccine reaction, especially to one of their own children, are framed as more understanding than those who have not. Internet writers frequently share this information either in one of the main pages or under a special section typically labelled “Bio,” “My Story,” or their child’s name followed by “Story.” For example, Barbara Loe Fisher, the co-founder and president of the National Vaccine Information Center, not only lists her extensive experience but also mentions in her biography section that “her oldest son was left with multiple learning disabilities and attention deficit disorder after a severe reaction to his fourth DPT shot in 1980 when he was two and a half years old” (Fisher 2007).

Sites use the positive and negative responses they have received as proof of their lay medical authority. By printing negative responses they indicate their openness to the argument and their knowledge of contrary opinions. Think Twice Global Vaccine Institute has extensive sections dedicated to both examples, which include positive statements such as the following personal experience narrative found on their “Love Letters” section:

Oh, My God! I have spent the last three days on this site and this is all I can say. I plan to tell everyone about your site, parents and physicians.

Will it work? Who knows? I could give you my family history on all three children's vaccination stories, but I will spare you the same stories you have read probably one thousand times, if not more. I pray to be spared any more grief as I am watching my 6 month old suffer right this very minute with a reaction. I am now completely armed with information. I am no longer sitting on the fence but am bursting at the seams with foresight that I want to share with others.

You are an Angel here on earth for the dedication and commitment you have given us ignorant parents. May God continue to give you the gift of intelligence and stamina to fortify us. God bless, and my sincere thanks!

A. Thanks for your supportive comments. We will continue to provide free information to anyone seeking answers regarding vaccines. Best wishes. (Think Twice Global Vaccine Institute 2007b)

They also include less than flattering comments as well:

Q. I seldom get to see such an amassing of ignorance and false "facts" in one place. I suppose you'd like to bring back the iron lung, because that's what you're calling for. Take a look at the statistics on death rates from childhood illnesses before vaccines. And what happens when you're pregnant and your first child gets rubella? Have you ever seen tetanus? I hope you never have to. And it's vaccines that make it possible for you never to see it. Please don't bother to reply. I've read enough of this stuff. Sincerely, a concerned educated person.

A. Please investigate this subject before you speak with incomplete information. Your self-righteous attitude, not our defense of every parent's right to accept or reject vaccines, is the true danger to humanity. You are so positive that you have all the answers that you've become blind to other possibilities. Where are your so-called "facts"? Show me your documentation. You make statements and expect them to be accepted as true simply because you made them. Intimidation and coercion are not good tactics. Instead, research this subject and then try exchanging ideas in an intelligent manner. (Think Twice Global Vaccine Institute. 2007c)

Replies by the website author are also interesting. One lay informant mentioned that the responses to these letters were, "everything I wish I could say to those people, you know, everyone who just believes in vaccination because they are told to" (Interview with lay



person with children. May 14, 2007.) In addition to comments such as these, we also see responses which use medical information to prove the writer is incorrect:

Q. You are living in a fantasy land where you don't accept the large numbers of deaths before immunizations as proof that the diseases are dangerous. I do not wish to "discuss" this any more with you. Please do not contact me again. Thank you.

A. I'm sorry to see you leave in such a self-righteous huff (again!). I will honor your request to not contact you again. However, your "proof" is not the sort that I was taught in graduate school. You say that thousands of cases of SIDS following the administration of a shot is NOT proof of a connection, but somehow you rationalize that deaths from a disease before vaccines and lesser deaths from that disease after vaccines ARE proof of a connection. Which is it? Either a correlation between two events DOES indicate causality and IS "proof," or a correlation between two events DOES NOT indicate causality and IS NOT "proof." You can't have it both ways. By the way, there are millions of cases of cancer, hyperactivity disorder, learning disabilities, autoimmune diseases, and numerous other "new" diseases today that DID NOT exist prior to mass vaccines. By your reasoning we can assume that these are caused by the shots. (Which many researchers now believe and have substantiating evidence to confirm. For example, check out the April 29, 1995 issue of Lancet. The measles vaccine was found to be linked to Crohn's disease and ulcerative colitis.) In other words, the medical establishment's so-called miracle shots are actually damaging the immune systems of healthy human beings and creating new diseases. I believe you are the one living in a world of make-believe. And you are too pompous to investigate the evidence that could help you to formulate unbiased and rational perspectives. God help our civilization. P.S. If you do decide to open your mind, my offer still stands. I will then send you a complimentary copy of the book that we discussed. (Think Twice Global Vaccine 2007c)

Think Twice also argues the distinction made between lay and medical authority:

Q. Do you have a scientific background, or are you an activist?

A. Do you have a background in health CARE, or are you an NIH (National Institutes of Health) scientist? I am an intelligent individual capable of thinking and reasoning on my own. I am also a sensitive and caring human being, disgusted by the pseudo-science the medical establishment fabricates and promotes. I am also concerned about the parents who are being forced to make life and death decisions regarding

the welfare of their children without the benefit of ALL available information relating to those decisions. You and I (and by extension, the medical establishment) may disagree on the safety and efficacy of vaccines, but parents are entitled to make informed decisions.

Also, there is a great irony in your insinuation that a "scientific background" is required to think and reason in a logical manner. You may exhibit your condescension and place labels on me, and others like me, if you wish, but that will not alter the larger debate now taking place within the public arena. Your incomplete ideas and faulty conclusions regarding the risks and benefits of vaccines are being questioned and scrutinized by intelligent people throughout the world. (Think Twice Global Vaccine Institute 2007c)

What makes this material intriguing is that both positive and negative examples are used to demonstrate the site's authority. In the "Angry Letters" section (although only mentioned in passing), the author reveals that he or she is also educated, possibly as educated as those contacting them. However, he or she only mentions graduate school, and there is little other information given on education (Think Twice Global Vaccine Institute 2007). Subjective information as provided by the site is more important than the educational level of the site's owner, again demonstrating the emphasis on subjective information.

The style and content of the Think Twice website contributes to the site's authority as a provider of alternative health information. Information on this site is easily found through the use of links and the overall design of the website, which make returning to the main page a simple process. The content focuses on vaccination information, however, the primary motivation is anti-vaccination, even though the site states that it is the choice of the parent. The promotion of the free exchange of vaccine information is clear with a subtle disarming of biomedical viewpoints. For example, the



introduction to the letters sections states that some of the responses are “angry and fearful” (Think Twice Vaccine Institute 2007).

The informants who recommended this site acknowledged these biases, but felt that Think Twice was still a good alternative to biomedical websites such as Health Canada. One informant stated:

I know, I know, it's not the best of sites. There's clearly an axe that's being ground there, but isn't that true of the medical sites as well? Isn't everyone invested in making their own thing work? (April 10, 2008).

Even though my informant realized there was a bias, she felt the site still had legitimacy since it offered an alternative viewpoint. Her need for additional and alternative information could be met and she could choose which information was sound and which was biased.

Personal experience is crucial in these websites, and narrative is the preferred method of displaying competency. Often within the text of the narrative, the person will include that it was this particular vaccine reaction which led them to find other information on vaccine reactions, frequently as a way to “understand” or deal with grief. This event leads to their discovery of a variety of information, such as the following case in which a father, Michael Belkin, a financial forecaster and statistician, began to research vaccines after his child's death which had been attributed to SIDS:

SIDS is a diagnosis of exclusion ... "it wasn't this, it wasn't that, everything has been ruled out and we don't know what it was." A swollen brain is not SIDS. Through conversations with other experienced pathologists, I subsequently discovered that brain inflammation is a classic adverse reaction to vaccination (with any vaccine) in the medical literature.

I set out to do an investigation of the hepatitis B vaccine and attended a workshop at the National Academy of Sciences, Institute of Medicine on "Neo-Natal Death and the Hepatitis B Vaccine," the Advisory Committee on Immunization Practices (ACIP) February meeting and a debate in New Hampshire between the Chairman of the ACIP Dr. Modlin and Dr. Waisbren about the safety of the hepatitis B vaccine. I also obtained the entire Vaccine Adverse Events Reporting System (VAERS) database on hepatitis B vaccine adverse reactions and have investigated it thoroughly. (Belkin 1999)

Anti-vaccination sites still use medical authority, especially quotes by physicians on the use of vaccination. One of the most widely used quotes is the following which is credited to Dr. Robert Mendelsohn, M.D.: "The greatest threat of childhood diseases lies in the dangerous and ineffectual efforts made to prevent them through mass immunization.....There is no convincing scientific evidence that mass inoculations can be credited with eliminating any childhood disease" (Whale). Quotes by physicians or Ph.D.s are frequently used to lend an aspect of medical authority, but they constitute very little of the space on a website. The real authority still lives within the subjective experiences of those who create the sites and post on them.

Other groups or organizations are used as alternative voices of authority. Natural health magazines and websites offer awards to other sites they feel have good information, such as the following posted on Think Twice:

Q. Dear New Atlantean Books, congratulations! Your parenting website has been chosen for the Nurturing Magazine Exceptional Parenting Site GOLD award -- the prestigious award for exceptional parenting sites on the world wide web. The Exceptional Parenting Award is for parenting websites that stand out with distinctive and interesting information that assists parents in making informed decisions for their family. Your site is truly exceptional at providing parents with information...that they can't get anywhere else. We hope that by providing you with this award, we may encourage our 40,000+ monthly web visitors to visit your site. Thank you for your valuable contribution to the parenting community on the web.



A. Dear Nurturing friends, thank you very much for the wonderful honor of selecting our site to receive the Nurturing Magazine Gold award. We appreciate your recognition of our efforts to reach out to the parenting and health-related communities. The Think Twice Global Vaccine Institute (and New Atlantean Books) take great pride in offering parents an opportunity to make truly informed decisions regarding their health and the health of their family members. We believe that the problems of the world could be resolved within a single generation (theoretically, at least) if parents were able to achieve full awareness of, and commitment to, their noble -- and nurturing -- responsibilities. We are dedicated to providing parents with appropriate resources to achieve this aim. Please let us know if there is anything else that we may do to support our mutual endeavor. Once again, thank you. (Think Twice Global Vaccine Institute 2008)

These awards lend additional credibility to such sites since they are often recognized as voices of authority within their own communities. These alternative forms of media can lend authority to each other by linking together, thereby giving both sources more power through their connections.

The next issue Goldstein highlights is that shared experience in the Internet community creates "patterns observed by the members as definitive of the syndrome and creates the basis of [a vernacular] health theory" (2000: 315). Upon reading the narratives posted by the creator of the group or website, many follow-up postings, personal experience narratives, "unsolicited stories," or quotes are added to the original narratives which show similar situations or similar results. These stories are passed on not only to confirm common symptoms, but are also used as a memorial or a cautionary tale. In the following personal experience narrative found on the Vaccination Risk Awareness

Network<sup>56</sup>, as in many stories posted, the parent first noticed a problem shortly after the vaccine was administered:

Clayton's first DPT-P shot was administered at 8 weeks. Within hours, I could not hold him, try as I might, for he was arched right over backwards. His screaming was non-stop, at an unnatural, terrifying pitch I had never heard before. I later learned this is called 'the encephalitic scream.' I called our family pediatrician at 2 a.m. asking if I should bring Clayton in to the ER. No, I was told, this was normal, and it was suggested to me that I should just let him 'cry it out.' I was then told that Clayton would be fine, and that I should leave him be and go get some sleep. This went on for 16 hours! Still another call, with me more and more frantic. Being told to relax, as my hysterics could be exacerbating the problem. I was exhausted and fearful, and once again, asked if I should bring my son to the hospital. Again the answer was no, and again, told to just go to bed. Sleep! Though my mind and body were screaming for just that, sleep was the last thing on my mind. All I could do was sit on the bed and cry; I'd never felt such a keen feeling of helplessness, and isolation in my life. There was no family to call for help - the Dr's were all I could count on to help us... or so I thought.

Clayton grew very quiet. At this point, I was able to encourage him to nurse weakly for perhaps a minute, before his little body shuddered, and he fell into a deep sleep. His limbs were flaccid and limp as I changed him and placed him into his bassinet. (Latta-Poole 2002)

This particular narrative continues on with other standard symptoms frequently reported: pain, screaming, fever, rash, limpness, and changes in personality. It also includes other secondary characteristics which are frequently, but not always reported, such as weakened immune system, severe allergies, mental health issues, emotional health issues, physical disability, mental disability, and attention deficit problems. Latta-Poole continues:

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<sup>56</sup> The Vaccine Risk Awareness Network (VRAN) is a Canadian vernacular vaccine safety organization which promotes parent's right to choose whether or not to vaccinate their children. This site does take a strong stance against compulsory vaccination.



In spite of all he had been through, Clayton survived, though his personality was never the same. He was much quieter, not cooing nearly as much as prior to his immunization, sleeping a lot, and wore a permanent frown....In spite of my questions and objections, Clayton was kept on a very strict vaccination schedule. Most of the first two years of his life were spent in the ER, or a Drs waiting room. We saw a specialist who inserted tubes in Clayton's ears. They fell out. Our medicine chest was overflowing with medications to treat Clayton's constant ear, nose and throat infections, which I was assured - were all part of growing up. Another shot (MMR) at age 2 caused Clayton's leg to swell so badly the injection site had a lump as big as a baseball and he could not walk for days. When he finally got up off the couch, he would sit and bang his head repeatedly upon the floor. Also present were the usual reactions of fever, ear and throat infections. These are examples of the many 'normal' reactions my son had. None were ever classified as vaccine reactions. I was told when I questioned the possibility of them being vaccine reactions, that they were NOT, but only mere coincidence. Later, prior to another routine vaccine when I questioned yet again the reaction factor, I was told that there was nothing in any of his files pertaining to any problems associated with vaccines. I could also safely assume that NONE of my middle of the night calls were ever documented. I assumed that to have a reaction documented, a severe reaction had to take place right in the Drs office. Since I have begun my quest for information, I have discovered that this is not necessarily the case, as I've read about infants who collapse into coma (now THAT'S severe!) on the examination table, and the parents are hustled out and told it's just a faint and that the child will be fine. In most cases I read about, these infants were not fine. Regarding Clayton's reactions, no explanations were ever offered to us, save to say that I somehow caused his illness by my ineptitude as a parent. (Latta-Poole 2002)

This case also mentions some of the tertiary symptoms which are less frequently reported, such as autism, idiopathic illness, severe personality disorders, severe mental or physical disabilities<sup>57</sup> and death (which is typically diagnosed as SIDS). Latta-Poole discusses:

Very early on, Clayton started stealing from schoolmates. Whatever anyone else had, be it food or toys, appealed more to him than anything he

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<sup>57</sup> I am considering "severe" to mean those types of disabilities which leave the patient unable to function in society and/or requiring constant supervision or care.

had. He had all the latest toys, and I knocked myself out trying to accommodate his food allergies. Nothing worked in that respect for very long. I could not put a sign on his forehead telling people not to feed him. Food dyes and preservatives had horrible effects on him, to the point of violence - punching or kicking walls, and breaking things. He once bit deep into his sister's back after a teacher gave him candy. Ordinarily he was not violent towards his sisters, though he'd often tease them mercilessly. He had no friends and no self worth, no matter what we did to help him fit in. He lacked enough focus to follow rules in organized sports, though he was not aggressive towards other children. Just different. He did his own thing and found excitement, (at twelve years old) in sniffing gas, stealing and breaking into schools and homes....Many times after Clayton reached age 12, we've had no clue as to whether or not he was still alive... he would disappear for days at a time, with police and ourselves out searching everywhere to find him. He would turn up - seemingly unaware of the distress caused by his disappearances....What will become of Clayton?? What sort of aspirations might he have? He has been incarcerated for his involvement in an armed robbery at age 13, car theft and petty theft. He has not regularly attended school since grade 7, and is now attempting to qualify for a permanent disability benefit from our government. Social Services have requested that Clayton visit a specialist and be re-diagnosed with his disorders. There are no Dr's available to do this - not even in neighbouring cities. They claim they will give him money to take a bus to another city to see a one. Clayton will be frustrated and confused by what is being asked of him. The social worker I spoke with tells me that it is inevitable that Clayton will have to fill out a job search, in spite of barely having the ability to print his own name. She admitted that she could see that he has an obvious disability, by his application for assistance. (it was a mess!) She then informed me that Clayton will eventually be cut off any assistance unless he is able to see a specialist to be re-diagnosed. I advised the woman to contact his old specialists here, rather than put the onus on Clayton to prove his worthiness to a disability claim. I can now understand why there are so many homeless. Our government needs to understand that by partaking in this billion-dollar industry today, they will be paying for it in some way shape or form tomorrow. The cost of paying for long term disabilities, health care and prison, most of which is absorbed by the taxpayers of this country.... Prisons everywhere are full of Claytons. So are the streets. This story had to be told. People need to know why. (Latta-Poole 2002)

Clayton's story is an extreme example of an adverse vaccine reaction narrative, but it is fairly typical. These narratives can be shorter in length, but the majority of them tend to



be quite long<sup>58</sup> For example, this narrative concerning the death of a child, which was written and posted on the website Think Twice, is one of the shortest personal experience narratives I have found:

Dear Think Twice,

I read your book, *Vaccines: Are They Really Safe and Effective?* I hope and plead that you might have some answers for me or recommend what I might be able to do or whom to speak to.

Let me start by telling you a little about me and why I am writing you. I am 23 years old, married, with NOW only one son, Michael, who is 27 months old. Michael was 5 months old when I got pregnant with my second son, Jonathan.

I went to the local health department to get Michael his 2nd series of shots. At that time Jonathan was only 6 weeks old. The only shot he had ever received was the Hepatitis B that they gave him at the hospital at two days old.

When I got to the health department, the nurse gave Michael his DPT and MMR shots, and said she should go ahead and give Jonathan his shots while he was there. I said that I thought he was too young and that he had a runny nose, and I would make a separate appointment for him, but she insisted that he have them. So he got DPT, HIB, Hepatitis B, and oral polio, which personally I think is a lot of shots to give a 6 week old infant.

She was very rough with both my children and they both screamed so much at the time of the injections that I almost started to cry. After a few minutes Michael stopped crying, but Jonathan took about 15 to 20 minutes to stop crying. He finally fell asleep in the truck on the way home. As soon as we got home and I took him out of his car seat he started screaming again. This time it was very, very high pitched, and I tried everything to get him to stop crying but nothing seemed to work.

I put him in his swing and after about two hours he fell asleep again. I called a service we have called Ask-A-Nurse. The nurse advised me that if the crying started again and lasted two or more hours to take him to the Emergency Room.

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<sup>58</sup> Clayton's story is actually much longer; it was edited for space.

Besides the crying, his leg was swollen and red. If you tried to touch his toes or anything pertaining to his left leg (the leg that had the injection) he would start crying again.

Well, six days later, December 15, 1993, Jonathan died in his sleep. He had been a very healthy child and not a bit of trouble, a good baby. The medical examiner told me that Jonathan died of SIDS, but I don't believe that and I never will. I've tried talking to [authorities], but no one seems to care. To them Jonathan was just a number. To me he is life.

I won't take up any more of your time, but if you have any suggestions please write and let me know. Thank you so much for your time and understanding. (Think Twice Global Vaccine 2007)

Even this short account includes many of the characteristics noted in vaccine reaction narratives, such as site reactions (redness and swelling), crying, and fatigue. It also demonstrates another common theme to vaccines narratives: the relative health of the child before the vaccine. Most children in these narratives are categorized at "healthy," "intelligent," "bright," "normal," "happy," "attentive," and "active." Their activities, such as "never missing a thing" or "smiling" and "laughing," are also used as markers of their fitness. Some parents also include before and after pictures to show the changes in their child. Also common is the comment that the child screamed during the injection and was already becoming ill on the way home, which is frequently phrased as occurring in the car seat. It is interesting that car seats are often mentioned, perhaps as further proof of the parent's vigilance.

These narratives also mention the dismissive attitude they experienced from the medical profession. Narratives seem to imply (sometimes overtly) that they feel that, if someone in the medical community had taken them seriously, something could have been done about the reaction. This is important because it shows a continued dedication to the



medical profession. Parents have not given up on medicine after only one incident, but rather after a series of incidents.

There is an implied idea that the medical community does not care about a single child. Parents mention that to others their child might just be a number, but to them they were much more important. Some make a statement that implies that if it could happen to their child, it could happen to yours as well.

The third issue identified by Goldstein is that in Internet health communities “the power of local control (that is joint control over the internal discourse of the group) can provide the basis for proactive behaviour extending beyond the boundaries of the group” (2000: 315). Lay vaccine safety advocates are very involved in their home communities, speak publicly, or petition for greater vaccine safety or a more comprehensive adverse reaction support system. Even those who are not involved at this level often speak to other parents on a more informal level or, at the very least, choose not to vaccinate their other children. Vaccine reaction narratives typically include conclusive paragraphs such as the following example, found on the Internet:

Many people ask me what I do about vaccinations now. I used to fill in phony dates on the vaccination forms so that my children could be accepted into camps, schools, etc. Now I tell the truth -- that I will never again blindly trust the so-called medical authorities. I make conscious decisions about medicines, and I will teach my children the same. If my rights as an American citizen to choose against poisoning my children are ever taken away, I'll move. We really need to educate ourselves about vaccines and what true freedom means. (Think Twice Global Institute 2007d)

Many of the websites promote advocacy. Vaccination Liberation lists a variety of ways to be an activist, including links to various petitions online and posters which can be printed (Vaccine Liberation). Think Twice provides the following list on their website:

The Think Twice Global Vaccine Institute often receives telephone calls and emails from concerned people seeking input on how they can get involved educating others about vaccines. Here are a few ideas that can make a difference in the lives of parents and children everywhere.

1. Write an editorial in your local newspaper or an article for a national magazine.
2. Contact local talk-radio stations and request guest speakers on vaccines. Be prepared with one or two contact names and telephone numbers or emails. (You may wish to peruse the support organizations listed on this website for appropriate contact names, i.e., Neil Z. Miller, Barbara Loe Fisher, Dawn Richardson, etc.)
3. Start your own vaccine support organization.
4. Develop a newsletter. Include information that you've researched, or solicit articles and data from other individuals and organizations.
5. Organize a vaccine lecture. (Public libraries often provide free meeting rooms.)
6. Purchase vaccine educational materials for resale. (New Atlantean Press can provide generous discounts on wholesale purchases of the vaccine books that we publish.)
7. Write your legislators. Let them know that you are concerned about vaccine laws. Try to influence legislation to provide better options for concerned parents.
8. Contact local public health officials and/or social workers to let them know that you are available as a vaccine resource for concerned parents.
9. Contact local and/or national TV stations and request stories on children who have been damaged by vaccines, or investigations into exaggerated pro-vaccine claims.



10. Send information to pregnant celebrities, or to famous people who you have reason to believe may be receptive to your data.

11. Coordinate your efforts with other vaccine organizations.

12. Request a Free Bumper Sticker [sic].

13. Purchase books from the Think Twice Bookstore or Make a Contribution to the Think Twice Global Vaccine Institute. Your support will help us to publish important vaccine books, continually improve this website and reach more people.

These are just a few ideas; you may have some of your own about how to increase vaccine risk-awareness and improve parental options. Remember, parents and children need your support. *You can make a difference.* (Think Twice Global Vaccine Institute 2008 Emphasis in original).

Other websites, such as the International Memorial for Vaccine Victims, combine advocacy with personal experience narratives. Sites such as these not only allow the opportunity to share a vaccine story, but also provide a searchable index of these stories which can be investigated by state, suspected vaccine, or primary reaction. In this way this site is both memorializing the victims and allowing their stories to benefit others who may want more information for their own decision-making process (International Memorial for Vaccine Victims). Although these narratives tend to be shorter, frequently only involving single words or sentences since the author answers a series of questions, some people still manage to make a larger statement, as shown in this personal experience narrative:

I am writing about myself tonight, because I wish to share my story involving the reaction I had to the MMR vaccine. I was vaccinated at age 1, but did not begin to show symptoms of a disease until I was 3 1/2. I developed linear scleroderma on my left leg, where the vaccine was injected. I still bear the scar on my thigh. Recently, I have been diagnosed with colitis \*possibly [sic] ulcerative\* which I believe is linked to a repurcussion [sic] of the MMR vaccine as well. I am 21 and in college

studying Humanities and Social Science--I hope to become either a psychologist or a journalist someday, but my autoimmune diseases limit my choices. I am going to seek legal action against either the pharmaceutical companies that have distributed the vaccine or the doctors office that administered it to me. The MMR vaccine has been the bane of my existence, and I plan to make sure what has happened to me will not happen to another innocent little boy or girl. Good luck to you all and thanks for reading. (Sara Lee 2007)

Most sites encourage parents to act both on a local and national level in any way that they are able. Many choose to do this by telling others about the information they have found and by reporting some of the reactions they have encountered. One of the most encouraged forms of advocacy is reporting adverse reactions to VAERS (Vaccine Adverse Event Reporting System) since members of the vaccine safety movement believe vaccine reactions are unreported. At this point we can see how this information combines with other sources and becomes the basis for public health beliefs, which will be discussed in greater detail later.

The fourth issue identified by Goldstein relates to the vernacular construction of health theory in Internet health communities:

Vernacular theory provides an experientially based, alternative construction of illness which while subjugated in terms of medical authority, is likely to address the actual daily concerns, experiences and worldview of those coping with illness. Vernacular theory raises questions about dominant cultural assumptions and, like all theory, it begins in specific interpretive complexities, proceeds by local rules, uses local forms of discourse, and makes its fullest sense in the cultural context out of which it arises. (Goldstein 2000: 315)

Those actively involved in posting on anti-vaccination websites also discuss the realities of raising children with physical or mental disabilities and are frequently involved in autism awareness groups or other groups which support the realities of their children's



conditions. Some of these groups, such as the autism awareness or advocacy websites, even challenge others' conceptions concerning autism, stating it is not actually an illness at all, but rather a different way of experiencing the world. This movement has gone as far as to ask the United Nations for minority status both as a means to reject treatment for autism as an illness and as a way of promoting autism awareness (Nelson 2004).

One also sees a significant amount of information on alternative therapies, typically to deal with symptoms, to "cure" diseases such as autism, or to act as a natural alternative to vaccination. Sites, such as Think Twice, offer lists of homeopaths who work with vaccine-damaged individuals and who use homeopathy to vaccinate. Articles on the subject are available, along with personal experience narratives, that discuss the use of homeopathy. The following describes the experience from a mother's point of view concerning the results of a homeopathic cure for her son's autism, which she believes was caused by his DPT vaccination:

These are pointed before and after behaviors/changes for my son. We have been doing homeopathy since early November. He is by no means cured, but even the homeopath can't believe it is the same child. Our first visit, he sat on the floor for 45 minutes and "colored" with a pen. He didn't interact, he didn't look at anyone, he didn't answer when spoken to. He didn't recognize any words or names, etc. He did not acknowledge toys put out for him to play with. This was an improvement as he had already been on the gf/cf/soy free/corn free diet [sic] since June....At our last visit, he smiled at our homeopath upon entering, he walked around the room, noticing everything, coming over to me and pointing things out. He discovered a little basket of toys and gestured if he could play with them. He played with them then investigated the plant. The whole time babbling away, looking to me as if to show me everything. Our homeopath was blown away and so mad at herself for not videotaping his first appointment! (MacPhee. 2003)

Stories such as these typically function as voices of authority for such treatments. Few sites link to any studies or other forms of evidence that homeopathy works; instead, they tend to rely on narratives to demonstrate the evidence behind the information.

### ***What Does This Mean for Health Care?***

It has been suggested by Rowena Cullen that, from the patient's perspective, medical information is more readily available on the Internet and more up-to-date, thereby making the patient an active medical consumer (Cullen 2006: 38). However, there are still areas of concern, including three discussed by Rees:

First it is evident that unwary consumers and patients face formidable traps in the form of outrageous rumours, myths, false claims, hoaxes, and slanted information. Second, even with the information gathered from reliable sources in hand there remains the very real problem of digesting, interpreting, and evaluating, the significance of the information that is so often fragmentary and contradictory. Third, the Web has limited value for those seeking a diagnosis. Professional skills are needed to sift through a patient's complex signs, symptoms, tests, laboratory values, and so on to define the specific problem involved. (Rees 2000: 3-4)

Although there are certainly challenges in distinguishing good information from bad, this comment assumes that this is a "formidable" task for the lay person. I agree that the process of determining what the information means is complex, but not impossible, and I agree that self-diagnoses is problematic. However, the Internet can be very useful for a patient after diagnosis for finding additional information on their condition or support. When looking for information, Morahan-Martin suggests that patients "...check source, sponsorship, and authors; objectivity (verify whether the information is factual rather than opinion); currency (check the date information is posted, currency and



maintenance); privacy (check the site's privacy policy); and site design" (Morahan-Martin 2004: 500-501). The study done by Fox et al. has indicated that the majority of people look at health information after their initial diagnosis, so it seems that those who use the Internet to diagnose themselves are in the minority (Fox et al 2000: 4).

There is no denying that the information on the Internet can be from any source with a variety of motivations. Rees states:

Information posted on the Internet stands in sharp contrast to professional sources of medical information. The publication of medical textbooks and journal articles is based upon a well-defined peer-review process prior to dissemination to physicians and researchers. Authors submitting themselves to peer review are, so to speak, witnesses on oath regarding the validity of their findings. Such quality control, with all its imperfections, ensures that published information is accurate and based upon established scientific scrutiny. In contrast, medical information communicated in unmoderated user groups and rapidly downloaded, transferred, hyper-linked, and e-mailed lacks quality filtering as to accuracy, veracity, and safety. (Rees 2000: 5)

Rees seems to see the peer review system in medicine as imperfect, but more accurate. It could be argued, however, that Rees is underestimating some of the problems involved in publishing in the medical community, such as those discussed in Richard Smith's *The Trouble With Medical Journals*. After all, it was in *The Lancet*, a peer reviewed and well-established journal, that the first possibility of a link between autism and the MMR vaccine was noted, even though this research has since been withdrawn by all but one of the authors after the article's conclusion was shown to be faulty by the medical community and conflicts of interest were made known. Even peer reviewed sources of information contain biases and mistakes.

Again, we must remember that information is not inherently false just because it is posted on the Internet. Cullen states:

Much of the latter material...appears on what are frequently identified as "advocacy sites," but not all such sites should be classed as unreliable sources of information. Many are maintained by significant and well-regarded professional associations, research foundations, and patient support organizations. It is difficult, however, to set a boundary between those organizations that can be assumed to have properly compiled information from peer-reviewed sources and those that have less-objective or less-impartial approach. Only by examining content and applying careful evaluation can information on advocacy sites be used with confidence, and then only as an indication of potentially valuable approaches to a clinical problem needing further exploration. (Cullen 2006: 39)

Websites, even those created by the lay public, can contain useful and pertinent information.

This information can have a variety of effects on the patient's decision-making process. To begin with, Cullen remarks that this information may lead to a delay in seeking treatment or attempting self-treatment since the patient may try to diagnose their own condition based on the information they have found online. Cullen is also concerned that patients may contest the treatment plan suggested by the physician based on the information they have found on the Internet (Cullen 2006: 4-5). However, studies have shown that physicians remain the primary source of information for almost all patients (Chen et al. 2001; Eysenbach and Köhler 2002). Additionally, it was found that many people reported that they would consult their doctor on any information they found on the Internet (Eysenbach and Köhler 2002). Patients have also reported that they have felt that their doctors are interested in what they have found online and were willing to discuss the information (Chen et al. 2001; Fox, et al. 2000).



Since there is a variety of up-to-date information on the Internet, it leads one to wonder if there is some concern on the physician's part that their patients may become more informed about their condition than the physician. This may be the case for generalists, such as family doctors, who deal with a vast array of conditions and do not have the time to keep up-to-date on all of the new research for every new condition. While the information is just as readily available for physicians, perhaps even more so since they have access to journal information, generalists cannot be expected to keep up to date on every new study or every condition available, thereby making the patient with the condition perhaps more knowledgeable than their primary care physician about the ailment. Additionally, they may be better versed on alternative forms of medicine for the condition and may have the combined knowledge of others who have experienced the disease through the use of online groups or message boards.

This issue of professionalism in a world where the Internet is one of the main sources of information has been widely debated. In Paul Starr's *The Social Transformation of American Medicine*, he suggests that the basic component of professionalism is the claim to distinctive competence, that a group or person can offer a specific service which is valued by the individuals within a society and the society as a whole by its recognition by laws and customs (Starr 1984). Blumenthal suggests that:

At the core of medical professionalism is an asymmetric competence between patient and physician. This does not mean that the patient lacks the ability to contribute to her or that the professional's contribution is inherently more valuable than the patient's. Rather it indicates that the profession offers something distinctive that society cannot find elsewhere. (Blumenthal 2002: 527)

What physicians offer rests on three elements: cognitive, moral, and collegial (Starr 1984). The cognitive skills of a doctor allow them to diagnose and treat conditions, while the moral skills ensure they use their cognitive abilities to the benefit of others. The collegial relationship is also crucial since it provides the scrutiny of other physicians to ensure the care of the public (Starr 1984). Blumenthal notes there is a lack of two other attributes that some might like to see: collective advocacy for social welfare and the existence of professional autonomy. Even though these attributes are important for the professionalism of other careers, it seems that they are not as crucial to the professionalization of physicians. (Blumenthal 2002: 528)

Blumenthal also points to some of the problems with this definition of professionalism:

One other point about the nature of professionalism in medicine deserves mention. It could be argued that this view of professionalism – defined by distinctive competence based on technical know-how selflessly applied and collectively monitored – is a serious misreading of the true basis of medical professionalism in society. This definition implies that if patients had a sufficient knowledge of health and health care, the asymmetry in competence between physicians and laypersons could be either eliminated or drastically reduced and that the consequence might be to de-professionalize medicine. Some people wonder whether the information revolution will achieve precisely this result. (Blumenthal 2002: 528)

Historically physicians enjoyed a professional status long before they had real competency (Tuchman 1978) which may indicate that their place in society is not based on their competence, but rather society's need to have a group of people with the ability to heal (Blumenthal 2002: 529). Both the placing of physicians into the folk group of "healer" and their acceptance of this role informs some of the core problems in communication. By the lay "folk" placing doctors into the category of "other", they are



infusing their position with authority and power. This role has readily been accepted by doctors, who have embraced the role of authority figure. However, the Internet has shown the public that medical information need not be specialized, secret, or unavailable to them, creating a new dynamic in the doctor/patient relationship, one in which the doctor's role is no longer mysterious, separate, or "other".

This idea has led Blumenthal to wonder what will happen next with medicine as a profession:

An important question posed by the information revolution is, now that the profession truly has a distinctive competence, will its claim to professionalism be compromised if the information revolution empowers patients (or other non-physicians) to make competent medical decisions that used to be the sole province of physician? Or will society sustain the physician's professional role out of the desire to preserve them as a healing class? (Blumenthal 2002: 530)

Only time will tell what will happen to the role of physicians in society; however, there is no doubt that aspects of this profession must change in order to survive.

If we consider the myriad of ways in which the medical community can use the Internet to communicate, we can see six primary types of communication: patients with other patients, patients with organizations, patients with doctors, doctors with organizations, doctors with other doctors, and organizations with other organizations (Blumenthal 2002: 531-532). Each of the interactions can affect the professionalization of medicine. If we consider the interactions between patients and other patients we can see that:

Better connections among patients allow them to exchange information more readily about their conditions, their experiences with doctors and health care organizations, and their treatments and their reactions to treatments. In many cases, the resulting information is available to patients

for the first time and makes them far more intelligent consumers of health care services. (Sangl and Wolf 1996: 8)

Patients report feeling more in charge of their health care and less isolated due to this type of communication. Anonymity can be preserved or portioned out as the patient uses the Internet, leaving those who would not normally attend support groups or other functions feeling more connected and more educated about their condition. This is an important issue for the professionalization of medicine as patients (especially those with chronic conditions) gain more knowledge from P2P (patient to patient) connectivity. These new connections between patients can lead to more informed patients who are more satisfied with the information they have received from others in similar situations, giving them a knowledge of their condition which rivals their physicians (Blumenthal 2002: 533) The public's knowledge base can be problematic for generalists, such as family doctors and public health nurses who may not have had the same measure of experience in dealing with certain conditions. With the case of vaccination there are some groups of children, including the immuno-compromised, who are not able to receive their vaccines on the same schedule as others their age or who may not have the same immunological response. While these children may be under the care of specialists at the time, especially if they are currently in treatment, some may have more knowledge of their condition than those who are currently vaccinating them. Blumenthal also mentions:

P2P communication will affect the collegial and moral bases of professionalism as well. Communication about experiences with physicians will inform patients' choice of physician. In this way, patients may create a collective mechanism for monitoring and regulating professional performance, thus reducing physicians' reliance on collegial self-discipline. (Blumenthal 2002: 533)



Although this system of recommendation has certainly existed for ages in face-to-face interactions in many communities, the ability to post this information to a larger group of people that one would not have had previous contact with could potentially “make or break” the practice of any physician. Websites such as RateMDs.com, DoctorScorecard.com, and FindADoc.com, rate physicians in a variety of ways and enable those who are unknown to each other to discuss their thoughts on particular physicians.

Patient to patient communication does have positive implications for the professionalization of medicine as well:

Like enhanced connectivity generally, P2P communication may also increase the importance to patients of the moral bases of professionalism. Confronted with a deluge of new data from other patients, consumers of health care services may come to value physicians more highly than ever as trusted advisers who can help them process new data and turn them into knowledge useful to their own care. Physicians’ dedication to the interests of the particular patient in their office becomes a critical source of distinctive competence under the influence of the information revolution. (Blumenthal 2002: 533)

In this way, patients would use doctors (and other health professionals) as a means to understand the information they have found. However, this is not always the role that physicians want to take. Although at first many of the medical professionals told me that they felt the Internet was a wonderful way for their patients to become more empowered, there is a degree of concern or ambivalence. In later interviews, more than one physician confessed that they found the Internet to be “more trouble than anything else” (Interview with medical professional. November 22, 2006). Doctors and nurses also complained that patients were coming in with information which did not apply to their situation and felt

that the process of explaining all of this to them required more time than they had to give.

One physician in his interview articulated this frustration:

I see a lot of people. A lot in a day. Some people come from across the province to see me. Then they come with all their questions, I don't mind the questions, what I mind is when they don't believe my answers. Then, I want to ask, why did you come and see me in the first place? (Interview with medical professional. June 27, 2007)

Medical students have also reported the difference between what the official view is towards the Internet and what they really feel. As one commented in her interview:

Oh yeah, officially we're all in love with the Internet. Our patients are more empowered and all of that. And sometimes they are and it is good, especially for the cancer patients. But most of the time? Most of the time the pros hate it. They hate the questions. They feel that people should trust them. I guess I'll probably feel that same way after I'm all done with this as well. You know, after all those years? Well, I'd expect people to trust me, too. (Interview with medical professional. October 5, 2007)

Other students reported only that they had heard "some pros rant about it" but did not want to get any more specific than that. One medical student went as far as to say "I know when I walk into the room and the patient is sitting there with a stack of papers, all printed off from the Internet....well, I just know it's going to be a bad day" (Interview with medical professional. August 24, 2006).

Most of my informants agreed that some of the other types of Internet communication, such as patient to organization, work well. "I don't mind at all when my patients visit the CDC [Centers for Disease Control] or Health Canada," one physician reported, "there's good information there" (Interview with medical professional. April 6, 2007). However, health seekers are not always satisfied with the information available on



these websites or with their doctors in general. Blumenthal is concerned with the possibility of patients reporting levels of satisfaction:

In the near future, information about patients' satisfaction with their physicians should become available for virtually all doctors, even though in many cases, professional associations and state regulatory boards do not themselves collect such data. Even when the professional organizations do have such data, internal opposition prevents them from using the information to improve physicians' performance. This stance threatens the collegial role of the profession in ensuring quality of care and service and thus the legitimacy of the medical profession in the public's eyes. (Blumenthal 2002: 534-535)

Although there are websites which allow patients to rate their physicians, word of mouth is perhaps more widely used in St. John's. I have both given and received advice on which doctors to see from a variety of people. I have also received an email forward which described one patient's experience with a local family physician and a birth control prescription, which I was encouraged to forward on. Approximately half of the informants I talked to also mentioned that they were recommended to various doctors by friends and warned away from others by word of mouth, although a few did state that they searched their doctor's name on the Internet before going to see them.

There is professional concern that some patients will be overwhelmed by the amount of information available and that some doctors may develop financial interests in certain websites, leading to other ethical issues (Blumenthal 2002: 535). If physicians choose to invest in forms of information online without the proper reflexivity, other concerns may arise, including additional medical distrust.

Other areas of Internet communication, such as patient to doctor may also prove useful. While physicians are reluctant to provide health advice over the Internet for

obvious reasons, other types of communication, such as being able to schedule doctor's visits online, could actually make the physician's job easier. Although some physicians worry that this accessibility will lead to uncensored patient access (Bazzoli 2000), they should remember that the same concerns were expressed upon the invention of the telephone (Spielberg 1998), a medium which has proved to be a great assistance to them with the proper access. Physicians should instead be reassured by their patients' desire to contact them as proof of their distinctive competence (Rybowski 2001).

Additionally, this transition to a more web-based practice may also be necessary:

Some of what patients want seems quite elementary: the ability to conduct administrative business, like scheduling appointments and learning about test results, using electronic methods. If physicians ignore these desires, they could turn an opportunity to improve service into an example of professional arrogance that will undermine the moral basis of medical professionalism. (Blumenthal 2002: 537)

If physicians employ these simple techniques, patients may be happier and perhaps more likely to trust in their physicians since the physician is putting the patients' needs above their own.

It would also be useful for physicians to continue to use the Internet and online resources to work with other physicians. This technique is being used with great success in Newfoundland at the main hospital in St. John's, The Health Sciences Centre. With the support of the department of Medical Education and Laboratory Support Services, doctors in remote areas can consult with specialists in St. John's (and other regions) concerning the care of their patients. Physicians can also receive additional training in many areas without leaving the community they serve, which is beneficial to their



patients. The same also applies for communication between doctors and other organizations, so long as physicians do not become dependent on these interactions.

Morahan-Martin makes three suggestions for health professionals: recommend sites, promote more effective search and evaluation techniques, and be involved in developing and promoting uniform standards for websites (2004: 506-508). Although Morahan-Martin's suggestions are clear, they unfortunately include one major bias, that health professionals are able to identify good websites with pertinent information. Once again, we have to consider issues of trust. While it would be considered appropriate to recommend the website of a trusted organization, many organizations do not offer the types of extensive advice or personal accounts that health seekers want. Approximately half of the informants I spoke with felt that the "reliable" Internet sites, such as the CDC or Health Canada, often repeated what their doctors had told them and had little to say when it came to alternative viewpoints or found that their response to alternative viewpoints was dismissive. They remarked that the websites they felt were the most effective were those that sponsored message boards or other means for members to communicate with others or ask specific questions. The recommendation of a website by a health professional is a good idea, but many patients will see it as a starting point instead of the place where they should get all of their information.

The promotion of better search and evaluation techniques is Morahan-Martin's best suggestion. It should be noted that medical journals in the past have reported that patients tend to use less sophisticated terminology in their searches. However, in the case of Wolf et al.'s study, it was not a matter of only using medical versus non-medical

terms, but also an issue of regional variations. In this study, the investigators commented that they found many veterinarian sites when using the search word "shots." This was not surprising to me since "shots" is the term used for pet vaccinations while "needles" is the term used for immunization in Newfoundland and other regions of Canada. It would be useful for health professionals to assist their patients in identifying accurate terminology for their searches, such as the terms "immunization," "inoculation," and "vaccination" and suggest that they try varying searches which employ all of those terms (Wolfe and Sharpe 2005: 537-551).

Concerning the last suggestion, that health professionals assist in the development of uniform standards for websites, the idea seems almost impossible. Since anyone can have a website, the suggestions that Morahan-Martin offers, while pertinent, may not make that much of a difference overall. Morahan-Martin's mention of the World Health Organization's idea of introducing the domain ".health" is a good one; however, it may or may not have any effect on what websites people actually use to find their health information.

Physicians must realize that the Internet has already and will continue to change the face of medicine today. Although physicians will continue to have a specific place in health care due to their abilities in the procedural areas of medicine and their ability to assemble and interpret health care information, they should realize that their place in society may be changing:

....physicians should not assume that time-tested sources of distinctive competence will be sufficient to sustain medical professionalism in the future. More patients will be better informed about the basic facts of health and illness. Thus, the physicians' traditional role as dispensers of



facts will decline in the future and, for a significant minority of patients, the well-educated chronically ill, may disappear altogether. The information revolution, however, creates opportunities to craft a new source of distinctive competence for physicians; the role of consultant. (Blumenthal 2002: 538)

Blumenthal states that doctors of the future will need two new roles: decision analyst and health care informatician (Blumenthal 2002: 538-539). Additionally, doctors may want to consider the ability to understand, value, and be able to work within their patients' belief system as equally important. As Hufford states, "Physicians imagine what they would feel and do in the patient's place. The problem, of course, is that this tells them little or nothing about what the patient feels or why they do what they do. Each person's reaction to sickness or anything else is heavily conditioned by their history" (Hufford 1997: 120). An awareness and empathy concerning this history, in addition to an acknowledgement that medical professionals themselves have their own history and biases, could result in a decrease of medical distrust.

### **The Media**

Schenda once stated that, "Never did folklore fare better than under the flag of mass culture" (1992: 30). Rumour, legend, gossip, and conspiracy theories thrive in the media and are often the basis of additional interpretations and retellings. Many times a news story will have an element of folk culture in it, which then adds to the original form of the narrative, giving it added authority (Brunvand 2001: 47-66). Legends also speak to modern-day concerns and appeal to a great number of people. Dégh states "The legend is a product of modern life; it reveals the interaction of oral tradition, mass media, and

written literature more directly than the venerable folklore forms and also cuts across different layers of modern society” (Dégh 1968: 72). This enables rumours, legends, conspiracy theories, and gossip to appear to be a legitimate way of reaching an audience:

The consistent relevance and popular appeal of contemporary legends in our society has meant that they are more and more often being reported in the media. Their single episode format, coupled with their plausibility and startling plots (and what press story doesn't aim to be startling), makes them highly newsworthy. Consequently, it is practical to consider that outside of the oral tradition, the major disseminators of contemporary legend are the news gathering agencies – i.e., newspapers, magazines, radio and television. Of these four institutions, possibly newspapers are the largest carriers of contemporary legends. (Smith 1992:42)

As Bengt af Klintberg has commented:

It is a fact that a large part of contemporary legendry has been published as news information in daily papers all over the world. This is not surprising; not even experienced journalists can be expected to recognize all those legend patterns and motifs which are created or revived in our time. The study of the interaction between oral tradition and mass media is an important aspect within the research of modern legends. Now the least important is to clarify that the daily press, now as well as earlier, satisfied not only the demand for information but also a demand for entertainment. (af Klintberg 1981: 153)

Newspapers and other forms of media are notorious for reporting legends as facts.

Legends and newspaper reports actually have several things in common. As de Vos notes, “Similarities between newspapers and contemporary legends exist in form, content and function: both are cyclical in nature; both attempt to represent the content in a factual and objective manner; and both present their audiences with confirmation for their fears and opinions” (1996: 34). If we work within de Vos’ model, we can see the ways in which vaccine information and legend are often portrayed side by side. Larry King’s interview with Jenny McCarthy and Jim Carrey on the MMR/Autism link (Airdate April



3, 2009)<sup>59</sup> for example, provided information that stated that vaccination was important and that people should vaccinate, but also mentioned that autism can be cured and that the number and ingredients in the vaccines were the cause of autism. These statements would be regarded as legendary or rumour-based by most in the medical community. The combination of legend and medical information found in the media can be confusing to the lay public since both fact and rumour are presented as equally true.

Due to the cyclical nature of legends and newspapers, we also see a cyclical nature to vaccine reporting. Beardsworth states, "Issues may re-emerge weeks, months or even years later when their novelty value has been re-established as the result of a period out of the public eye" (1990: 12). Every flu season we are bombarded with a deluge of information on the flu vaccine and the possibility of bird flu, topics that are rarely discussed outside of the fall and winter months. There also tends to be more information reported whenever a court case is covered by the media, such as cases over vaccine injuries or reports from the American military concerning Gulf War Syndrome. Typically, we see additional reporting during the early months of the school year when many students are attending school for the first time or moving to a different school which may require an updated immunization record. All of these topics appear predictably, but many vaccine stories, such as the HPV vaccine which has recently reached the media, come into play more sporadically, typically when the vaccine is first introduced. Even if the vaccine is not well received, the protests eventually leave the

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<sup>59</sup> A copy of the transcript can be found at: <http://transcripts.cnn.com/TRANSCRIPTS/0904/03/lkl.01.html>

news scene. Typically it takes another event, such as the marketing of a new vaccine or another court case, to reintroduce the cycle.

As for de Vos' second topic, that legends and news stories attempt to report the story in a factual and objective manner, we see that many of the vaccine reports and legends use authoritative voices to add weight to their argument. Newspaper articles may include an interview with a local doctor, while legends may cite discussion with a medical health professional. Both sources will seek outside authority to lend weight to their argument. Oddly enough, this is frequently done by newspapers through citing another newspaper as the source.

Oring has stated that the news cannot possibly be a credible source for the following reasons:

1. the selection of what is to serve as news can be neither factual nor objective;
2. the news is organized and communicated as "stories"; and
3. the news can never be independent of the process of collecting it (Oring 1990, 164-167).

Here Oring touches on issues of reflexivity and points out that any piece of information will be biased. Our biases (both explicit and inherent) are bound to colour our perceptions of any event and will come out in the reporting of that event.

In both the media and legend, sensationalism plays on the opinions and fears of the public. One informant stated,

I was home, just flipping through the channels, when I heard "Next, the vaccine that is killing your children!" Well, I was riveted. I watched almost twenty minutes of that show, I can't remember what it was called, just to find out it was nothing. (Interview with lay person with children. August 6, 2007)



These openings target the concerns of parents and others to keep them watching the story. Legends frequently contain similar elements which are intended to shock, such as beginning the story with "Did you know that your children could be kicked out of school if they aren't vaccinated? They said so, on the news, just the other day" (Interview with lay person with children. November 10, 2007). All of these opening lines are intended to grab the attention of the audience and cause concern. Perhaps what is more problematic is when audience members do not actually read the article or watch the report and instead use those openings and headlines as the basis for information, as my previous informant did, mistaking a news report from the United States as being from Canada (Interview with lay person with children. November 10, 2007).

In these ways, reporters play into opinions that have already been established, especially if they include other threatening elements such as government control. Those who agree with vaccination often question that agreement if they encounter threats of making inoculation mandatory. As one of my informants stated:

Oh yeah, I basically have no opinion about vaccinations. I remember successfully avoiding my boosters in high school (which was I think a suspension-worthy offence). It was a point of principle, really, that the state (in the guise of the Ottawa Board of Education) shouldn't force its constituency to do anything against their will. It's not a health issue so much as a rights issue. I guess libertarianism, in its own way (like being opposed to seatbelts or age restrictions on tobacco). It's okay when the state is acting for the common good (like drinking and driving laws, where an individual's actions can affect others: even smoking bans in public places would qualify), but when it's paternalistic, I get antsy. So that IS an opinion, I guess: but I don't think I have any beliefs about vaccinations per se one way or the other. (Interview with lay person without children. July 10, 2007)

The media tends to focus on shocking ideas, such as government control, even if it is not key to the story. This focus on the more sensationalized aspects of news reporting is common as journalists are taught to look for impact, emotional appeal, conflict, timelines, proximity, prominences, and the unusual (Stephens 1988:32), focusing on the bizarre rather than the ordinary, even in the case of the “respectable” press (deVos 1996: 35). Often, it is the most sensational information which is published, not necessarily the mundane or the well-researched.

### ***The Media and Folklore Content***

Paul Smith has identified that newspapers have six basic approaches to contemporary legends, which include:

1. *Reporting* contemporary legends as “factual” news.
2. *Exposing* oral or reported contemporary legends as “untrue” stories.
3. *Retracting*, and thereby exposing contemporary legends.
4. *Educating* the reader via the presentation of contemporary legends.
5. *Entertaining* the reader via the presentation of contemporary legends.
6. *Advertising* commercial products for sale using contemporary legends. (Smith 1992: 45)

These categories are not exclusive, legends may combine approaches, and may be categorised in a variety of ways because each is context dependent (Smith 1992: 45).

Regarding Smith’s approach to reporting contemporary legends as “factual” news (1992: 45), arguments both for and against the correlation between MMR and autism have been hotly debated. The medical community states that the MMR/autism link is inconclusive, while one of the researchers in the original study, Andrew Wakefield,



maintains that the study is significant. We see similar issues with the flu vaccine. News reports on the after-effects of the flu vaccine, including mild, flu-like symptoms, are common; however, medical research provides evidence to the contrary (Bridges et al. 2000, Nichol et al. 1995).

Perhaps more disturbing are cases of tainted vaccines reaching the media without hard evidence. It would be absurd to say that a batch of vaccines has never been tainted; however, there have been numerous reports of vaccines being tainted without real evidence, as in the case of the so-called "Hot Lots" mentioned earlier. Reports have also included the possibility that vaccines were tainted on purpose and that many batches of vaccines are untested.

The next news approach to legend identified by Smith is, "exposing oral or reported contemporary legends as "untrue" stories" (1992:45). This debunking is demonstrated in legends concerning the flu vaccine shortage in the United States, which inspired some journalists to research these legends for truth or falsity. The legend that a flu vaccine shortage was John Kerry's fault because he was involved in a lawsuit over a vaccine injury, for example, was proven false by both *The Washington Post* and *The (Raleigh) News & Observer* (Brown 2004; Avery 2004).

Retracting, and thereby exposing contemporary legends (Smith 1992: 45) is common in vaccine-lore. Perhaps the most well known vaccine-related retraction did not necessarily begin with a newspaper, but rather a journal. The news of this event, however, quickly spread to all forms of media. As previously mentioned, this infamous event was the retraction *The Lancet* printed after its initial printing of the Wakefield et al.

study that linked the MMR vaccine with autism<sup>60</sup> (Wakefield et al. 1998). This story was immediately featured in a variety of news stories in all forms of media and on the Internet (Deer 2007).

Interestingly enough, since the retraction, all of the researchers save one (Andrew Wakefield) have also rejected their research, stating that there was not enough evidence for the claim. *The Lancet* has maintained that it was the fault of the editor, Dr. Richard Horton, who supported Wakefield's findings. The following was reported on February 22, 2004 by *The Sunday Times* (London):

The reputation of Richard Horton, editor of *The Lancet*, has been tied to that of Andrew Wakefield ever since the controversial study on MMR was published six years ago. He ran his old colleague's research to the surprise of some experts. Last week, after being shown the evidence of *The Sunday Times* investigation, he admitted publishing was a mistake. He was apparently so startled by our findings that he immediately went public, despite an agreement that he was shown them in confidence. Medical insiders now wonder if he can survive the scandal that has damaged *The Lancet*. (Deer 2004)

In some circles, this has turned Wakefield into a martyr, making him one of the kingpins of the anti-vaccination movement. Some news sources and Internet sites have labelled him as "the only doctor not afraid to tell the truth," while others in biomedicine have shunned him. Amidst all of this uncertainty one thing is certain, after this event the credibility of *The Lancet* was scrutinized by the medical community. As one of my medical student informants said, "Well, I expected it of them, you know, it was *The Lancet*. Not a real medical journal" (Interview with medical professional. April 23, 2007). This is an interesting statement, considering *The Lancet* is one of the oldest peer-

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<sup>60</sup> The link between autism and the MMR vaccine will be discussed in greater detail in Chapter Five.



reviewed medical journals and they retracted the faulty research as soon as possible. The legend grew in spite of this retraction.

Brian Deer's website is dedicated to the education of readers concerning the MMR vaccine, following Smith's concept of "educating the reader via the presentation of contemporary legends" (1992:45). Brian Deer, a journalist for *The Times* in London, has done a great deal of investigative reporting on the link between MMR and autism. His website is full of articles and information on his documentary, which debuted on Channel Four in Great Britain. This information breaks down all of the events concerning Wakefield and the MMR/Autism debate. Deer states his primary interest is in educating the public about the dangers of refusing vaccinations and exposing Andrew Wakefield as a fraud.

Other media, such as Autism Vox, which both functions as a website and a newsletter for those with autism, warn of the dangers of believing Wakefield's claim that there is a cure for autism:

We do not need to "canonize" Dr. Wakefield and make him a "martyr" and a sort of "autism folk hero." Our autistic children, with all their struggles and small and large triumphs, are the real heroes and it is *they* who the media, and all of us, should put at the center of autism discussions, and it is to *them* that we need to look in determining how best to help them. (Chew 2006)

However, others feel that the real legend illustrates that there is no link between autism and MMR:

It takes a man of great courage and integrity to stand up against overwhelming pressure from his scientific colleagues and refuse to say what is false when he knows what is true. Andrew Wakefield will not sell his soul to be protected from those government and drug company officials and doctors subservient to both government and industry who

have tried to destroy him and prevent him from proving a scientific hypothesis. (Fisher 2003)

The areas where we see the least information concerning vaccine legends is identified by Smith as “entertaining the reader via the presentation of contemporary legends” (1992: 45). Although some forms of media make light of common vaccine legends under a context of condemnation, the majority do not. Perhaps it is because this topic is too important to those involved.

A common practice with vaccination and the media is identified by Smith as “advertising commercial products for sale using contemporary legends” (Smith 1992: 34). Many websites have links to products, or more commonly books, which contain additional information on the topic. Although it would be incorrect to say that all of these products are associated with or use legends since the issue of truth is still under review, there are some sites that play up the scare factor of certain legends in order to sell products. The most common item for sale is chelation therapy, which is a process to remove heavy metals from the body. This process is used in Western medicine as a way to treat heavy metal poisoning; however, alternative care practitioners also use it to treat heart disease (specifically the hardening of the arteries) and vaccine reactions. The belief is that if the mercury in vaccinations caused the autism, then the removal of this mercury should cure or improve the patient. Although this treatment is mostly harmless, there has been one case of death reported in an autistic child in Pittsburgh that was not caused by the treatment itself, but rather incompetence. At first there was question as to what caused the child’s death:



A 5-year-old autistic boy who went into cardiac arrest in his doctor's office died as a result of the controversial chelation therapy he was receiving as a treatment for his autism. The manner of death of Abubakar Tariq Nadama, of Monroeville, has been listed as accidental while the investigation continues. The findings released by the Butler County coroner's office don't say whether the treatment itself is dangerous or the child died from the way the treatment was administered....The determination is sure to spark debate among parents, many of whom support chelation as a safe and effective therapy for autism. Others condemn the treatment as voodoo medicine<sup>61</sup>. (Kane January 6, 2006)

However, it was later discovered that it was the administration of the wrong drug which proved fatal (Kane January 18, 2006). The debate over the use of chelation therapy for autism remains an issue:

Howard Carpenter, executive director of the Advisory Board on Autism and Related Disorders -- the largest autism advocacy group in the region -- said the determination by Dr. Brown clears up the mystery surrounding Tariq's death but not the uncertainty over chelation itself. "Since this child died, there have been parents who are pro-chelation who have been very angry that there's talk against it. On the other side, they say the death was a natural consequence of a dangerous activity. Maybe what happened to [Tariq] is explained, but we still don't have a conclusion about whether chelation is an effective treatment for autism," he said. (Kane January 18, 2006)

Perhaps the most intriguing part of this story is that the legend is prevalent enough that treatments are available.

Regardless of whether it is an Internet site, newspaper, news report, or other form of mediums, one could argue that these mediums tap into the current thoughts and fears of the public as a whole. As Bird has written, "The tabloids appear to pick up on existing ideas and beliefs, restating them in narrative form, performing much the same function as

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<sup>61</sup> This is a good example of how pro-vaccinators attempt to make alternative medical standpoints less valid by likening them to practices which already fall into our traditions of disbelief.

the teller of an urban legend” (Bird 1992: 188). Cohen and Young compare news and “myth” (what folklorists would call “legend”), arguing:

Myth outlines the boundaries of acceptable behaviours by telling stories....So all news media report crime and deviant behaviour, and not primarily as a duty to inform; the average reader does not require the quantities of information offered on crime....A central meaning of crime news is symbolic....such news in a main source....about the normative contours of a society....about right and wrong, about the parameters beyond which one should not venture and about the shapes that the devil can assume. A gallery of folk types – heroes and saints, as well as fools, villains and devils – is publicized not just in oral tradition and face-to-face contact, but to much larger audiences with much greater dramatic resources. (Cohen and Young 1981: 431)

These legends are not only told to inform, entertain, advertise, or educate. They are also told to show us the difference between right and wrong as perceived by the author in particular or society in general. Many of these articles use loaded words, for example the term “voodoo” used to describe chelation therapy above. One can see the same concerns in alternative forms of media, such as some of the anti-vaccination websites and alternative health care publications, where conventional medicine is subjected to the same author biases.

Manoff and Schudson state, “Journalism, like any other storytelling activity, is a form of fiction operating out of its own conventions and understandings and within its own set of sociological, ideological, and literary constraints” (1987: 6) which indicates that an understanding of the function of journalists in society would be beneficial. de Vos offers some of the cultural roles of journalists, which include stressing commonalities, organizing events in a way that makes sense to the reader, exploring the inexplicable,



education of the audience, and seasonal cycles which revolve around the environment. (de Vos 1996: 44-45).

Grider has noted that there is an interchange between the media and the population as a whole:

The mass media, particularly television programming, and oral tradition have a symbiotic relationship. Students often use supernatural plots gleaned from television and films to spice up both their oral storytelling and creative writing. The media provides the content, often based on folklore motifs and plots, and the oral tradition provides the performance opportunity, not only for professional storytellers, but for storytelling individuals....The term "media narraform" has been coined to refer to those retellings of mass media presentations of the supernatural, which use traditional storytelling techniques and folklore motifs (Grider 1981, 125)

The same is true for disease and vaccination narratives. The morning after Oprah's special on bird flu (Airdate: January 24, 2006) I was swarmed in my classroom upon my arrival. My students wanted to know what I knew about bird flu and if it was true that there was no vaccine for it. I quickly explained that since the human-to-human form of bird flu had not developed yet, it was impossible to create a vaccine. My students were very concerned. The doctor who appeared on the show stated that it would be too late to create a vaccine, which led to stories about West Nile virus, the plague, smallpox, and HPV. The students often reported that they had heard things from "somewhere"; however, I recognized some of the narratives as a combination of recent news reports and folk beliefs concerning shortages of vaccines, efficacy of vaccines, and disease which could kill at a moment's notice. The information they were the most concerned about from the Oprah special was linked to other beliefs they already had concerning illnesses and vaccines, including a lack of a vaccine, a shortage of vaccines, and concerns about

the sudden appearance of such illness, like HPV, SARS, and bird flu. Interestingly enough, they inquired if, as with SARS, they should wear a sterile mask while flying. This demonstrates the lasting power of the SARS panic, the efficacy of public health messages, and the idea that these epidemics come from somewhere else.

Perhaps the most crucial effect that the media and contemporary legends have on the lay public is their relationship to medical decision-making. As Goldstein states:

Whether circulated by mass Internet postings, reported in the newspaper, or discussed face to face in more traditional storytelling contexts, contemporary legends retain certain important features: as noted, they are told as true, factual, or plausible and therefore assume a level of authority; they provoke a dialogue about the narrative events, their interpretation, and their plausibility; they both articulate and influence beliefs and attitudes toward the subject matter, and they have the capability of affecting the actions and behavior of the listening audience. These features, combined with the intense mass circulation made possible by popular culture, the media, and the Internet, provide contemporary legend with the potential of widespread cultural impact. As a genre that advises, warns, and informs with incredible speed and authority (Shibutani 1966), the contemporary legend can become a formative motivating factor in personal decision making, including decisions related to individual health-seeking and health-care provision. (2004: 28)

In a world where the majority of information comes from the Internet and media, more consideration must be placed on the information that is found there and how it combines with the existing beliefs of the individual and society.



## **Chapter Five**

### **Medical and Ethical Issues as Perceived by the Medical Community**

*"....Parents may be free to become martyrs themselves. But it does not follow that they are free in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves." (Prince v. Commonwealth of Massachusetts, 321 US 158. 1944)*

Narratives abound when it comes to ethical and moral issues concerning vaccination. Although some of these stories are easily dismissed, others are harder to ignore and they make their way into court cases and on television, and are transmitted more informally through regular folklore channels. These legends require consideration, primarily because they tell us much about the underlying fears and concerns of the lay public as well as those in the medical profession, legal profession, and those who deal with the ethics of such cases. In this chapter, I will discuss some of these tales told by medical professionals, consider how these stories are linked to both legend and personal experience narrative, examine the function of these stories for specific folk groups, and address some of the ethical issues behind both these stories and the greater issue of vaccination.

#### **Shaken Baby Syndrome**

Shaken Baby Syndrome (SBS) is "A syndrome in infants in which brain injury is caused by shaking of such violence that the child's brain rebounds against the skull, resulting in bruising, swelling, and bleeding of the brain and often leading to permanent,

severe brain damage or death” (The American Heritage Medical Dictionary 2007). This condition in medical literature is synonymous with child abuse, but there are those who believe that, in some instances, SBS might be the result of an adverse vaccine reaction. Harold E. Buttram, MD states that the first problem with court cases which involve SBS is that they start with some primary assumptions:

...the following beliefs have become prevalent in courts dealing with the SBS: 1) Shaking alone in an otherwise healthy child can cause a subdural hematoma; 2) non-traumatic new bleeding in an existing subdural hematoma will always cause only minor symptoms; 3) a child suffering from an ultimately fatal brain injury will not experience any lucid interval; 4) short-distance falls by children are never fatal; and 5) retinal hemorrhage occurs only in shaken babies. There is, however, a body of literature that casts doubt on the validity of these assumptions. (Buttram 2001: 83-89)

Buttram goes on to show that early work with SBS did not involve an experimental model and none of the cases reported ever had a witness, so there was no proof that the baby was shaken. In later studies, a model was developed to prove an infant's susceptibility to shaking; however, the authors concluded that in order to see the types of injuries mentioned, some impact is needed, which means that shaking alone did not cause these injuries (Buttram 2001: 83-89). This does make a significant difference in some cases since there is not always proof of impact.

Buttram lists multiple conditions which involve the same or similar symptoms, such as brain oedema, perivascular lymphocytosis, vasculopathies, and others that are conditions not uncommon in vaccine reactions. Although Buttram never says that there is some sort of conspiracy in the medical arena to cover adverse vaccine reactions, conspiracy theorists point to this assumption. Buttram instead blames the medical system



for not encouraging doctors to even see this as a possibility. He mentions that when others have tried to find information on vaccine reactions they have:

....found an almost insuperable difficulty in obtaining dependable data....due to the extreme reluctance of doctors to report vaccine reactions, a pattern which has existed since the early days of vaccine programs. There are a number of reasons for this reluctance. From their earliest years of training, doctors have been taught to look upon vaccines as one of the greatest achievements of medical science, and any question about them is often looked upon as disloyalty to the profession. (Buttram 2001: 83-89).

Unless a physician specializes in these fields, they may not know the signs of a vaccine reaction. Medicine requires some level of specialization to ensure proper diagnosis since it would be impossible to know everything.

This issue is crucial not only because it involves a life and death situation, but also because it becomes an issue of legality. Any time child abuse is suspected, physicians and other medical professionals are required by law to contact the appropriate authorities and, on that basis, arrests or other interventions are put into action. Perhaps the most well-known of these events is the Alan Yurko case, both for its legal issues and the persistent rumours and legends about the Yurkos. This story was mentioned by name twice among my informants with medical backgrounds and debates over cases of abuse versus vaccine reactions were mentioned by an additional five informants, although no specific cases were mentioned. For this narrative, I will use "Baby Alan Yurko" to distinguish the son from the father, Alan Yurko, Sr.

Baby Alan was born with multiple medical conditions due to his premature birth, including respiratory issues and many other problems. He was vaccinated at six weeks of age:

The day after the vaccine administrations, the mother noticed increasing lethargy and feeding problems. Ten days later there was a high-pitched cry (which can exist when there are some cerebral problems, such as encephalopathy). On November 24, while under the care of the father, Alan Yurko, the baby began to wheeze and then stopped breathing. There was apparently up to 5 minutes of a degree of apnea. (Kalokerinos 2007)

Alan Sr. recalls the event in his own words, from prison<sup>62</sup>:

On the 24th of November, she left for work. We had decided to take Alan to the pediatrician when she got back from work because, even though the doctor said he'd be fussy, something didn't seem right. We never had the chance. I fed Alan and then while changing his diaper he spit up a fair amount of his feeding. As I grabbed a clean burp rag, I then noticed that he was pretty still. I cleaned him up and noticed that he was not breathing! He sometimes would stop breathing for little short periods of time and always was grumpy and congested, but this time he wasn't catching his breath. During this whole time, our daughter was at my side. My adrenaline kicked in--we had planned for this, since Alan was a premature baby. I checked for something obstructing his air passages. Nothing. I gave CPR. Nothing.

My wife had the car! Alan was still naked when I ran next door to the neighbors while shouting to my daughter to get her "shoesies" on. I didn't knock. I yanked the door open with my right hand and grabbed his car keys. I didn't ask. I shouted, "He's not breathing!" as I left to get in the car, Alan in my left hand. My daughter got in the car as I kept breathing into Alan's mouth when I could to get oxygen in him. My daughter was crying and kept asking me, "Daddy, what's wrong?" "It's an emergency!" I drove to the hospital, which was only about two miles away, with the accelerator floored. I ran a red light. One hand on the horn and steering wheel; Alan's mouth to mine. Breathing. I shouted to my frightened daughter, "Put your seatbelt on!" I never shout at my princess. She was scared. More breaths. I fishtailed into the E/R parking lot and opened the door. I even put the car in park before we stopped moving. I ran into the E/R with my naked blue baby and daughter in tow. I handed Alan over the counter and said, "He's not breathing!" The nurse whisked him through some back entrance behind the counter. I tried the access door. Locked. I jumped over the counter. Another nurse tried to block my way. We locked eyes. "Watch

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<sup>62</sup> After Baby Alan Yurko was pronounced dead at the hospital, Alan Yurko Sr. was arrested and charged with aggravated child abuse and first degree murder. He was to serve a lifetime sentence until a series of hearings exonerated him of the charges after six years of imprisonment. This narrative is posted on his website (Free Alan Yurko 2008).



my daughter!" A pause. She nodded and I passed her. Where did they go? There. Commotion. Small room with doctors/nurses and yelling.

They stuck a tube thing that looked like a huge turkey baster down his throat. They pumped. His stomach blew up like a beach ball. The doctor's shout, "Wrong tube! Wrong tube!" They pull it out and air releases in a gurgle from his stomach. They put the thing in his throat again. Pump. Again, his stomach balloons up. More shouts. I scream, "What the hell are you doing to him???!!!" They all look at me. A nurse asks me to leave. They hadn't noticed me until now. I told her I would shut up and stay in the corner and that I didn't want him to be without his family if he died. She pushed me in a corner and gave me a stern look. They then put a huge needle in his chest. Then they got the shock pads. I had to step to step out of the room because of some machine they had to bring in.

A doctor came out and said, "He's breathing." I hugged him. I thanked him. A nurse came out and I hugged her. This is when I finally broke down and cried. I had to call my wife. I saw a phone behind the counter. I helped myself. "Honey. Get to the hospital right now! He stopped breathing!" She hung up before I could get any further. A cop came in and asked me to move my car. I had left the car running, door open, and it was blocking the entrance. I saw my daughter with the nurses playing with toys. Thank God. I moved the car. My wife arrived. She was crying. I told her he was breathing now. She sobbed with relief in my arms. The doctors told us they thought he was septic and that he needed a machine to help him breathe. They then life-flighted him to a bigger hospital. When we got there, we waited and waited and waited.

Your son is going to die/you are under arrest: The doctor called us into a room and told us Alan was going to die and that he had broken ribs and his brain was bleeding. Just like that. I asked him if he had the right baby. He shook his head, yes. My wife went into shock. She was hysterical and needed to be sedated. I still believed it was a mistake until police detectives came and interviewed me. They kept asking me if he fell. No. Did you drop him? No. Did you shake him? No!! Did anyone ever hurt him? No, No, No. He never fell, was never dropped, rough housed or abused. Never. They kept asking me how it could have happened. If this or that was possible. Over and over in a hundred ways. They separated us and interviewed us all: Mom, Dad,...everyone. They even went and interrogated our neighbors. No explanation was ever given. I was soon arrested and placed in a maximum security isolation cell. They took our daughter away to interrogate her. I was denied bond. My wife was left alone, desolated. They convinced her to terminate life support and donate Alan's organs. (Yurko 2001)

After Baby Alan's death, an autopsy was performed. Buttram discusses the results of the autopsy report on Baby Alan:

Autopsy findings comprised retinal hemorrhages, subdural hematomas (blood-filled swellings on the brain), brain changes interpreted as diffuse axonal injury (axon: nerve impulse conductor), and four rib calluses on the left interpreted as the result of prior fractures. The father was therefore accused, and subsequently convicted by a jury, of murdering his son by physical violence. As mandated by Florida law, a life sentence was imposed. Anyone familiar with the medical/legal procedures in SBS cases is aware that these pathology findings have been deemed exclusively diagnostic of SBS. However, investigation has revealed a significant body of medical literature, much of it by pathologists and specialists in the United States and Great Britain, criticizing this interpretation and showing that these conditions can, and commonly do, arise from a number of other causes. (Buttram 2002)

Although many friends supported Yurko and his case, and felt the autopsy did not definitely show SBS was the cause of death, other elements of the autopsy report were key in Alan's release. The autopsy included several discrepancies including:

- Detailing the condition of the child's heart in the autopsy report, when the organ had been donated before the autopsy.
- Noting in the autopsy report the child's head circumference was 22 centimeters, when the medical records prior to death show his head size as 37.5 centimeters.
- Identifying the baby as a 2-month-old black male. Alan, who was white, was 10 weeks old at death. The autopsy report was later changed to indicate the baby's correct race. (Ripple 2003)

Some of Yurko's critics feel that if the autopsy had been performed correctly, the trial would have proven that Yurko was a child abuser; however, the majority of those supporting Yurko are not involved in any organizations which deal with child abuse, they are actively involved in the anti-vaccination movement.



The debate over vaccine reactions as a way to cover child abuse has been the theme of numerous web discussions, including the following criticism of Dr. Buttram and the Yurko case:

This site<sup>63</sup> is a disgraceful apology and defence of a man who held a ten-week-old baby by its feet and beat it to death. There appears to be no depth to which the anti-vaccination liars will not descend in their attempt to frighten parents with their lies. The evidence for physical abuse presented on this site is overwhelming, but the fact that it is reported there just indicates the hypocrisy that can arise when someone sets out on an ideological crusade. One of the authors (Buttram) is now touring the lecture circuit with the murderer's wife. These people must have no mirrors in their houses. How could they stand to look at themselves? Then again, perhaps they do not have reflections<sup>64</sup>. (Bowditch 2008).

Alan Sr.'s credibility has also been called into question because he was said to have a criminal record:

Alan Yurko now has seven convictions for violent crimes recorded against his name - four for aggravated burglary in Ohio, one for battery of a police officer in Florida, one for aggravated child abuse, and a manslaughter conviction gained by plea bargaining down from a murder charge. He was also convicted for escaping from custody at the time he bashed the police officer. He is a violent man, who only seems to be able to control his violence while in prison surrounded by other, possibly more violent, criminals. As soon as he was paroled from prison in Ohio he broke his parole and fled to Florida to set up house with Francine Ream, so there is an encouraging possibility that he will soon be back in an Ohio prison to finish the time he owes there. It says much about the anti-vaccination liars that they can use a man like this to advance their agenda, but, as I have said before, if your *raison d'être* is causing harm to children then it makes a kind of perverse sense to respect someone who commits the ultimate form of harm. (Bowditch 2008)<sup>65</sup>

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<sup>63</sup> Reference to the Yurkos' website: [www.freeyurko.bizland.com/](http://www.freeyurko.bizland.com/)

<sup>64</sup> This is another excellent example of disarming the anti-vaccination movement by likening them to an already established tradition of disbelief, in this case, vampires.

<sup>65</sup> Also of interest are the discussions between Peter Bowditch and other anti-vaccinators. Bowditch has attacked many of those who are anti-vaccination by stating that he has proof; however, according to his attackees he never offers any to them, but instead continues to personally attack them, frequently using very derogatory terms and accusations. Those who respond only report being attacked further, and

None of these claims have any further proof displayed on the website, such as references or links to the information referenced. Instead, the readers are asked to investigate the matter themselves, but not given the resources or information to do so.

The way Yurko has been depicted by both groups is very interesting. By those who are pro-vaccine, Yurko has been labelled as a common criminal with various arrests and little education. Among the vaccine safety activists, Yurko is shown as a loving father and an educated man. Anti-vaccinators see Yurko as a hero, someone who was wrongfully imprisoned for his rebellion against the medical establishment. Since his release, Yurko and his family have been active in the anti-vaccination movement and many of the anti-vaccination cartoons Yurko drew in jail are available on various anti-vaccination websites.

The Yurkos' story is certainly a terrible one, regardless of one's position on vaccines, but it is not the only story like it. Other SBS narratives exist, as do countless personal experience narratives and legends about the legal, medical, and social consequences of a refusal to vaccinate<sup>66</sup>. These later stories are sometimes used by health care professionals to pressure their patients into vaccination, but they are not the only stories used as a means of coercion.

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warnings have been issued on anti-vaccination sites about Bowditch ("Peter Bowditch Explained" Accessed February 18, 2008. <http://www.whale.to/a/bowditch.html>).

<sup>66</sup> One source for such narratives is Dr. Mohammed Ali Al-Bayati's website <http://www.toxi-health.com/>



## Functions of Legends for Physicians

Anti-vaccination legends serve a different set of functions for physicians, primarily as a part of their occupational folklore. As Robert McCarl states:

Canon of work technique refers to this body of informal knowledge used to get the job done; at the same time, it established the hierarchy of skilled workers based on their individual abilities to exhibit that knowledge. The canon of work technique is not law or a written set of rules but a standard that workers themselves create and control. It lies at the heart of any work culture because it forms the technical base out of which workers must derive their satisfaction or dissatisfaction with a particular job. (McCarl 1986: 72.)

For medical professionals, this canon of work technique includes not only the practical application of skills learned in medical school, but also more informal forms of folklore. Legend is just as important as fact when facing stress, hierarchy, and compliance in medical settings, and narrative plays a major role in the lives of medical professionals as a learning tool and a way of distinguishing correct from incorrect behaviour. As mentioned above, narratives and the knowledge they impart are not set by a governing agency, but rather focus on the standards that a group sets for themselves.

Many of these work techniques take place in what is known as a "cultural scene" (Spradley and McCurdy 1972: 21-37). Cultural scenes are "recurrent social situations in which two or more people share some aspect of their cultural knowledge or folklore" (McCarl 1986: 72-73). McCarl gives examples, such as break rooms, the bar after work, and teacher's lounges. Doctors in this province do not have central locations such as these to discuss their jobs; instead they tend to use hallways and nurses stations for discussions, and informal get-togethers and retreats for more elaborate bonding and discussion. All of these cultural scenes are crucial for the residents and clerks since this is

where much of their learning takes place, not only of the job at hand, but also of the politics and malleability of the rules of their trade.

Narratives are perhaps one of the most important tools used to educate residents and clerks. Stories of life-saving events teach what to do in emergency situations, narratives of the failures of senior members of the team both teach and comfort less experienced doctors, and legends can provide insight into the acceptable behaviour and beliefs of the group:

This linkage of current knowledge to the experiences of the past forms perhaps the most important aspect of a scene from a folklorist's perspective. It illustrates that not only a continuum of experiential knowledge forms the traditional canon of the trade, but also the verbal evaluation of these past techniques provide opportunities for members of the culture to experience events and evaluate performances they did not even witness. (McCarl 1986: 75)

When less senior members of the team begin to have their own stories, they also become a part of the learning process and "reveal and confirm their position in the informal canon of technique performance" (McCarl 1986: 79).

While personal experience narratives are the most popular forms of narrative, legends also are present and frequently told in the same "friend of a friend" format, citing past co-workers and colleagues. Although some of the stories are humorous, there are others, such as vaccine-related narratives, which are used seriously to teach appropriate technique when speaking to patients. They can also indicate where the doctor's control begins and ends and how far they are able to push their influence, as will be demonstrated later in this chapter.



For parents, who often also hear these legends from their doctors, these narratives may be seen as a form of social control. Of my informants with children, all were outraged to hear that a doctor would have threatened to have children taken away because the parents refused to vaccinate. In some cases the narrative is told as a story of an event in a different location and is offered as proof of their health professionals' reasonableness. It is important to mention that Public Health manages all of the regular vaccine appointments. Therefore, a child might not see a pediatrician unless something is wrong – which is typically when stories such as these might be told. In the case of a compromised immune system or other issues which may decrease the immunity in a child, a vaccine would probably not be recommended; however, if a child was brought in for something such as a minor illness or a fracture, their vaccination status might be mentioned. This might not be by a pediatrician, but a specialist, emergency room worker, clerk, or resident. One informant reported:

I'm not sure who it was that said this to us. Might have been a nurse, doctor, student. I don't know. Too much was going on right then. But they told us that it was wrong that we didn't have Danny<sup>67</sup> vaccinated. Of course, I didn't want to hear that. I wanted to hear that he was Ok and the airbag hadn't injured him. But they kept going on and on about the vaccine, saying they could have him taken away, asking if I abused him. Finally I freaked out at them. I didn't even feel bad about it. I mean, my child is in hospital! We were in a car accident! It wasn't like he had multiple fractures and I made some excuse about falling down stairs. We were brought in by ambulance! (Interview with lay person with children. August 6, 2007)

Many of the questions this informant was asked are standard, and it is unlikely that the person asking the questions was withholding information concerning her child. The

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<sup>67</sup> Not his real name.

medical professional, however, did invoke the legendary motif that children can be taken away from their parents if they are not vaccinated.

### **The “Doctor from Toronto” Legend**

This legend, which I have titled “The Doctor from Toronto,” is a common narrative told within the medical and parental communities in St. John’s. I first became aware of the legend from one medical student during an interview:

Some days I wish it could be like it was in Toronto. Did you hear about that? There was this doctor in Toronto and when the parents of his patient refused to immunize their kids, he called child protection services on them and they took the child away for negligence and endangering their child. And they should have, too. I wish we could do that. (Interview with medical professional without children. October 5, 2007).

I began to hear similar stories from others, both medical professionals and patients. Often these stories were not detailed, as the one above, but they all contained the same elements. A doctor in Toronto calls child protection services and has the child taken away from its parents when they refuse to vaccinate. Often the child is genderless as are the parents, while the doctor is always male. The child is always in hospital, but the reason is frequently not mentioned, although some versions state the child has succumbed to one of many childhood diseases, measles being the most common. Some versions elaborate on the details of the specific event when child protection services arrive:

So, the parents didn’t even know about it, lu’h? They were just coming in to see their kid and they wouldn’t let them in, wouldn’t let them in the room to see their sick kid in hospital. Says they weren’t allowed to see them and as soon as the kid’s well, they’re going to a foster family. So the mom’s crying and the dad’s threatening them, but they says no, you can’t see your kid. (Interview with lay person with children. November 10, 2007)



Over half of the parents I interviewed said they had heard this story from other parents, from family members, or from medical professionals. In the case of hearing it from parents, the story served as a warning – a way of telling other parents who did not want to vaccinate that they might face problems or prejudice. When the stories came from family members, they could serve as warnings, but the majority of the time they were used to coerce the parents into vaccinating. This story told by medical professionals was almost always used as a way to convince vaccine-resistant parents to vaccinate. In only one story did a parent tell me otherwise:

Now when I lived out around the bay, in Gambo, well, the nurse there said she didn't mind that I didn't vaccinate, but told me, if you ever have to go into St. John's or somewhere else, expect problems. Said they've even got problems with it in Alberta and whatever you do, don't go to Toronto!  
(Interview with lay person with children. April 10, 2008)

Since Newfoundland and Toronto have not always had the best of relationships, these narratives embody more than something simply happening somewhere else. They also refer to a long-standing tradition of jokes which express the tension between Newfoundlanders and Mainlanders. Davies stated that every country has certain targets for stupidity jokes, which tend to focus on people who live on the edge of an area and are seen as culturally different than the dominant people of the centre (Davies 1990). Newfoundland and Labrador's geographic location, late association with Canada, and distinct culture certainly fall into this category. One Newfoundlander jokingly mentioned:

We have a hierarchy of dislike. Anyone from Newfoundland is best kind, unless you're a townie and they're a baymen or the other way around. Anyone not from Newfoundland, well, some Americans are okay and most of the time they're the best of the bunch when it comes to mainlanders. Alberta is full of Newfoundlanders so some of those fellas

are okay, but not Toronto. They're a bunch of bastards. (Interview with lay person. November 10, 2007)

This tension is frequently expressed in jokes, such as the "Newfie Joke" (Byrne 1997; Davies 1990; Thomas 1976); however there is underlying tension, even among Newfoundlanders, about the term "Newfie". One of my informants stated:

Yeah, that's "our" word (laughs), our "N" word, ya know? It's fine for me to call another Newfoundlander a Newfie because I'm one or to tell a Newfie joke, but if you're from away, you can't do that.

Author: Can someone from away ever be able to do that?

Informant: Right, you're from away, I forget that. Maybe once you're here a bit longer, thirty years or so, you'll be allowed to call certain people Newfies. And maybe some day you'll be lucky enough to be called a Newfie yourself! (Interview with lay person. May 23, 2007)

Although many of the medical professionals claim that they would love to be able to contact child protection services, when I asked them why they did not, the answers were often divided. Many felt that Newfoundlanders would not do anything about the call, while others felt that it "just wasn't the way things worked here" (Interview with medical professional with children. March 13, 2007). The general consensus of this group was that it would not be appropriate to do such a thing here, perhaps in part because it is something people in Toronto would do.

Since there were so many who insisted this story was true, I contacted the Ministry of Youth and Child Services in Ontario. They reported that they do not have any information indicating that a child was taken away from their parents because they did not vaccinate (Ministry of Youth and Child Services, June 17, 2008, personal



correspondence with author). However, there have been different and conflicting reports from the States:

Unfortunately, doctors in positions of authority in a state's health, education or social service system can report parents for failing to vaccinate their children according to state laws and charge parents with child medical neglect. If they persuade a judge to order it, a child can be forced to be vaccinated according to state laws. This does not happen frequently, but it does happen, especially during divorce cases involving child custody battles between parents. It is also more likely to happen when parents take a child to a hospital or clinic for an illness and, when asked if the child is up-to-date on vaccinations, the parents say "no" and then refuse to have the child immediately vaccinated. Some hospitals and clinics have a policy that requires attending personnel to make a report to the state social service agency when parents refuse to vaccinate a child. ("Fisher" 2008)

On an open parenting forum, one mother stated that she had been threatened, but that when she called Child Protection Services, they told her it was her choice, an event which she discussed online:

I was bullied about vaccinating. I was even turned into Child protective services for it. When I called the doctor's office I was told by a nurse on staff that not vaccinating my child was neglect and could be grounds for child abuse! Obviously I freaked. I called CPS back and demanded to know why I was being harassed. I spoke with a supervisor and she informed me of what I already knew that it is my decision to vaccinate (or not to) my child. ("tiroph0302" 2008)

Officially, child protection services may be called; however, it seems the cases rarely result in any action. While there are reports on the Internet of CPS being called, only one instance was found which resulted in an arrest. The *British Medical Journal* reported that two sets of parents in Belgium were convicted for not vaccinating their children against polio in February 2008. They were summoned to court, but did not appear, which led to a conviction based on police reports. The parents were fined €5500 (approximately \$8,508

Canadian dollars) and sentenced to five months in prison; however, the judge stated that he would suspend the prison sentence pending the vaccination (Stafford 2008).

Responses such as the contacting of Child Protection Services or involving the legal system may seem extreme. Pro-vaccinators also suggest that this type of response may be unwarranted:

In reference to the news story reporting fines and prison sentences for parents whose children did not receive polio vaccinations, it's relevant to note that Belgium has reported but 2 cases of polio since 1980 - the last one being in 1989. In that light, I have to wonder at the justification that immunization be mandatory, reportedly the only mandatory immunization in Belgium, and that noncompliance should warrant such draconian penalties.

I also wonder at the sentiments attributed in the story to the president of the Belgium Medical Association - ' "Usually I believe in individual freedoms," he said "But we need polio vaccinations to protect the children and the population. Polio is a very serious disease." ' Polio is indeed a serious disease - and one that has virtually disappeared in Belgium. Is the subordination of individual freedoms justified in this case? (Geis 2008)

There are still debates concerning the issues surrounding physician and medical professionals who harass those refusing to vaccinate or choose more extreme legal measures. An online poll that asked if doctors should end their relationship with people who refuse vaccination received many passionate responses:

This is the most uniformed answer, and sadly one I hear often. First of all, if we are going off of YOUR "beliefs", that people SHOULD be vaccinated, then those of us who are not should be no threat to you correct? If you have your vaccinations, aren't they supposed to "protect" you from such disease?, if we play by your rules then we should be the ones worried. The truth is however is that you are not protected. People are bullied into vaccinations, being threatened with being removed from school, and are never really told they have a choice in the first place. On top of all of this, have you ever looked up what's in this "vaccine" you are INJECTING into your bloodstream?, I'm guessing no so I will go ahead and share a few of them; human diploid cells from aborted fetal tissue,



ammonium sulfate, formaldehyde, vesicle fluid from calf skins, chick embryo, aluminum hydroxide, aluminum phosphate, thimerosal, monkey kidney cells, residual components of MRC-5 cells including DNA and proteins, bovine serum, hydrolyzed gelatin, rhesus monkey fetal lung cells. Now I would honestly like to see someone, if handed that list which only includes SOME of the ingredients in COMMONLY administered vaccines and sign their name at the bottom saying that it is 100% okay with them to be injected with that, and if you do, than that is your right, is it is mine to say no. I don't think the battle here should be to shoot or not to shoot, we should be more concerned with people getting the chance to make an informed decision by letting them know it's their right to decide in the first place. ("Danielle" 2007 Emphasis in original)<sup>68</sup>

. Additional websites and discussions have indicated that some offices are charging fees for those who have refused to vaccinate:

...So my pediatrician just instated a rule that they are now going to charge a \$20 fee for 'delaying' or opting out of any vaccinations for 'inconvenience.' Neither of my kids have received any their 4-year old shots and some we have passed up completely, so I had to pay \$20 for both kids at each check-up. Of course, insurance would never pick that up... (Tenpenny 2007)

From the advice given according to the following website, it seems that other offices might also institute rules such as these:

*From Medical Economics, October 19, 2007 (p57)*

We've had teens and tweens [sic] walk out of the office in protest when we've tried to give them the meningitis or the human papilloma virus vaccination that their parents have consented to. **Can we hold parents financially responsible when vaccine is wasted because a child refuses the injection?**

**Answer:** Yes...it's a real cost you can justifiably pass on to parents but only if you've explained beforehand that once the vaccine is drawn they'll be charged, whether the vaccine is delivered or not. HOWEVER, as long as older children normally don't refuse injections at your office, there is no need to routinely advise parents of your policy. Just tell the staffer responsible for getting consent to watch the child for signs of ambivalence

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<sup>68</sup> This comment was found on a website called "Science Buzz" which is supported by the National Science Foundation's Informal Science Education Programs.

or rejection. If she notices anything, THEN she should explain your billing policy. (Tenpenny 2007 emphasis in original)

However, this particular website does not feel that parents are being advised:

**Parents are frequently bullied, threatened or intimidated to vaccinate their children.**

This is often done without accurately informing parents of the adverse vaccine risks, or their parental rights. Threats can include judicial punishment, removal of children, or exemption from access to public services (e.g. education). (Vaccination Truth 2008 emphasis in original)

Other anti-vaccination and vaccination safety websites address the issue of bullying or coercion, and from the information found on the Internet and from my informants, this appears to be a common problem. One informant stated that the “public health nurse really tried to push me around, telling me that no doctor in the province would see us if we didn’t vaccinate” (Interview with lay person with children. August 6, 2007).

Other techniques have been utilized and reported, both by my informants and on the Internet. Displaying pictures of children with diseases or describing the effects of childhood diseases is sometimes used:

Oh yes, my doctor tried to scare me by showing me all sorts of pictures of children with diseases and telling me how many people are hospitalized a year from the chicken pox and other diseases. He even gave me the CDC’s website to look at and I did. It’s just full of information about how many people used to die. But that didn’t help me. I’m more scared of all the babies I know with autism than I am some pictures from the 50’s. (Interview with lay person with children. June 20, 2007)

Medical professionals frequently complain that it is because parents have not seen various childhood illnesses that they are not afraid of them. One pediatrician stated, “If we still had the polio scares every summer and if kids were walking around with mumps,



then people would still be afraid!” (Interview with medical professional with children. March 13, 2007). Some parents claim that only certain childhood diseases are to be feared; one of my informants, a parent who refused some, but not all of the vaccines available to her stated, “Why do they also bring up polio? I vaccinated against polio. I vaccinated against mumps, measles, and rubella, just not at the same time. Why do they assume that we don’t understand?” (Interview with lay person with children. April 10, 2008).

Other parents also reported that they understood the risk they were taking and they became angry with others who thought they did not understand. Approximately thirty percent of my informants reported that scare tactics, such as showing pictures of ill children, only infuriated them and strengthened their resolve. One informant found it offensive:

One nurse at the hospital, she showed me this picture of kids with polio, measles, and whatever. And I said to her, where are these kids? She said she didn’t know. I said, ‘I might not know exactly where they are, but that sure as hell isn’t Newfoundland there in the background’. Well, she didn’t know what to say to that! (Interview with lay person with children. August 6, 2007)

Most of these pictures described to me by informants are either from another era or they depict children in third world countries, and informants reported feeling offended because they felt the medical professional believed they were too uneducated to realize that the pictures were historical, from a different geographical location, or that they did not know the symptoms and history of the disease. However, one of the medical professionals I interviewed pointed out that Newfoundland could quickly become just like those pictures if vaccination ceased, due to its isolation and lack of medical services (Interview with

medical professional. May 10, 2008). As my informant mentioned, if the diseases are virulent and one does not see them, but they do see children with auto-immune diseases and autism (which some believe are caused by vaccination), then it only stands to reason that parents are more afraid of what they see on an everyday basis. Childhood illnesses now seem exotic to parents, while the threat of conditions which have been linked to vaccination seem very real.

### **The Refused Education Tactic**

Refusing to educate unvaccinated children is a tactic often used both by medical professionals and school boards. Although areas in the United States do require vaccination, some areas of Canada do not require students to be inoculated or are willing to accept homeopathic vaccines. Currently there are only three provinces in Canada that require proof of immunization for school entry (New Brunswick, Ontario, and Manitoba), and all three allow exemption clauses for philosophical or religious objection (West 2008). The exact ground for exemption depends on what each state or province has determined is appropriate action. For example, all fifty states have medical exemption, forty-eight states offer religious exemption, and seventeen offer philosophical or personal exemption (Salmon and Seigel. 2001: 290; Hinman et al. 2002: 14-125). However, the Supreme Court has never ruled on whether or not religious exemption from vaccination is constitutional (Salmon and Seigel 2001: 291), and some have argued that if religious beliefs are an acceptable means of refusing a vaccination, then philosophical exemption must also be accepted or the matter is unconstitutional (Salmon and Seigel 2001: 293).



Either way, what constitutes proof varies and often hinges on the “sincerity” of the claim, and scrutiny of the beliefs or sincerity of an individual is often argued to be arbitrary and extremely difficult to prove without biases or in a just manner (Salmon and Seigel 2001: 293). There have also been changes over time in the types of exemptions given:

The change in the pattern of medical exemptions granted over time—medical exemptions declined as nonmedical exemptions increased—suggests that historically, medical exemptions may have been used to avoid immunizations. This possibility is supported by the decrease in medical and increase in philosophical exemptions when the latter were allowed. (Thompson et al. 2007: 199)

Approximately twenty percent of my informants confided that they had used medical exemption in order to avoid vaccination. Although this was extremely difficult to do in most situations, my informants often either had a contact in the medical field who supported their decision not to vaccinate or they fought very hard (sometimes for years) in order to refuse their vaccinations:

Honestly, it took years to find a good doctor who didn't care about vaccinations. I mean, I had an “in” myself and I think our doctor respected our decision because it was well thought out, but it wasn't easy. Even today she still asks me if I'm sure – as if it were some sort of phase I was going to grow out of. (Interview with lay person with children. August 6, 2007)

However, as one study pointed out, the increase in the number of philosophical objections to vaccination may have more to do with the process of obtaining exemption than anything else. Since philosophical exemptions are done on the basis of an expressed belief and require no other documentation, parents may choose this option simply because it takes less time:

It is also possible that some parents whose children would have qualified for a medical exemption before the mandate claimed a philosophical

exemption after modifications because it was easier than obtaining a physician's statement. (Thompson et al. 2007: 199)

It may be more cost effective as well since a doctor's appointment may mean lost wages, gasoline expenses, or additional costs. Many are against the idea of philosophical objections because they believe the process is too easy and parents may opt out of vaccination because it is easier to claim an objection (Thompson et al. 2007: 194-201; Salmon and Seigel 2001: 289-295). It seems likely that the increase in numbers of those who philosophically object to vaccination, coupled with the decrease in numbers for those who are medically exempt, suggests that there is not an overwhelming increase in the number of unvaccinated children, but rather parents who formerly sought out medical exemption are now seeking philosophical exemption, due to ease. It is likely that these parents would have received an exemption anyway, which is why we see these differences in the numbers. If a parent truly does not believe in vaccination, they will find a means to avoid it. For these people, making the process easier does not encourage them to seek exemption; they would have found a way to be exempt, regardless (Thompson et al. 2007: 194-201, Salmon and Seigel 2001: 289-295).

Some studies also cite that parents will opt out of vaccination stating philosophical reasons merely because they do not want to take their children to be vaccinated (Thompson et al. 2007: 194-201, Salmon and Seigel. 2001: 289-295). However, even if the process of obtaining a philosophical exemption is sometimes easier, it is hardly the path of least resistance. Anyone who chooses not to vaccinate faces challenges to their decision both from the medical community as well as their peers. Social responsibility is often used as a strategy for vaccination, and all of my informants



who refused vaccination stated that the pressure they face from friends and family is much harsher than what they experience with the medical community.<sup>69</sup>

Parents may also find that the media and other sources make it more difficult to understand the exact nature of legislation concerning vaccinations, and some even claim that certain organizations deliberately attempt to confuse parents about their rights:

The Ontario government has done a remarkable job of intimidating and bullying parents into believing that children can't go to school without their shots and the Ministry of Health is clearly enacting a policy to disinform the public of its right to vaccine exemptions. Routinely, parents are sent harassing letters demanding vaccine compliance and threatening expulsion of their children from school, without any mention that legal exemptions are available. School officials, health officials, and private doctors all reinforce the myth that vaccination is compulsory, and without it children can't go to school. The media dutifully regurgitates this misinformation when it publishes press releases intended to create the impression that students will be barred from school if they haven't got all their shots, and consistently fails to inform the public that legal exemptions are available to everyone. People need to challenge this and write letters to editors demanding that they inform the public about available exemptions. (West 2008)

Although all of these concerns certainly make the vaccine decision-making process more difficult, they do bring up the issue of ethics regarding vaccines and vaccination policy.

## **Ethical Implications**

Unfortunately, there is a discrepancy between personal health care and public health care. Autonomy and personal rights are very important to society; and North American medical culture values the rights of patients. For patients, it is acceptable to undertake a treatment when ill, but it is harder to accept a preventative measure,

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<sup>69</sup> Please see previous chapters for more detail on the perceived social pressures to vaccinate.

especially when the person in question is not sick. Add to this the risk of a healthy individual being potentially harmed by a preventative measure, and there is no surprise that many will refuse this treatment.

There are discrepancies in the perception of risk activities as well. The medical community or organizations such as Public Health may have a different perception of which activities are perceived as risky than the lay public, giving the public an etic perspective on risk activities (Goldstein 2001: 130). Since this perspective does not take the actual activities or perceived risks of the lay public under consideration, it is possible that health information based on these etic perspectives may not be accepted by the public. The failure to recognize that risk is a social construct (Goldstein 2001: 130-131) can be detrimental to health education programs.

Wherever there is a risk to ourselves or others, we feel a sense of obligation to either eliminate that risk or at least lessen it. This is certainly true when the risk taken causes little to no harm to the individual (Dawson 2006: 91) Dawson argues the importance of this concept:

This is because the harm is brought about precisely as a result of that individual's actions or omissions, and so is especially open to reflection and criticism as a result. Here, the issue is not about charity and whether or not I have a pressing duty to provide aid, the issue is a different one, that is whether I have an obligation not to increase the risk of introducing new sources of harm. (Dawson 2006: 91).

Although Dawson is specifically arguing the case of vaccination for travelers, the same could be said for any individual who may introduce harm to others, either in their own community or others. Not only are they increasing the risk of infection, they may even be introducing a new disease which would harm the population. This is especially true for



certain diseases which have been eradicated in some parts of the world, but not all. In countries where these diseases have ceased to exist in the population, it is possible that natural immunity has been lost or that vaccinations for these illnesses are no longer given. In other parts of the world, common illnesses that are prevalent in certain populations may be life-threatening to populations who have not been exposed.

As discussed in previous chapters, it is often the parent(s) who are perceived to be the blameable party in the case of vaccination, even if they are only trying to do what they recognize as best for their child:

For example, in relation to competent and autonomous adults, we might hold those individuals who have chosen not to be vaccinated as responsible for the consequences of their actions. On the other hand, in relation to incompetent and non-autonomous children, such as infants, who may act as a source of infections, we are likely to hold the relevant decision-maker responsible for the non-vaccination (and any resultant harm). In most cases this will be the parent(s). (Dawson 2006: 92)

There are certain illnesses which are also more contagious than others. For example, in the case of a blood borne illness, the carrier may have a degree of control over who is exposed to this illness, whereas an illness which is spread by coughing is less under the control of the carrier. In the case of a blood borne illness, the carrier may be considered less to blame since it is unlikely the disease would spread to the general population. In the case of the illness spread by a cough, the carrier may know they are contagious, and instead of quarantining themselves, may choose to expose the general population. The level of transmission can be a crucial issue when it comes to the ethics of the unwell (Dawson 2006: 92). In many cases carriers do not know they are carriers; in those instances, the carrier is not acting unethically since they have no knowledge of their

illness. This differs from those who refuse to vaccinate since they are not ill, although one can argue that they are at a higher risk of becoming ill. The refusal of a vaccine is not the same as the refusal of a treatment which benefits only the patient (such as a blood transfusion) since others may be harmed by one person's decision not to vaccinate (Dawson 2006: 93). It is difficult to ignore "harm-to-others" arguments regarding vaccination:

Harm-to-others arguments are powerful arguments because they suggest that there are limits upon our freedom of action where such actions might harm others. They are common in current discourse because of the widespread acceptance of liberal political philosophy in the developed world, and can be accepted even by strong advocates of the importance of freedom or liberty....they suggest clear reasons why someone might be motivated to consider the consequences of their own actions, and accept the imposition of a moral obligation to perform certain actions in an attempt to reduce harm to others. (Dawson 2006: 92)

For a harm-to-others argument to be effective, one must accept that there is a risk involved. If there is no perceived risk, then there is no chance of harm. Since approximately half of my informants agreed that it was highly unlikely to be exposed to vaccine-preventable illnesses, they did not perceive there to be any harm to others. In these instances, the vaccine itself could cause more harm than the disease, and concerns such as personal choice and freedom were challenged. Dawson states:

....restrictions on personal liberty can be justified where such actions prevent harm to others but that restriction on the ground of preventing harm to that particular individual (once fully informed of any risk) are an immoral interference in personal liberty. (Dawson 2006: 93)

Some parents may also argue that such control is paternalistic, which Dawson states is often considered to be "morally wrong by definition" (Dawson 2006: 93). Instead he suggests that paternalism is "acting (or not acting) with the intention of reducing harm or



bringing about greater good for the subjects(s) of the action” which leaves open the idea that the action may be morally justifiable (Dawson 2006: 93). While this argument is sound, it is unlikely that vaccine safety advocates will automatically accept that all vaccinations are being done for the greater good, especially considering the amount of information they have which indicates that vaccination is done for reasons such as profit.

Dawson states in the case of travelers that “It might be argued that the non-vaccinated traveler did not *cause* the individual(s) in the host population to catch the disease because they performed no *action* that brought this about” (Dawson 2006: 94). The health transgression appears passive, unlike the “Welcome to the World of AIDS” legend in which transmission is intentional (Goldstein 1995). As we saw in the early anti-vaccination movement, there is an argument that one cannot be charged for the things they failed to do, only for direct actions that cause others harm. Dawson states this “...relates to the supposed different moral obligations that arise in relation to acts and omissions. On this view, common in much moral philosophy, we are only responsible for the situations we intentionally create (not those that arise because we fail to do something” (Dawson 2006: 94). However, the argument for the benefit of the greater good is still of great importance:

....the suggestion is that we have a moral obligation to create, maintain and support the existence of public goods (especially where we derive benefit from their existence). Herd protection might count as an example of such a public good, and vaccination is the best way to create and maintain herd protection from particular diseases (where this is possible). If this is true, then the best way to fulfill an obligation to contribute to the maintenance of herd protection as a traveler is to be vaccinated against a transmissible disease before traveling (where one exists). (Dawson 2006: 94)

It is crucial to note the difference between herd or contact immunity and herd protection; herd or contact immunity is accomplished through the secondary spread of the agent used in the vaccine to an un-vaccinated population (Offit 2008), while herd protection is achieved when the high rates of vaccination in a population protects the unvaccinated from exposure to the disease (Dawson 2006: 94-95). Vaccination is seen as an act that has benefits for both the individual and society as a whole (Cookson 2001; Sadique 2006; Dawson 2006: 95).

It has been argued in the vaccine safety community that there is little risk in a small number refusing to vaccinate, which may be statistically true, but it is impossible to calculate such a risk since it varies depending on the situation. Dawson does recognize the argument that anti-vaccinators have utilized; the idea that one particular individual cannot make that much of a difference when it comes to the herd protection of the group. Although this is true, it does not work on a greater scale, since every unvaccinated person contributes to the overall number of those not immune:

Herd protection would not cease to exist as a result of one person's action. This is technically a sound objection. However, the more individuals that choose to free ride on the existence of herd protection, the more the public good is threatened. The arguments above relating to justice and respect provide some reason why it might be considered morally wrong to use this argument to justify non-vaccination. In other words, it can be argued that we are obligated to make even a small contribution to supporting this particular public good given the benefits to all in that society (benefits that the traveler shares). (Dawson 2006: 93)

My own informants have argued the ethics of herd immunity since those not vaccinated are still benefiting from the overall immunity of the group, even though they have not taken the same risks as others in the society. Approximately sixty-three percent



of my informants who were medical professionals commented that it was not fair for patients to benefit from immunization if they are healthy and able to be vaccinated, but choose not to receive their vaccinations. However, there is more than one positive outcome of vaccination for society:

This is an important argument because vaccination for many contagious diseases has two potentially positive outcomes. The first is that it provides some protection to the individual qua individual by raising the level of their personal immunity to a particular disease. The second is that it contributes to protection at the level of the group or population by increasing the general level of immunity within the relevant population, ensuring that an outbreak of that particular disease is less likely. (Dawson 2006: 94)

Vaccination falls under the definition of “non-excludable goods,” which means that everyone receives the same good regardless of social status (Dawson 2006: 95). These forms of good do often exist at the cost of the society as a whole, whether it is higher taxes for better roads or adverse reactions for increased immunity in populations. Because everyone benefits from these goods, it is easy to understand why those who take the risk are angry at those who do not take the risk but enjoy the benefits:

In some sense, persons who do not have their children immunized are getting a “free ride” without putting their children to the very low risk of an adverse event, because they are benefiting from the impact of the vaccination of others. (Hinman et al. 2002: 126)

Regardless of what people do or do not do, maintenance of the public good is seen as crucial. Forcing an individual to vaccinate does seem extreme to many since it then becomes an issue of personal freedom. As we saw in previous chapters, forced vaccination has been nothing short of a disaster historically, so it seems the issue is at an impasse. We want people to vaccinate; however, we also value personal liberty. Dawson

argues that while freedom does matter, the issue of the greater good is still more important:

....in a trade-off between different values, we should give priority to liberty in any conflict between liberty and a requirement for action to preserve a public good. In other words, it might be argued that the production and maintenance of public goods is something that should be commended but not obligated, and that it does not provide a legitimate justification for restricting the free actions of individuals. The claim might again be made that requiring the priority of public good generation over liberty is paternalistic. In my view, this should be resisted because the creation and maintenance of public goods is aiming at more than the good of that particular individual. They share in the benefit, and are asked to contribute to it, through their actions, but it is not clear that this can be counted as paternalism at all. (Dawson 2006: 96)

He goes on to argue that, "Where herd protection exists and we derive a benefit from that, arguably we have a duty to contribute towards it" (Dawson 2006: 94).

Although one would doubt that any parent would choose to not benefit from herd immunity or protection, the simple fact is they do not have a choice in the matter. We are dealing both with an act not taken and a benefit not accepted. While those in the pro-vaccination front may argue that it is unfair for those who refuse to vaccinate to receive the benefits of vaccination, there is nothing they can do about it since it is impossible to take away the benefits of a non-excludable good. Even if a person wished to opt out because they agreed that it was not fair for them to receive the benefits of a program to which they have not contributed, there is nothing they can do to exclude themselves.

With competing ideas such as personal freedom and public good, it should be noted that if a culture decides to make vaccination mandatory, then they should also be prepared to accept the consequences and provide for those who have been harmed:



Immunization programmes are ethically defensible and society has a significant role to play in providing vaccination against measles and safeguarding her immunity to optimize its individuals' capabilities. Acceptance of the role also means that society has an obligation to follow up and evaluate both short- and long-term effects of immunization programmes. The latter is especially important for the identification of rare side effects. Another obligation of utmost importance for public confidence is that any suspected association between vaccinations and possible side effects must be taken seriously by health authorities, and reasonable support given to those who claim such a connection. (Krantz et al. 2004. 176-177)

This very issue is often discussed by both the medical community and the vaccine safety community since deciding exactly what qualifies as a vaccine reaction has been debated, and since the adverse reaction reporting system itself has received criticism. Even in instances where the family has been compensated<sup>70</sup>, that does not counteract the pain experienced by the family or the individual, as well as the community. Of course, the reactions towards such an event also vary both by individual and community. As Krantz, Sachs, and Nilstun stated, "One cannot assume common interest among communities; community health need and assumptions of risk vary in space and with disease context" (Krantz et al 2004: 173). Again we must remember that we are discussing the illness or death of a formerly healthy child. Tragic events such as these remain in the cultural memory for long periods of time.

Although it is important to note that twelve of my informants stated that they accepted the consequences of their actions and would even opt out of herd immunity if they could, there is still yet another issue to discuss. Approximately forty percent of my

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<sup>70</sup> The U.S. Department of Health and Human Services runs the National Vaccine Injury Compensation Program (VICP) for more information, please see their website: <http://www.hrsa.gov/Vaccinecompensation/>. Since vaccination is not mandatory in Canada, there is no compensation program. This lack of a compensation program has been argued to be a contributing factor to lower immunization rates in Canada (Kutlesa 2004).

informants did not believe that vaccination increased their immunity to diseases. The idea that vaccination has no affect on immunity was discussed in previous chapters.

Historically, this was due to unsafe medical practices but also included the same concerns that we see today. Both then and now, there are groups of people who feel that the lowered rates of disease can be attributed to other factors, such as sanitation, cleaner drinking water, improved diet, and drugs, such as penicillin. While all of these certainly helped lower the rates of infection, vaccine safety activists feel that some or all of these reasons are why rates of childhood diseases are lower today. Medical professionals may disagree with these ideas; however, this is not the place to begin this discussion. Instead we must consider lay perceptions of risk.



## **Chapter Six**

### **Notions of Risk**

One of the most significant issues in the gap between pro-vaccinators and anti-vaccinators is the difference in the vernacular construction of risk versus medical constructions. Effective health education requires understanding where these constructions overlap and where they differ, how risk and benefit are defined and weighed, and the relationship between objective and subjective experience. Powell and Leiss, in their extensive work on risk and the perception of risk, state:

Problems in communicating about risks originate primarily in the marked differences that exist between the two languages used to describe our experience with risks: the scientific and statistical language of experts on one hand and the intuitively grounded language of the public on the other. (Powell and Leiss 1997: 26)

Powell and Leiss discuss some of the barriers between the languages used, such as the scientific views of the “expert” versus the intuitive views of the “public.” They also note that “expert” assessment is probabilistic, concerned with acceptable risk, burdened by the changeability of knowledge, values population averages and, sees “A death as a death” (Powell and Leiss 1997: 27). The public is looking for “yes or no” answers, is concerned with safety over acceptable risk, wants to know if something is true or not, values personal consequences, and feels that it matters how a person dies (Powell and Leiss 1997: 27).

As seen here, the ambiguity of the “expert” assessment of risk, which is a necessity when dealing with scientific matter, versus the public assessment of risk, which places a value on the individual and wants definite answers, are at odds with each other.

Medical science cannot provide the public with definite answers, since it is often unaware of long-term effects and various adverse reactions. The public, however, does not understand how the medical community can be stoic in the face of death, or how it perceives any death as an acceptable risk:

The most complex task in evidence-based medicine, however, lies in the communication of specialized medical knowledge to non-professionals. Information is seldom simply the neutral transmission of facts. It is interpreted and evaluated from a particular perspective in a specific context. In all medical consultation the process of communication is not just a matter of transmitting information from one who knows to one who does not. Knowledge created and disseminated in a scientific context is recontextualized, first in a clinical situation and then as interpreted version in people's real lives. (Krantz et al. 2004: 174)

Despite attempts to inform the public, negative consequences can happen, such as approaching the public as "irrational" or "mis-educated":

Traditional views of risk communication have been concerned with a need to better inform the public and reduce what is seen as 'irrational' thinking. This one-way 'hypodermic' approach has been suspended by a more inclusive process, where the public, technical experts and other stakeholders present information and discuss their concerns about risk in an atmosphere where emphasis is placed on negotiation. (Leask 2002: 125)

The public needs to feel included in this communication process. Over half of my informants stated that they felt they were being "lectured to" or that conversations with medical professionals were condescending, did not place a value on their concerns or fears, and did not consider their own level of education. Bioethicist Thomas May states that, "No policy for vaccine distribution is likely to succeed until public fears that motivate counter-productive behaviors are addressed" (2005: 408). May is still thinking in terms of compliance. In order to have a successful dialogue between patients and



medical professionals, the goal of the conversation should be to understand the viewpoint of the other party. If either participant is motivated only by compliance or by forcing their viewpoint on the other person, it is unlikely that they will reach a concordance.

## **Disease Awareness**

Perhaps one of the most crucial aspects to understanding the difficulty of risk communication is to consider the awareness of certain vaccine-preventable diseases:

Why is vaccine risk communication so challenging? Perhaps the most important factor may be the lack of disease awareness. The dramatic decline of vaccine-preventable diseases has inevitably decreased public awareness of these illnesses, likely prompting greater reluctance to accept adverse reactions after vaccination. (Ball et al. 1998: 453)

The lack of visible childhood diseases certainly affects vaccination decision-making.

Parents do not see many of the common threatening diseases of the past in children today (May 2005: 417), nor did they experience these diseases as children. However, they commonly see children with conditions, such as autism, personality disorders, allergies, and asthma – something they may not recall from their own childhood:

Do you remember kids having allergies like these when we were young? I took peanut butter sandwiches to school every day. I don't remember anyone being allergic to things like they are today. People say it's the vaccines. Well, I'm not sure, but it's something! (Interview with lay person with children. March 3, 2006)

Although parents understand the severity of these diseases, perhaps the virulence of these conditions are forgotten. Parents perceive themselves as minimizing what they see as the greater risk to their child, demonstrating that public support for vaccines declines as the disease is forgotten (Ball et al. 1998; Gellin et al. 2000).

Parents do understand risk, and my informants clearly understand that by refusing a vaccine that it is likely that their child is at risk. Petts and Niemeyer recognize that parents understand the risks, but also mention that in their study “....it was evident that the seriousness of the three diseases was learned not experienced” (Petts and Niemeyer 2004: 20). While parents may understand the risk, they have not experienced it in the same way as medical professionals and previous generations may have. The perceived risk of visible empirically understood “new” conditions takes precedence over the unseen objective risks identified by health professionals.

Parents also place associations around the events in their children’s lives. The medical community argues that these events are not cause and effect: “Another factor in the power of temporal association – i.e., *post hoc, ergo propter hoc* – or what follows immunization must be caused by it” (Ball, et al. 1998: 453). They argue that a diagnosis near a vaccine event does not necessarily mean that the vaccination caused the event. However, parents report that symptoms, such as those associated with autism, occurred after the vaccination. The medical establishment counters these arguments with the information that many of these conditions do not present themselves or are obvious until a certain age, such as the symptoms of autism presenting around the same time as the vaccination for MMR. To the medical community, these events are not linked; however, parents can easily see the link.

They aren’t going to get me with that BS. Symptoms do not present themselves overnight and when I said that to my doctor, they basically told me that I just wasn’t paying attention and they were there all along. So, now not only are they treating me like I don’t understand simple science, they’re also telling me I don’t pay enough attention to my child.



Can you imagine? (Interview with lay person with children. June 20, 2007)

If the suggestion had not included the accusation that the parent did not notice the symptoms previously, there may have been room for successful dialogue.

### **Lack of Information/Conflicting Information**

Approximately sixty-five percent of my informants reported difficulty in finding information, and stated that the information they found typically conflicted with other information. Participants reported anxiety and frustration at the process, especially since they were often doing their research while raising a young child or children.

More than half of my informants in the medical community have reported the same problems with information concerning vaccination. However, they placed blame on the vaccine safety movement for encouraging anti-vaccination information and distributing it widely on the Internet (whereas many medical journals are only available to those who have access or the money to pay for the articles):

In addition, vaccine risk communication is hampered by a lack of data. In 1991 and 1994 the IOM (Institute of Medicine) undertook extensive reviews of adverse events associated with childhood vaccines, and concluded that there was either no evidence or insufficient evidence to establish a causal relationship for two thirds of the conditions it studied. Moreover, experts often disagree about the interpretation of existing data, further confusing a public looking to science for answers. (Ball et al. 1998: 454)

All of these issues make it difficult for the public to discern the validity of information. However, this does not necessarily mean that the public accepts health information

blindly. It simply takes time to do the research, which is something parents may not possess.

## **Health Care and Consumerism**

We are also shifting to a consumer model of health care, especially in areas without socialized medicine (despite these effects being felt in countries with socialized medicine as well). Patients now see health care as a service industry, which means that they want to be more involved in the process:

One of the manifestations of the change in which medicine now finds itself is the shift from a “supply” to a “demand” dominated model based on the perceived needs of the individuals and populations served. The pros and cons of public health interventions are no longer an issue solely for the medical profession; the general public will want their say in the matter. (Krantz et al. 2004: 172)

Because the general public considers itself to have a say in the system (especially in the case of vaccination since it is a risk which also benefits society) patients will expect to have more input in the process as well – which means that good risk communication will become increasingly crucial over time. More than half of my medical informants lamented this process; however, it is clear that the consumerization of the medical system will continue, and that there will be both positive and negative consequences of consumerization for the implementation of health care.



## **Information Overload**

The sheer amount of information on vaccination can discourage parents, making their vaccination decisions more difficult:

....health professionals are not the only source of vaccine information, which can come from family members, neighbours, and an array of media outlets such as newspapers, magazines, and television. More recently the Internet, with its home pages and electronic bulletin boards, has emerged with vast potential for information dissemination but without any editorial control, much less peer review. (Ball et al. 1998: 454)

Despite the overwhelming amount of information, multiple informants reported a lack of trustworthy information. Although this seems initially contradictory, it is typical because it takes a great deal of time to find the information. Once they do locate information on vaccination from both sides of the argument, each page seems to link to others in a seemingly endless chain of articles, websites, public boards, and other information. Informants reported that much of the information they find is reputable in the beginning, but slowly becomes more and more unreliable. Parents often found themselves frustrated that they could no longer trace the path back to the “good” information, but instead had to begin their search all over again.

## **Different Risks for Different People**

Every vaccination decision is based not only on the information found in the decision-making process, but also the variety of risks the parents perceive. These risks vary and are often culturally based:

Of paramount importance is that individuals perceive risk differently. Although physicians may focus on the statistics regarding general vaccine effectiveness and know risks of vaccine-preventable diseases, parents

making vaccination decisions may perceive risks in a broader religious, cultural, and personal context. (Ball et al. 1998: 455)

From my interviews, I identified that the themes of allergies, autism, asthma, and personality disorders discussed at the beginning of the chapter were often present. However, the themes were not found in every informant's interview and are not representative of all of the reported beliefs, but instead are the most common. Less common beliefs and the risks associated with them were often personal, such as a strong opposition to using aborted fetal tissue in vaccines. These factors were often more important to the individual making the inoculation decision than the most commonly reported themes. Ball et al states:

Individual characteristics affect decisions to vaccinate; data from the CDC tell us that immunization rates vary by race, education, socio-economic status, and other factors. (Ball et al. 1998: 455)

Perhaps these "other factors" are the most crucial because they are not easily quantified or understood. These risks were certainly understood by my informants, typically in a way that was highly personal. However, even if there is a risk involved, the social, religious, cultural and philosophical needs of the family still warrant consideration.

Some parents have reported that they feel more in control of risks their child may face in a way that paediatricians may not recognize (Ball et al. 1998: 455). All of my informants reported that they felt they knew their children better than their family doctor, although the majority admitted that their doctor certainly knew more about the medical side. All of the parents I interviewed also stated that they understood how their child would react to a vaccine or medication better than the doctor. One informant mentioned an incident involving an antibiotic:



So, I told them that he needed something that wasn't as strong and that didn't have codeine in it. I said the last time we did codeine, he started to break out in these little spots, you know, at the end of the medicine? But they gave it to him anyway and, well, he broke out into spots. An allergic reaction. But this time it happened a few days in. I told them, but they said it was unrelated. And they wouldn't even believe me over the phone, I had to bring that poor sick baby in again. Now they say he has a codeine allergy. I could have told them that months ago! (Interview with lay person with children. August 6, 2007)

As this incident demonstrates, the personal experiences and observations of parents are not always regarded as accurate. Although physicians need to see patients in order to properly diagnosis them, the parents' observations and perceived risks must be addressed.

### **Medical Distrust**

Not only is there a problem in communication, but there is also distrust because vaccines are seen as preventable risk if only the public knew more about it: "Voluntary, controllable risks are more acceptable than involuntary risks" (Ball et al. 1998: 455). The public wants to be informed of the risks. A risk can be acceptable if the public knows what can happen. At the heart of this distrust is the feeling that some information is being withheld:

.... members of the public expect experts to understand that it is harm to particular individuals that concerns them above all; that some ways of falling ill and dying are more feared than others; that, in view of the massive scientific databases on the familiar chemicals, there should be more certainty in expert judgments, as opposed to the familiar refrain, "more research is needed"; that lifestyle choices (with their attendant risks) voluntarily made are legitimate and may not be questioned, whereas risks involuntarily imposed on individuals are suspect; that the distributions of risks and benefits often do not appear to be equitable; that experts appear to be condescending and arrogant in their relations with non-experts; that experts employed by governments and industry

obviously cannot be trusted to be forthright about risks; and so on. (Powell and Leiss 1997: 26)

Powell and Leiss bring up some very crucial points that also apply to inoculation decision-making. My informants echoed the thoughts in the above-mentioned quote, and these experiences left them frustrated and angry at the medical establishment - which only furthered their distrust.

Groups who resist immunization have been described as struggling with state control over individual choice (Dew 1999; Streefland et al. 1999), this resistance itself reflects a general (Mori 1999) but recognised deterioration in trust, authority, and experts. Flynn et al, Kasperson, and Petts have contended that doubt intensifies public responses to risk messages and leads to a questioning of the work and decisions of anyone not perceived to be independent (Flynn et al. 1993; Kasperson et al. 1992; Petts 1998) Various studies have attempted to unravel the nature of trust, and a wide range of apparatuses including: perceived competence, predictability of arguments, objectivity, accountability, fairness, and caring, have been identified (Kasperson et al. 1992; Petts 1998; Renn and Levine 1991). It should be noted that patients want to trust their doctors; they may, however, perceive the role of a physician to be more involved in patient care and education (Petts and Niemeyer 2004: 21)

Petts and Niemeyer's study and my informant interviews both demonstrate that people perceive their doctors to be experts. However, both of our sets of informants comprehend the dynamic nature of knowledge and understand that new studies are coming out every day. As was mentioned in Chapter Three, our society may not only want, but need, physicians to know everything. However, that is not practical:



But common to all groups was the fact that expressed concern extending beyond MMR itself to the level of scientific/expert knowledge about the risks, with understanding that not even 'the experts' are certain. (Petts and Niemeyer 2004: 12)

My informants appreciated the difficulty of remaining current with vaccine information, but also reported that it was the doctor's job to be an expert. The real failing for my informants, as well as the participants in Petts and Niemeyer's study, was communication:

I don't even mind if they say they don't know and that they'll look into it and get back to me. But they never say that. They'll never admit that they don't know. They talk around it like they do and before you know it they've changed the subject and are arguing with you about a point you both agree on, then once that's settled they think it's done. But it's not done. I still don't have my answer and they still don't know. (Interview with lay person with children. May 14, 2007)

In both the minds of the patient and doctor, physicians should have all the answers. However, patients realize that doctors are human, and they do not expect them to be perfect. When asked, my informants felt their doctors should know all the basics and be able to find the rest of the information. All of my interviewed informants professed the same ideal doctor/patient relationship when asked: a partnership where they could come with questions and get answers (if not immediately, then eventually) from someone they can trust. They understood the reality, especially with the shortage of medical professionals in this province, and reported their doctors desired a similar relationship, but were too overworked to form a close partnership with all of their patients.

Even in ideal situations where patients and physicians work together, medical professionals should encourage their patients to question the information they receive:

Distrust in information sources emerges as an important generator of questioning of authorities (particularly the government). However, our evidence would seem to support Poortinga and Pidgeon's (2003) definition of 'critical trust'. While our parents relied on institutions for knowledge they combined this trust with a healthy scepticism as to whether they were being given impartial, unbiased advice and hence were continuing to (constructively) question the correctness of information. Trust was not simply an issue of competence but a combination of competence and care and a vested interest dimension. (Petts and Niemeyer 2004: 20)

Informed patients who ask questions are actively involved in their own health care, which makes them more likely to take preventative measures:

People seem to think doctors don't like patients who ask questions. That's not it, we do, we just want them to accept our advice when we answer those questions. Personally I don't think my patients follow half of what I tell them. I don't have any notion that they're all out there, eating right, exercising, not smoking, et cetera. But I know if they ask about quitting smoking or how much exercise they need, well, then they're at least trying. Health care isn't just something that happens to them, it's something they're involved in. (Interview with medical professional. May 7, 2007)

Involved patients are less likely to perceive they are being coerced, but rather feel as if they are a part of their own health care team.

Making the patient an active participant in their own health care keeps the dialogue open. When communication breaks down due to a lack of patient involvement, it can have a negative effect on medical information. Patients need to know they can discuss their questions with medical professionals; otherwise, communication problems can begin. These effects on communication can resonate far beyond the local level, entering national and global media as well as the Internet.

Medical professionals need to at least allow for the possibility that patients are rational when it comes to risk assessment. Bellaby's research states:



...that parents are acting conscientiously as norms dictate, not selfishly. They act in what they perceive to be the interest of their children. If there seems to be any risk to their child, responsible parents will avoid it. (Bellaby 2003: 727)

While parents may be rational and responsible, they also need to be informed so legend and conspiracy theory do not take the place of health information. Information which is based on the specific event and addresses alternative viewpoints in respectful manner may help. However, without pertinent information, the "risk information vacuum" may take the place of health information, mixing partial scientific information with the fears of the public (Powell and Leiss 1997:31).

Powell and Leiss address what will happen if this vacuum is allowed to continue:

Society as well as nature abhors a vacuum, and so it is filled from other sources. For example, events reported in the media (some of them alarming) become the substantial basis of the public framing of these risks; or an interest group takes up the challenge and fills the vacuum with its own information and perspectives; or the intuitively based fears and concerns of individuals simply grow and spread until they become a substantial consensus in the areas of public opinion; or the vacuum is filled by the soothing expressions beloved of politicians: 'There is no risk of...[fill in the blank]'. (Powell and Leiss 1997: 31-32)

As discussed previously, too much information can be problematic, especially when the information does not focus on the local. It is crucial to address health information at the community level so the risk information vacuum does not become the main source of public health information. Although good communication is fundamental, it is also important that those on a community level are involved in the current issues in medicine. Additionally, medical professionals should be willing to discuss health issues in both public and private forums. Working on a local level is paramount since it enables

participants to focus on the real needs of the community and individual instead of focusing on the conclusions of the current literature.

However, even with specific, thorough, and considerate information, the risks foreseen by the biomedical community may not be the same as the risks perceived by the public. Information alone cannot solve this problem, rather negotiation of risk and an openness to work within the realm of what the public deems acceptable is necessary.

### **The Needs of Health Care Providers**

The needs of the health care providers have been frequently overlooked in the literature. Although the majority of articles state that health care workers need to spend more time educating the public and mention that time is an issue, there are no solutions to the problem. Additionally, parents need to express their desire for information: "While parents expect to receive reliable information, the two major barriers to this for providers were time, and the sometimes mistaken belief that parents did not want information about risk" (Leask 2002: 125). Unless parents clearly ask about the risks associated with vaccination, the risks are frequently not mentioned or glossed over. After discussing this issue with parents who did vaccinate, the majority reported that they were not informed about the risks associated with vaccination or they did not remember discussing risks with anyone. Although it is possible that risks were discussed, but not remembered, the risk associated with a vaccination should warrant enough of a discussion to recall it. According to Leask, this is a problem in the United States:

Despite the mandatory requirement that all USA parents receive the Vaccine Information Statement from providers, one study showed that



40% of providers did not mention vaccine risks to parents (Davis, et al. 2001, 1-11). The authors concluded that providers might benefit from further training, that practical material to support communication should be readily accessible, and that efforts to improve communication more generally should take into account the limited time available. (2002: 126)

Leask's study is one of the first to mention that providers should be educated about vaccination risks.

Although other studies have suggested that nurses or other medical professionals should be trained, this is the first to suggest that physicians may need training in communication as well:

Misconceptions about vaccine risk also exist among providers. One national survey found that up to one-third of physicians over-estimated the risk of serious adverse events associated with pertussis vaccine. In addition, 36% were concerned about litigation from alleged vaccine-related injuries and such concerns affected their belief and practices. (Leask 2002: 126)

Throughout the literature, physicians' personal belief systems have been ignored. Other medical care professionals, such as nurses, may suffer from the same inherent biases, the same as any other person. Physicians may be affected by their patients' perceptions as well since a survey of health professionals who provided vaccination also remarked that parents' unease rubbed off on the professionals (Bellaby 2003: 726; Petrovic et al. 2001: 82-85). Jolleyman et al. also found that one-third of health providers in New Zealand still had significant uncertainty about whether MMR caused autism (2004: Y769). For the health system to work, we have to look at both patients and health care professionals in order to improve communication. Studies in the past have largely ignored the education of the medical professional and have instead focused on the education of the patient. Providers should be trained not only in biomedicine and risks of vaccination, but also in

risk communication. Health care professionals should be aware of their own inherent biases in order to properly educate others.

## **Media**

The media frequently receives the blame when it comes to the failure of risk communication. Additionally, mass shifts in public confidence in immunization have been attributed to media-generated controversy (Clements and Ratzan 2003; Gangarosa et al. 1998; Leask 2002; Mason and Donnelly 2000; Petts and Niemeyer 2004). It is true that once the media covers an issue, there is both a heightened sense of awareness about that issue and a heightened sense of risk (May 2005: 409). Although the media tends to use stories which will warrant the most interest, members of the media feel it is not their job to educate the public, but merely to inform them:

It is common to hear news stories justified by the idea that 'the public has a need to know', yet this basic justification ignores the fact that neither scientists nor journalists regard their role as one of educating the public in a straightforward sense. (May 2005: 409)

Because no one has taken the responsibility of educating the public, the media takes the information given to them by scientists and uses it in a way that is engaging and interesting. Neither group is primarily concerned with educating the public; they are both working under their own agendas. If we want to educate the public, the best way to do so would be to make everyone responsible for that education. However, even if either scientists or the media took responsibility, there would be an improvement in risk communication.



May gives some advice to journalists on how to better communicate health information:

Journalism needs to downplay the 'personalized' and 'dramatic' characteristics of news reporting in favour of developing the historical, institutional, and social context of stories as its leading recommendation for better and more accurate media communication. (May 2005: 418)

Although this would improve the quality of the stories and make them more relevant, it probably would not make the headlines:

Journalists spoke about the media perspective on vaccine controversies. They addressed the perennial accusation that the media report vaccination in a biased and sensationalized fashion. They noted that the job of the media is not to promote or oppose vaccination, but to report 'what is out there' [sic]. (Leask 2002: 126)

The above statement is important to emphasize because it demonstrates the attitude that the media is not responsible for the promotion or opposition of vaccines (or any other medical information). Even though it would be naïve to think the media is without bias, both on a personal and corporate level, their overall goal is not the same as a goal of scientists or medical professionals. Additionally, the media is not able to provide all of the information, especially considering constraints on the time or space they can use for their reports:

Although the benefits of MMR vaccination are well documented the difficulties were two-fold. Firstly, it was difficult to briefly and simply explain the concepts of individual risk, herd immunity, coverage rates, and the possibility of outbreaks to the public. Second, the lack of coverage the media gave to these 'dry' scientific arguments meant that the public was not fully informed. (Burgess et al. 2006: 3925)

It is common for the media to amplify risks and use attention-getting headlines. The use of these tactics, although effective, can backfire and harm public knowledge and trust (May 2005: 418; Guttman and Salmon 2004: 531-532).

While parents do not passively receive this information, they are affected by information that is reported over and over again:

Although most of the parents held childhood immunisation to be a good thing, exposure to media evidence about MMR had clearly shaken beliefs. The media reporting was frequently portrayed as a catalyst of concern and worry not only about whether to have MMR but whether previous decisions had been wise. (Petts and Niemeyer 2004: 13)

If a news story is repeated multiple times, it can increase awareness and cause fear. It may be easier to disregard a news story heard once, but in the case of MMR, for example, which is covered frequently (especially in Great Britain), the situation becomes more difficult. Approximately half of the parents in my research reported that the more they saw a story, the more they not only worried about it, but started to believe it, even if their own research and education dictated they should not believe. They remarked that if the story was not true, then it would disappear from the headlines. Clearly, both quality and quantity matter when it comes to health risk perception.

As mentioned previously, parents do not passively accept the information given to them. Petts and Niemeyer's study reported:

The research did not provide evidence that parents had passively received media information without questioning nor that despite support for MMR parents had not still been concerned about making the 'right' decision and worried about the accuracy and veracity of information available to them. (Petts and Niemeyer 2004: 19)



Parents also have biases toward the information given by the media, and only accept information which is pertinent to them:

The conduct of the media may have contributed to the miscommunication of risk, but it would be a mistake to suppose that the media led the public. Parents were predisposed to act in what seemed to them to be the interests of their children. (Bellaby 2003: 726)

However, this does work in favour of vaccination as well:

Trust was an important factor, affecting both relationship with GPs and propensity to seek and listen to their advice. Participants talked about the MMR information they looked at being 'trustworthy', but had difficulty articulating exactly what this meant without prompting. Some suggested that they trusted it because it had supported their own decision to go ahead with the vaccination. (Petts and Niemeyer 2004: 14)

Although parents are generally committed to acting in the best interests of their children, my research showed that once parents make a decision about vaccination, they stand by their decision. However, if parents were approached early in the decision-making process, they were more likely to accept information from opposing viewpoints. Parents also responded positively to direct conversations rather than media reports or other printed information:

The primary problems seem to have been that other information had not always been available to parents, particularly directly and verbally from their own GPs. This situation represents a fundamental compromise of the 'decision-making partnership'. (Ball et al. 1998)

It is vital to discuss vaccine decision-making early with parents. These discussions should begin at pregnancy and form a continuous dialogue between patient and health care provider. This ongoing dialogue will enable parents to feel more comfortable approaching their care providers with conflicting information from the media: "Media discussion of MMR has served to worry and has challenged embedded

understandings of the value of immunisation, but for our participants, it does not seem to have irreparably damaged a positive change” (Petts and Niemeyer 2004: 19). This, of course, does not mean that the medical community can ignore the media. May states, “Streamlining communication requires that primary, ‘authoritative sources’ of information be made available early in the reporting process” (2005: 420). The earlier the medical information reaches the media, the less time available for speculation.

In addition, scientists and medical care providers should form bonds with the journalists reporting their stories:

Speakers emphasized that establishing good relationships with journalists was most important. An accessible and reliable expert who is not overly wary means that a journalist can access accurate information rapidly. (Leask 2002: 126)

The media can be beneficial to the medical community in the dissemination of health information. A good partnership, coupled with a responsibility to the public, can result in positive outcomes for all involved.

## **Risk out of Control**

The risk information vacuum is problematic for reasons that go beyond communication problems. When ideas in the public realm are not addressed, they can grow out of proportion and eventually must be handled. Powell and Leiss state:

.... there are substantial monetary and other costs attributable to risk communication failures. Many of these damages stem from what happens when a risk information vacuum is allowed to develop – namely, a process of ‘amplification’ whereby the risk issues are ‘put into play’ and develop in ways that might otherwise never have happened. (Powell and Leiss 1997: 33)



Powell and Leiss later address how the public's concerns can spiral out of control, which can eventually lead to conspiracy theories and medical distrust. They assert:

Risk communication failures can initiate a cascade of events that exacerbate risk controversies and render risk issues difficult to manage. At the core of all risk issues there are problematic aspects – lack of timely information, uncertainties in the risk estimates, lack of trust, lack of credibility, complexity of the scientific descriptions, and so forth – which breed apprehensiveness, suspicion, and concern over personal safety among the public. In a risk information vacuum, this latent apprehensiveness, suspicion, and concern feeds upon itself and, in the absence of the dampening effect that good risk communication practise might supply, **may be amplified to the point where credible and pertinent information makes no difference in the formation of popular opinion.** (Powell and Leiss 1997: 214 emphasis in original)

As noted previously in legend research, when a perceived risk loses context and is amplified, it can be impossible to rectify the situation, which demonstrates why risk communication is so vital.

## **Cultural Memory**

Throughout my research a pattern has become evident that regions with vaccination disasters are the same areas that have a strong anti-vaccination presence. After discovering the various vaccine disasters mentioned in Chapter Two, such as the Cutter incident, I noticed that these regions have a higher number of anti-vaccination groups and websites and that the groups and websites are more developed and comprehensive. Clearly this demonstrates that these events have remained in the cultural memory of the region. As Burgess, Burgess, and Leask state: "Images of 'damaged' children are particularly memorable" (Burgess et al. 2006: 3923), and they seem to have a long-term impact on the community's cultural memory. In the article "How Rumor Begets Rumor:

Collective Memory, Ethnic Conflict, and Reproductive Rumors in Cameroon” the authors demonstrate the importance of cultural memory in rumour transmission, showing that rumours do not exist independently, but rather are the results of the cultural environment and interact and gain credibility from it (Feldman-Savelsberg, Ndonko, and Yang. 2005). People do remember rumour, even if it has fallen out of fashion, rumours do not fade completely from memory. Collective memory can create an environment in which legend and rumour can grow since there is a shared experience and events which are similar can be linked to vernacular knowledge of the area (Fine and Khawaja 2003:4, 28-29; Kapferer 1990:116). Additionally, new narratives may surface which draw on the cultural memory of past events and the tales associated with them (Feldman-Savelsberg, Ndonko, and Yang 2005: 141)

Extra care must be taken in regions with a history of vaccine disaster. Due to the sensitivity of the community’s cultural memory, these regions may have supplementary or dissimilar risk concerns than other populations. Locations with previous vaccines disasters may also be more sensitive to vaccination information, and their desire for safety will likely be higher than other regions. Both knowledge and belief come from experience and neither should be ignored.

### **Individual Freedom and Public Health**

Ball, Evans, and Bostrom agree that when it comes to vaccination, “[u]nderlying this issue is the inherent tension between protecting public health and allowing individual autonomy” (Ball et al. 1998: 454). Throughout this text, it is obvious that compulsory



vaccination will never work. The public must be a part of the decision-making process and an active participant in their own care. Additionally, if our society wishes to respect individual freedoms, it will need to involve the lay public more in the planning and acceptance of health programs while respecting the decisions made by the public: "If the goal is solidarity rather than conformity, we must have parents free to decide what they think is right, because that is what moral responsibility is all about" (Krantz et al. 2004: 177). Good risk communication is essential in order to facilitate patients' trust in the medical community. Although there is no possible way to rid the world of conspiracy theories, especially those concerning vaccines and other newer medical technologies, medical professionals can help the public understand advances in medicine. By addressing the real concerns and beliefs of the public instead of dismissing them as false, medical professionals practice good risk communication. A careful consideration of urban legends and conspiracy theories will enable folklorists and medical professionals alike to understand the concerns of the public and address those concerns in a real and, hopefully, viable way.

### **What Should Good Risk Communication Accomplish?**

Ball, Evan, and Bostrom offer four components for effective risk communication:

First, it communicates existing knowledge, taking into account what individuals already know. Second, successful risk communication recognizes factors influencing parental risk perception and addresses vaccine decision heuristics. Third, it acknowledges potential risk communication pitfalls. Finally, effective risk communication engages parents appropriately, which for active, concerned parents means a decision-making partnership with their physician. (Ball et al. 1998: 456)

These four components are an excellent place to begin. If the provider proceeds with the parents' current level of vaccination education, it is likely that they will not offend or belittle the educational status of the parents. If health care professionals next consider the real fears of the parents regarding vaccines, they will be able to address those fears in a way which is relevant to the family. Acknowledging the risks (and being honest about those risks) will engage the parents in the decision-making process. However, these risks should not be understated. The provider will need to be as honest as possible. While there may be some temporary concern at first, any additional questions or concerns can be addressed if the relationship is good between the provider and the family. These methods can lead to an involved discussion, and parents who are actively engaged in the decision-making process.

Additionally, Leask offers the seven cardinal rules of risk communication:

1. Accept and involve the public as a partner.
2. Plan and evaluate efforts.
3. Listen and be responsive to specific public concerns.
4. Be honest, frank and open.
5. Work with other credible sources.
6. Meet the needs of the media.
7. Speak clearly and with compassion. (Leask 2002: 126)

The first of these rules, that the public is accepted and involved as a partner, is key. It is easy to disengage the public as a partner, but this concept of both accepting and involving the public indicates that the provider has accepted the public's place in the decision-making process, a step which my informants felt was overlooked:

I feel as if I'm really not a part of the process. It's all lip service. They're just saying what they have to, what they're supposed to, in order to make it seem like they want me involved. They don't. They just want me to shut



up and take the vaccine. (Interview with lay person with children. June 20, 2007)

Both the planning and the evaluation of efforts can improve the overall climate of risk perception. In order to adequately understand if the process is working, it is important to evaluate the process and outcomes – not only according to the audience, but also the media and the facilitators.

Listening and responding to the public's real concerns is one of the focuses of this research. Being as honest as possible to those questioning risk is the only way to demonstrate understanding and offer validation. Working with credible sources (especially websites – the preferred research method of many lay people) and the media will ensure that the right message is reaching the public. Finally, speaking both clearly with compassion will enable communication and trust, demonstrating to the patients that they are being spoken to in tandem with their education and experience.

### **Dealing with Dissent**

Medical care providers should accept that opposition is a part of the process, and not a reflection on the provider:

The first [lesson] is that challenges to authority, including the authority of science, should be expected in a healthy democracy. The second is that the establishment should disseminate evidence to the public in a transparent way that is sensitive to the ways of understanding of diverse groups. The third lesson is that communicating risk effectively to the so called masses, and so priming people to act appropriately, is about much more than providing even the best of information: it is a matter of two way communication and obtaining agreement. Concordance has to be the aim if compliance is to fall into place. (Bellaby 2003: 727)

Research shows that the information must be pertinent to the culture, and there needs to be communication, not just education. In any healthy society, there will be opposition and questioning, especially to bodies of higher authority. Opposition should not be perceived as negative, but rather as proof that patients want to be involved in their own healthcare.

### **Communicating the Other Side of the Issue**

Many websites and health care providers have taken an “ignore it and it will go away” stance with the anti-vaccination movement. If the movement is not addressed, it can lead patients to believe that all of the information is true. Burgess, Burgess, and Leask state: “Failure to acknowledge and discuss an issue, however speculative, may allow parents to uncritically accept misleading information, believing all doctors agree” (2006: 3926).

If the issue is dismissed without explanation, then patients may feel that their concerns are being disregarded:

I asked the nurse to explain to me why vaccines are safe and she basically told me that they were safe and why would people get them if they weren't? She said her kids were vaccinated, and well, I guess that made me feel better, but it didn't exactly answer my questions. (Interview with lay person with children. April 10, 2008)

Petts and Niemeyer also found in their study, which included a video they showed to educate their informants, that it was important to discuss both perspectives. They found that the video “...made no attempt to explain the ‘alternative science’ and yet this lay at the heart of parental concerns” (Petts and Niemeyer 2004: 20). While their video was informative, it did not address the anti-vaccination movement – which made some people



suspicious. Health care providers (and the websites they run) must be prepared to explain these concerns from a scientific standpoint so that the family is able to understand exactly what these studies have shown or not shown.

### **Lay Understanding of Risk and Science**

There is an unfortunate assumption in the medical literature that demonstrates that the public is not able to understand the complexities of medicine (Ritvo et al. 2003). I found that my informants may not have understood the exact details, but clearly understood the general concepts. Many of my informants who questioned vaccine safety were also very educated. Typically, at least one parent had an advanced degree (master's or above), but more often, both parents either had or were in the process of obtaining advanced degrees. Even those without university degrees demonstrated a basic knowledge of science and a strong understanding of vaccination. If there were any misunderstandings, they typically favoured Western medicine and resulted in compliance, such as the belief that the flu shot was able to prevent all types of flu. Petts and Niemeyer found similar results in their own study:

Our participants displayed grounded and experiential 'lay' knowledge about the science of health, of childhood diseases and also of the conduct of medical science that provided support to their ability to interpret and understand the information, particularly when given verbally, in lay language and with the opportunity for direct questioning. (Petts and Niemeyer 2004: 20)

I also noted that my informants understood that medicine is constantly changing and involves new information daily. Informants understood the risks involved with medical procedures and, although they expected medical care providers to understand

why an event happened, they did not believe that any aspect of medicine was risk-free.

These findings are similar to the results of Petts and Niemeyer's study:

Participants understood that medical knowledge is continually developing and that the causes of diseases such as autism are uncertain with evidence taking time to be generated. However, uncertainty did not result in demands for zero risk. Participants readily identified and accepted concepts of precaution and the need to balance risks, costs and benefits. The comparative risk data although not universally understood nevertheless did seem to support the information that was being provided, contributing to a rich tapestry of knowledge that was interpreted against a backdrop of understanding and experience. (Petts and Niemeyer 2004: 20)

Petts and Niemeyer's research as well as my own, demonstrates that parents understand immunization risks: "The balancing of risk was not confused with demands for zero risk. Indeed throughout the group discussions of child health there seemed to be acceptance that immunisation is not risk free" (Petts and Niemeyer 2004: 14). Parents are able to understand both risk and science, especially if it is presented to them in lay terminology with the opportunity to ask questions.

### **What Can We Do About It?**

Discussing vaccination as early as possible is crucial if one wants to maintain an open dialogue between patient and practitioner. This must be an effort made not only within the medical community, but also by the patients. The simplest way to begin this dialogue would be to start discussions during pregnancy. Since it is likely that patients and their children will not have the same health care providers throughout the birthing process to childhood, it is also advisable to schedule a visit to the Office of Public Health during pregnancy. It would also be advisable to establish other contacts after the birth of



the child and to involve both the pediatrician and the Public Health nurse as early on as possible. One parent mentioned that she did visit the Office of Public Health and picked up many pamphlets, but had lost them by the time the information had become relevant. She suggested a mailing system where pertinent information would be sent to parents, based on the age of their children.

It is important to establish these relationships early so the family feels comfortable and has a place where they feel relaxed and can discuss their concerns, “Because belief systems are difficult to change once established, it is appropriate to provide parents with understandable, reliable information on vaccination at the outset so their first impression is correct” (Ball, et al. 1998: 456). Again, it should be noted that an open discussion is key to establishing a good relationship and trust: “In the clinical encounter, risk communication is more than a top-down supply of information; it is an exchange between both parties. Trust is fundamental to a relationship in which discussions about risks and benefit can occur” (Leask 2002: 126). Without an exchange of ideas and information, trust cannot exist between patients and physicians.

### **Speaking to Patients**

In discussions, providers should give more than just facts and numbers, they should be able to “relate emotionally” to patients (Burgess et al. 2006: 3926) and speak to them about vaccine-safety without fear of refusal:

Parents expressing reluctance to vaccinate their children require more than a quantitative analysis of the risks and benefits; physicians should seek to understand the cultural, religious, and other personal factors influencing vaccination decisions. (Ball et al. 1998: 456)

The perceived beliefs and real risks of the patients need to be addressed, not just the most commonly known beliefs. Providers will need to address the concerns mentioned by the family, not the ideas providers think the family believes. A practitioner should never assume that they know what the patient believes, regardless of their knowledge of the patient including religious or personal beliefs or affiliations. The health care provider should always ask about the specific concerns. Even though the parents may present a common concern, providers should ask what the family has heard and what concerns them the most.

One technique that can be used for emphasis is discussing the concerns on a personal level. As noted in previous chapters, the most effective narratives are the ones which involve emotion and draw in the reader/listener, regardless of whether or not the narrator is known to them. Ball, Evans, and Bostrom state:

Because risks which are easily accessible to the imagination are more compelling, examples given in the context of a personal story can be persuasive. For example, parents reluctant to vaccinate against pertussis can be told pediatrician's personal experience treating children hospitalized with pertussis. (Ball et al. 1998: 456)

However, these stories should not be used to scare or threaten parents. As we saw in Chapter Six, using pictures or "scary stories" often had the opposite of the desired effect. Instead, health care professionals should discuss their experiences from an emotional, but non-threatening, stance. This will inform the parents that the provider is sympathetic to the victims. Narratives such as these can be effective in both increasing trust and reinforcing humanity, but only if these stories are true. This is especially important in the



context of Newfoundland culture, which favours oral communication and has historically been a primarily oral culture (Crellin 1994: 33).

In the past, it was common for health care providers to take a strong opposition to anti-vaccination discourse, ignore it completely, or attempt to be “neutral”:

How should health workers address misconception about immunization? Many believe that scientifically accurate ‘neutral’ information will reassure parents. Others suggest that messages should be crafted to account for ‘non-rational’ ways of understanding risk including advocacy or a social marketing approach. (Leask 2002: 126)

Whenever these techniques were used on my informants, they typically reacted poorly, stating either that their concerns were not being addressed or that the provider felt that they were “uneducated” or “stupid.” Honesty is best, and an appropriate display of emotion or sympathy will elicit a more positive response than strong opposition or even a neutral stance.

Providing the family with alternative viewpoints may also be an effective way of reframing the event, especially if one uses the viewpoint of the child (Ball et al. 1998: 456; Baron 1992: 320-330). One informant commented on this tactic saying:

It really got me thinking, I don’t know what my child might end up doing and I don’t mean that in a negative way. Maybe they’ll work or volunteer in a foreign country where there is Hepatitis. I don’t know who they’ll become. Sure, the chances of them getting a disease right now is very low, but I want them to always be safe. (Interview with lay person with children. January 13, 2007)

Sometimes reframing the way a parent looks at vaccination can be helpful, as long as it is not used in a way that may increase the parent’s guilt or challenge their education.

We can learn from the mistakes made in risk communication in the past.

Burgess, Burgess, and Leask offer some suggestions learned from the MMR

controversy:

1. Assess how much hazard the community will perceive and plan for their reaction.
2. Do not over reassure.
3. Listen to public's concerns – frightened people need compassion and understanding, not just more science.
4. Be involved in the debate, withdrawing gives the wrong message – critics and mavericks are more credible when they are the only voice.
5. Acknowledge uncertainties and that this uncertainty is distressing.
6. Provide a narrative or human face to support your case...
7. Be responsive – the risk communication must adapt to the issues if a response is not working....a new response is required...
8. Be clear about your key message and always return to it....
9. Draw attention to overwhelming medical, scientific and community support for vaccination. Media reporting in general will present a story as if the opinion is split, making outlandish theories seem to be more mainstream.
10. Broaden coalition of voices supportive of cause, such as general practitioners, parent support groups – not a single government body or 'experts' telling parents what they must do. (Burgess et al. 2006: 3927)

These suggestions are an excellent place to start; however, individuals may want to take care with number nine. Although it is important to draw attention to the data, it can be easy to go too far or not acknowledge alternative viewpoints when the public is curious about those viewpoints. Attention should be paid to all viewpoints and parents should feel that practitioners have considered alternative viewpoints, in addition to those which fall into the beliefs of Western medicine.



### **Speaking to Medical Professionals**

There is a large body of vaccine safety literature focusing on the damaging effects of vaccination and how to opt out of vaccination. There is not, however, much information on how to speak to practitioners about vaccination. There are many books which point out in great detail the effects of each vaccine (Coulter and Fisher 1991; Miller and Rimland 2003; McTaggart 1998) or discuss how to avoid these vaccines (Miller and Rimland 2003; Miller 2005; Think Twice Global Vaccine Institute). While a few books do give a list of questions to ask your provider (Cave and Mitchell 2001), the majority of the information on how to talk to your health care professional can be found on the Internet. However, most of the information on how to speak to your health care professional about a vaccination is on pro-vaccination sites, such as CDC and Health Canada. A general search on Google did not lead to these sites, and the information could only be accessed by being on the website or specifically using “CDC” or “Health Canada” in the search parameters – which is something that parents might not do, especially if they were already leaning toward refusing the vaccination. While these sites do provide some information, they do not provide details about how parents can discuss this issue with their health care providers.

Anti-vaccination sites demonstrate the same trends as anti-vaccination books and pamphlets<sup>71</sup>. There is more information about opting out of vaccination than there is on how to speak to your doctor. There is very little detailed information for parents looking for advice on discussing vaccines with health care professionals. The parents I

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<sup>71</sup> These books and pamphlets are frequently for sale on anti-vaccination websites with the proceeds going to support the website itself.

interviewed mentioned that this is a stressful situation, and often they are anticipating confrontation. Many parents did not talk to their public health nurse or pediatrician; they just avoided all contact, due to fear of conflict.

### **Personal Bias**

Personal biases exist for both parents and medical care professionals. As mentioned earlier, it is important to acknowledge these biases and try to overcome them. As Ball et al. states, "Physicians must recognize their own use of heuristics, as professional training does not preclude biases and errors in judgment" (1998: 456). Both parents and physicians must address their own personal biases in order for risk communication to be successful.

It is also possible that the research suffers from biases. As Ball, Evans, and Bostrom discuss "Researchers describe the tendency for experts to extrapolate from limited data and fit equivocal data into preconceived patterns" (1998: 456). Informants have mentioned problems in some medical studies, including conflicting funding sources and small sample sizes. There will always be biases in any research, which is why it is so important to recognize these biases.

### **Involving Oppositional Viewpoints**

Involving those with oppositional viewpoints can be very productive for a variety of reasons:

It is advantageous to involve anti-vaccination groups in policy forums as this can give them a voice, while at the same time exposing them to the



challenges that face policy makers. This may also be an opportunity to challenge the stereotype of the 'faceless bureaucrat' or the juxtaposed myth that all people opposed to vaccination are deliberately malevolent in their intent. Those who protest vaccine policies are not a homogeneous group: individuals and groups may range from the fanatical to the reasonable. Engaging with the former would be fruitless, but others may be highly attuned to system weaknesses, and with them could be a shared desire to improve adverse events reporting and vaccine injury compensation, even though such goals might arise from very different agendas. (Leask 2002: 127)

Those in the vaccine safety movement are often portrayed as unreasonable and illogical. However, much can be learned from them, not only concerning the beliefs of the particular group, but also regarding some valid concerns. Vaccine safety advocates are a part of the reason why safer vaccines exist today, and these advocates contribute to important aspects of vaccination history and policy. Instead of disregarding those who oppose vaccination, researchers and medical personnel should seek their advice as a means to understanding some of the concerns of the vaccine safety movement.

It is also incorrect to assume that everyone involved with the anti-vaccination and vaccine safety movement has similar opinions. The beliefs of the individuals vary greatly, and lumping them into one homogenous group does not acknowledge the diversity of their beliefs and methods. As Leask mentions above, if the medical community engages with members of the vaccine safety community, it may highlight weaknesses in the system and lead to better risk communication.

### Trickery

Throughout my research, I have been asked if I am providing the medical community with "tricks" it can use to force parents to vaccinate. My goal for this project

was to provide suggestions for both parents and medical care professionals to assist them in communication with one another. However, I was not offended by these questions, which came from both sides of the debate, since there is a history of trickery in vaccination and compliance:

In most years, the problem faced by the public health community is one of convincing the public to accept vaccination, rather than restricting access to flu vaccine. Ironically, the shortage of flu vaccine has seemingly increased demand, despite the lack of serious risks for many who are now seeking access to the flu vaccine. In this context, fear motivates refusal of vaccination rather than demand, but the basic problem remains the same: irrational behavior (in non-compliance with vaccination policy) motivated by misperception of risks. (May 2005: 411)

The above paragraph has been interpreted as a way to force compliance. If the number of vaccines are limited, the public will panic and run out to get them. Members of the anti-vaccination movement believe this to be true, including Dr. Mercola, an osteopathic physician and the owner of [www.mercola.com](http://www.mercola.com), who writes, “....we<sup>72</sup> are so obviously manipulated by the government and drug companies to scare you into taking the flu vaccine” (Mercola 2007). He later states in the same posting:

What might the purpose of these scare tactics be you ask?

Well how about the United States purchasing huge quantities of antiviral drugs and an increase in flu vaccine production, along with purchasing 20 million doses of the highly questionably effective Tamiflu. Guess how much one treatment of Tamiflu costs? Give yourself a slap on the back if you guessed \$100. (Mercola 2007)

One of my informants (Interview with lay person, no children. May 15, 2005) also felt the shortage of flu vaccines was a scam devised by the government to get people to panic and vaccinate. However, the anti-vaccination movement provides its fair share of

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<sup>72</sup> Mercola is not specific as to who “we” refers.



information, which could also be perceived as trickery, including purchasable information on how to opt out of vaccination in various states. Of course, providing this information is not trickery, but in the case of websites who sell this information, it might be seen as a way to profit from the anti-vaccination movement.

### **Forced Compliance**

As mentioned previously in this chapter, the concept of forced vaccination has been continually debated. Historically, forcing vaccination has been a disaster, and would continue to be a debacle if attempted again. May states, "Enforced compliance, however, poses special problems that are particularly worrisome in a society that values both individual freedoms as well as respect for the right of minority groups" (2005: 414). While we might all agree that forced inoculation does not work, parents still report that they feel coerced:

Although the parents' choice to vaccinate their children with MMR was voluntary, there were components that may have led to a feeling of coercion, in that general practitioners were reimbursed for having good coverage rates in their practice and the cost of the alternative suggested by Wakefield (use of single rather than combined vaccines) was refused support by the National Health Service. (Burgess et al. 2006: 3922)

Additionally, one informant stated:

I didn't even know I could refuse a vaccine. They never tell you that. You hear all about your kids not being able to go to school or get into university, they don't tell you that you have a choice. (Interview with a lay person with children. January 13, 2007)

Compliance is much simpler if patients do not know they have a choice, but it does not help the patient to trust the individual or the system. While it may seem dangerous to

inform parents of their choices, it is necessary both legally and personally if a good relationship is the desired outcome.



## **Chapter Seven**

### **Conclusion**

As demonstrated in the previous chapters, it is evident that a disconnect exists between the belief systems of anti-vaccinators and pro-vaccinators. While there are a variety of beliefs present and several variations, seven themes emerge from both sides of the argument. The four major themes of the anti-vaccination movement are: 1) vaccines cause disease; 2) vaccines are for profit; 3) vaccines have no effect on immunity; 4) vaccines are not “natural.” On the other side of the discussion, three main themes become evident: 1) vaccination is one of the greatest achievements of medicine; 2) people who refuse vaccinations are wrong; 3) people who refuse to vaccinate are putting the lives of others in danger.

#### **Common Beliefs of the Anti-Vaccination Movement**

##### **1. Vaccines cause disease**

As discussed in previous chapters, my research participants and many sources on the Internet both state that vaccination is the reason for an increase in medical conditions, such as autism, ADD/ADHD, and allergies. Historically, it is noted that vaccines cause diseases and allergic reactions. Although the medical community admits that allergic reactions are possible and that vaccine production is not infallible, they maintain that the research shows no connection between vaccinations and these conditions. Medical research also states other reasons, such as an increase in awareness of certain illnesses, as to why these conditions are prevalent.

## 2. Vaccines are for profit

Both throughout my research and within Internet communities, one can find a wealth of information stating that vaccines are primarily made as a way to generate income for pharmaceutical companies. These companies and the medical community have responded by reinforcing their stance on the efficacy of vaccination, often citing a decrease in illnesses such as polio and smallpox. They also note that many other drugs are more profitable than vaccines, since they are taken more often than once or twice in a lifetime.

## 3. Vaccines have no effect on immunity

This is a core belief on which many of the other beliefs are based. As stated throughout this work (both by my informants and those in Internet communities), people simply believe that vaccines do not work and that the decrease in incidences of certain diseases is linked to sanitation, quarantines, and/or a healthy lifestyle. The medical community disagrees, citing the history of these diseases and scientific research as proof.

## 4. Vaccines are not “natural”

In an age where terms such as “green,” “environmentally friendly,” and “all natural” are commonplace, it is no surprise that these beliefs have found their way into the anti-vaccination movement, including a march on Washington, D.C. by actors Jennifer McCarthy and Jim Carrey where participants wore green t-shirts with the logo, “Green our Vaccines.” Interest in natural foods and methods that sustain the environment



has also created the desire for more medicines perceived as “natural.” When ingredients are listed, such as those mentioned in Chapter Six, the response can be quite significant. Overall, natural risks are generally more accepted than man-made risks (Ball, et al. 1998: 455; Covello et al. 1991: 66-90), and the issue of vaccines not being “natural” is prevalent throughout the history of vaccination (Burgess et al. 2006: 3922).

### **Common Beliefs of the Pro-Vaccination Movement**

#### **1. Vaccination is one of the great achievements of medicine**

Throughout the literature and my interviews with medical professionals, vaccination was frequently mentioned as one of the greatest achievements of western medicine (Bellaby 2003: 727). Citing research, medical professionals discussed the overall success of immunization and recognized that some individuals will have an adverse reaction. They argue, however, that this reaction is an acceptable risk in order to preserve society as a whole. Vaccine safety activists do not agree that this risk is acceptable, especially when the medical community refuses to recognize certain medical conditions they view as arising from vaccination. The vaccine safety movement also states that the medical community cannot admit or accept the risks because vaccination is central to their own belief system; admitting the risk associated with vaccination would cause harm to the medical system and to the faith of both patients and practitioners.

## 2. People who refuse vaccination are wrong and should be dismissed

As mentioned previously, much of the medical literature concerning discussions of vaccination with parents is dismissive and frequently does not offer specific advice, but rather gives blanket statements such as “more education is needed.” The medical literature does not prepare professionals or offer advice to practitioners on how to discuss the decision-making process nor does it offer any concrete suggestions. Instead, many of these works cite the history of vaccination and reinforce the beliefs of the medical community. Although this is certainly helpful from the standpoint of educating the practitioners, it does very little to advise them on how to have discussions with their patients. Instead, it reinforces the “Me Doctor, Me God” stereotype where physicians dictate choices to their patients (Pauker 1995). Parents’ perception of risk also seems to be disregarded: “Parents seem to neglect the easily perceptible risk, to reject the expert assessment, and to amplify the virtual risk” (Bellaby 2003: 726). However, parents argue they do understand the risks of refusing a vaccination and understand the likelihood of their child having a reaction to a vaccination. They also understand the improbability of their child being exposed to the diseases that these vaccines prevent.

## 3. People who refuse vaccination are putting the lives of others at risk

Pro-vaccinators state that in order for herd immunity to be maintained, a certain percentage of the population must be vaccinated. Since anti-vaccinators do not believe that vaccines provide immunity to disease, they do not feel the same moral obligation to vaccinate for the sake of the community. Instead, they feel that they are actually doing



the community a service by not vaccinating since they are preventing other conditions such as autism, which would be a financial burden to the government, especially in the case of socialized medicine. Pro-vaccinators feel that an outbreak of illness is much more likely to occur due to this failure to vaccinate, which would have much greater financial costs to the system. Both parties feel that death is an unacceptable risk, but their perception of the greater risk differs. Coupled with these tensions, there is an underlying accusation that parents who refuse to vaccinate are taking advantage of the benefits of vaccination without participating in the risks.

Vaccine narratives and beliefs are crucial to understanding the vaccine safety movement. Both anti-vaccinators and pro-vaccinators utilize these narrative forms as a way to discuss their beliefs, warn others, and occasionally coerce others to their side of the debate. For some individuals, these stories can take the place of medical information. There is still reluctance on the part of approximately thirty percent of the health care professionals I interviewed to respond to the anti-vaccination movement. Since over half of my lay informants commented that they believed health care professionals were not aware of anti-vaccination information, this is something which must be addressed. The anti-vaccination message is becoming more prevalent, available, and understandable than the pro-vaccination message. The Internet has both empowered patients and challenged the medical community. As Goldstein notes, the Internet:

...has created a context for challenging the construction of health expertise; questioning the credibility and claims of scientists, physicians, and others in positions of power; and brought to the forefront the thinking,

researching, credible, political, and active lay person. (Goldstein 2008: 25-26)

The role of the health care worker is often oversimplified and overlooked. As Hufford has noted, "Doctors are a prototype of the asymmetrical political relationship of experts and lay people, a relationship that is characterized by tacit conflicting interests and thus requires reflexive analysis" (Hufford 1995: 63). The Internet signifies much more than a battleground for information, it is also central to changes happening in the power structure of the medical system. Reflexivity in the vaccine safety movement has been addressed here, but a more in-depth study is needed.

Community understandings of risk and the creation of health information based on the community is essential, as one can see from previous studies (Goldstein 2004; O'Connor 1995; Hufford 1997; Brady 2001). In order to achieve this depth of understanding, ethnographic investigation must be utilized to understand the real fears and concerns of the public. This information can change drastically from area to area; therefore, an understanding of the specific targeted community is essential if the information is to be accepted and understood by the community.

### **Why is it so Important to Understand Vaccination Safety Movements?**

It is crucial that those in the medical field know and understand the anti-vaccination and vaccine safety movements for a variety of reasons:

1. These movements demonstrate common concerns not only of parents, but of the lay public, which reflects sources of apprehension within the culture. Specific themes seem to reoccur in anti-vaccination literature, such as: contamination, racial and class conflicts,



the struggle between authoritative and vernacular knowledge and belief, and victimization caused by the abuse of authority. These matters go beyond vaccination and speak to other medical (and social) conditions as well. A knowledge and understanding of these broader social trends will inform potential concerns and help to focus on the larger fear, not just specific incidents.

2. Anti-vaccination themes are consistent over time and space, reoccurring continually, typically when a new vaccine is introduced or a health concern comes to light. Awareness of themes which occur at the onset of a disease or the introduction of a vaccine will help to educate and inform the public. Understanding these subjects may also help identify which rumours and legends are likely to occur and provide health information in a timely manner.

3. History has shown us that some of these legends are true and, if taken seriously, may lead to the discovery of safety concerns for a variety of conditions.

4. The presence of anti-vaccination narratives gives the lay public a forum to discuss their concerns, dispute them, and deny or accept them. If the medical community gives the public information they can trust and understand, they will make the right decision for themselves. However, if the medical community continues to deny or dismiss information instead of working with the public to understand it, they lose their authoritative voice within the community.

6. The persistence of these narratives does not demonstrate public ignorance, but rather shows that the public is interested and involved in their own health care. It shows a desire to be an active participant in their well-being and demonstrates they are knowledgeable, capable of observing trends, and logical based on their experiences. All these characteristics imply that they are able to properly describe symptoms and understand the causes and effects of healthy living. In a time when some of our greatest health concerns are preventable through life-style choices, a patient's ability to observe trends in their own wellness should be encouraged.

Vaccination will continue to be an issue in years to come. With new vaccinations being developed, more celebrity involvement, and greater access to the media and Internet, people will continue to question if vaccination is right for them. If the medical community wants the public to believe that vaccination is the best choice, then they will need to ensure safety standards are high, and they will need to be more involved and take a personal interest in both vaccination and their patients. This task is certainly difficult because of the time constraints and personnel shortages faced by health care professionals. One suggestion would be to appoint specific people whose sole job is to handle vaccination within each organization or system. While this may not seem cost effective at first, it would certainly help to improve communication and promote patients who are actively involved in their own well-being. This could result in even greater gains than originally anticipated.



For parents and anyone making a decision concerning vaccination, it is important to be aware of the source of information. This is a difficult task since most parents are making vaccination decisions while trying to raise a small child in addition to the duties they had before their child was born. Vaccine decision makers should be educated about vaccination (whichever route they decide to take), and they should involve those concerned with their health in any discussions or decisions they make.

Both groups should always remember that honesty is a crucial element. One may not feel comfortable discussing certain aspects of one's viewpoint but should do so nonetheless. It is important for the family to be informed of the risks, and the provider to be informed of the concerns of the family. Hiding information from either party can only result in a breakdown in communication or even a worse medical condition.

New information is continually being announced by the media and will no doubt affect the future of vaccine narratives. The Newfoundland Right for Life group has spoken out against the HPV vaccines (CBC News. August 8, 2007), and young women are angered by the idea that HPV is linked to promiscuity. The ad campaigns "Because I'm smart" and "Be one less" can currently be viewed on every major television channel and have already caused much debate. A recent study of YouTube has demonstrated that videos with an anti-vaccination message are rated higher than those with a pro-vaccination message (Keelan et al. 2008). Physicians and residents in the province have already begun to complain about celebrity endorsements of the anti-vaccination movement, wondering why celebrities are treated as "experts." Even non-informational media should be studied, as I realized upon overhearing two women discuss the plot of

the pilot episode of the television show “Eli Stone”, in which a judge rules in favour of the MMR/Autism link, as fact. These are just some of the areas which need to be explored in future studies.

A quote by May sums up this project, “The result is that politically-oriented health policy may fail to resonate with an intended audience if it lacks an accompanying explanation that sufficiently relates the information to existing public perceptions” (May 2005: 419). Perhaps the most important thing we can do to ensure good medical communication is to recall that health information must be culturally understood and community based. Unless there is an exchange between health care professionals and the public, good health communication will suffer.



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## **Appendix I**

### **Surveys Distributed and Preliminary Questions Used**

#### **Questionnaire Concerning Vaccines**

Please answer all of the questions with as much detail as possible – take the back of the sheet or extra pages if necessary. All information given in this questionnaire is purely voluntary and you may choose to only answer some of the questions. Your responses may be used in my dissertation or other scholarly papers/presentations.

1. Your Name:
2. Age:
3. Do you have children? If so, what are the ages of your child/children?
4. Home Town/Community/Province/Country:
5. Have you ever heard or experienced any stories about vaccines?
6. How did those stories affect your opinion on vaccines?
7. Did any of the stories you heard affect your decision to vaccinate in any way?
8. Did you consult the internet for information on vaccines? What types of information did you find?
9. Would you be interested in being interviewed on this subject? If so, please provide contact information.

Thank you very much for your time and participation. If you have any questions or concerns, please do not hesitate to contact me, Andrea Kitta. E-mail: [akitta@mun.ca](mailto:akitta@mun.ca)

**Preliminary Interview Questions:**

1. Please state name, place of residence, age or age range, occupation.
2. Do you consent freely to this interview and its recording?
3. Do you have advanced medical knowledge? Please explain.
4. Are you a parent or guardian?
5. Could you please expand on your vaccination story?
6. What was your reaction to this story?
7. How do you feel about media and internet representations of vaccines?
8. Do you believe that people who refuse vaccination are more or less likely to refuse other forms of treatment?
9. Do you use the internet for health information? Do you know others who do so?



## Appendix Two

### Vaccine Ingredients from the website of the Center for Disease Control (CDC)

#### Vaccine Excipient & Media Summary



This section begins with a summary of the excipients included in licensed vaccines in the United States, as of the revision date at the bottom of the page.

Excipients are inactive ingredients of a drug product necessary for production of a finished pharmaceutical formulation.

After the list of excipients is a list of culture media used in the manufacturing process of vaccines licensed in the United States.

Growth media are culture materials used to produce mass quantities of a microorganism anti-body, or other immunologic agent, suitable for further processing into a finished pharmaceutical product.

All reasonable efforts have been made to ensure the accuracy of this information, but manufacturers may change product contents before that information is reflected here.

Excipients Included in US Licensed Vaccines*		
Excipient	Use	Vaccine
Albumin, egg (Ovalbumin)	Growth medium	Rabies ( <i>RabAvert</i> )
Albumin, human serum	Component of growth medium, protein stabilizer	Measles ( <i>Attenuvax</i> ), MMR ( <i>MMR-II</i> ), Mumps ( <i>Mumpsavax</i> ), Rabies ( <i>Imovax</i> ), Rubella ( <i>Meruvax II</i> )
Albumin or serum, bovine	Component of growth medium, protein stabilizer	Hepatitis A ( <i>Havrix</i> , <i>Vaqta</i> ), Measles ( <i>Attenuvax</i> ), MMR ( <i>MMR-II</i> ), Mumps ( <i>Mumpsavax</i> ), Rabies ( <i>Imovax</i> , <i>RabAvert</i> ), Rubella ( <i>Meruvax II</i> ), Vaccinia ( <i>Dryvax</i> ), Varicella ( <i>Varivax</i> )
Aluminum hydroxide	Adjuvant	Anthrax ( <i>BioThrax</i> ), DTaP ( <i>Infanrix</i> ), DTaP-Hep B-IPV ( <i>Pediarix</i> ), DT (Massachusetts), Td (Massachusetts), Hepatitis A ( <i>Havrix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Hepatitis B ( <i>Engerix-B</i> ), Tdap ( <i>Boostrix</i> )
Aluminum phosphate	Adjuvant	DTaP ( <i>Daptacel</i> ), Td (Aventis Pasteur, Massachusetts), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Pneumococcal ( <i>Prenmar</i> ), Rabies ( <i>BioRab</i> )
Aluminum potassium sulfate	Adjuvant	DTaP ( <i>Daptacel</i> , <i>Tripedia</i> ), DTaP-Hib ( <i>TriHibit</i> ), DT (Aventis Pasteur)
Amino acids	Component of growth medium	Anthrax ( <i>BioThrax</i> ), Hepatitis A ( <i>Havrix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Td (Aventis Pasteur), Typhoid oral ( <i>Vivotif</i> )
Ammonium sulfate	Protein fractionation	DTaP-Hib ( <i>TriHibit</i> ), Hib ( <i>Acr-HIB</i> )
Amphotericin B	Antibacterial	Rabies ( <i>RabAvert</i> )
Ascorbic acid	Antioxidant	Typhoid oral ( <i>Vivotif</i> )
Bactopeptone	Component of growth medium	Influenza (varies seasonally)

## Vaccine Excipient & Media Summary

Excipients Included In US Licensed Vaccines*		
Excipient	Use	Vaccine
Beta-propiolactone	Viral inactivator	Influenza ( <i>Fluvirin</i> ), Rabies ( <i>Imovax</i> , <i>RabAvert</i> )
Benzethonium chloride	Preservative	Anthrax ( <i>BioThrax</i> )
Brilliant green	Dye	Vaccinia ( <i>Dryvax-historic</i> )
Chlortetracycline	Antibacterial	Rabies ( <i>RabAvert</i> ), Vaccinia ( <i>Dryvax</i> )
DNA	Manufacturing residue	Hepatitis A ( <i>Vaqta</i> )
Ethylenediamine-tetraacetic acid sodium (EDTA)	Preservative	Rabies ( <i>RabAvert</i> ), Varicella ( <i>Varivax</i> )
Egg protein	Manufacturing residue	Influenza (all brands), Yellow fever ( <i>YF-Vax</i> )
Formaldehyde, formalin	Antimicrobial, preservative	Anthrax ( <i>BioThrax</i> ), DTaP (all brands), DTaP-Hep B-IPV ( <i>Pediarix</i> ), DTaP-Hib ( <i>TriHIBit</i> ), DT (all brands), Td (all brands), Hepatitis A ( <i>Havrix</i> , <i>Vaqta</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Hib ( <i>ActHIB</i> ), Hib-Hepatitis B ( <i>Comvax</i> ), Influenza ( <i>Fluzone</i> ), Japanese encephalitis ( <i>JE-Vax</i> ), Poliovirus inactivated ( <i>Ipol</i> ), Tdap ( <i>Boostrix</i> )
Gelatin	Stabilizer in freeze-drying, solvent	DTaP ( <i>Tripedia</i> ), DTaP-Hib ( <i>TriHIBit</i> ), Influenza ( <i>Fluzone</i> ), Japanese encephalitis ( <i>JE-Vax</i> ), Measles ( <i>Attenuvax</i> ), Mumps ( <i>Mumpsavax</i> ), Rubella ( <i>Meruvax II</i> ), MMR ( <i>MMR-II</i> ), Rabies ( <i>RabAvert</i> ), Typhoid oral ( <i>Vivotif</i> ), Varicella ( <i>Varivax</i> ), Yellow fever ( <i>YF-Vax</i> )
Gentamicin	Antibacterial	Influenza ( <i>FluMist</i> )
Glutaraldehyde	Toxin detoxifier	DTaP ( <i>Infanrix</i> ), DTaP-Hep B-IPV ( <i>Pediarix</i> ), Tdap ( <i>Boostrix</i> )
Glycerin	Solvent	Vaccinia ( <i>DryVax</i> )
Glycine	Protein stabilizer	DT (most brands), Td (most brands)
Hydrochloric acid	Adjust pH	DTaP (most brands), DT (most brands)
Lactose	Stabilizer in freeze-drying, filling	BCG ( <i>Tice</i> ), Hib (some packages), Meningococcal ( <i>Menomune</i> ), Typhoid oral ( <i>Vivotif</i> )
Magnesium stearate	Lubricant for capsule filling	Typhoid oral ( <i>Vivotif</i> )
Monosodium glutamate	Stabilizer	Influenza ( <i>FluMist</i> ), Varicella ( <i>Varivax</i> )
Mouse serum protein	Manufacturing residue	Japanese encephalitis ( <i>JE-Vax</i> )



## Vaccine Excipient & Media Summary

Excipients Included in US Licensed Vaccines*		
Excipient	Use	Vaccine
MRC-5 cellular protein	Manufacturing residue	Hepatitis A ( <i>Havrix</i> , <i>Vaqta</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Rabies ( <i>Imovax</i> ), Poliovirus inactivated ( <i>Poliovax</i> ), Varicella ( <i>Varivax</i> )
Neomycin	Antibacterial	DTaP-Hep B-IPV ( <i>Pediarix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Influenza ( <i>Fluvirin</i> ), Measles ( <i>Attenuvax</i> ), Mumps ( <i>Mumpsavax</i> ), Rubella ( <i>Meruvax II</i> ), MMR ( <i>MMR-II</i> ), Poliovirus inactivated ( <i>Ipol</i> ), Rabies ( <i>Imovax</i> , <i>RabAvert</i> ), Vaccinia ( <i>DryVax</i> ), Varicella ( <i>Varivax</i> )
Phenol	Preservative, antibacterial	Pneumococcal ( <i>Pneumovax-23</i> ), Typhoid inactivated ( <i>Typhim Vi</i> ) Vaccinia ( <i>Dryvax</i> )
Phenol red (phenolsulfonphthalein)	pH indicator, dye	Rabies ( <i>Imovax</i> )
2-Phenoxyethanol	Preservative	DTaP ( <i>Infanrix</i> , <i>Daptacel</i> ), DTaP-Hep B-IPV ( <i>Pediarix</i> ), Hepatitis A ( <i>Havrix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Poliovirus inactivated ( <i>Ipol</i> ), Td (Aventis Pasteur)
Phosphate buffers (eg, disodium, monosodium, potassium, sodium dihydrogenphosphate)	Adjust pH	DTaP (most brands), DT (most brands), Hib ( <i>Act-Hib</i> ), Hepatitis A ( <i>Havrix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Hepatitis B ( <i>Engerix-B</i> ), Influenza ( <i>FluMist</i> ), Measles ( <i>Attenuvax</i> ), Meningococcal ( <i>Menactra</i> ), Mumps ( <i>Mumpsavax</i> ), Poliovirus inactivated ( <i>Ipol</i> ), Rabies ( <i>BioRab</i> ), Rubella ( <i>Meruvax II</i> ), MMR ( <i>MMR-II</i> ), Typhoid inactivated ( <i>Typhim Vi</i> ), Varicella ( <i>Varivax</i> )
Polydimethylsiloxane	Antifoaming agent	Typhoid inactivated ( <i>Typhim Vi</i> )
Polyethylene glycol p-isooctylphenyl ether (Triton X-100)	Nonionic surfactant (viral inactivation)	Influenza ( <i>Fluzone</i> )
Polymyxin B	Antibacterial	DTaP-Hep B-IPV ( <i>Pediarix</i> ), Influenza ( <i>Fluvirin</i> ), Poliovirus inactivated ( <i>Ipol</i> ), Vaccinia ( <i>Dryvax</i> )
Polyoxyethylene9-10 nonyl phenol (Triton N-101, octoxynol 9)	Nonionic surfactant (viral inactivation)	Influenza ( <i>Fluvirin</i> )
Polysorbate 20	Surfactant	Hepatitis A ( <i>Havrix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> )
Polysorbate 80	Surfactant	DTaP ( <i>Infanrix</i> , <i>Tripedia</i> ), DTaP-Hep B-IPV ( <i>Pediarix</i> ), DTaP-Hib ( <i>TriHIBit</i> ), Tdap ( <i>Boostrix</i> )
Potassium glutamate	Stabilizer	Rabies ( <i>RabAvert</i> )

## Vaccine Excipient & Media Summary

Excipients Included in US Licensed Vaccines*		
Excipient	Use	Vaccine
Sodium acetate	Adjust pH	DT (some brands), Td (some brands)
Sodium borate	Adjust pH	Hepatitis A ( <i>Vaqta</i> ), Hib-Hepatitis B ( <i>Comvax</i> )
Sodium chloride	Adjust tonicity	Most vaccines, including Anthrax, BCG, Measles, Meningococcal ( <i>Menactra</i> ), Mumps, MMR, Pneumococcal, Polio inactivated, Rabies, Rubella, Typhoid inactivated, Varicella, Yellow fever, Tdap ( <i>Boostrix</i> )
Sodium hydroxide	Adjust pH	DT (most brands), Td (most brands)
Sorbitol	Stabilizer, solvent	Measles ( <i>Attenuvax</i> ), Mumps ( <i>Mumps</i> ), Rubella ( <i>Meruvax II</i> ), MMR ( <i>MMR-II</i> ), Yellow fever ( <i>YF-Vax</i> )
Streptomycin	Antibacterial	Poliovirus inactivated ( <i>Ipol</i> ), Vaccinia ( <i>Dryvax</i> )
Sucrose	Stabilizer	DTaP-Hib ( <i>TriHibit</i> ), Hib ( <i>Act-HIB</i> ), Influenza ( <i>FluMist</i> ), Measles ( <i>Attenuvax</i> ), Mumps ( <i>Mumps</i> ), MMR ( <i>MMR-II</i> ), Typhoid oral ( <i>Vivotif</i> ), Varicella ( <i>Varivax</i> )
Thimerosal	Preservative in some multi-dose containers (see package labeling for precise content)	DTaP (some multidose containers), DTaP-Hib ( <i>TriHibit</i> ), DT (some multidose containers), Td (some multidose containers), Hepatitis B (some multidose containers), Hib (some multidose containers), Influenza (some multidose containers), Japanese encephalitis ( <i>JE-Vax</i> ), Meningococcal ( <i>Menomune</i> ), Rabies ( <i>Bio-Rab</i> ). Some single-dose containers contain trace amounts of thimerosal from the production process, but substantially lower concentrations than if used as a preservative. Consult product monographs and labeling for details.
Urea	Stabilizer	Varicella vaccine ( <i>Varivax</i> , refrigerator stable)
Vitamins unspecified	Component of growth medium	Anthrax ( <i>BioThrax</i> ), Rabies ( <i>Imovax</i> ), Td (Aventis Pasteur)
Yeast protein	Component of growth medium	DTaP-Heb B-IPV ( <i>Pediarix</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Hepatitis B ( <i>Engerix-B</i> , <i>Recombivax-HB</i> ), Hib ( <i>HibTiter</i> ), Hib-Hepatitis B ( <i>Comvax</i> )

\* Proprietary names appear in italics.



## Vaccine Excipient & Media Summary

Vaccine-Production Media*	
Vaccine Culture Media	Vaccine(s)
Bovine protein	DTaP-Hep B-IPV (poliovirus component, <i>Pediarix</i> ), Pneumococcal ( <i>Pneumovax-23</i> ), Typhoid oral ( <i>Vivotif</i> )
Calf skin	Vaccinia ( <i>Dryvax</i> )
Chick embryo fibroblast tissue culture	Measles ( <i>Attenuvax</i> ), Mumps ( <i>Mumpsavax</i> ), combination vaccines containing them, Rabies ( <i>RabAvert</i> )
Chick kidney cells	Influenza (master viruses for <i>FluMist</i> )
Chicken embryo (fertilized egg)	Influenza (all brands), Yellow fever ( <i>YF-Vax</i> )
Cohen-Wheeler, modified (pertussis components)	DTaP (alternate is Stainer-Scholte media)
Fenton media containing bovine casein	Tdap ( <i>Boostrix</i> )
Human diploid tissue culture, MRC-5	Hepatitis A ( <i>Havrix</i> , <i>Vaqta</i> ), Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Poliovirus inactivated ( <i>Poliovax</i> ), Rabies ( <i>Imovax</i> ), Varicella ( <i>Varivax</i> )
Human diploid tissue culture, WI-38	Rubella ( <i>Meruvax II</i> ), combination vaccines containing it, Varicella ( <i>Varivax</i> )
Lathan medium derived from bovine casein	DTaP ( <i>Infanrix</i> , tetanus component), DTaP-Hep B-IPV ( <i>Pediarix</i> ), Tdap ( <i>Boostrix</i> )
Linggoud-Fenton medium containing bovine extract	DTaP ( <i>Infanrix</i> diphtheria component), DTaP-Hep B-IPV ( <i>Pediarix</i> ), Tdap ( <i>Boostrix</i> )
Monkey kidney tissue culture, Vero (Vervet or African green monkeys)	DTaP-Hep B-IPV (poliovirus component, <i>Pediarix</i> ), Poliovirus inactivated ( <i>Ipol</i> )
Mouse brain	Japanese encephalitis ( <i>JE-Vax</i> )
Mueller-Hinton agar medium	Meningococcal conjugate ( <i>Menactra</i> )
Mueller-Miller medium	Diphtheria and tetanus vaccines (most brands), meningococcal conjugate ( <i>Menactra</i> )
Rhesus fetal lung tissue culture	Rabies ( <i>BioRab</i> )
Stainer-Scholte medium	DTaP ( <i>Daptacel</i> , <i>Infanrix</i> , pertussis component), DTaP-Hep B-IPV ( <i>Pediarix</i> ), Tdap ( <i>Boostrix</i> )
Soy peptone broth	Pneumococcal ( <i>Prevnar</i> )
Synthetic/semi-synthetic	Anthrax ( <i>BioThrax</i> ), BCG ( <i>Tice</i> ), DT (all brands), Td (all brands), Hib (all brands), Meningococcal ( <i>Menomune</i> ), Pneumococcal ( <i>Pneumovax-23</i> ), Typhoid inactivated ( <i>Typhim Vi</i> )
Watson-Scherp medium	Meningococcal conjugate ( <i>Menactra</i> )
Yeast or yeast extract (typically <i>Saccharomyces cerevisiae</i> )	Hepatitis A-Hepatitis B ( <i>Twinrix</i> ), Hepatitis B ( <i>Engerix-B</i> , <i>Recombivax-HB</i> ), Hib ( <i>HibTiter</i> ), Hib-Hepatitis B ( <i>Comvax</i> ), Medium for growing <i>Corynebacterium diphtheriae</i> strain C7 (b197) to obtain CRM <sub>197</sub> protein for conjugation to polysaccharides ( <i>HibTiter</i> , <i>Prevnar</i> ).

\* Proprietary names appear in italics.

## Vaccine Excipient & Media Summary

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<http://www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/B/excipient-table-1.pdf>











