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# SHOTS, EVERYBODY?: BRITISH ANTI-SMALLPOX VACCINATION AND THE DEVELOPMENT OF MULTIFACETED ANTI-VACCINE RHETORIC ON INTERNET PARENTING FORUMS

by

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### SUBMITTED TO SCRIPPS COLLEGE IN PARTIAL FULFILLMENT OF THE DEGREE OF BACHELOR OF ARTS

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#### Introduction

The Internet serves much of the population as an easy way to learn about almost any topic, including health information. Approximately eighty percent of Internet users search for health information online, and surveys indicate that the Internet now rivals physicians as the most common source of health advice. The Internet is also a place where information can be spread quickly and easily. Information is available in many venues, including user-generated Internet forums. Parenting forums are good places for information to spread quickly because of highly dedicated readership and personal connections made on the forums between parents. However, due to the fact that the information on these forums is not monitored or validated by anyone, information on forums can often be changed or distorted by personal opinions. I am interested in how information about vaccines spreads on parenting forums, in particular, arguments that advocate against vaccination. Although substantial evidence exists that vaccines are safe and effective at reducing the incidence of diseases like pertussis, measles and cervical cancer, there is also evidence that anti-vaccine arguments on the Internet are effective in convincing people not to vaccinate.

Advocates for vaccination, such as the Centers for Disease Control and Prevention, state that vaccination is an important public health measure that efficiently prevents harmful illnesses from affecting large populations. Vaccination is most effective when vaccines are administered to an entire population, due to the concept of herd

<sup>1</sup> Anna Kata, "Anti-vaccine activists, Web 2.0, and the postmodern paradigm-An overview of tactics and tropes used online by the anti-vaccination movement," *Vaccine* 30 (2012): 3778-3789, accessed 17 October, 2013. Doi: 10.1016/j.vaccine.2011.11.112

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immunity.<sup>2</sup> Herd immunity, or community immunity, decreases the opportunity for an outbreak to occur because there are fewer people who are susceptible to the disease of interest. Mass vaccination is important because it can protect those who are not eligible for vaccines, such as infants, pregnant women and immunocompromised individuals, because the disease is contained and harder to spread. Thanks to vaccines, the occurrence of all vaccine preventable diseases has declined significantly compared to before the vaccines were available. For example, there were an average of 503,282 annual reported cases of measles in the United States before a vaccine was available, and in 2007 that number had shrunk to 23, representing a 99.9% decline. For Diphtheria, there were 175,855 average annual cases in the United States before the vaccine was available, and there were 0 reported cases in 2007.<sup>3</sup>

We are all subject to the potentially biased information that is available on the Internet, as it is extensive, sometimes hard to recognize and often difficult to ignore. In many cases exposure to these sources can influence our health and lifestyle decisions. It is important to know how this information can be influential, and ways to recognize these sources so that we can be mindful of avoiding information posing as scientific in favor of claims that are accepted in the scientific community. Recognizing rhetorical strategies that are used to advocate against vaccination is important in order to think critically about information on the Internet and ultimately make informed choices about health.

In *The Rhetoric of Science*, Alan Gross explains how scientists are engaged in the process of persuasion. Gross explains that rhetoric is an essential component of social

<sup>2</sup> Vaccines.gov, "Community Immunity: 'Herd Immunity,'" last Modified October 16, 2013, http://www.vaccines.gov/basics/protection/.

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<sup>&</sup>lt;sup>3</sup> Business Insider, "Two charts that should make anti-vaccine people ashamed," last modified July 15 2013, http://www.businessinsider.com/jenny-mccarthy-the-view-the-benefits-of-vaccines-2013-7.

change, so rhetorical analysis is indispensible when it comes to analyzing science in society. I am interested in the ways that arguments against vaccination are made on Internet forums. In this paper I will begin by offering a history of the anti-vaccination movement in mid 19th century to early 20th century Britain and examine the groups that took up anti-vaccination as a cause. I will demonstrate that anti-smallpox vaccination proponents, who came from several pre-established dissenting groups, believed that compulsory vaccination impinged upon their individual freedoms to make decisions for themselves and their families. I will then show how the Internet, particularly parenting forums, has facilitated the spread of anti-vaccine sentiment, focusing on the diphtheria, pertussis and tetanus (DPT) vaccine, measles, mumps and rubella (MMR) vaccine, and the human papilloma virus (HPV) vaccine. In each section I will explore the rhetorical strategies used in anti-vaccine propaganda on the Internet, which aim to convince people that they should not vaccinate because vaccines are unsafe, unnecessary or ineffective, and compare these tactics with those of the Victorian anti-smallpox vaccination movement.

Scholars in the fields of history, anthropology, sociology and communication motivate my work on anti-vaccine arguments. Nadja Durbach, Professor of History at University of Utah, demonstrates that the debate against smallpox vaccination in Victorian Britain in the era of the Compulsory Vaccination Act, from 1853 until 1907, was complex. This movement was central to the social and political climate in nineteenth- and early-twentieth-century England. At this time, vaccination against smallpox was no small feat. The process involved cutting lines into the flesh and rubbing

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<sup>&</sup>lt;sup>4</sup> Alan G Gross, *The Rhetoric of Science* (Cambridge: Harvard University Press, 1990),

vaccine matter, or lymph into the cuts. The possibility of infection was high, and to many, the disfiguring procedure seemed to do more harm than good. It was also in conflict with medical doctrines that stressed the importance of bodily purity, since vaccination contaminated the blood and disrupted the essential flow of the blood through the body. Durbach argues that the topic of who controlled the body was a highly charged political issue because pro- and anti-vaccinators had different ideas of how to best safeguard people from disease. In addition to the unpleasant vaccination process and its conflict with the medical beliefs of the time, there were also other factors that played into the anti-vaccine debate. The issue of increasing state control was troubling to many people, who believed that they had the right to decide what was done to their bodies. Anti-vaccinators were also associated with many other dissenting movements, like religious dissenters, feminists, heterodox medical groups and labor groups. These groups took up anti-vaccination as a cause over arguments that individuals should be free to make decisions for themselves and their families. Anti-vaccine information was communicated through pamphlets and newsletters that were widely distributed and contained graphic images of the effects of vaccination on children. There were also anecdotes shared in these publications about the complications that follow vaccination. Overall, Durbach asserts that the anti-vaccine movement was essential to understanding the political atmosphere of the British state in the nineteenth- and early-twentiethcentury.

Anna Kata, an anthropologist at McMaster University, studies the tactics and tropes used online by the anti-vaccination movement. She argues that anti-vaccine websites can influence whether or not people choose to vaccinate themselves or their

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<sup>&</sup>lt;sup>5</sup> Nadja Durbach, *Bodily Matters: The Anti-Vaccination Movement in England, 1853-1907.* (Durham: Duke University Press, 2005), 3.

children, and that the techniques used by the movement take advantage of the current postmodern medical paradigm of patient empowerment.<sup>6</sup> According to Kata, the Internet is used to spread uncertainty, fear and doubt about vaccines, through rhetorical strategies such as attacking the opposition, censoring dissenting opinions, proposing alternative theories about vaccine danger when other theories are disproven, rejecting science that fails to support anti-vaccine positions and endorsing studies that promote anti-vaccine agendas.<sup>7</sup> Kata is motivated by the idea that recognizing anti-vaccine rhetorical strategies can help avoid them in the future.

A study conducted by Nan and Madden, a professor and graduate student at the University of Maryland Department of Communication, investigated how information on blogs affected student opinions about the HPV vaccine. College students looked at three mock blogs, one neutral, one favorable and one unfavorable toward HPV vaccination, and the results showed that the unfavorable blog resulted in significantly lower perceived vaccine efficacy than the positive blog compared with the control. This demonstrates that the influence of these online resources affects the public's perceptions of vaccination, and shows that the blog viewers are susceptible to unfavorable vaccine information on the web. Nan and Madden also showed that there was a difference in the strategies used for conveying information on the different types of blogs. For example, while favorable blogs shared statistical summaries about the vaccine, the unfavorable blog shared individualized stories about the danger of the vaccine. According to Taylor, Professor of psychology at UCLA, a phenomenon called negativity bias causes negative information

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<sup>&</sup>lt;sup>6</sup> Kata, Anna, "Anti-vaccine activists," 3784.

<sup>&</sup>lt;sup>7</sup> Kata, Anna, "Anti-vaccine activists," 3784.

<sup>&</sup>lt;sup>8</sup> Nan, Xiaoli, "HPV Information on the Blogosphere," 829.

<sup>&</sup>lt;sup>9</sup> Nan, Xiaoli, "HPV Information on the Blogosphere," 829.

<sup>&</sup>lt;sup>10</sup> Nan, Xiaoli, "HPV Information on the Blogosphere," 835.

to have a greater psychological impact than positive information, which would make the information coming from the unfavorable blogs inherently more powerful. This research implies that individuals who are looking for vaccine information on the Internet and doing a thorough search could be more impacted by the anti-vaccine information from sources that are critical of vaccination than of sources that advocate vaccination, like the Centers for Disease Control and Prevention.

Harry Collins, a sociologist of science at Cardiff University and Trevor Pinch,
Professor of Science & Technology studies at Cornell University (2005), argue that
although science can be wrong, the opposite view is not always right. Today, health is
highly politicized, with factors like insurance companies profiting from high-cost
medicine and complicating the relationship that people have with their health and health
care providers. With respect to vaccination, the authors do not conclude that parents
should blindly follow doctors' orders with respect to vaccination. They explain that these
doctors are a part of the medical establishment and can be authoritarian, failing to explain
their cases to anxious parents. From the other side, they also do not suggest that parents
should automatically react against authoritarian doctors just because of this authoritarian
behavior. According to Collins and Pinch, the public needs "to know how to weigh antiestablishment scientific opinions and discriminate between kinds of scientists. To
understand this, they need to know, not more science, but more *about* science."
In order
to do this, the public must understand that there is a difference between information and
expertise, and not mistake the gathering of information for the acquisition of expertise.

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<sup>13</sup> Collins, *Dr. Golem*, 202.



<sup>&</sup>lt;sup>11</sup> Shelley E Taylor, "Asymmetrical effects of positive and negative events: the mobilization-minimization hypothesis," *Psychological bulletin* 110, 1 (1991): 67.

<sup>&</sup>lt;sup>12</sup> Harry Collins and Trevor Pinch, *Dr. Golem, How to Think About Medicine*, (Chicago: University of Chicago Press, 2005), 202.

Information and knowledge are just one part of expertise—expertise involves learning from experience. Even though science is full of uncertainties, it is impractical to take precautions in respect of everything that has not been proven to be completely safe. Rather, Collins and Pinch explain that "the pragmatic path has to be illuminated by what science we have." With respect to vaccinations, there are an infinite number of worries that can be associated with the procedure, as there are an infinite amount of problems that can be imagined to occur after vaccination. Because vaccines are found to be safe at the population level, it is difficult to prove whether or not there is a danger to a specific individual. Danger to an individual may become obvious in rare circumstances due to significant variability and heterogeneity of genetic background of vaccinated subjects. This is responsible for extreme cases of unpredictable adverse reactions to occur, and these rare cases feed anti-vaccine argumentation. Unless there is some reason for suspicion in addition to this, it is impractical to worry about every possible side effect of vaccines, and more important to educate yourself on how to understand scientific arguments.

In order to expand upon the work of these scholars, I will explore how the antivaccine movement has changed from anti-smallpox vaccination in 19<sup>th</sup> and early 20<sup>th</sup> century Britain to the current anti-vaccine movements occurring on Internet forums. I argue that the anti-vaccination movement of today still has links to the 19<sup>th</sup> century ideas of individual freedom to choose whether or not to vaccinate. In addition, I will explain that in the 19<sup>th</sup> century, a sense of social trust existed due to the more visible risks inherent in vaccination that was further supported by pre-existing dissenting groups. These factors assured that anecdotes and gruesome images of the harm done by vaccines

<sup>14</sup> Collins, *Dr. Golem*, 214.

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were sufficient to make the case against vaccination. Today, however, this social trust is missing. Anti-vaccine proponents argue that vaccines can cause effects like autism and other behavioral changes that cannot be captured in a photograph. The lack of visual proof for harmful effects of vaccination makes a multifaceted approach to anti-vaccine arguments necessary. These arguments include questioning the safety, efficacy and necessity of vaccines, and appeal to science in different ways.

In exploring the anti-vaccine movement on Internet forums, I mainly turn to two different parenting forums with large audiences. The first is mothering.com, which is the premier online community for parents interested in natural family living. <sup>15</sup> Mothering started over thirty years ago as a US based magazine that expanded to a website in 1995. The site contains philosophical inspiration and advice on how to live naturally with a family, and addresses lifestyle, medical, personal and environmental issues. It has a highly active forum, with threads ranging from vaccination and homebirth to homeopathy and organic foods. I believe that the vaccination forums are especially interesting on mothering.com, as some of the forums on this site specifically exclude those who advocate for mandatory vaccination from posting on the forum. The guidelines of the "I'm Not Vaccinating" forum, for example, explicitly state that members who are vaccinating their children should not post on the forum to debate with non-vaccinators or start arguments about the accuracy of their claims. 16 However, the forum is visible to any of the 1.5 million unique viewers who visit the site each month. According to mothering.com's forum guidelines, this exclusion is in place in order to foster discussion of issues to lead to an informed decision. There are also threads that fall under other

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<sup>15</sup> mothering.com, "About Us," last modified 2014.

<sup>&</sup>lt;sup>16</sup> "Vaccination Forum Guidelines," accessed December 1, 2013. http://www.mothering.com/community/a/vaccination-forum-guidelines

categories, such as "Vaccinations Debate" and "Selective and Delayed Vaccination," which are more inclusive towards diverse opinions about vaccinations, and can similarly be viewed by anyone who visits the site.

The other parenting forum where I gathered the bulk of my information is mumsnet.com. Mumsnet.com is the largest parent network in the UK, and has over 10 million visits per month. My choice to include site that is not based in the United States was to show the pervasiveness of anti-vaccine sentiment. Conceived in 2000, the site aims "to make parents' lives easier by pooling knowledge, advice and support." Like mothering.com, Mumsnet also has active forums, with topics that are similar to mothering.com. However, the focus of mumsnet is not explicitly natural living, and there are no forums that explicitly exclude certain opinions from the threads like mothering.com does. Rather, all of the conversations about vaccinations are held within one common topic of "Vaccinations."

In order to do the primary research on these forums, I started with the mothering.com "I'm Not Vaccinating" and "Vaccinations Debate" threads in order to find the most impassioned anti-vaccinating parents. Reading over the forums, I mainly focused on threads with more than 15 posts, to make sure that I was reading forums that were actually active and generating discussion among parents. On Mumsnet, I similarly looked for threads with multiple posts. Mumsnet is helpful in that it sorts out "zombie threads" that are inactive or have few responses. On both forums, I searched keywords like "DPT," "MMR," and "Gardasil" in combination with other words like "danger", "reaction," "autism" and "bad." I read through posts that were primarily from 2013, but dated back to 2007 in some cases. Specifically with regards to HPV vaccination, where

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<sup>&</sup>lt;sup>17</sup> Mumsnet.com, "About us," last modified March 26 2014

forum posters point more frequently to outside information sources, I analyze the arguments made on Sanevax.org, an anti-vaccination website that has primarily anti-HPV vaccine information.

Before delving into the anti-vaccine arguments on the parenting forums, I will give the historical context of the anti-vaccine movement in mid 19<sup>th</sup> and early 20<sup>th</sup> century Britain. This is significant because it shows that anti-vaccine arguments are not a 21<sup>st</sup> century issue, but rather have existed since long before modern vaccination came into existence. I will demonstrate that in the British anti-smallpox vaccination movement, the main arguments against vaccination concerned the freedom of individuals to make decisions about their own bodies. Vaccination was not only dangerous, but also went against the principles of many widely held beliefs about health. In future chapters, I will show anti-vaccine rhetoric has evolved to encompass more than just appeals to danger, and now involves arguments about necessity and efficacy of vaccines.

### The Anti-Vaccine Movement in Victorian Britain

Nadja Durbach (2005), gives an illustration of the gender, class, social and political resistance to compulsory vaccination in mid 19<sup>th</sup> to early 20<sup>th</sup> century Britain. Durbach argues that the movement against vaccination fought against the medical orthodoxy and was also intimately entwined with other dissenting movements of the time, such as religious dissenters, feminists, heterodox medical groups and labor groups. These movements were tied to the anti-vaccination movement because of the perceived

relationship between physical and spiritual health. Before delving into these other dissenting movements, it is important to understand the history of compulsory vaccination to recognize why other dissenting movements took up the danger of vaccines as one of their causes.

Vaccination against smallpox began in the 1790s when Edward Jenner, an English surgeon, discovered that inoculation with cowpox allowed humans to ward off smallpox without the disease being spread from person to person. <sup>18</sup> Compulsory vaccination in England began with the Compulsory Vaccination Act of 1853, which mandated that all British infants be vaccinated against smallpox. This act marked a shift in public health from simply state-sponsored sanitation projects to an era of medicalized public health, where medical professionals were making decisions as part of the parliament.<sup>19</sup> The vaccination process itself in Victorian Britain was different than vaccination today. There was no use of needles—vaccinators would use a lancet, a small, broad surgical knife, to cut lines into the flesh of the unvaccinated in a scored pattern. Once these incisions were made, the vaccinator would smear vaccine matter, or lymph, into the wound. This process was both painful and unsanitary, often leaving those who were vaccinated with infections and permanent scarring. 20 However, Durbach argues that the real opposition to compulsory vaccination at this time was not solely based on the disfiguring side effects of the process. Instead, she suggests that anti-vaccination grew "out of well-established traditions of medical dissent that pitted the people against the alliance of orthodox

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<sup>&</sup>lt;sup>18</sup> Durbach, *Bodily Matters*, 20 Durbach, *Bodily Matters*, 18.

<sup>&</sup>lt;sup>20</sup> Durbach, *Bodily Matters*, 3.

medicine and a bureaucratic state."<sup>21</sup> This is important because it shows that underlying dissenting groups gave force to the anti-vaccination movement.

There were explicit class differences in the kinds of concerns expressed about vaccination. The working class and poor were concerned with how the policies explicitly targeted the physical human body and focused on the oppressive actions of the government against individuals. This sentiment was expressed in the *Vaccination Inquirer*, the official periodical of the National Anti-Vaccination League, which was in print from 1874-1971. In 1903, a correspondent to this publication stated, "It is not a question of vaccination, it is a question of a working man's right to call his body his own."22 The middle class was less focused on the desecration of the physical body and more concerned about liberal ideas of individual rights and personal freedom.<sup>23</sup> Durbach argues that this is because vaccination laws implicitly targeted the working class and implementation of these laws was discriminatory against them. Since employers could demand that their employees were vaccinated in order to keep their jobs, the bias against those who didn't want to vaccinate was much more obvious. Labor movements mobilized the working class against discrimination from their employers. This was necessary because the working-class was under more scrutiny from authorities than other social classes because these individuals were stereotyped as dirty, "conduits of disease." 24 Vaccine officials openly singled out the working class due to social stigmas against these groups, and they bore the impact of compulsory clauses much more so than the middle class. Working class individuals were both subject to vaccination against their will and

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<sup>&</sup>lt;sup>21</sup> Durbach, *Bodily Matters*, 36.

<sup>&</sup>lt;sup>22</sup> Vaccination Inquirer, in Durbach, Bodily Matters, 109.

<sup>&</sup>lt;sup>23</sup> Durbach, *Bodily Matters*, 85.

<sup>&</sup>lt;sup>24</sup> Nadja Durbach, "They Might as Well Brand Us': Working-Class Resistance to Compulsory Vaccination in Victorian England," Social History of Medicine 13: 54.

prison time because of their inability to pay the fines associated with vaccine resistance.<sup>25</sup> Interestingly, middle-class dissenters defended the individual rights of the working-class. They created a discourse that emphasized the vulnerability of the infant at the hands of the government. However, the middle class dissenters failed to understand and address the concern of the working class resistance because their social class made their adult bodies invulnerable to the compulsory clause, since vaccine enforcers specifically targeted the bodies of lower social classes by forcing vaccination upon them.<sup>26</sup> Regardless, there was a shared discourse among both the middle and working class of undue government control of their individual freedoms.

There are several main patterns to the dissenting groups that adopted antivaccination as an issue during this time. The first of these was working and lower-middle class individuals who had a culture of using alternative medical treatments rather than consulting allopathic physicians. It was common for working- and lower-middle class citizens to prefer unorthodox medicine, which included medical botany, hydropathy, hygienanism and other self-healing techniques.<sup>27</sup> Part of the goal of alternative medicine was to make individuals independent of their caregivers and instead, make medical treatment self-administered. This strategy led working- and lower-class individuals to align with these treatments since it allowed them to be more independent from bodily control, which was appealing in light of preference for independence from the state.

These techniques were all different, but alike in that they were, as Durbach argues, "consciously constructed...in belligerent opposition to orthodox doctors," and treated the

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<sup>&</sup>lt;sup>25</sup> Durbach, 'They Might as Well Brand Us,' 53.

<sup>&</sup>lt;sup>26</sup> Durbach, *Bodily Matters*, 90.

<sup>&</sup>lt;sup>27</sup> Durbach, *Bodily Matters*, 25-26.

body as a whole system that needed to be balanced.<sup>28</sup> The language used in alternative medicine used generalized theories of disease that were easy to understand and therefore available to everyone. The practitioners in these heterodox medical sects sought the participation of the patient, and also claimed that orthodox medicine, as Durbach explains, "was a tyrannical system of state-sanctioned interference with the lives and health of an oppressed people."<sup>29</sup> Practitioners of alternative medicine wanted the government to allow citizens to make their own decisions about medicine, and were against regulation of the medical industry. Regulation, they feared, would put an end to their profitable trade in medicines." These alternative medical doctrines were also alike in the sense that they looked for cures based in the "healing powers of nature in an effort to contrast gentle herbs with damaging minerals" that were used in medical allopathic medicine.<sup>31</sup> To the heterodox practitioners, medicine was a healing art, and regular doctors were overly concerned with death and performing autopsies rather than curing the sick.<sup>32</sup> Despite differences in curing styles and techniques, the issue of anti-vaccination brought alternative medical communities together around a single issue and brought a focus to the culture of medical dissent.

Heterodox medical practitioners argued against vaccination with the idea that vaccination was both dangerous and unnecessary. The notion of self-care that was so important in the alternative medical community contended that keeping the body clean, eating wholesome foods and breathing fresh air would ensure health and keep smallpox

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<sup>&</sup>lt;sup>28</sup> Durbach, *Bodily Matters*, 27.

<sup>&</sup>lt;sup>29</sup> Durbach, *Bodily Matters*, 27-28.

<sup>&</sup>lt;sup>30</sup> Durbach, *Bodily Matters*, 28.

<sup>&</sup>lt;sup>31</sup> Durbach, *Bodily Matters*, 29.

<sup>&</sup>lt;sup>32</sup> Durbach, *Bodily Matters*, 29.

at bay.<sup>33</sup> For example, one hydropath named John Pickering successfully treated over 100 smallpox victims, many of whom contracted smallpox despite being vaccinated, further showing that vaccination was both dangerous and unnecessary, since it conferred risks and was not completely effective.<sup>34</sup> Practitioners in the alternative medical community shared similar experiences that focused the medical debate against vaccination, especially among members of lower social classes.

During the Victorian era there was a connection between religious and medical freedom. Medical and religious dissent in the mid-nineteenth century provided a pattern and base for other modes of social reform, including anti-vaccination.<sup>35</sup> Anti-vaccinators were often affiliated with religious groups that were not the Church of England, such as Quakers, Baptists, Methodists and Unitarians.<sup>36</sup> Part of the explanation for this was that in its early years, religious figures such as preachers and members of the clergy actually administered vaccinations. Children were not considered "English Christian Children" until they were registered, vaccinated and christened.<sup>37</sup> The strong ties between the church and vaccination were an impetus for alternative religious groups to oppose the practice. Additionally, there was a consensus among medical and religious dissenters at the time that if there was freedom of religion, there should also be freedom from forced medical procedures.<sup>38</sup> Medical and religious dissenters against vaccination likened forced vaccination to a forced religious sacrament, mocking the connection between the church and vaccination by joking that children confused vaccination with baptism or

<sup>&</sup>lt;sup>33</sup> Durbach, *Bodily Matters*, 34.

<sup>&</sup>lt;sup>34</sup> Durbach, *Bodily Matters*, 34.

<sup>&</sup>lt;sup>35</sup> Durbach, *Bodily Matters*, 44.

<sup>&</sup>lt;sup>36</sup> Durbach, *Bodily Matters*, 44. <sup>37</sup> Durbach, *Bodily Matters*, 45.

<sup>&</sup>lt;sup>38</sup> Durbach, *Bodily Matters*, 45.

circumcision.<sup>39</sup> Additionally, medical dissenters conveyed their relationship to orthodox medicine through religious metaphors, claiming that alternative medicine was to orthodox medicine as the non-conforming religions were to the Church of England.<sup>40</sup> As did different medical traditions, different religious groups connected with anti-vaccine sentiment with the shared idea that individual freedom was important.

In addition to the use of religious dissent as a mode of social reform, the Victorian idea of bodily purity also contributed to the anti-vaccination movement. Bodily purity was an important rhetorical device that was used in the anti-vaccination movement in relation to both alternative medicine and religion. Anti-vaccinators considered themselves very vulnerable to contamination and violation, rather than potentially contagious people that would be strengthened by vaccination. There was a widely held concern with purity of the body, and anti-vaccinators believed, "scarifying the flesh and introducing disease into the system... threatened strongly held beliefs regarding bodily integrity." Wounding the skin allowed access to the blood, which was the life force. The rhetoric of bodily purity was connected both to the disfiguring effects of the vaccination procedure as well as the freedom to keep the body safe from vaccines.

Similar to bodily purity's concern with bodily integrity, blood purity was a focus for groups that encouraged ideas like avoiding unclean food and drink.<sup>43</sup> For example, vegetarians, a group that emerged in the 1840s, believed that since all animal products polluted the purity of the body, both ingesting and inserting animal matter via vaccination

<sup>&</sup>lt;sup>39</sup> Durbach, *Bodily Matters*, 45.

<sup>&</sup>lt;sup>40</sup> Durbach, *Bodily Matters*, 44.

<sup>&</sup>lt;sup>41</sup> Durbach, *Bodily Matters*, 113.

<sup>&</sup>lt;sup>42</sup> Durbach, *Bodily Matters*, 120.

<sup>&</sup>lt;sup>43</sup> Durbach, *Bodily Matters*, 123.

into the body were "contaminating." Many alternative medical circles believed that keeping the skin clean, the bowels regular, getting fresh air, exercise and consuming nourishing foods was the key to keeping the blood pure and the individual healthy. Since these medical circles focused on the proper circulation of blood as central to health, and the practice of vaccination intrinsically disrupted the proper flow and purity of the blood, there were fundamental differences in frameworks of health. This difference was another rationalization against smallpox vaccination.

While both anti and pro-vaccine proponents agreed that smallpox was a horrible and "monstrous" disease, anti-vaccinators also maintained that subjecting the body to vaccines would make the people become monstrous themselves. Due to the invasive and unsanitary nature of vaccination in the 19th century, in the transfer of lymph from arm to arm, blood tainted with syphilis could also be passed from person to person. Anti-vaccinators used the idea that the compulsory vaccination laws were part of a national plan to incorporate syphilis into the population in order to instill fear in people who questioned vaccination. Unlike other blood-borne diseases, syphilis carried a moral dimension because of its association with prostitutes and impure sexual relations. This message further connected vaccination with impurity. Thomas Colley, the Archdeacon of the English parish of Natal explained the notion that vaccines were "always tainted by syphilitic conditions that could literally engulf the soul," corrupting its victims both physically and morally. Even though there was a growing body of knowledge that focused on non-sexual transmission of diseases like syphilis, the Victorian anti-vaccination literature "did not sever syphilis from its explicitly sexual connotations," in

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<sup>&</sup>lt;sup>44</sup> Durbach, *Bodily Matters*, 122-123.

<sup>&</sup>lt;sup>45</sup> Durbach, *Bodily Matters*, 121.

<sup>&</sup>lt;sup>46</sup> Durbach, *Bodily Matters*, 132.

<sup>&</sup>lt;sup>47</sup> Durbach, *Bodily Matters*, 133.

order to maintain the idea that vaccination was dirty and impure.<sup>48</sup> The rhetoric of blood purity and the incorporation of diseases with moral dimensions, like syphilis, was an important part of anti-vaccination arguments, including aspects of bodily freedom and cleanliness into the justification.

The purity of blood and the body is just one facet of the resistance towards compulsory vaccination. Another important actively dissenting group included female social reformers who absorbed anti-vaccination into their feminist platform. During this time, these anti-vaccinators asserted that mothers held a domestic role as well as a public position. According to this platform, a woman's right was the right to make decisions for herself and her children. Hence, compulsory vaccination inherently took away rights from women, as it precluded them from making these decisions. Anti-vaccination parents believed that a mother's rights were explicitly biological and derived from the understanding of "maternal instincts" which give mothers the authority to decide what is best for their children. Women questioned traditional gender hierarchies by attacking the notion that male doctors could perceive the damage that poisonous vaccines impart on children better than the children's mothers. The ability to make decisions independently of the authority figures was an important facet of maternal anti-vaccination, as it was for anti-vaccinating heterodox medical practitioners and participants in dissenting religions.

Mothers were particularly publically vocal about their decisions to forego vaccination of their children. The role of women in the movement was tied specifically to their roles as mothers, as vaccination was understood by both men and women to be "a

<sup>&</sup>lt;sup>48</sup> Durbach, *Bodily Matters*, 132.

<sup>&</sup>lt;sup>49</sup> Durbach, *Bodily Matters*, 46.

<sup>&</sup>lt;sup>50</sup> Durbach, *Bodily Matters*, 61.

<sup>&</sup>lt;sup>51</sup> Durbach, *Bodily Matters*, 61.

mother's question."52 Anti-vaccination literature linked maternal love to suffering. Essentially, a mother's love would cause these women to be tormented by the image of their babies getting sick or dying from vaccinal injuries.<sup>53</sup> This rhetoric is echoed through the ways that mothers protested and circumvented compulsory vaccination. Antivaccinators staged mock funeral processions that allowed women to publically portray themselves as grieving mothers, mourning over the death of their children lost to vaccination.<sup>54</sup> These mothers would protest in full mourning clothing for publicity and passed handbills to passerby to recruit for the movement, inciting "working women" to "join...[in an] appeal to the legislature." The very public display of anger toward the policies combined with a sense of solidarity in the movement to gain attention and support for anti-vaccination among women. Women strayed from their expected role as obedient and complacent to defend their biological rights as mothers to choose not to vaccinate their children. This motherly love also extended to how mothers protected their children against the lancet. Some mothers called their children by false names instead of their real names to avoid their children's names being passed onto vaccination officers in order to forestall the vaccination process or avoid it all together. <sup>56</sup> Other forms of dissent and protection involved writing false addresses on birth registrations so that the children could not be found, which was a fairly common practice. Another common practice was called "moving house." This practice involved registering children's birthdays late in order to avoid vaccination. According to one working-class mother, "when the arrangements for moving house were decided, the birth was registered and six clear

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<sup>&</sup>lt;sup>56</sup> Durbach, *Bodily Matters*, 65.



<sup>&</sup>lt;sup>52</sup> Durbach, *Bodily Matters*, 60.

<sup>&</sup>lt;sup>53</sup> Durbach, *Bodily Matters*, 62.

<sup>&</sup>lt;sup>54</sup> Durbach, *Bodily Matters*, 62.

<sup>&</sup>lt;sup>55</sup> National Anti-Compulsory Vaccination Reporter, September 1884, 198, in Durbach, Bodily Matters, 63.

weeks still remained to get well clear of the menacing poisoner." The willingness of mothers to scheme against vaccination is evidence of their profound investment in their individual freedoms as mothers. Some mothers were involved in "demonstrations that often resulted in a violent outburst," putting the mothers in danger for the sake of their children. In 1892, a woman chased a vaccination officer through the streets with a knife, while in another instance, in 1881 a mother was reported to have assaulted a doctor when she lost a child to complications of vaccination. From these examples, it is clear that the passion behind anti-vaccination was strong, so strong in fact that in some extreme cases, women who could afford it were known to have medical practitioners falsify a vaccine by making incisions with a lancet but not administering any lymph. The impetus for action against vaccination was spurred by the feminist concern for property rights, as children were rightly their property as mothers, and the idea that vaccination was an invasion of the home.

A 19<sup>th</sup> century physician and proponent of vaccination, Francis T. Bond, argued that mothers objected to vaccination because it was ordered within the first few months of life, when the infant was still "doted on and 'lavished' with 'sympathy."<sup>61</sup> From this view, the property rights that Durbach considers a prime concern for mothers was only pertinent when the babies were very young. Bond argued that if the compulsory period were extended into the time that children were older and had turned into a "brat," nine out of ten mothers would relent and have their children vaccinated. Contrasting Bond, anti-vaccination campaign leaders such as Mrs. S. J. West encouraged mothers to resist

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<sup>&</sup>lt;sup>57</sup> Goss in Durbach, *Bodily Matters*, 66.

<sup>&</sup>lt;sup>58</sup> Durbach, *Bodily Matters*, 68.

<sup>&</sup>lt;sup>59</sup> Durbach, *Bodily Matters*, 68.

<sup>60</sup> Durbach, Bodily Matters, 67.

<sup>&</sup>lt;sup>61</sup> Durbach, *Bodily Matters*, 55.

vaccination in order to be a good parent. According to Durbach, West saw mothers as "sentimental nurses overcome by emotional attachment to their children," which was her primary concern for why mothers would not vaccinate their children. 62 Her rhetoric emphasized the women's roles as guardians of their children's welfare—their choice to vaccinate would put their children at risk. She stressed that vaccination was unnatural and criticized the practice for "perverting the true meaning of motherhood." According to S.J. West, women who brought their children to be vaccinated would be responsible for their children's pain and suffering. From this example, the mother's choice to vaccinate her children now not only puts her children at risk but also puts her at risk for guilt if her children are harmed. Mothers were passionate about their commitment to antivaccination and therefore fundamental to the anti-vaccination movement. Their position of biologically derived authority over their children allowed them to argue that forced vaccination was a property violation. Their active and public display of anti-vaccination sentiment like mock funeral processions helped gain support for their cause as a group, while subversive techniques protected their children as individuals from mandatory vaccination.

Durbach asserts that anti-vaccinators made the public aware of the unfortunate effects of vaccination with various types of propaganda, both in print and in public spaces. She explained, "Working- and middle-class parents wrote thousands of letters to various newspapers recounting the fate of their children, whom vaccination had transformed from angelic infants...to terrifying monstrosities." The stories worked to represent vaccination as disfiguring and transformative, both of the body and of the spirit.

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<sup>&</sup>lt;sup>62</sup> Durbach, *Bodily Matters*, 56.

<sup>63</sup> Durbach, *Bodily Matters*, 56.

<sup>&</sup>lt;sup>64</sup> Durbach, *Bodily Matters*, 115.

One prominent anti-vaccinator, WJ Furnival, collected photographs of babies in coffins, children with rotting body parts, and those depicting disfigured limbs, which he later published. 65 Before publishing the album, the photographs were used in anti-vaccination propaganda. The distribution system ensured a wide dissemination of the images, including handing out leaflets at vaccination stations, sending them to vaccine supporters through the mail, making the publications available through anti-vaccination societies, and targeting new parents by sending them postcards that warned them of the dangers of vaccination. 66 Although there was pro-vaccine material to counter this propaganda, it was much less effective. <sup>67</sup> Ernest Hart, the editor and chief of the *British Medical Journal* attributes this to the fact that the pro-vaccine side was lacking the "energetic system of distributing" that the anti-vaccine side had. 68 Pictures in anti-vaccine journals depicted children with rotting flesh accompanying their obituaries. <sup>69</sup> One image in a pamphlet titled Professional Opinion Adverse to Vaccination (1906) depicts a child with a gaping hole in his underarm, showing the gruesome effects of vaccine complications and offers visual evidence of the vaccine dangers (Figure 1). Another image shows an image of an infant girl in a coffin, with a footnote that lamented that her death was recorded as "blood-poisoning" less than a month after vaccination and that doctors did not have "enough evidence to show how the blood-poisoning was caused" (Figure 2). This footnote demonstrates the medical community's refusal to acknowledge vaccination as dangerous, building distrust of vaccination in the process.

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<sup>65</sup> Durbach, Bodily Matters, 49.

<sup>&</sup>lt;sup>66</sup> Durbach, *Bodily Matters*, 49-50.

<sup>&</sup>lt;sup>67</sup> Durbach, *Bodily Matters*, 50.

<sup>68</sup> Hart in Durbach, *Bodily Matters*, 50.

<sup>&</sup>lt;sup>69</sup> Durbach, *Bodily Matters*, 116.



**Figure 1:** Image depicting a child who died from complications of early vaccination, published originally in *Professional Opinion Adverse to Vaccination.* 70



**Figure 2:** Image depicting a child poisoned by vaccination in her coffin published originally in *Professional Opinion Adverse to Vaccination*<sup>71</sup>

Additionally, some who survived their infantile vaccinations went on to tell the tale of the effect of the procedures. While most stories published in anti-vaccine propaganda were stories of vaccine damaged children, occasionally there were narratives

<sup>&</sup>lt;sup>70</sup> "A Scottish Child," in WJ Furnival, *Professional Opinion Adverse to Vaccination* in Durbach, *Bodily Matters*, 116.

<sup>&</sup>lt;sup>71</sup> "Ivy Beatrix Patten," in WJ Furnival, *Professional Opinion Adverse to Vaccination* in Durbach, *Bodily Matters*, 49.

of adults whose lives were ruined by vaccination. Ira Connell, who was vaccinated as a child, suffered as a victim to vaccination for twenty-two years. He wrote in 1869:

"Soon after vaccination, my health was seen to decline...large wounds broke out in different places about my person, which have caused the left arm and hand to be quite useless...there is not even one limb that has escaped the malady...The right foot is almost the size of two feet. The pain I suffer from these wounds is of an indescribable character."

This sensational imagery is graphic and instilled fear in those who read it, making vaccination seem unappealing. Recounting stories of the dangers of vaccination and instilling fear in viewers was a major technique of anti-vaccine propaganda.

As is clear from these examples, the effects of vaccination were very visible—the scars were long lasting, and the complications of the vaccination could be too. It was difficult to argue that vaccination had no inherent risks. These visible adverse manifestations of vaccination were visible to people who viewed the propaganda, or who experienced the vaccination procedure, through their children or with their own vaccinations. The visible adverse effects of vaccination allowed propaganda with gruesome images to be distributed and have an impact on new populations.

Most readers today would agree that the anti-vaccination movement in 19<sup>th</sup> and early 20<sup>th</sup> century Britain was predictable and understandable as the consequences of vaccination were obvious. I have argued that anti-smallpox vaccination in the 19<sup>th</sup> and early twentieth century grew out of pre-established groups, which all had similar relationships with government control. Anti-vaccination supporters argued that they should have autonomy over their bodies. The consumers of heterodox medicine had notions of self-care and vaccination did not align with their ideas of how to stay healthy. The understanding that blood and bodily purity were important for health left vaccination

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<sup>&</sup>lt;sup>72</sup> Ira Connell in Durbach, *Bodily Matters*, 117.

in fundamental opposition to this understanding of the body. Some anti-vaccination supporters shared the idea that if there was religious freedom, there should also be freedom from forced medical procedures, likening forced vaccination to a forced religious sacrament. Mothers were also staunch anti-vaccinators, who believed that it was their biologically derived right to have authority over what was best for their children instead of the government. Today, the anti-vaccination movement is has evolved. For one, with advanced medical technology, vaccination is sanitary and less painful and physically disfiguring than it once was. Mothers were vocal about their resistance to vaccination, staging public displays of their anger surrounding the loss of their individual freedoms. Related to this, anti-vaccination arguments are less acceptable than they once were, because much of the danger inherent in the practice of vaccination is less visible and overall much more speculative. I draw a parallel between the public displays of anger against vaccination and the distribution of propaganda with the visible effects of the vaccination procedure. Because of the overt danger of the practice of vaccinating with a lancet, the anger and demand for bodily independence was justifiable and understandable to the public: by the time the movement ended with the implementation of a conscientious objection option in 1907, only 56.3 percent of births were vaccinated.<sup>73</sup> Today, lancets are not used to create multiple deep incisions and vaccination is safer—for one, the use of sanitary needles makes the infections that were so pivotal to anti-smallpox vaccination argument a thing of the past. Now, the complaints that parents have about the safety of vaccination are related to problems like autism that cannot be captured in a photograph. Because of the lack of overt visual proof, anti-vaccine proponents today must resort to a more multifaceted approach to anti-vaccine arguments. On the forums,

<sup>73</sup> Durbach, *Bodily Matters*, 196.



parents discuss the safety, efficacy and necessity of vaccines, sharing personal anecdotes as well as appeals to science to support their arguments. Despite the difference in vaccination practices, parents today still employ the rhetoric of personal freedom in their anti-vaccine justifications. Taking the concerns of the Victorian anti-vaccination movement into consideration, the rhetorical strategies of anti-vaccination movement of today will be investigated.

Much of the anti-vaccine dissent that occurs today is on the Internet forums. In the next sections, I will explore the arguments of individuals who express anti- DPT, MMR and HPV vaccine sentiment on parenting forums and relate these arguments to that of 19<sup>th</sup> and early 20<sup>th</sup> century anti-smallpox vaccination. I will show that the arguments against vaccination have expanded to include assertions that vaccines are unsafe, unnecessary and ineffective.





#### **DPT: Pertussis Vaccination**

Pertussis is one of the most severe vaccine preventable diseases among children in the developing world. The condition often lasts months and complications are common, with pneumonia occurring in about 15% of infants with the disease. <sup>74</sup> Prevention of pertussis is possible with the DPT or DTaP vaccine, licensed in 1949 and 1996, respectively, which confer immunity against diptheria, tetanus and pertussis. Despite widespread availability of these vaccines, in the United States, there has been an upward trend of pertussis diagnosis since 1981. On parenting forums, there are discussions about how the pertussis vaccine is unsafe and ineffective. The danger of the pertussis vaccine is communicated through personal anecdotes. Stories of children getting seizures after DPT are relatively common. Although physicians attribute these episodes to the fact that the time when the pertussis vaccine is given is typically the same period when neurological conditions develop in infants, the personal anecdotes concerning the safety of pertussis vaccination are still compelling to parents who are questioning vaccination. Parents also assert that pertussis vaccination is ineffective. Since the vaccine only confers immunity 80-90\% of the time, they are uncomfortable with the risk of vaccinating knowing that there is a 10-20% chance that pertussis could still occur. The arguments that the vaccine is ineffective use distinctly scientific language to bolster their validity and maintain the idea that vaccination provides less long-term benefit than having an actual pertussis infection; therefore "natural immunity" rather than "vaccine induced immunity" is a better choice for their families. The responses on these forums to these posts indicate that these scientific-sounding posts are well received by readers.

<sup>74</sup> Centers for Disease Control and Prevention, "Pertussis (Whooping Cough)," last modified December 13, 2013.



The controversy surrounding pertussis vaccination dates back to 1948, before the combination diphtheria, pertussis and tetanus vaccine existed. At that time, a pertussis-only vaccination was available. An article in *Pediatrics* described a case of encephalopathy in a child following the pertussis vaccine, but overall suggested that infants are safer when vaccinated rather than unvaccinated. Because the vaccine is associated with mild or moderate fever in about half of cases, the vaccine became anecdotally linked to a broad range of neurological conditions which were previously unexplained. Parents whose children developed neurological issues used the vaccine as a scapegoat without medical or scientific support. For the next several decades, reports were published in the medical literature in efforts to answer the questions brought about by these rare events.

In addition to this anecdotal evidence and the subsequent medical reports published to address them, the media also contributed to the growing questions of vaccine safety. For example, in 1974, dramatic television portrayals of children with brain damage caused by the pertussis vaccine led to a decline in the acceptance of this vaccine in the UK. According to Gangarosa et al (1998), persistent portrayals of the vaccines' danger in the media were a catalyst leading to the vaccination rate in England and Wales plunging from around 80% in 1974 to as low as 31% in the years following. The decline in acceptance and subsequent decline in vaccination led to two major pertussis outbreaks

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<sup>&</sup>lt;sup>75</sup> Gary L. Freed, Samuel L. Katz and Sarah J Clark, "Safety of vaccinations: Miss America, the media, and public health," *Journal of the American Medical Association* 276 (1996): 1869, accessed 14 November 2013.

<sup>&</sup>lt;sup>76</sup> Freed, Katz and Clark, "Safety of Vaccinations," 1869.

<sup>&</sup>lt;sup>77</sup> Freed, Katz and Clark, "Safety of Vaccinations," 1869.

<sup>&</sup>lt;sup>78</sup> Alan R. Hinman, "The Pertussis Vaccine Controversy," *Public Health Reports* 99 (1984): 258.

<sup>&</sup>lt;sup>79</sup> EJ Gangarosa et al, "Impact of anti-vaccine movements on pertussis control: the untold story," *The Lancet* 351 (1998): 358, accessed 4 February, 2014.

in the late 1970s and early 1980s, with over 165,000 cumulative cases and 50 deaths from pertussis in the UK.<sup>80</sup>

In April of 1982, a documentary entitled *DPT: Vaccine Roulette* aired on NBC in the United States. This film presented a well-researched story of the pertussis vaccine, and included interviews with medical professionals on both the pro and anti-vaccine side, in the style of an exposé. This documentary did not explicitly take an anti-vaccination stance but, as sociologist Jacob Heller states, it "publically raised the question of whether pertussis vaccine caused significant neurological problems." Because of the style of this documentary, questions about the danger of the vaccine began to surface. People who saw the film called doctors, hospitals, and state officials, concerned about the dangers of pertussis vaccine. Several rationales, including difficulty of pertussis diagnosis, modern modes of therapy that drastically reduced mortality from pertussis, and belief that the DPT vaccine could cause encephalopathy led to pertussis vaccination skepticism. The film and the uproar that it generated acted as an impetus for the US Congress to call for public hearings about the vaccine in 1984-1984. Although after the hearings it was found that the vaccine was safe and necessary, the hearings resulted in a social movement comprised of parents who were concerned about the vaccine's safety.

The organization, founded in 1982 around the parents concern, was called Dissatisfied Parents Together and advocated for reform of the vaccination system.<sup>83</sup>

Heller notes that these critics "maintained a fundamental faith in science," and combined scientific evidence against vaccination with compelling personal narratives of vaccine

<sup>&</sup>lt;sup>83</sup> Kata, Anna, "Anti-vaccine activists," 3779.



<sup>80</sup> Hinman, Alan R, "The Pertussis Vaccine Controversy," 258.

<sup>&</sup>lt;sup>81</sup> Jacob Heller, *The Vaccine Narrative*, (Nashville: Vanderbilt University Press 2008), 86.

<sup>82</sup> Heller, Jacob, *The Vaccine Narrative*, 86.

damage. He Unlike the narratives of the Victorian anti-smallpox vaccination movement that described in detail and documented with photographs the physical pain and infections that vaccination caused, these anecdotes stress the neurological changes that occurred in children after vaccination. This organization further brought public attention to the vaccine's safety and efficacy, leading to increased public skepticism in the justification of pertussis vaccination. The medical community in the United States feared that publicity about the pertussis vaccine's safety would lead to a falloff in compliance of completely unrelated vaccines. The Dissatisfied Parents Together activists, who used court cases to gain publicity in addition to compensation for vaccine damages, were a main reason for this fear.

Prominent lawsuits filed on behalf of those purportedly injured by DPT brought further attention to the topic of vaccine safety. Vaccine injury litigation grew tremendously in the late 1970s and early 1980s, increasing from two suits related to DPT in 1978 to 250 suits in 1986. According to the laws at that time, scientific proof was not a requirement for judgment against a vaccine manufacturer. Ellen Clayton and Gerald Hickson of the Vanderbilt University School of Law and the Division of General Pediatrics explain that this allowed more vaccine-injured children to receive compensation. Because families seeking compensation did not have to prove that the vaccine did something wrong and that the wrong actually caused the purported injury, as they would have to do under state tort law, it was easier to get compensation. The controversial climate surrounding vaccines prompted several vaccine manufacturers to

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<sup>&</sup>lt;sup>84</sup> Heller, Jacob, *The Vaccine Narrative*, 87.

<sup>85</sup> Heller, Jacob, The Vaccine Narrative, 91.

<sup>&</sup>lt;sup>86</sup> Freed, Katz and Clark, "Safety of Vaccinations," 1870.

<sup>&</sup>lt;sup>87</sup> Freed, Katz and Clark, "Safety of Vaccinations," 1870.

<sup>&</sup>lt;sup>88</sup> Ellen Wright Clayton and Gerald B. Hickson, "Compensation under the national childhood vaccine injury act," *The Journal of pediatrics* 116, no. 4 (1990): 508-513.

stop production out of fear of liability, prices to rise drastically, and a vaccine shortage to occur. <sup>89</sup> Public health officials feared that the shortage of vaccines could cause pertussis to spread to epidemic proportions. In response to this problem, Congress established the 1986 National Childhood Vaccine Injury Act (NCVIA). <sup>90</sup> This act created the National Vaccine Injury Compensation Program (NVICP), which aimed to serve as insurance fund for confirmed vaccine-related injuries. <sup>91</sup> This program implemented a system of scientific investigation, which Dissatisfied Parents Together desired: scientific evidence to back up their claims of vaccine injury. <sup>92</sup> Between 1986 and 2004, over \$1.5 billion was awarded to 120 claimants under the NVICP. <sup>93</sup>

It is clear that there was a significant amount of anti-DPT activism before the dawn of the Internet. There has been an evolution of anti-vaccine arguments since Dissatisfied Parents Together fought for compensation for vaccine damages and scientific proof that the DPT vaccine was dangerous. Today on Internet forums, there is an evolution of arguments against vaccination. In addition to the arguments that pertussis vaccination is unsafe, parents are now motivated by the idea that the vaccine is also ineffective and unnecessary.

Aamer Imdad et al., doctors and public health experts at State University of New York Upstate and members of the New York State Department of Health's Bureau of Immunization, showed that the rates of religious exemptions from pertussis vaccination in New York have increased by over 100% in 34 counties between 2000 and 2011. The study also found that religious exemption to vaccination was directly correlated with

<sup>&</sup>lt;sup>93</sup> Heller, Jacob, *The Vaccine Narrative*, 107.



<sup>&</sup>lt;sup>89</sup> Centers for Disease Control and Prevention, "History of Vaccine Safety," last modified February 8, 2011, http://www.cdc.gov/vaccinesafety/vaccine\_monitoring/history.html.

<sup>90 &</sup>quot;History of Vaccine Safety"

<sup>91 &</sup>quot;History of Vaccine Safety"

<sup>&</sup>lt;sup>92</sup> Heller, Jacob, *The Vaccine Narrative*, 107.

increased rates of pertussis in those counties.<sup>94</sup> In this example, there is a connection between alternative religions anti-vaccination sentiment, resembling the 19<sup>th</sup> century arguments. In the 19<sup>th</sup> Century anti-smallpox vaccination movement, non-English Christian religions saw a link between the freedom of religion and the freedom to forego vaccination and resisted vaccination. Further, now that the Internet exists as a place to disseminate information about the dangers of vaccines, anti-vaccination sentiment now has the potential to be more pervasive than ever, because it can reach people more quickly and form communities that bolster anti-vaccine sentiment.

On Internet forums, parents frequently discuss their decisions to forego the pertussis vaccine. The community that opposes the pertussis vaccine on the Internet uses many of the same arguments as the Dissatisfied Parents Together activists did in the late 80s—often appealing to science. On the forums, the main strategy for opposing the DPT and DTaP vaccines is to claim that the vaccine itself is ineffective and does more harm than good and the alternative of "natural immunity". Forum posters discuss the science behind "natural immunity," arguing that vaccine induced immunity is less effective than actually enduring and surviving the illness. These arguments, combined with personal anecdotes, convince people that vaccination against pertussis should be avoided, as evidenced by the positive reactions from other parents on the forums.

According to the Centers for Disease Control and Prevention, the combination diptheria, tetanus and pertussis vaccine is 80-90% effective in preventing pertussis. 

Additionally, the 10-20% of those vaccinated who are not fully protected are less likely

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<sup>&</sup>lt;sup>94</sup> Aamer Imdad, Boldtsetseg Tsernpuntsag, Debra S. Blog, Neal A. Halse, Delia E. Easton and Jana Shaw, "Religious exemptions for immunization and risk of pertussis in New York State, 2000-2011," *Pediatrics* 132 (2013): 42.

<sup>&</sup>lt;sup>95</sup> Centers for Disease Control and Prevention, "Pertussis Frequently Asked Questions, last modified December 19 2013, http://www.cdc.gov/pertussis/about/faqs.html

to get a severe infection, and are less infectious to others if they experience the infection. Although unvaccinated individuals are not the only group that is susceptible to the pathogen, unvaccinated children have an eightfold greater risk for pertussis than children who are fully vaccinated. On the parenting forums, parents have conversations indicating that they do not believe the vaccine is effective. One mothering.com thread entitled "non-vaxer contemplating vaccination," Micah\_mae\_ states:

"I have considered vaxing as well, but I thought I'd let you know that the 2 biggest concerns for you are 2 things I wouldn't worry about. The vaccine isn't very effective for whooping cough, up to 90% of kids who get it are vaccinated." 98

The claim that the vaccine is ineffective is also apparent in Ssun5's post, when she replied:

"Given that booster shots don't increase the bactericidal qualities in the blood why recommend them? The shot will never stop transmission to anyone else. The shot will not help you not get it. The shot might lesson severity (which is a crap shot [sic] to say what percentage-some seem to have no symptoms while others get horrible cases)." "99

These quotes show that there is a profound mistrust of the efficacy of the vaccine. The confusion here is that there are significantly more people vaccinated against pertussis than unvaccinated. The 10-20% of this large vaccinated population that is not completely protected is larger than the population that is not vaccinated, leading to more incidences, even if the disease itself is less severe. Micah\_mae\_'s claim that 90% of pertussis victims

http://www.mothering.com/community/t/1393704/non-vaxer-contemplating-vaccination



<sup>96 &</sup>quot;Pertussis Frequently Asked Questions."

<sup>&</sup>lt;sup>97</sup> Centers for Disease Control and Prevention, "Pertussis Epidemic—Washington, 2012, last modified July 20, 2012,

http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6128a1.htm

<sup>&</sup>lt;sup>98</sup> Micah\_mae, November 30, 2013 (7:42 p.m.) comment on Mothering, "non-vaxer contemplating vaccination," *mothering.com*, November 30 2013,

http://www.mothering.com/community/t/1393704/non-vaxer-contemplating-vaccination Ssun5, November 30, 2013 (9:12 p.m.) comment on Mothering, "non-vaxer contemplating vaccination," *mothering.com*, November 30 2013,

are vaccinated selectively uses statistics to elicit a response from the original poster, calming her worries, as she replies, "thx this makes me feel better!" Implicit in this statement is the idea that only 10% of pertussis cases are from unvaccinated individuals, but ignores the fact that unvaccinated individuals have an eight-fold higher risk of contracting the illness, and are vulnerable to more severe infections and hospitalizations.

The language used on parenting forums is defintiely worth noting because it subtly indicates skepticism surrounding the efficacy of vaccines such as DPT. The term VPD, or Vaccine Preventable Disease, refers to diseases that have vaccines available. However, on forums like the "I'm not vaccinating" mothering.com forum, the term VAD, or vaccine available disease, is used commonly instead. There are 163 posts that mention "VAD" within the "I'm not vaccinating" forums, but it seems that this term is not a well-known acronym outside of the anti-vaccination community. On a post titled "I don't like the term VPD," a parente called Purslane explains why she prefers VAD to VPD, explaining, "the term VDP bugs, me I guess. It seems an untruth to say "vaccine preventable diseases" when indeed, the diseases are not necessarily preventable through vaccinating." This use of language speaks to the disbelief that parents have towards the efficacy of vaccines against diseases like pertussis, diphtheria and measles. Referring to these diseases as "vaccine available" rather than "vaccine preventable" indicates that parents are not confident in the efficacy of the vaccines.

One rhetorical trope that comes up frequently in these discussions is the idea of natural immunity. Arguing that "natural immunity" is better than vaccination-induced

VPD," *mothering.com*, March 11 2010.

http://www.mothering.com/community/t/1301982/i-do-not-like-the-term-vpd



Apeydef, December 1, 2013 (10:02 p.m.) comment on Mothering, "non-vaxer contemplating vaccination," *mothering.com*, December 1 2013, http://www.mothering.com/community/t/1393704/non-vaxer-contemplating-vaccination Purslane, March 9 2010 (11:51 a.m.) comment on mothering, "I don't like the term

immunity is another way of incorporating scientific-sounding evidence into anti-vaccine arguments. According to epidemiologists Aaron Wendelboe et al., vaccine induced immunity for pertussis wanes after 4-12 years and infection induced immunity wanes after 4-20 years. There are 240 out of 5,406 threads on mothering.com within the vaccination category alone that have "natural" and "immunity" in the title, and 749 posts that mention natural immunity. The general consensus on the pertussis-specific threads is that natural immunity, as opposed to vaccine-induced immunity, is better because it confers immunity for a longer period of time and ensures that pertussis is not spread to others, further supporting a lack of value for pertussis vaccination.

The posters that discuss natural immunity on these threads employ distinctly scientific terms like "antibody," "cilia" and "bronchial," to bolster scientific validity.

They support the claim that the vaccine is not effective, and therefore, not useful. On a mothering.com forum titled "Whooping cough questions (we've just had it)," the benefits of natural immunity vs. vaccine-induced immunity are delineated. According to ssun5:

"Natural *mucosal immunity specifically targets the infection <u>process</u> - how the bacteria sets up shop - and the specific toxins the bacteria switch on and then start once their little claws attach to the cilia in the bronchi at "ground zero".* 

Another [sic] words, the current whooping cough vaccines create antibodies at the "back-end", to antigens which come later in the infection. Vaccines MIGHT reduce disease severity for the few months those antibodies exist, but the current whooping cough vaccines don't create the powerful "front end" protection which will immediately clear the bacteria on re-infection. Does that make sense?

The vaccine antibodies, if they are around, *might* ... lessen the effect of pertussis toxin when it Finally hits the blood supply.

Again: The vaccine creates **back end** antibodies, BUT natural infection requires a specific **bronchial** immunity not made by the current vaccines, and not provided by the antibodies detected in antibody tests." [emphasis hers]

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<sup>&</sup>lt;sup>102</sup> Ssun5, January 24, 2014 (1:08 p.m.) comment on Mothering, "Whooping cough question (we just had it)," *mothering.com*,

In the post, Ssun5 did post a link to a peer reviewed study: this study by Giorgio Fedele discussed a potential intranasal pertussis vaccination for humans and the success of the mouse model. However, the study did not mention front end or back end antibodies or bronchial immunity. When asked about her qualifications, Ssun5 acknowledged, "having a degree not related to medicine" and a general interest in vaccine reactions. However, this did not affect the positive reactions to the post. Parents "reposted" the description of natural immunity, suggested that she make a new thread about natural immunity in general, and described it as fascinating and important. From this example it is clear that the scientific-sounding arguments are effective in eliciting a positive response from readers against vaccination.

Other forms of rhetoric are used in addition to scientific-sounding arguments.

Anti-DPT vaccine advocates also discuss how dangerous the vaccine is, citing personal anecdotes about how the vaccine affected their children. The anecdotal evidence often links vaccination to earlier concerns. One reason cited by doctors from the University of North Carolina is that primary immunizations for infants take place at 2, 4 and 6 months, around the same time that neurological conditions such as seizure disorders and white

http://www.mothering.com/community/t/1396342/whooping-cough-questions-weve-just-had-it

<sup>&</sup>lt;sup>105</sup> Mirzam and Li27, comment on mothering "whooping cough questions (we just had it).



Giorgio Fedele, Manuela Bianco, Anne-Sophie Debrie, Camille Locht, and Clara Maria Ausiello, "Attenuated Bordetella pertussis vaccine candidate BPZE1 promotes human dendritic cell CCL21-induced migration and drives a Th1/Th17 response," *The Journal of Immunology* 186:9 5388-96, accessed (2011): 5388-5396.

Ssun5, January 25, 2014 (12:13 a.m.) comment on Mothering, "Whooping cough question (we just had it)," *mothering.com*,

http://www.mothering.com/community/t/1396342/whooping-cough-questions-weve-just-had-it

matter degenerative diseases show their first symptoms. 106 According to these doctors, anecdotal evidence linking vaccines to these diseases is often the result of parents, quite expectedly, reacting to the unfortunate surprise of a sick child, searching for the cause of the new neurological symptoms. 107 On one forum sponsored by the Think Twice Vaccine Institute, an anti-vaccine information source, an anonymous person asked "My son was born 10lbs, 22 inches, a healthy baby boy...He had his DPT shots then [sic] started doing mild jerks that increased each day. By the tenth day he was put into the hospital with infantile spasms...today, my son is almost seven, with global developmental delays and seizures." Another parent, liquidambar on mothering.com, posted, "My son reacted to his third DPT shot. [W]ithin a few hours with a catatonic episode and when he came out of it he then started drooling and jerking of his chin (does that sound like a seizure to you all? It sure looked like one to me!)."109 Taximom5 explains, "My oldest had a seizure reaction to his 2-month vaccines; it start [sic] 1 hour after the vaccines were given, and lasted nearly 4 hours. Diagnosed and documented by pediatrician." As is indicated by these examples, it is not uncommon to see dozens of parents sharing their stories on one thread over just a few days. In addition to these personal anecdotes, there is also evidence that they are effective in influencing other readers. In response to these stories, ma2two commented, "Yes! It is because of parents' stories that I started researching before I had

Taximom5, September 13, 2013 (5:51 a.m.) comment on Mothering, "Anybody here whose children have had severe reactions to vaccines?," *mothering.com*, http://www.mothering.com/community/t/1389941/anybody-here-whose-children-have-had-severe-reactions-to-vaccines



<sup>&</sup>lt;sup>106</sup> Freed, Katz and Clark, "Safety of Vaccinations," 1869.

<sup>&</sup>lt;sup>107</sup> Freed, Katz and Clark, "Safety of Vaccinations," 1869.

<sup>&</sup>lt;sup>108</sup> ThinkTwice Vaccine Institute, "Pertussis (DPT and DTaP)," last modified 2010, http://thinktwice.com/dpt.htm

Liquidambar, September 16, 2013 (7:26 p.m.) comment on Mothering, "Anybody here whose children have had severe reactions to vaccines?," *mothering.com*, http://www.mothering.com/community/t/1389941/anybody-here-whose-children-have-had-severe-reactions-to-vaccines

kids. I decided not to vaccinate, even though I had no idea at the time that they would most likely be extra susceptible to vaccine injury." From this comment we see the tangible effects that personal anecdotes have with relation to vaccination exemption and avoidance.

It is difficult to understand today's resistance to DPT vaccination without looking into the historical context of the anti-vaccine movement with regards to this specific vaccine. In the 1980s, Dissatisfied Parents Together argued for scientific evidence that the vaccine caused damage. Today, the arguments have evolved. Now, instead of just arguing that the vaccine is dangerous, the rhetoric used on forums focuses on the safety and efficacy of the vaccine. This involves scientific-sounding arguments, with a focus on natural infection and resulting immunity vs. vaccine-induced immunity, frightening and personal anecdotes about vaccine damages caused by DPT. These strategies contribute to questioning of the vaccine's safety and efficacy of pertussis vaccination. It is interesting how the vaccine is still questioned when the threat of pertussis is very real—it is a vaccine preventable disease that still affects many people in this country, unlike diphtheria, which has essentially been eradicated. Because pertussis is still an imminent threat, it makes the question of whether or not to vaccinate more difficult and the global health impact of the small group of pertussis vaccination opponents more relevant.

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ma2two, September 18, 2013 (12:16 p.m.) comment on Mothering, "Anybody here whose children have had severe reactions to vaccines?," *mothering.com*, http://www.mothering.com/community/t/1389941/anybody-here-whose-children-have-had-severe-reactions-to-vaccines





## Measles, Mumps and Rubella Vaccine (MMR)

In this chapter, the measles, mumps and rubella (MMR) vaccine will be discussed. Unlike pertussis, these sicknesses are much less common than they used to be and for this reason, fewer people are familiar with the severity of the diseases. I argue that parents on the forums focus on the danger of the vaccine and its association with neurological problems like autism. Although the forum posters claim to not be influenced by Andrew Wakefield's study that linked MMR to autism, they believe that he was treated too harshly and his ideas still come up in the forums. Personal anecdotes are the main mode for arguing that the vaccine is dangerous, and they also are used to show that the natural infections of measles, mumps and rubella are not that severe, rendering the vaccine unnecessary. Additionally, graphs are used to support their arguments that the MMR vaccine did not have a great impact on measles mortality. Next, I will argue that the images used in the vaccine debate serve a different purpose than they did in the antismallpox vaccination movement—instead of eliciting fear, they are used to depict the moral challenges surrounding vaccination, serve to minimize the impact of vaccination on global health and also serve to solicit advice from other parents.

The MMR vaccine has garnered a lot of media coverage in recent years around the world. Beginning in 1992, British officials ordered the discontinuation of some MMR vaccine brands because the mumps component was linked to meningitis in a small fraction of recipients (estimated at about 1/6000 to 1/11000). This spurred a panic that led to decreased vaccination and a huge spike in reported measles cases in the UK in the beginning of 1994. Worried that a full-blown epidemic would occur, the government

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<sup>&</sup>lt;sup>112</sup> Seth Mnookin, *The Panic Virus: A True Story of Medicine, Science, and Fear.* (New York: Simon and Schuster, 2011), 98.

began a vaccination campaign in the fall of that 1994. This campaign was met with opposition from parents claiming to be uninformed about the program. There was also resistance from the Catholic community, based on the allegation the vaccine was developed using tissue from aborted fetuses. This speculation was due to the fact that in the 1960s, human fetal lung cell strains were used to grow viruses to make attenuated strains of the viruses. 114 At the end of 1994, the JABS, or Justice, Awareness and Basic Support, "a group dedicated to protecting Britain's children," was founded in part to create a class action lawsuit against the vaccine manufacturers, further reinforcing distrust in this vaccine. 115

At the same time, British physician Andrew Wakefield began his studies that attempted to link the measles virus to a persistent infection of the gut. Subsequently in 1995, he started to research the impact of the measles vaccination the incidence of inflammatory bowel disease. In 1998, he published "Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children" in *The Lancet*, along with a twenty-minute promotional video addressing the report. 116 This paper claimed that the MMR vaccine caused autism and chronic enterocolitis in certain children, because their immune systems were unable to handle the combination of the three vaccines at once. This lead to a rise in the number of parents who opted-out of vaccination due to worries that the shot was dangerous. Although this article was retracted in early February 2010, there is still an extensive discussion about the dangers of the MMR vaccine and its link to autism. On mothering.com, there are 1264 individual

<sup>&</sup>lt;sup>113</sup> Mnookin, Seth, *The Panic Virus*, 98-99.

<sup>&</sup>lt;sup>114</sup> History of Vaccines, "Human Cell Strains in Vaccine Development," last modified January 10, 2014, http://www.historyofvaccines.org/content/articles/human-cell-strainsvaccine-development.

<sup>&</sup>lt;sup>115</sup> Mnookin, Seth, *The Panic Virus*, 101.

<sup>&</sup>lt;sup>116</sup> Mnookin, Seth, *The Panic Virus*, 106.

posts that include the words "MMR" and "autism" within the vaccination threads. There are also 304 thread titles within the vaccination category that include both the words "autism" and "MMR." As of April 11, 2014, about 58% of the threads within the "Vaccination" category that had "MMR" in the title also had "autism" in the title.

It is important to note that before the Wakefield article, there were no allegations that this MMR vaccine caused autism. Yet even after the study was retracted, people still associate MMR with autism, indicating that this study's impact on the vaccine debate is impossible to ignore. Parenting forums continue to give insight into the beliefs of groups of vaccine-questioning individuals, and reading these forums sheds light on the discussion surrounding Wakefield and the MMR debate even years after the paper was retracted.

Despite talking about the Wakefield study on the forums, parents on these blogs allegedly do not make their decisions against vaccination based on his study. On a mothering.com poll titled "Does the Wakefield study affect your decision?" eleven out of eleven mothers said that that Wakefield study did not affect their decision to not vaccinate. This survey indicates that the parents' decisions not to vaccinate are not due to the fact that they still think the Wakefield article is true—they accept that the study was flawed and provides an invalid argument against vaccination. The parents in the anti-MMR community empower themselves as individuals to forego vaccines in a variety of ways. In a similar way to anti-DPT activism, parents use rhetorical strategies such as frightening personal anecdotes to highlight the danger of the vaccine. The parents on the forums stay strong in their decisions not to vaccinate and the website communities seem

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MamaMunchkin, November 9, 2012 (5:37 p.m.) comment on mothering, Does the Mothering "Does the Wakefield Study Affect your Decision?," *mothering.com*, http://www.mothering.com/community/t/1367803/does-the-wakefield-study-affect-your-decision

to serve as powerful support groups that reiterate the dangers of the MMR vaccine and fulfill the need for reinforcement of parent's decisions.

On the same mothering.com forum with the survey, one parent, kathymuggle, noted:

"I am not 100% convinced vaccines do not play a role in autism- there are simply too many parents who say their child was fine before a vax, and wasn't afterwards...While his work did not *directly* influence my decision, maybe his work did in an *indirect* way? It is very hard to quantify how much Wakefield contributed to concerns about vaccines and autism in society. I think it is a lot less than some pro vax people would like to think, but perhaps more than nothing?"

In fact, all of the posts on this particular discussion claimed that the study did not influence their decisions not to use the MMR.

Despite the parents' claims that the Wakefield article did not affect their decision not to vaccinate, Andrew Wakefield still gets defended on parenting forums. Although parents do not admit to believing the Wakefield's study still has merit, their posts suggest that they may still believe it, illustrating the power of these communities and their commitment to anti-vaccination. Posts on both mumsnet.com and mothering.com suggest that the parents know that using the study to justify their decision not to vaccinate is not a good idea because with this belief, they will not be taken seriously or accepted socially. The ways that parents relate to Wakefield's article are interesting considering their awareness that the study was retracted and cannot be used as evidence that MMR causes autism. Andrew Wakefield is often glorified as a martyr to the autism and MMR debate, discussing how "anytime someone in medicine goes against the status quo, they are crucified", and that he "simply he quantified what people suspected and shook up the

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Kathymuggle, comment on mothering, "Does the Wakefield Study Affect your Decision?"

status quo."<sup>119</sup> They are sympathetic to him, but also resentful that his flawed study gives anti-vaccinators a bad name. One parent, emmy526, complains "EVERY media reporting on [anti-vaccination] just HAS to throw Wakefield in there, and how nonvaxers are to blame for listening to him."<sup>120</sup> They are also distrustful of the greater medical establishment and it's connection to governmental policy, lamenting that no one who challenges vaccination will ever be taken seriously. Parents feel that the medical establishment is out to get anyone who challenges the vaccination system, bringing them a fate similar to Wakefield if they argue against vaccination. For example, a parent called Scattershoot explains, "They are saying [Wakefield] "faked" data so they can try to ridicule all the case studies and smear his name completely...what they are really doing is dragging him and his family through the mud as a warning to all the others who might get an itch to challenge vaccination."<sup>121</sup> Another parent on a thread entitled "Was the Wakefield study on MMR really fake?" stated:

"All Wakefield and others at the Royal Free did was suggest more research was needed...the way the medical community has completely freaked out over this and gone after Wakefield and his two colleagues just shows that vaccinations are untouchable...The only research obviously allowed is that which sets out to prove vaccinations can't possibly be linked [to autism]." <sup>122</sup>

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<sup>&</sup>lt;sup>122</sup> Scattershoot, February 10, 2009 (1:55 p.m.) comment on mothering, What do you think of this article: MMR Dr. Wakefield fixed data on autism?," *mothering.com*, http://www.mothering.com/community/t/1040039/what-do-you-think-of-this-article-mmr-dr-wakefield-fixed-data-on-autism



<sup>&</sup>lt;sup>119</sup> Applejuice, March 24 2014, (6:26 a.m.), comment on mothering, "really sick and tired of the Media Blaming Wakefield," *mothering.com*,

http://www.mothering.com/community/t/1399250/really-sick-and-tired-of-media-blaming-wakefield

emmy526, comment on mothering, "really sick and tired of the Media blaming Wakefield."

Scattershoot, February 10, 2009 (1:55 p.m.) comment on mothering, What do you think of this article: MMR Dr. Wakefield fixed data on autism?," *mothering.com*, http://www.mothering.com/community/t/1040039/what-do-you-think-of-this-article-mmr-dr-wakefield-fixed-data-on-autism

From these posts it is clear that the Wakefield study was instrumental in shaping attitudes about people opposed to vaccination are portrayed in general attitudes that vaccinators have towards non-vaccinators.

Even when parents do not credit Wakefield in their decision not to vaccinate their children with the MMR, the fear of vaccine-associated autism is still imminent. This fear perpetuates the rhetorical trope of the danger of vaccines. One mumsnet.com post titled, "MMR!!!! Have just cancelled it," a concerned mother informs the forum readers that she has cancelled her son's MMR appointment because of her vaccine fears relating to autism. Several mothers commended her decision, sharing their personal anecdotes as reassuring evidence. IndigoBell mentions, "I think you've done the right thing. • My eldest [son] was advised not to have any more vaccinations after he was vaccine damaged (leading to ASD [Autism Spectrum Disorder]) - so my younger 2 haven't been vaccinated either..." These comments both perpetuate the fear of the vaccine, and support skepticism of the vaccine's safety. Another mumsnet.com post titled "What would you do? MMR and autism question," CeilingThomas posts that she is unsure of whether or not to vaccinate her son because she has family history of autism. 124 There are several posts that recommend that she should "do what you can live with," and some who mention that "there is a definite connection between vaccine triggering autism in kids who are genetically or hereditarily predisposed to autism...if I were you, I would

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<sup>&</sup>lt;sup>123</sup> Indigobell, January 27 2012 (10:13 a.m.), comment on mumsnet, "MMR!!!! Have just cancelled it.," *mumsnet.com*, January 27 2012, http://www.mumsnet.com/ Talk/special\_needs/a1393119-MMR-Have-just-cancelled-it

<sup>&</sup>lt;sup>124</sup> CeilingThomas, April 5 2013 (8:54 p.m.) comment on mumsnet, "What would you do, MMR and autism question," *mumsnet.com*, April 5 2013,

http://www.mumsnet.com/Talk/special\_needs/a1725249-What-would-you-do-MMR-and-autism-question

NEVER take the chance.<sup>125</sup> Parents who post on the forums create their own anonymous support communities that validate their decisions not to vaccinate, when the mainstream medical community would usually not. As doctors typically encourage vaccination, trips to the doctor's office can be isolating for parents who are not planning to vaccinate. Sharing their stories builds trust, and shows that other parents are questioning the medical community's opinion about vaccination, which in turn makes people more comfortable with their decisions not to vaccinate and provides a safe and supportive environment to persist with the non-vaccination decision.

The other most common argument against the MMR is that all three illnesses, measles, mumps and rubella, are not that bad, and are "normal" childhood diseases. Many parents use their own experience with the illnesses to support their decisions not to vaccinate. For example, mrsfossil on mumsnet.com shared "I had all the childhood disease in the 70s and I have always been fit and healthy. 1st time in the hospital was to have [my son]." On another thread discussing measles outbreaks in New York, a parent states, "my entire family has had and recovered very easily from Measles. At ages just over 40, mid 30s and then 12, 6 and 18 months." These examples show that the danger of measles, mumps and rubella is not significant, so the vaccine is not worth the risks. On the same thread, applejuice states that "I had measles as a child also, so I should have had enough immunities to pass on to [my son]." She is not worried about the illness in the

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<sup>128</sup> applejuice, comment on mothering, "worried about measles in NYC."



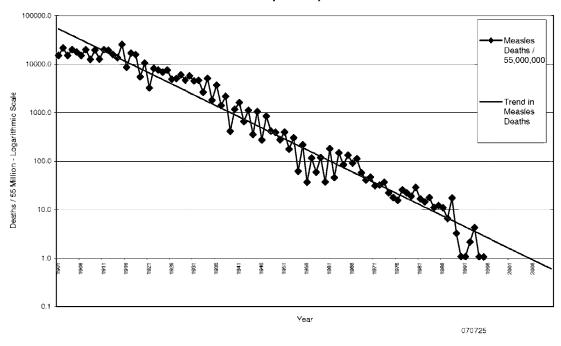
<sup>&</sup>lt;sup>125</sup> Zumbaleena, comment on mumsnet, "What would you do, MMR and autism question."

mrsfossil, February 2 2009 (4:42 p.m.) comment on mumsnet, "your view on vaccinations?," *mumsnet.com*, February 2 2009

http://www.mumsnet.com/Talk/childrens\_health/691545-your-view-on-vaccinations sun5, March 13, 2014 (9:35 p.m.) comment on mothering, "Worried about measles in NYC," *mothering.com*, http://www.mothering.com/community/t/1398801/worried-about-measles-in-nyc

city where she lives because of the natural immunity that she was able to pass to her child in breast milk. Invoking the idea of natural immunity in a different way, she rationalizes not vaccinating her child because her previous experience with measles leaves him protected from the illness. In a similar manner as DPT, the idea that having the actual illness is better in the sense of conveying stronger immunity than the vaccine is used to rationalize avoiding vaccines.

On some parenting forums, parents show images and "memes" about vaccination. Occasionally, the images are used on the "I'm not vaccinating" threads to support claims about the futility of vaccination. Since treatment for measles, mumps and rubella is likely to be successful with more advanced hospital technology, death from these diseases is much less likely than it was in the beginning of the century. In one thread entitled "BMJ-measles not the scary disease the press want you to think it is," the conversation centers on a graph of measles mortality England and Wales from 1901-1999, posted by Mirzam. The image shows a steadily decreasing trendline in measles mortality over time.



**Figure 3**: Logarithmic scale of measles mortality, deaths per 55 million, 1901-1999 in England and Wales from mothering.com.

At a glance the trend line indicates that deaths are constantly decreasing over time and there is not a significant decrease indicating where vaccination changed anything. However, at a closer look, the y-axis of the graph indicates that the deaths are on a logarithmic scale. If the deaths were plotted on a linear scale, the steadily decreasing trend line would change to an exponentially decreasing line. The scaling obscures the exponential decrease that is due to the introduction of vaccines against measles. This graph also looks at measles deaths, which are uncommon now because fever-reducing medicines are available and more is known about hydration during measles treatment. This graph was originally posted on an anti-vaccine blog called ChildHealthSafety, which

advocates for better treatments rather than preventative measures like vaccination. The blog also argues that death rates are more important to look at than incidence rates because measles has gotten less severe over the last century. The responses to the graph in the thread were positive and indicated that the readers appreciated Mirzam's post. Additionally, some posters lament that children with measles today are unlucky to "not have the benefit of those calm 1950s docs who knew how to treat measles." The graph is misleading in that it presents information—death rates—that is less useful to understanding measles prevalence than hospital admissions or documented cases, and further influences viewers by manipulating the y-axis scaling. Although anti-vaccination arguments on parenting forums prioritize personal anecdotes when safety is concerned, parents utilize statistics and graphs from epidemiological studies when the graphs support their claims that vaccines lack efficacy, failing to highlight the impact that vaccines have on reducing mortality from measles.

Sometimes vaccination and anti-vaccination images are used in the context of a debate. One thread entitled "Fun thread for a change! Anyone up for a meme-off" under the Vaccinations Debate forums begins with a pro-vaccine parent looking for debate using memes and infographics. However, the images that are posted are almost entirely in support of vaccinations. The parents who do not support vaccination argue, "There is a difference between whether a vaccine is useful world wide and whether or not your

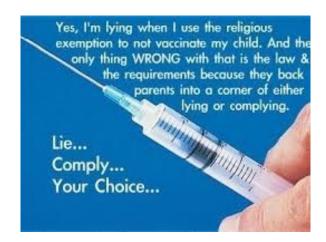
http://childhealthsafety.wordpress.com/2013/04/15/british-medical-journal-tells-us-measles-is-not-the-scary-disease-the-press-want-you-to-think-it-is/.

the-press-want-you-to-think-it-is

Child Health Safety, "British Medical Journal tells us Measles is not the Scary Diesase the Press Want You to Think it is," last modified April 15, 2013,

Mirzam, April 15, 2013 (7:26 a.m.) comment on mothering, "BMJ- measles not the scary disease the press want you to think it is," *mothering.com*, http://www.mothering.com/community/t/1381700/bmj-measles-not-the-scary-disease-

particular child needs it."<sup>131</sup> This attitude aligns with the culture of personal anecdote that prioritizes personal decision-making and knowing what is best for one's family rather than statistics backed by science. It is also reminiscent of resistance to smallpox vaccination in 19<sup>th</sup> century Britain, which focused on individual rights, especially the rights of mothers, to choose whether or not to vaccinate. On the threads, once the debate began to seem too one-sided, those who were anti-vaccine decided they would rather not participate, stating that "this thread was not fun [for the record]" and "This thread really belongs in Vaccination on Schedule." Only four of the 29 images were explicitly anti-vaccination. One of them addresses the issue of lying about religious exemptions and the structural barriers to parent choice within the legal system.



**Figure 4:** Image used on mothering.com to argue against vaccination. This image sets up the medical establishment in an alliance with the government as a tool to take away civil liberties and invokes rhetoric of civil disobedience.

The above image depicts a syringe and the thoughts of a parent who is lying about

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kathymuggle, October 25, 2013, comment on mothering, "Fun thread for a change! Anyone up for a meme-off?, *mothering.com*, October 24, 2013, http://www.mothering.com/community/t/1391962/fun-thread-for-a-change-anyone-up-for-a-meme-off.

Dinahx, comment on mothering, "Fun thread for a change! Anyone up for a meme-off?"

a religious exemption in order to avoid vaccinating their child. To this parent, the problem is not that they are lying, but rather that the government puts undue pressure on people to vaccinate when they should have a choice. This sentiment connects with the culture of civil disobedience in the anti-smallpox vaccination movement in Victorian Britain. Middle class individuals in the Victorian anti-smallpox vaccination movement resented and retaliated against the laws that limited their individual rights to personal freedom, creating a discourse that emphasized the vulnerability of the infant at the hands of the state. This particular image and accompanying text depicts the challenge of the moral questions involved when the government enforces vaccination. In the antismallpox movement, subversive tactics to avoid vaccination also existed. The culture of hiding and secrecy was seen when parents wrote false addresses or birthdays on their children's birth certificates. However, today it isn't as easy to hide or falsify documents—"lying or complying" are the only options if there is no medical reason or religious credence that warrants a sanctioned exemption. Both in the 19th century and today, the belief that parents should be free to make decisions as individuals and used subversive techniques to do so. The arguments in the 19<sup>th</sup> century and today are very similar.

Unlike in the anti-smallpox vaccination movement in the mid to late 19<sup>th</sup> Century, the use of images of vaccine reactions or children mutilated by vaccines is uncommon with contemporary vaccination. An image search on mothering.com of "vaccine" returned only 100 images. Most of the images were graphs of vaccination rates and images that are pro-vaccine. There was only one image of a child with a vaccine reaction—an infant who had received the MMR and chicken pox vaccine and had a fever

of 101.5 and a rash.<sup>133</sup> The parent was soliciting advice from her peers as to what the rash could be. Although none of the responders are themselves medical professionals, they offer insight as to what the rash could possibly be. They conclude that the baby "might be having a vaccine-induced case of measles, or it could be an adverse reaction, a rash that is not measles but something a bit more serious," or "it could be chicken pox." They also offer advice like "never give Tylenol" and "he doesn't need the second shot." They also recommend that she see a doctor to get a true diagnosis of the rash. The fact that parents on the forums solicit advice from the other people on the forums indicates that there is a degree of trust among forum posters.



**Figure 5:** Image of a rash on a child post-MMR and chicken pox vaccination posted on a parenting forum on mothering.com.

The image is not particularly remarkable; rather, it is a faint rash that is far from the gruesome images of rotting flesh of the anti-smallpox vaccination campaign. It is

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whompingwillow,, June 29, 2013 (5:49 p.m.) comment on mothering, "My son got the MMR and chicken pox vaccine but is having some kind of reaction? Help!," *mothering.com*, http://www.mothering.com/community/t/1385861/my-son-got-the-mmr-and-chicken-pox-vaccine-but-is-having-some-kind-of-reaction-help

taximom5, comment on mothering, "My son got the MMR and chicken pox."

Momtezuma tuatara, comment on mothering, "My son got the MMR and chicken pox."

worth noting that the reactions to vaccines like MMR that parents fear are typically less visible, as they are focused on the behavioral and neurological changes that occur after vaccine and cannot be captured on film. Today, images are not used in the antivaccination debate to induce fear as they did in the anti-smallpox vaccination campaign in Britain, but rather, to gather information and build trust, because vaccination practices today do not cause as severe physical infections as they did in the past. This is partially because the serious reactions to the small pox vaccination were due to the unsanitary practice of vaccinating with a lancet, whereas today physical changes after vaccination are less associated with severe infections.

In summary, the MMR forums show a unique side to the anti-vaccine conversation. Although the parents' concerns about the MMR's connection to autism are allegedly not influenced by Andrew Wakefield's retracted paper, it is still incorporated into their conversations and it is clear that his paper had an effect on the conversation. The Wakefield paper and the resulting controversy that it spurred ignited discussion about the safety of the vaccine, and impacted the way that non-vaccinators are viewed in the public eye. The arguments against MMR revolve around both rhetoric of personal anecdote and arguments that all the diseases that the vaccine prevents are not actually worth vaccinating against because they are "normal childhood diseases." In addition, graphs and statistics are used to support claims that vaccinations did not impact the decline in measles deaths. Although the idea that individuals should be able to make their own decisions about vaccination is still significant as it was in the anti-smallpox vaccination movement in Britain, the use of images has changed. Rather than using images to elicit fear of vaccination, images show that the community has a sense of trust are used to gather information from other parents, and to express the desire for

independence from government authority.





## Human Papilloma Virus Vaccination (Gardasil)

In this section, the human papilloma virus (HPV) vaccine, Gardasil and its position in the anti-vaccination movement will be explored. The HPV vaccine debaters use some of the rhetoric that is common in the anti-DPT and MMR dispute, and share some rhetorical strategies with the smallpox vaccine resistance movement in the 19<sup>th</sup> century. I will highlight the HPV vaccine controversy that has spurred such contention about the necessity, safety and efficacy of the HPV vaccine. Anti-HPV vaccine proponents make leaps from medical claims that not all HPV strains cause cervical cancer to argue that HPV does not cause cervical cancer at all, rendering the vaccine useless. I will also argue that parents on the forums talk about how HPV vaccination is unnecessary and ineffective because with regular Pap smears, the danger of advanced cervical cancer is greatly diminished. In a similar vein, the danger of Gardasil in the sense that it confers a false sense of security about the need for long-term monitoring of cervical cancer risk. The HPV vaccine's potential danger is also demonstrated with appeals to case studies, indicating a relationship that anti-vaccination proponents have with scientific discourse. More so than with MMR or DPT vaccination, anti-HPV vaccine proponents share information from other Internet sources to prove that the vaccine is dangerous. These websites interact with scientific discourse by misrepresenting statistics from clinical trials to show that the vaccine is dangerous and commissioning scientific studies, which they then discuss on the site.

The human papilloma virus (HPV) is a common virus that is responsible for nearly 100% of cervical cancers in women and can cause other malignancies such as vulvar, vaginal, penile, anal and oropharyngeal cancers. Cervical cancer is the second leading cause of cancer deaths among women in the world, with about 12,000 new



cervical cancer cases and 4,000 deaths every year in the United States alone. <sup>136</sup> There are two vaccines available for cervical cancer, Gardasil and Cervarix, although Gardasil is the one most commonly used in the United States. Licensed in June of 2006, the Gardasil vaccine protects against HPV types 16 and 18 that cause cervical cancer most commonly, and against strains 6 and 11 that cause genital warts most frequently. The vaccines are recommended for both girls and boys age 11-12 or up to age 26 if they did not receive the vaccines when they were younger, but the vaccine is approved for children as young as nine years old. It is important to vaccinate against HPV before any sexual activity with another person begins, because it is possible to contract HPV on the first sexual interaction. Additionally, the vaccine produces higher antibody titers at this age than when it is given when individuals are older. <sup>137</sup>

The HPV vaccine has spurred a lot of controversy in the few years that it has been approved for use. Medical researchers Haber et al. at the Florida International University and the University of Indiana School of Medicine critically examined controversy related to the HPV vaccine including the HPV vaccine school mandate. The HPV vaccine school mandate relates to the concern that parents had when in 2006, several states began considering mandated HPV vaccination for girls to enter middle school. In 2007, Texas governor Rick Perry issued an executive order that required all girls to receive the HPV vaccine to enter middle school. This controversy was heightened when it became public that Merck, the company that produced the Gardasil HPV vaccine, contributed significantly to Perry's re-election campaign, indicating a possible conflict of interest. 138

<sup>&</sup>quot;HPV Vaccine- Questions & Answers," last modified July 20, 2012, http://www.cdc.gov/vaccines/vpd-vac/hpv/vac-faqs.htm

<sup>&</sup>quot;HPV Vaccine- Questions & Answers."

Gillian Haber, Robert M. Malow and Gregory D. Zimet, "The HPV Vaccine Mandate Controversy," *Pediatr Adolesc Gynecol* 20: 325-331, accessed 28 March 2014.

Haber et al. also discussed arguments against vaccination of young girls, for example, that giving girls an HPV vaccine encourages them to engage in sexual activity and confers a false sense of security and protection that would lead to sexual promiscuity. Further, a question is why a vaccine that prevents a non-casually transmitted disease would be required for entry to school. There are also concerns about the utility and safety of the vaccine. Opponents to HPV vaccination argue that regular Pap smears can detect irregular cell growth caused by HPV in the cervix and lead to the successful removal of any pre-cancerous lesions before they can harm the patient. As with other vaccines like DPT and MMR, there are questions about whether or not the vaccine is worth the risk of potential side effects and the risk of increase promiscuity while conferring few notable benefits. As for the safety of the HPV vaccine, clinical trials suggested the vaccine had no serious adverse consequences. Despite this, parents questioned why conversations about mandating the vaccine occurred so hastily after the vaccine was licensed and felt that not enough time elapsed to properly assess the long-term risks and insisted that the recommendation of the vaccine was premature.

Parents on mothering.com began discussion of the HPV vaccine shortly after the vaccine was licensed in 2006. Since then, there have been 235 threads on mothering.com under the category of "vaccinations" that include both the words "Gardasil" and "dangerous." Much of the discussion on both mothering.com and mumsnet.org relates to the idea that HPV vaccination gives people an excuse not to be conscientious about getting their regular Pap smears for cervical cancer. On mumsnet.org, bumbleymummy claims, "the vaccine creates a bit of false security. There seem to be an awful lot of

<sup>139</sup> Haber et al, "The HPV Vaccine Mandate Controversy," 326.

<sup>&</sup>lt;sup>140</sup> Haber et al, "The HPV Vaccine Mandate Controversy," 329.

people thinking that if they've had the vaccine, they won't get cervical cancer." The idea that the vaccine creates a false sense of security makes parents question the HPV vaccine and makes them view the adoption of the HPV vaccine as a risk. Similarly on mothering.com, a parent called Wednesday worries about "all the young women who will blow off getting appropriate checkups because "I don't need a pap smear, I got the cervical cancer shot."" This particular argument against HPV vaccination is somewhat supported in the literature. Specifically, a study published in the Journal of Medical Screening by Henderson et al, Primary Care and cancer researchers from the Universities of Oxford, Birmingham and Cardiff in the UK, found that some parents made the decision to vaccinate their daughters because of the understanding that it would save their daughters the discomfort of Pap smears in the future. The study found that daughters who were being vaccinated were actually more knowledgeable the level of protection that the HPV vaccine confers than their mothers, but were generally unaware of cervical screening programs. However, this study concluded that raising awareness about the importance of cervical screening regardless of vaccination status is important when girls are young and when they are of age for cervical screening, but not, as vaccine opponents believe, that HPV vaccination should be avoided because it would reduce intention to screen. 143 The false sense of security that the Gardasil allegedly provides is perceived as a risk to parents, and is used as an argument against HPV vaccination.

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bumbleymummy, October 11, 2013 (9:37 a.m.) comment on mumsnet, "HPV Gardasil," *mumsnet.org*, October 11, 2013,

http://www.mumsnet.com/Talk/vaccinations/a1877958-HPV-gardasil

Wednesday, February 5, 2007 (7:44 p.m.) comment on mothering, "Gardasil lies," *mothering.com*, February 5, 2007,

http://www.mothering.com/community/t/610255/gardasil-lies

Lorna Henderson, Alison Clements, Sarah Damery, Clare Wilsinson, Joan Austoker and Sue Wilson, "'A false sense of security'? Understanding the role of HPV vaccine of

One of the ways that forums argue that HPV vaccination is ineffective in the prevention of cervical cancer is by spreading the idea that HPV does not actually cause cervical cancer. For example, in a thread called Gardasil lies, Ajp argues:

"HPV is *associated* with cervical cancer, not proven to *cause* it. There's a good chance they have it backwards, that precancerous and cancerous cells on the cervix are an inviting place for HPV to live, so it takes up housekeeping and is often detected there, but that the virus is not responsible for the cancer. Where's the solid evidence this vaccine actually would have any impact on cancer? There doesn't appear to be any."<sup>144</sup>

The confusion here relates to the fact that not all HPV strains actually cause problems. In addition to these comments, several parents link their posts to articles that deny a link between HPV and cervical cancer, deeming Gardasil useless. One such article is on NaturalNews. According to the "about" section on the website, NaturalNews is a science-based natural health advocacy organization based in the United States that empowers consumers with information. In an eight-page article called "The Great HPV Vaccine Hoax Exposed", parts of the Federal Drug Administration (FDA) documents regarding Gardasil safety and approval are cited. The article explains, "the FDA knew in 2003 that HPV infections are not associated with cervical cancer" and "HPV is no threat to the lives of young girls...infections resolve themselves, without vaccines. Doctors agree that most strains of HPV resolve themselves on their own. They acknowledge that most strains of HPV do not cause any symptoms at all, and the immune system clears the body of these viruses without much difficulty. However, a leap is being made from a medical claim that not all strains of HPV cause cervical cancer to the claim that, "HPV

future cervical screening behaviours: A qualitative study of UK parents and girls of vaccination age,"

http://www.cdc.gov/hpv/cancer.html



<sup>&</sup>lt;sup>144</sup> Ajp, comment on mothering, "Gardasil lies."

<sup>&</sup>lt;sup>145</sup> Natural News, "The Great HPV Vaccine Hoax Exposed: The Text of the Petition, last modified 2012, http://www.naturalnews.com/Report\_HPV\_Vaccine\_2.html "HPV and Cancer," last modified February 5, 2013,

infections do not cause cervical cancer!" and "it is not the HPV virus that causes cancer but rather a persistent state of ill-health on the part of the patient that makes her vulnerable to persistent infections." Just because not all strains of HPV cause cervical cancer does not mean that no strains of HPV cause cervical cancer—rather, almost 100% of all cervical cancers are caused by HPV. The large readership and rapid exchange of posts on parenting forums helps quickly spread information like that which is contained in this article.

There are also arguments that testing of the Gardasil vaccine is insufficient, and the relative novelty of the vaccine leads to questions about its long-term effects. The distrust in the vaccine stems from distrust of the pharmaceutical industry and leads to doubts regarding the safety of Gardasil, especially related to Gardasil's impact on the fertility. On a mothering.com thread entitled "two sisters claim Gardasil caused their infertility," a news story about two sisters who had premature ovarian failure following Gardasil is posted. The parents discuss the news, and later add the paper referenced in the article to the discussion board. The paper, published in the *American Journal of Reproductive Immunology*, is a case study and the publication was not peer reviewed. Additionally, a causal relationship between Gardasil and ovarian failure is not clear. In a letter to the editor of the case study about the sisters diagnosed with ovarian failure, doctors from the University of Milan argue that the fact that the two victims to infertility were sisters points to a genetic basis to their ovarian failure rather than a vaccine-induced

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<sup>&</sup>quot;The Great HPV Vaccine Hoax Exposed: The Text of the Petition."

<sup>&</sup>lt;sup>148</sup> Serena Colafrancesca, Carlo Perricone, Lucija Tomljenovic and Yehuda Shoenfeld, "Human papilloma virus vaccine and primary ovarian failure: another facet of the autoimmune/inflammatory syndrome induced by adjuvants," *American Journal of Reproductive Immunology* 703 (2013): 309, accessed 12 April 2014.

cause. 149 The paper about the sisters served as a personal anecdote about the dangers of vaccination with the backing of medical science to give it more legitimacy.

One parent, Serenbat, questions whether safety testing for Gardasil was sufficient, especially related to the important and HPV related issue of fertility. She questions the forum, "Why would they *not have* done testing on the effects of the reproduction system? Last time I checked "genitals" were very much a part of the reproduction system. Since the whole reproductive system is to work together, why would one not want to see that testing had been done?" This question spurs more alarm and concern from parents on the forum. Another parent, duckytate, expressed her concern, sharing, "I am so worried that the facts the news will be getting straight in 10 or 15 years will be about the number of girls who can not [*sic*] have babies because they had a Merck shot to protect against a condition that can be effectively treated after you have it," referring to Gardasil's potential effect on fertility. Another parent similarly shared that she had "this niggling feeling that there will be a huge infertility epidemic in oh, 10-15 years?" The fertility cases in question here were shown to be unrelated to the vaccine, as none of the 25,000 patients in whom Gardasil was tested had these symptoms post-vaccination.

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http://www.mothering.com/community/t/560341/gardasil-hpv-vax-vaers-reports "Clinical Review of Biologics License Application Supplement for Human Papillomavirus Quadrivalent (Types 6, 11, 16, 18) Vaccine, Recombinant (Gardasil®) to extend indication for prevention of vaginal and vulvar cancers related to HPV types 16



Paolo Pellegrino, Carla Carnovale, Valentina Perrone, Dionigi Salvati, Marta Gentili, Tatiana Brusadelli, Marco Pozzi, Stefania Antoniazzi, Emilio Clementi, Sonia Radice, "On the Association between Human Papillomavirus Vaccine and Primary Ovarian Failure," *American Journal of Reproductive Immunology* 71: (2014), 4.

serenbat, November 13, 2013, (6:45 p.m.), comment on mothering, "Two sisters claim gardasil caused their infertility," *mothering.com*, November 13, 2013, http://www.mothering.com/community/t/1392875/two-sisters-claim-gardasil-caused-their-infertility

duckytate, comment on mothering, "Gardasil lies."

Laurel273, January 23, 2007 (9:54 p.m.), comment on mothering, "Gardasil HPV vax VAERS reports," *mothering.com*, January 23, 2007,

parents use the uncertainty about the vaccine's safety based on this anecdotal evidence to rationalize their decision not to vaccinate their children against HPV.

More so than on other vaccine forums, that parents who discuss HPV vaccination tend to share links from outside sources like blogs, other websites or scientific papers. Sharing websites in this manner is especially important to understanding how antivaccine messages are spread. One such website is Sanevax.org. The mission of Sanevax is to promote only safe, affordable, necessary and effective vaccines and vaccination practices. 154 The creators of the site "believe in science based medicine" and have the goal to "provide the information necessary for you to make informed decisions regarding your health and well-being." The website has a lot of information about the dangers of certain vaccines, especially Gardasil for HPV. In fact, every link on the home page has to do with HPV vaccination, and to find information about other vaccines, it is necessary to look through the archives. However, this website does not actually feature any vaccinepositive information, and therefore is one sided. The one-sidedness of this website raises questions about its credibility. For example, the CDC website presents the benefits of vaccination against HPV while acknowledging the potential risks that vaccination against HPV might have, including who should and should not be vaccinated. In other words, information about the risks and benefits are available side by side and allows readers to weigh these risks and benefits for themselves. The Sanevax website does not offer a balanced critique of the HPV vaccination, which raises questions about its reliability.

Dissecting the information on the Sanevax "Global Concerns About HPV Vaccines" fact sheet is a good way to outline how anti-vaccine proponents skew

<sup>&</sup>lt;sup>154</sup> Sanevax, "Who We Are," last modified 2013.



and 18," last modified September 8 2008,

http://www.fda.gov/downloads/BiologicsBloodVaccines/Vaccines/ApprovedProducts/ucm111274.pdf.

One fact on the fact sheet states, "it will take decades before the impact of vaccine on cervical cancer is observed." This "fact" implies that there is no known impact of this vaccine on preventing cervical cancer, and that it should not be administered until the outcomes are known. However, reviewing the article that is referenced as the source this fact demonstrates that the purpose of this paper was misconstrued. The article highlights the ways to monitor the impact of the vaccine post-licensure, including some systems that are already used for non-HPV vaccines, and the intentions are to expand these plans in order to monitor the effect of the vaccine. Citing this peer-reviewed article brings credibility to the fact sheet, but upon closer examination, the message of the fact sheet does not communicate the findings in the article. Instead, parts of the article are cherry-picked to make a point about HPV vaccination. This example highlights the need to be critical of the fact sheet's use of scientific articles to argue against HPV vaccination.

Another fact on the Sanevax Global Concerns about VPC Vaccines Fact Sheet states that "in the September 2008, FDA Closing Statement on Gardasil it was noted that 73.3% of girls in the clinical trials developed 'new medical conditions' post vaccination" and that "17 girls died during the clinical trials." After reading this document as provided by the FDA, it is indeed true that 73.3% of subjects who were administered the Gardasil vaccine (N=11778) had new medical history after day one of the trial. This shows that the creators of the Sanevax fact sheet must have read the Closing Statement on Gardasil in order to find this statistic. However, the fact sheet doesn't show is that within the control group who received the placebo, 76.3% had new medical history after

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<sup>157</sup> Sanevax, "Global Concerns About HPV Vaccines," last modified 2011.



<sup>&</sup>lt;sup>155</sup> Sanevax, "Global Concerns About HPV Vaccines," last modified 2011.

<sup>&</sup>lt;sup>156</sup> Lauri E Markowitz et al, "Post licensure monitoring of HPV vaccine in the United States," *Vaccine* 28: 4731-4737, accessed 14 December 2013.

day one of the trial (N=9686). The reports of deaths in the FDA report were also comparable between the Gardasil group and the control, (10 in the Gardasil group and 7 in the control group) and none of the deaths were related to the administration of the vaccine or the control injection. Because the creators of the fact sheet must have read the Closing Statement to find the statistics about the new medical history and deaths, they must have known that they were excluding the information about the new medical history and omitting the fact that seven of the "17 girls [who] died during the clinical trials" were in the control group. The decision to exclude the information about the control group points to an intentional decision of Sanevax to overemphasize the risk of Gardasil vaccination.

For a website claiming to promote science based medicine, Sanevax's efforts to be scientific are debatable. For example, several of the recent articles feature information about dangerous recombinant DNA (rDNA) in the Gardasil vaccine. One article mentioned that, "a biohazard, the rDNA of HPV" was found in the vaccine bound to an aluminum adjuvant. This post was in reference to a study published in *the Journal of Inorganic Biochemistry*, which was sponsored and commissioned by Sanevax. Although the study concluded that the HPV DNA was indeed found in the vaccine samples analyzed, the clinical significance of the DNA fragments "is uncertain." However, the

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<sup>&</sup>lt;sup>158</sup> "Clinical Review of Biologics License Application Supplement for Human Papillomavirus Quadrivalent (Types 6, 11, 16, 18) Vaccine, Recombinant (Gardasil®) to extend indication for prevention of vaginal and vulvar cancers related to HPV types 16 and 18," last modified September 8 2008,

http://www.fda.gov/downloads/BiologicsBloodVaccines/Vaccines/ApprovedProducts/ucm111274.pdf.

<sup>&</sup>lt;sup>159</sup> SaneVax, "Gardasil HPV Vaccines Found Contaminated with Recombinant HPV DNA," last modified December 16, 2011.

SH Lee, "Detection of human papillomavirus (HPV) L1 gene DNA possibly bound to particulate aluminum adjuvant in the HPV vaccine Gardasil," *J Inorg Biochem* 117 (2012) 85-92, accessed 13 November, 2013. Doi: 10.1016/j.jinorgbio.2012.08.015.

authors of the posts about the study on the Sanevax "Research Blog" use the article to argue that more research must be done on "the toxicity of this chemical" and urge medical consumers to "hold national health 'authorities' accountable" to the truth about the safety of Gardasil. Sanevax is engaging with the scientific process by sponsoring studies and highlighting the need for more scientific trials to be done to elucidate the suspected dangers. This engagement with the process of medical research is interesting because it is at a much higher level than engagement with medical research in MMR or DPT. By commissioning the study, Sanevax is more intimately involved in the creation of knowledge. Although the results of the research did not point to any inherent danger of the vaccine, Sanevax was able to use the results to demand that more research be done to determine the safety of the vaccine. The appeals to intensify scientific research are useful rhetorical tools for websites like Sanevax because it is easy to demand more research when results of the study are unclear or leave certain questions unanswered. The fact that Sanevax sponsored this paper and also argues that more research must be done points to the importance of observing the website's claims with more scrutiny.

Arguments for more research about the HPV vaccine appear in relation to other scientific articles as well. Notably, one article that Sanevax references is actually positive towards HPV vaccination, and Sanevax advocates for more research. The paper, by Jessica A. Kahn MD, MPH et al., explains the herd immunity benefits of HPV vaccination in a population of mostly African American women who were between 13 and 26 years old and had had sexual contact. The Sanevax discussion of the article claims that the published study raised more questions than answers, which poses a concern to medical consumers. The study found that a "decrease in vaccine-type HPV not

<sup>161</sup> Jessica A. Kahn et al., "Vaccine-type human papillomavirus and evidence of herd protection after vaccine introduction," *Pediatrics* 130, no. 2 (2012): 249.

only occurred among vaccinated (31.8%–9.9%, P < .0001) but also among unvaccinated (30.2%–15.4%, P < .0001) post surveillance study participants." It also found that nonvaccine-type HPV increased in the vaccinated population but not the unvaccinated population, and explains that this is likely because the people in the vaccinated group reported a lower average age of first intercourse than the vaccinated population, not because suppression of one subtype stimulates the growth of other types. <sup>163</sup> However Sanevax has questions about what the study means. They argue that test results from a population with high disease prevalence cannot be extrapolated to the general population, and in turn, that the herd benefit is non-existent. They also question if this study provides "evidence of herd immunity or potentially dangerous HPV mutation/type replacement?" in reference to the increase in non-vaccine-type HPV in the vaccinated population. <sup>164</sup> This hypothesis in the Sanevax article is ration and more in depth evaluation of the mechanisms of resistance to HPV subtypes should be studies. However, this does not provide an argument that the overgrowth of the non-vaccine subtypes is harmful, and should not discourage vaccination. Sanevax uses articles published in medical journals to push for more research about HPV vaccine safety, and while the call for more research may be appropriate, it also supports the uncertainty about the risks and benefits of HPV vaccination.

The arguments against HPV vaccination on parenting forums are unique and interesting, especially considering the controversy surrounding mandating the HPV vaccination for young girls. Parents on the forums purport that the vaccine should not be

<sup>162</sup> Kahn, Jessica A, "Vaccine-type human pappilomavirus and evidence of herd protection after vaccine introduction," 252.

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<sup>&</sup>lt;sup>163</sup> Kahn, Jessica A, "Vaccine-type human pappilomavirus and evidence of herd protection after vaccine introduction," 253.

<sup>&</sup>lt;sup>164</sup> SaneVax, "New study: HPV Vaccine Evidence of Herd Immunity or Type Replacement?," last modified July 18, 2012.

mandated because it cannot be causally transmitted, and also that it has the potential to create a false sense of security about HPV susceptibility. Arguments are also made about skepticism surrounding the actual cause of cervical cancer, questioning whether or not HPV is actually the causal agent of cervical cancer. On the forums and websites that parents post to the forums, leaps are made from the medical claim that not all strains of HPV cause cervical cancer to the idea that none of the strains cause cervical cancer, rendering the vaccine useless. Parents also worry about the safety of the vaccine, questioning its effect on fertility. They include websites like Sanevax in their arguments, which have anti-vaccine materials with information that can be misleading because it is presented in a very one-sided way. Sanevax also engages directly with the scientific process by commissioning studies and interpreting them in ways that support an anti-vaccine position. Parenting forums are important venues for anti-vaccine ideas coming from websites like Sanevax to get more exposure to anti-vaccination trends.



## Conclusion

Vaccination was mandatory in mid 19th to early 20th century Britain to prevent the spread of smallpox. The practice of vaccination, which involved cutting into the flesh with a lancet and rubbing vaccine matter into the wounds, was unsanitary often led to infection. As soon as mandatory vaccination was instated, anti-smallpox vaccination sentiment grew out of pre-established dissenting groups such as feminists, vegetarians, the followers of alternative medical traditions, religious dissenters, groups focused on bodily purity, and the middle and working class. These groups used an array of strategies to gain support for their resistance to vaccination. The middle class employed rhetoric of personal freedom, resenting the government's control. The working class and poor, which still concerned about individual freedoms, focused on the desecration of the physical body of individuals, and were angered that the government explicitly targeted the poor people who were stereotyped as dirty and disease-ridden. Both passive tactics such as lying to avoid vaccination and active forms of protest like marches and attacking physicians were not uncommon. These manifestations of dissent accompanied anti-

vaccination propaganda, which depicted the gruesome side effects of infection following vaccination. The resistance to the practice of vaccination itself, which was unsanitary, was easy to rationalize because of the physical, visible manifestations of vaccination and the high incidence of infection after the procedure. Arguments against vaccination often appealed to negative incidents, such as rotting flesh and disease after an unsanitary vaccination, and anti-vaccinators spread this message with visual images in pamphlets and other publications.

The pre-established dissenting groups were important in mobilizing people against smallpox vaccination, using arguments of individual freedom to move forward their claims. But are anti-vaccinators of today parts of other dissenting groups? Is membership in these groups important for anti-vaccine sentiment? As online profiles of forum posters are publically available, it is possible to view the profiles of parents who commented frequently on anti-vaccine forums, and to go into their online profiles to see if they posted comments in forums associated with other groups. From this search, it is possible to see whether or not underlying dissenting movements motivate anti-vaccine attitude. The following parents on mothering.com provide insight into the relationships between other dissenting groups and the anti-vaccination arguments found on the Internet.

Kathymuggle, a parent who posted 3028 times on mothering.com between July 2012 and March 2014, posted only 152 times about issues in threads that were not within the categories "I'm not vaccinating", "Vaccination Debate" and "Selective & Delayed Vaccination." This means that 95% of her posts are on these threads. Some of the other threads that she posted in were within "Parenting (40)," "Women's health (19)," "Preteens and Teens (18)," "Unschooling (16)," Special needs parenting (16),"



"Nutrition and good eating"/"Vegetarian and Vegan" (7) and "Breastfeeding" (3), "Gentle Discipline" (5), "Homebirth (2)." From these examples, the theme of natural living, which is the purpose of the mothering.com website, is apparent. Parallels can be drawn between the forums about nutrition and dietary choices with the vegetarians of the anti-smallpox vaccination movement. However, since this parent clearly has a larger investment in vaccination choice, it is safe to assume that the alternative living groups she posted in were not mobilizing her vaccine dissent.

Another mothering.com parent, Micah\_mae\_, who describes herself as "a loving, breastfeeding, baby wearing, cosleeping mama to two boys (so far) and a wife to my soldier husband" is a lot more active on non-vaccine-related threads than Kathymuggle. Between July 2010 and March 2014 she posted 1179 times, and on the I'm Not Vaccinating thread 12 times and "Vaccinations Debate" thread a total of 10 times. Many of the threads that she posts on have to do with "Living Frugally & Finances" (70), "Homebirth" (56), "Single Parenting" (25), "Gentle Discipline" (8), "I'm Pregnant" (25) and "Fitness and Weight Management" (10). Connections between these groups and the Victorian anti-smallpox movement could be the idea of homebirth as opposed to a birth in a hospital. This pattern is opposite of Kathymuggle's posting preferences, as the majority of Micah\_mae\_'s posts are on non-vaccine related threads. This shows that interest in other groups does not necessarily mobilize vaccine opposition, but may have in this specific case.

Ssun5, whose first post was in September of 2011, posts almost exclusively in the non-vaccinating forums. Out of 134 on the site in total, there was only one that was not related to vaccination (it was about supplement usage for brittle hair). This individual does not seem to identify closely with any other sort of groups on the site.



Taximom5, like Kathymuggle and ssun5, posted primarily in non-vaccinating threads. Out of the 2502 times that she posted between January 2012 and March 2014, only 32 of them were on non-vaccine threads. These sparse posts related to special needs parenting (7), "Babywearing (4), "Dental" (3), "Breastfeeding/lactivism/child-led weaning" (3), "Preteens and Teens" (2), "Life with a Toddler" (1), "Nutrition and Good Eating" (1) and "Unschooling" (1).

There are a few commonalities among these individuals. Firstly, many of them are interested in what could be considered "natural living," which makes sense as mothering.com and its associated forums are dedicated to the natural living philosophy. They have an interest in breastfeeding, being gentle parents, nutrition and more. However, the interest level in anti-vaccine conversations compared with other conversations makes it difficult to declare whether or not the common interests spur their anti-vaccine sentiment or their anti-vaccine sentiment led to their common interests. Because some parents comment almost exclusively on non-vaccine threads and others are much more varied in their vaccine forum time investment, it is unlikely that the common interests drive the anti-vaccine sentiment. Additionally, this idea is supported in the sense that there are people who use the website and are interested in "natural living" groups and do not post in vaccine discussion threads. Although the natural living theme among anti-vaccine proponents likely did not drive anti-vaccine movement on Internet forums, the existence of these links should not be ignored.

Today, all of the aforementioned anti-vaccine forums appeal in some way to a certain danger in vaccination, as was one of the main arguments of anti-smallpox vaccine activism in 19th Century Britain. Yet, the sanitary process vaccination today that has replaced vaccination with a lancet causes a different type of danger. The negative



incidents that allegedly occur post-vaccination are not visible infections or graphic scars, hence, simple appeals to danger of the vaccines through a photograph are not convincing enough.

Anti-vaccine proponents on Internet forums employ a variety of contemporary strategies to rationalize and defend their decisions not to vaccinate, because the lack physically visible complications from vaccination mean that the original graphic images are not enough to convince people of vaccine dangers. The forums developed a more multifaceted approach to anti-vaccination arguments than existed in 19<sup>th</sup> and early 20<sup>th</sup> century Victorian Britain. While personal anecdotes continue to appeal to the danger of the vaccines, now the arguments also appeal to the necessity and efficacy of the vaccines. The rhetoric throughout the forums is varied—especially in the way that parents appeal to science in their arguments against different vaccines.

The anti-DPT, MMR and HPV vaccination proponents all argue that the vaccines are dangerous. The danger of DPT is communicated through personal anecdotes. Stories of children getting seizures after DPT are relatively common. Although physicians attribute these episodes to the fact that the age when DPT is given is typically the same time when neurological conditions develop in children, the personal anecdotes are still compelling to parents who are questioning vaccination.

The MMR vaccine garners a different sort of argument from the parents on the forums regarding safety and danger. The MMR opponents seem to reject the scientific arguments that the MMR vaccine does not cause autism. Although parents do not admit to being convinced of the danger of MMR by Andrew Wakefield's study, they still defend his arguments that MMR causes autism. Personal anecdotes that parents share act

as scare tactics to question the safety of the vaccine, communicating their own experiences of possible side effects to forum readers.

Parents on forums also argue that the HPV vaccine could be dangerous. Firstly, they explain that the false sense of security that HPV vaccination could engender is a liability—if people are vaccinated, they might not be as inclined to get regular Pap smears to check for cervical cancer. They also declare that the HPV vaccine has not been around long enough, and distributing the vaccine before long-term effects can be determined is risky. They assert that vaccine trials were not adequate because no assessment of the long-term effects of the vaccine was performed. In order to bolster this point, they turn to case studies of girls who lost their fertility after Gardasil, and wonder about the long-term side effects of the vaccine on the fertility of young girls who receive it. Unlike the attitude towards MMR and autism, these parents are not rejecting the science behind the HPV vaccine, but rather realize that scientific backing is important, and want more research—meaning more testing on things like long-term effects and the effects on reproductive organs to address their points.

On the Sanevax website, there is a marked interaction with scientific studies. For one, Sanevax became involved with the creation of knowledge when it sponsored a study about recombinant HPV DNA in the Gardasil vaccine. Although the study was not conclusive about the danger of the vaccine, this was still an opportunity for Sanevax to debate with the results of the study and demand that the truth about vaccine safety be illuminated. Sanevax also relates to studies that are explicitly positive towards HPV vaccination, arguing that those studies are performed on the wrong populations and cannot be extrapolated to the general population. By questioning methodology, Sanevax

ignores results that advocate for HPV vaccination and instead seeks more studies to prove that HPV vaccination is dangerous.

Further, Sanevax cites the scientific literature, but does so in a way that bolsters their arguments that vaccination is wrong. For example, Sanevax shows that adverse effects and deaths happened in Gardasil trials, but did not mention that there was no significant difference in number of deaths or adverse effects in Gardasil group vs. the control group in the trials. This misrepresentation of statistics published by the FDA portrays Gardasil as dangerous, and only shows one side of the picture, whereas other sources, like the CDC website, show a more balanced view of vaccines.

Arguments that vaccines are ineffective are used in concert with arguments challenging the safety of vaccines. To explain how the DPT vaccine is ineffective, parents on the forums use scientific language to substantiate their claims. Words like "antibody" and "bronchial" bolster perceptions of validity. For example, the idea that "natural immunity" is better than vaccine-mediated immunity permeates the conversation, especially related to pertussis. Parents argue that they would rather have their child get pertussis so that they would have immunity from the illness for a longer than the vaccine confers. They also use statistical arguments about vaccination and selectively use statistics that help bolster the parents' arguments. For example, they explain that more vaccinated individuals actually suffer from pertussis than unvaccinated individuals. However, they ignore the relevant statistic that unvaccinated individuals are eight times more likely to contract pertussis than vaccinated individuals, and in this way support the ineffectiveness argument.

Another way that anti-vaccinating parents subtly argue against vaccination is through the use of skeptical language that is not commonly used outside of the forums.

Calling vaccine preventable diseases (VPDs) vaccine available diseases (VACs) shows that they are not confident that the vaccines actually prevent the illnesses the claim to prevent.

Parents similarly selectively use data to argue that the MMR vaccine is ineffective. Graphs with accompanying text and misrepresent the impact that vaccines have had on measles mortality in the 20<sup>th</sup> century, showing a linear decrease over the 20<sup>th</sup> century rather than an exponential one because of the choice to use a logarithmic scale. Using the logarithmic scale has the effect of making the MMR vaccine seem like it had no significant impact on measles mortality.

Another argument made on the forums is that HPV does not cause cervical cancer, so the HPV vaccine would not be effective in preventing cervical cancer. On these forums, leaps are made from evidence that that not all strains of HPV cause cervical cancer to the idea that none of the strains cause cervical cancer, rendering the vaccine ineffective against cancer and otherwise useless.

Aside from the argument that HPV vaccine is ineffective and also unnecessary because it does not prevent cervical cancer, parents discuss how other vaccines are unnecessary, like the MMR. Parents on the forums argue that the diseases that MMR protects against (measles, mumps and rubella) are not dangerous diseases, but rather "normal childhood diseases" so they are not worth vaccinating against.

User-generated information, like the information seen on vaccine forums, is unregulated and open to use by virtually anyone with access to a computer. Individuals can easily be influenced by information found on these forums. For this reason, it is important to understand how and why people argue against vaccination, because if their

arguments are sufficiently convincing and vaccination rates dip below the threshold for herd immunity, it puts populations at risk.

As is visible in the anti-vaccine parenting forums, there are strong communities of people who question vaccinations. At first, I approached this project with the mindset that anti-vaccine proponents are uneducated and unwilling to cooperate with the vaccination process that has proven to be one of the most effective public health efforts of history. I was curious how to best communicate with these individuals. However, after reviewing the historical background, witnessing the conversations on forums and the information that exists on the Internet, and thinking about the impact this movement may have on society, I realized that stopping this movement is a daunting task.

As in 19<sup>th</sup> century Britain, the parents of today care for their children, but today's parents educate themselves on how to best do this with 21<sup>st</sup> century methods—namely, the Internet. There are similar sentiments today and in the 19<sup>th</sup> and early 20<sup>th</sup> centuries about the power of individuals to make decisions for themselves based on the information that they have. Today, there is a lot of information about vaccines on the Internet, and there are people who have vested interests in making sure this information gets spread, whether it is to validate the cause of their child's disabilities or bring in advertising revenue on their website. As long as these people exist and have access to public forums, it will be very difficult to stop the spread of anti-vaccine sentiment.



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