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Gretta Richardson

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## INDIVIDUAL BODIES, INFORMED CONSENT, AND SELF-DETERMINATION: A RHETORICAL ANALYSIS OF THE VACCINE REFUSAL MOVEMENT

by

## GRETTA K. RICHARDSON

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

### **PROFESSOR THOMAS KIM**

### **PROFESSOR MARK GOLUB**

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#### **INTRODUCTION**

On January 25, 2018, Governor Jay Inslee declared a state of emergency in Washington State. Despite the eradication of measles from the United States in 2000, local officials reported 55 confirmed cases in Clark County, Washington, just north of Portland, Oregon.<sup>1</sup> Overall, vaccination rates in the United States remain high. Due to mandatory vaccination, which requires people to have obtained certain vaccinations before attending public school, an estimated 90 to 95 percent are vaccinated.<sup>2</sup> However despite strong federal vaccination legislation, Washington and 17 other states, allow philosophical exemptions, meaning parents can excuse their children from vaccination by citing any personal objection.

Despite high rates of vaccination overall, those seeking philosophical exemptions tend to cluster geographically. In Clark County, some public schools reported vaccine rates under 40 percent, which threaten herd immunity and allow for the disease to spread rapidly.<sup>3</sup> The outbreak gained mass media attention and centered vaccine refusal on the national stage. It spurred an onslaught of criticism for parents that participate in vaccine refusal for philosophical exemptions, many calling them "conspiracy theorists," "stupid," or "selfish."<sup>4 5 6</sup> This project seeks to examine the

<sup>&</sup>lt;sup>1</sup> United States, Center for Disease Control and Prevention, *Measles History*, February 5, 2018, accessed March 22, 2019.

<sup>&</sup>lt;sup>2</sup> United States, Center for Disease Control and Prevention, *Immunization*, March 17, 2017, accessed March 22, 2019.

<sup>&</sup>lt;sup>3</sup> Clark County, Washington, Public Health, Measles Investigation (2019).

<sup>&</sup>lt;sup>4</sup> Jon Sarlin, "Anti-vaccination Conspiracy Theories Thrive on Amazon," CNN, February 27, 2019, accessed March 22, 2019.

<sup>&</sup>lt;sup>5</sup> Catherine Ball, "The Anti-vaxx Movement Has Reached Peak Stupidity – More than Half of US Parents Believe Immunization Causes the Flu," *The Independent*, January 3, 2019, accessed March 20, 2019.

<sup>&</sup>lt;sup>6</sup> Nadine Gartner, "How Do You Get Anti-vaxxers to Vaccinate Their Kids? Talk to Them — for Hours." *The Washington Post*, February 19, 2019. Accessed March 10, 2019.

rhetoric of the vaccine refusal movement and dissect the narratives provided by the movement that perpetuate and promote vaccine refusal.

Despite the widespread success of vaccinations, vaccine hesitancy or refusal is on the rise amongst white, affluent families. This wave has been bolstered and expanded by a study conducted by Andrew Wakefield that speculated that the measles vaccine, MMR, was associated with autism in children.<sup>7</sup> Although the study retracted in 2004 due to falsified evidence, the work still created mass distrust for vaccines, vaccine refusal, and decreased immunization rates. The study is still cited by anti-vaccine advocacy groups and nonprofits as evidence of scientific doubt in vaccinations. Parents reject vaccinations for a variety of reasons, such as distrusting science and the pharmaceutical industry, a belief that vaccines are untested or may cause their children harm, or that the government does not have the authority to impose certain healthcare measures on their children. Parents receive information from a variety of sources including non-profit organizations, lobbying and advocacy groups, and celebrities and politicians, and social media and blogs. For this project, I examined newsletters, published work, and press releases from several anti-vaccine or vaccine-choice groups as well as interviews and released statements from leaders in the anti-vaccination movement in an attempt to understand the rhetorical themes and narratives these groups were promoting. In this project, I will analyze the rhetoric of the anti-vaccination movement and how it appeals to ideas of individual choice, bodily autonomy, and the habit of being self-determined, independent, and self-reliant.

<sup>&</sup>lt;sup>7</sup> Fiona Godlee, "Wakefield's Article Linking MMR Vaccine and Autism Was Fraudulent," *The BMJ*, March 15, 2011.

#### HISTORICAL CONTEXT

Vaccination is considered to be one of the greatest achievements in public health. Success in immunizations is largely attributed to increased life expectancy and the eradication of many infectious diseases, such as polio in the United States and smallpox globally.<sup>8</sup> However, vaccine skepticism and resistance to mandatory vaccination has existed as long as the vaccines themselves. Vaccines have extremely low rates of adverse complications, and more serious side effects are extremely rare. For example, less than one child out of one million will develop long-term seizures after receiving the DTaP vaccine, which develops immunity to deadly diseases caused by bacteria such as tetanus, whooping cough, and serious infections such as diphtheria.<sup>9</sup>

Through widespread acceptance and usage, they generate and maintain herd immunity, a public good necessary to prevent disease, particularly for those who are unable to receive immunizations due to medical conditions or age. In the middle of the 19th century, the United Kingdom passed a series of legislative acts aimed at increasing smallpox vaccination rates. In 1853, Parliament mandated that all babies receive the smallpox vaccination within three months of birth and subsequent laws expanded this requirement to include older children and introduced penalties for non-compliance.<sup>10</sup> In the United States, public health legislation is largely left to individual states, and some states, such as Massachusetts and New York, followed the United Kingdom and made vaccines mandatory for children to enter public school.<sup>11</sup> The first wave of vaccine

<sup>&</sup>lt;sup>8</sup> "Ten Great Public Health Achievements -- United States, 1900-1999," *Morbidity and Mortality Weekly Report:* April 2, 1999, accessed April 12, 2019.

<sup>&</sup>lt;sup>9</sup> United States, Center for Disease Control and Prevention, *DTaP (Diphtheria, Tetanus, Pertussis) VIS,* August 24, 2019, accessed April 12, 2019.

<sup>&</sup>lt;sup>10</sup> Nadja Durbach, *Bodily Matters: The Anti-vaccination Movement in England, 1853-1907*(Durham, NC: Duke University Press, 2005).

<sup>&</sup>lt;sup>11</sup> Navin, Mark. Values and Vaccine Refusal: Hard Questions in Ethics, Epistemology, and Health Care.

refusal movements emerged in direct response to compulsory vaccination laws in the United Kingdom and the United States. Resistors in the United Kingdom formed the National Anti-Vaccination League which organized support for vaccine choice and pressured the British Labour Party to adopt a commitment to "No Compulsory Vaccination" in their 1900 General Election Manifesto.<sup>12</sup> In the United States, parallel groups formed such as the Anti-Vaccination Society of American, the New England Anti-Compulsory Vaccination League, and the Anti-Vaccination League of New York City. These groups had a varying list of demands and motivations for opposing mandatory vaccination. Some believed that vaccines violated biblical teachings on bodily mutilation, others that vaccines were untested and deadlier than the diseases themselves and still others believed that the government did not have the right to mandate vaccination.<sup>13</sup> The anti-vaccine movement remains diverse in motivations and beliefs and some of these themes have continued to the present day.

The anti-vaccination movements of the 19th century successfully pressured the United Kingdom to pass laws providing a means for "conscious objectors" or vaccine refusers to be exempt from mandatory vaccinations.<sup>14</sup> In response to the antivaccination movement, the United States Supreme Court held that in *Jacobson v*. *Massachusetts*, that mandating vaccines and fines for non-compliance was a legitimate exercise of state's power in order protect the public health and safety of its citizens.<sup>15</sup> The Court found that local boards of health determined when compulsory vaccinations

London: Routledge, 2018.

<sup>&</sup>lt;sup>12</sup> Dale, Iain. Conservative Party General Election Manifestos, 1900-1997. London: Routledge, 2000.

<sup>&</sup>lt;sup>13</sup> Navin, Mark. Values and Vaccine Refusal: Hard Questions in Ethics, Epistemology, and Health Care. London: Routledge, 2018.

<sup>&</sup>lt;sup>14</sup> Navin, Mark. Values and Vaccine Refusal: Hard Questions in Ethics, Epistemology, and Health Care. London: Routledge, 2018.

<sup>&</sup>lt;sup>15</sup> "Jacobson v. Massachusetts." Oyez. Accessed 22 April. 2019.

were necessary, which made the requirement reasonable and not arbitrarily imposed. However, this decision did not uphold the constitutionality of forcible vaccination, only that states have the power to impose economic or social punishments on vaccine refusers, such as fines or exclusion from workplaces or schools.<sup>16</sup>

During World War I, the United States used propaganda machines to urge men to enlist and encourage support for the war effort on the home front through buying bonds and reporting neighbors they believed were disloyal to the country. Public health officials used these same mechanisms to encourage vaccination and discourage participation in anti-vaccination movements by portraying vaccine refusal as unpatriotic, domestic treason, and self-sabotage.<sup>17</sup> Government effort to utilize values of patriotism, nationalism, and collective action to promote vaccination programs, continued and expanded through World War II.

Recently, parents in the United States, Australia, and the United Kingdom are increasingly refusing routine vaccines for their children. While rates of refusal for childhood vaccinations are low, an increasing number of parents are choosing to refuse certain vaccines or slow down their child's vaccination schedule. The most commonly refused vaccination is the MMR vaccine, which prevents measles, mumps, and rubella. Some parents today are concerned that the MMR vaccination may cause or contribute to autism spectrum disorders. This is partially due to a retracted study by Andrew Wakefield that found a link between inflammatory bowel disease and behavior regression caused by the MMR vaccine to protect against measles, mumps, and rubella.

<sup>&</sup>lt;sup>16</sup> "Jacobson v. Massachusetts." Oyez. Accessed 22 April. 2019.

<sup>&</sup>lt;sup>17</sup> Navin, Mark. Values and Vaccine Refusal: Hard Questions in Ethics, Epistemology, and Health Care. London: Routledge, 2018.

However, despite the study being debunked by multiple scientific groups, vaccination rates have not recovered in certain geographic hotspots, making areas susceptible to a disease outbreak.

#### LITERATURE REVIEW

My project will attempt to thematically group and analyze the rhetoric of the anti-vaccination movement. Shockingly, despite mass media attention focused on vaccine refuser parents, there have been few scholarly projects dedicated to this subject. Many public health experts have investigated how local and national policy allowing for philosophical exemptions have decreased vaccination rate.<sup>18</sup> Many scholars note that vaccine refusers gather their information from an online network of bloggers, nonprofits and advocacy groups, as well as politicians and celebrities. However, few scholars have analyzed or thematically grouped the information and communications coming from these sources in order to better understand the movement as a whole.

In 2011, Larson and Cooper found that public decision making related to vaccine acceptance is driven by a mix of psychological, sociocultural, and political factors, all of which need to be understood and considered by policymakers and public health officials.<sup>19</sup> Empowered by the internet, current anti-vaccination groups have new levels of global reach and influence and are able to rapidly share information and organize. Internet usage has changed a once top-down, expert to consumer or doctor to

<sup>&</sup>lt;sup>18</sup> Jacqueline K. Olive et al., "The State of the Anti-vaccine Movement in the United States: A Focused Examination of Nonmedical Exemptions in States and Counties," *PLOS Medicine* 15, no. 6 (June 12, 2018): accessed February 22, 2019.

<sup>&</sup>lt;sup>19</sup> Heidi J. Larson et al., "Addressing the Vaccine Confidence Gap," *The Lancet* 378, no. 9790 (2011): accessed February 10, 2019

patient communication, towards a non-hierarchical, dialogue-based communication through which the public can question the recommendations of experts and public institutions based on their own internet research. Larson and Cooper found that this "democratization of expert thought" allows for dissenting groups, such as the antivaccination movement to possess a larger voice in the conversation about vaccine policy. Additionally, the media attempts to balance coverage and create equal opportunity for all viewpoints, which allows small extremist views the same space as scientifically validated views. However, although Larson and Cooper recognize the power of anti-vaccination social networking groups, this study focuses on the methods and strategies of communication and fails to look at the actual rhetoric perpetuated and supported by the anti-vaccination movement as a whole.

In 2014, Jennifer Reich interviewed 25 mothers who rejected recommend vaccines and examined the gendered discourse of vaccine refusal.<sup>20</sup> She found that vaccine refuser mothers deemed themselves to be experts on their children and weighed the perceived risks of infection against their perceived risks of vaccines while dismissing expert claims that vaccines are necessary. Many parents believed that their own intensive mothering practices surrounding nutrition and natural living were superior means of supporting their child's immunity and were sufficient to protect against a variety of infectious diseases. Additionally, many parents attempt to control risk through careful monitoring of social exposure, believing disease lays outside of their social networks. Reich asserts that these ideas frame vaccination as an individual choice and that individuals should actively manage themselves and their children and

<sup>&</sup>lt;sup>20</sup> Jennifer A. Reich, "Neoliberal Mothering and Vaccine Refusal," *Gender & Society* 28, no. 5 (2014)

avoid calculable risk through informed decision making rather than collective government action. Discourse, Reich asserts, that emerges from neoliberal ideologies of the 20th century.

In 2006, Benin, Wisler-Scher, and Colson conducted a similar study, concluding that attempts to provide care to children with vaccine-skeptic mothers must not only on present facts about vaccines but should focus on developing trusting relationships between mothers and health professionals.<sup>21</sup> While both of these studies examine the rhetoric of mothers and their decision-making to not vaccinate their children, neither Benin, Wisler-Scher, and Colson, nor Reich examines the rhetorical themes of the communication and information sources that they may be consuming.

There is extensive sociological research on the role of choice in parenting, particularly mothering. Bobel conducted multiple studies centering women she defined as "natural mothers," or those who reject mainstream parenting advice in favor of natural and instinctive mothering practices. Through her research, she inferred that they "wrested control of their personal lives away from institutions and experts and others who claim to 'know best' and return to the site of the individual family."<sup>22</sup> Bobel and Reich seem to agree, that through intensified parenting whether it be vaccine refusal or organic eating, mothers advocated for individual choice, self-autonomy, and managing for their children over collective action. Additionally, Kaufman and Silverman examined how mothers become advocates for their children's' health needs, often

<sup>&</sup>lt;sup>21</sup> A. L. Benin, "Qualitative Analysis of Mothers Decision-Making About Vaccines for Infants: The Importance of Trust," *Pediatrics* 117, no. 5 (2006), accessed February 16, 2019,

<sup>&</sup>lt;sup>22</sup> Shu-Ju Ada Cheng and Chris Bobel, "The Paradox of Natural Mothering," *Contemporary Sociology* 32, no. 2 (2003), accessed February 11, 2019.

identifying themselves as "experts" in their child's health, above the authority of medical professionals.<sup>23 24</sup>

Although Reich does examine the rhetoric of vaccine refusal mothers, she fails to dissect the communication presented to them and how they absorb and dissect media from nonprofit groups or other sources. My project will build on Reich's frames but examine the language and targeting of anti-vaccination advocacy groups and the formal communication of the movement and rather than the rhetoric of individual parents. However, I predict I will encounter similar themes favoring individual decision-making rather than collective action in the mass communication efforts surrounding the antivaccination movement.

#### METHODOLOGY

This project seeks to analyze the rhetoric of the anti-vaccination movement. I have collected data from several types of sources as I am attempting to encompass the anti-vaccination movement as a whole. Vaccine refuser parents gather their information from a variety of sources including nonprofits, blogs, and social media pages. Additionally, there are vaccine refusal or vaccine choice activist groups which work to promote their ideals in the political arena through lobbying against increased restrictions to philosophical vaccine exemptions. Initially, I aimed to investigate rhetoric advocating for abstaining from all vaccinations. However, vaccine refusers are

<sup>&</sup>lt;sup>23</sup> Sharon R. Kaufman, "Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom," *Ethos* 38, no. 1 (2010), accessed January 22, 2019

<sup>&</sup>lt;sup>24</sup> Chloe Silverman, "Understanding Autism: Parents, Doctors, and the History of a Disorder," *Princeton University Press*, 2011, accessed February 22, 2019.

a diverse group without clear membership lines and as I gained more information, it became increasingly clearer that few parents refuse all vaccinations for their children. The vast majority of vaccine refusers reject certain vaccinations or slow the schedule of their child's vaccination. I have decided to expand my definition of the anti-vaccination movement to include those who advocate for vaccinating on a schedule other than that is recommended by state law and medical organizations.

I acknowledge that this data is only a small sample of all the available information, particularly regarding the vast sea of social media content and blogs creating and spreading information about the anti-vaccination movement. Although it would be impossible to analyze every blog and publication, I chose a variety of types of sources to attempt to identify overarching themes of the mobilization and explain and understand further the arguments for vaccine choice. In totality I analyzed over 130 published works, such as press releases, newsletters, interviews, and other communications.

#### **Non-profit Organizations**

This project examines press releases, newsletters, and other published media from two prominent nonprofits, Generation Rescue and VacTruth. These nonprofits are information sources for vaccine-skeptic and vaccine refuser parents, as well as cited by bloggers and social media pages which provide information to the vaccine refusal grassroots movement.

VacTruth was founded by Jeffry John Aufderheide. The site supports expanded vaccine research and testing and has over 75,000 subscribers.<sup>25</sup> This project analyzed 55 newsletters from VacTruth from March 2016 to March 2019.

Generation Rescue is a leading national organization dedicated to immediate treatment assistant to families affected by autism spectrum disorders.<sup>26</sup> Generation Rescue believes that autism is primarily caused by environmental factors, specifically vaccines. The organization was started in 2005 by Lisa and J.B. Handley but has become the platform for former model and television personality, Jenny McCarthy's vaccine refusal advocacy. McCarthy's son was diagnosed with autism in 2005 and her celebrity status has drawn attention to the vaccine refusal movement. This project performed a rhetorical analysis on Generation Rescue's guide, "Vaccine Safety: Making the Most Informed Decisions for Your Family."<sup>27</sup>

#### **Lobbying and Activist Groups**

This project analyzes advertisements and publications from three advocacy groups, the National Vaccine Information Center (NVIC), Physicians for Informed Consent, and Children's Health Defense from March 2016 to March 2019. Each group used distinct methods to target their constituencies and adhere to individual mission statements. Many have participated in crafting legislation for expanding philosophical vaccine exemptions or compensating vaccine injury victims. These advertisements are

<sup>&</sup>lt;sup>25</sup> Abby Haglage, "The Navy Fraud Fronting the Anti-Vaxxer Movement," *The Daily Beast*, February 6, 2015, accessed March 18, 2019.

<sup>&</sup>lt;sup>26</sup> "Who We Are," Generation Rescue | Jenny McCarthy's Autism Organization, accessed April 20, 2019,

<sup>&</sup>lt;sup>27</sup> Generation Rescue, Your Complete Guide to Vaccine Safety: Making the Most Informed Decisions for Your Family (2017).

targeted towards general audiences and as well as elected officials. This project includes the National Vaccine Information Center (NVIC) press releases, and newsletters. NVIC is one of the oldest and largest pro-vaccine choice nonprofits. Barbara Loe Fisher, Jeff Schwartz, and Kathi Williams founded NVIC after observing the health of their children deteriorate after receiving a dose of the DPT vaccine. In the early 1980s, NVIC joined the American Academy of Pediatrics to co-author the National Childhood Vaccine Injury Act of 1986. This act created a federal vaccine injury compensation program and mandated that medical professionals provide parents with vaccine risk information.<sup>28</sup> This project includes 30 newsletters and 10 press releases from the NVIC.

Physicians for Informed Consent is an activist group formed by a coalition of doctors dedicated to expanding informed vaccination consent with the ultimate goal of a society without mandatory vaccination laws.<sup>29</sup> This project examined 8 press releases, including 2 letters to the U.S. Senate Committee on Health, Education, Labor & Pensions and the U.S. House Committee on Energy and Commerce.

Lastly, Children's Health Defense, formerly known as the World Mercury Project, is a nonprofit organization founded by Robert F. Kennedy Jr. which works to improve children's healthcare by eliminating mandatory vaccinations. For this project, I analyzed 28 press releases and newsletters produced by the Children's Health Defense.

<sup>&</sup>lt;sup>28</sup> "About National Vaccine Information Center," National Vaccine Information Center (NVIC), accessed February 10, 2019.

<sup>&</sup>lt;sup>29</sup> "About," Physicians for Informed Consent, February 5, 2019, accessed April 23, 2019.

#### **Celebrity and Politicians' Statements and Interviews**

Politicians and celebrities such as Robert F. Kennedy Jr, Pres. Donald Trump, Jim Carrey, Michele Bachmann, and Rand Paul have given validity to claims of vaccine-risk and inefficiency, I analyzed several statements, interviews, and op-eds from March 2016 to March 2019. Additionally, I will include the U.S. Senate Committee on Health, Education, Labor, and Pensions full committee hearing, "Vaccines Save Lives: What is Driving Preventable Disease Outbreaks?" from March 5, 2019.<sup>30</sup>

In order to narrow the vast amount of information available to me, I have decided to examine a time frame of March 2016 to March 2019. I chose these parameters because I want to include as much recent information as possible to keep my project relevant and up to date with the current media vaccine refusers are consuming. I have chosen a three-year frame to narrow down the amount of information available to me. If I had more time for this project, I would have chosen a larger time frame and I acknowledge this is a flaw in my data collection.

I have decided to omit social media pages, posts, and blogs. Although many vaccine refusers cluster in online communities, such as Facebook groups, Reddit threads, and Pinterest pages, it is extremely difficult to measure individual bloggers influence and distill which pages are the most dominant and reaching the most people. Additionally, with the emergence of "bots" on social media platforms, it becomes nearly impossible to determine the number of followers, likes or shares an account or post has. From what I could deduct, many social media posts just re-package or "share"

<sup>&</sup>lt;sup>30</sup> U.S. Congress. Senate. Committee on Health, Education, Labor, and Pensions. Vaccines Save Lives: What Is Driving Preventable Disease Outbreaks?. 116th Cong., 1st sess., March 5, 2019.

information from the major non-profit groups I examined and utilize similar language, rhetorical strategies, and themes.

I have coded and grouped the newsletters, press releases, op-eds, and other media into six main rhetorical themes, which I will analyze later in my Findings section. The themes I have found are the following: (1) a belief that vaccines are not fully tested and are dangerous, (2) a distrust of experts, scientists, and doctors and a rejection of consensus-based medicine (3) an aversion to pharmaceutical companies and the medical-industrial complex, (4) an emphasis on American Constitutional civil liberties, (5) a rejection of government overreach and authoritarianism and an embrace of libertarianism, and finally (6) an interest in the individual and self-determined health care rather than utilitarian or collective action.

#### **KEY TERMS**

There is a fairly contentious debate what term to assign to individuals who reject commonly accepted beliefs regarding vaccinations. Some experts categorize these people as *anti-vaccine* while others, more sympathetic with the movement describe these groups as advocates for *vaccine safety* or *vaccine choice*. For this project, I will use the standard terms *vaccine refuser* and *anti-vaccination movement*, which are consistent with scholarship in this field.

I will use the term *vaccine refuser* to identify people who have declined or intend to decline routine childhood vaccines for non-medical reasons. For the sake of this paper, I will only be focusing on individuals that cite personal, philosophical beliefs, but there are also several prevalent communities that refuse vaccines for

religious reasons. Similar to vaccine denialism, vaccine refusal exists on a spectrum. Some extreme refusers never vaccinate their children against any disease, while more moderate refusers may delay some vaccines, but do intend for their children to become fully vaccinated, just at a slower pace than medically recommended. Additionally, vaccine refusers are distinct from the *undervaccinated*. The parents of undervaccinated children are generally socially or economically disadvantaged and their failure to fully vaccinate their children is a symptom of a lack of accessible medical care, rather than a philosophical or personally held belief that is purposely pursued. Additionally, this paper discusses *vaccine hesitancy*, which means a hesitation to defer to medical and public health experts about what to believe and what action to take regarding vaccine choices.

#### FINDINGS

The data I collected suggests that the vaccine refusal movement uses several commonly repeated rhetorical themes. Firstly, through explicit personal stories of children who have allegedly suffered vaccine-related injury or death, the movement frames vaccines as largely untested and dangerous. Pharmaceutical companies are portrayed as parasitical and as bankrolling government officials in order to push mandatory vaccinations for profit. Together, through a dismissal of vaccine science, medicine, and politicians, the vaccine refusal movement encourages parents and other parties to dismiss expert opinion, conduct their own research, and find their own conclusions. Additionally, the sources I examined suggest that mandated vaccination is an overuse of federal force and impeding on bodily freedom, autonomy, and civil

liberties. Finally, by combining the following themes, the movement urges parents to act as individuals and to exercise their personal choice, rather than act collectively. In the following sections, I will break down these rhetorical themes. My full recorded data chart is available in Appendix A.

#### DISCUSSION

#### Perceptions of Vaccine Risk and Narratives of Vaccine Injury

Humans are natural storytellers. Minds tend to create narratives to explain unanswered phenomenon. Thomas Gilovich, and many other scholars, argue that this is because humans tend to see non-existent patterns in observations and then create narratives to explain these patterns, even when lacking substantive evidence.<sup>31</sup> When seemingly healthy children fall sick, people seek explanations, even without a background to investigate or make sense of it. Friedrich Nietzsche described the human tendency to create narratives of the origins of pain, "The sufferers…enjoy being mistrustful and dwelling on wrongs and imagined slights: they rummage through the bowels of their past and present for obscure, questionable stories that allow them to wallow in tortured suspicion."<sup>32</sup> From the data I collected, I can infer that the vaccine refusal movement embraces narratives of vaccine injury and spreads these stories widely, generally without a careful examination to the source of the story or the correlation between vaccination and the child's injury or death. VacTruth, a nonprofit

<sup>&</sup>lt;sup>31</sup> Thomas Gilovich, *How We Know What Isn't So: The Fallibility of Human Reason in Everyday Life* (New York, NY: Free Press, 2011).

<sup>&</sup>lt;sup>32</sup> Friedrich Wilhelm Nietzsche, Keith Ansell-Pearson, and Carol Diethe. 1994. On the Genealogy of Morality. Cambridge Texts in the History of Political Thought. New York: Cambridge University Press.

organization dedicated to illuminating the "truth" about vaccinations often publishes narrative accounts of parents who claim their children have died or contracted injuries after receiving routine vaccinations.

On January 19, 2017, VacTruth published a newsletter titled, "A 7-Pound Premature Baby Died After 8 Vaccine Doses, Her Death was Blamed on Co-Sleeping Instead of Toxic Vaccines."<sup>33</sup> Although an autopsy determined the baby's death was attributed to positional asphyxiation related to co-sleeping, VacTruth mentions that the autopsy fails to include that she had recently been vaccinated and that the parents now believe that "vaccinations are the hidden cause of her infant's mortality" and that their daughter's death was "covered up."<sup>34</sup> In the newsletter, the infant's mother then describes a scene in which her daughter, Aysia, was injected with a synthetic vitamin K shot, Phytonadione, which caused her daughter to stop breathing. The nurse was able to resuscitate Aysia, but the incident was not noted in her medical records. Weeks later, a pediatrician detected a heart murmur and neonatal jaundice. However, in the same appointment, despite Aysia's less than perfect health, the doctor "insisted" that Aysia receive the Center for Disease, Control, and Prevention's recommended eight routine vaccinations.<sup>35</sup> Aysia died ten days after receiving the vaccinations. The newsletter even published Aysia's vaccination records to prove that she indeed received all eight doses, adding to its perceived credibility. This is only one of many narratives of vaccine-

<sup>&</sup>lt;sup>33</sup> Augustina Ursino, "A 7-Pound Premature Baby Died After Receiving 8 Vaccine Doses, Her Death Was Blamed On Co-Sleeping Instead Of The Toxic Vaccines," VacTruth.com, November 23, 2017, accessed February 23, 2019.

<sup>&</sup>lt;sup>34</sup> Augustina Ursino, "A 7-Pound Premature Baby Died After Receiving 8 Vaccine Doses, Her Death Was Blamed On Co-Sleeping Instead Of The Toxic Vaccines," VacTruth.com, November 23, 2017, accessed February 23, 2019.

<sup>&</sup>lt;sup>35</sup> Augustina Ursino, "A 7-Pound Premature Baby Died After Receiving 8 Vaccine Doses, Her Death Was Blamed On Co-Sleeping Instead Of The Toxic Vaccines," VacTruth.com, November 23, 2017, accessed February 23, 2019.

related death or injury. Many narratives include common events such as the failure of multiple pediatricians and nurses to communicate the risks associated with routine vaccinations and allow parents an opportunity to opt out of the vaccination. The newsletter writes, "Aysia's parents will never get to hold their baby again in this life and a part of them died when their baby did. They have to live with their regretful decision to vaccinate."<sup>36</sup>

Many vaccine-injury and vaccine-related death descriptions published by vaccine refusal nonprofits follow a similar structure. Generally, there is a perceived failure of medical professionals to properly inform the parents of the risks of vaccination and to insist that the vaccination is necessary and harmless. The infant or child receives the vaccination and then develops strange symptoms, which the parent and vaccine-refusal community believe, without expert information, is correlated to the vaccination. The child falls ill or dies and the parents regret allowing the vaccination to take place and urge other parents to perform their own research, ask questions of medical professionals, and refuse or slow vaccination.

Medical professionals recommend many vaccines in the first year of life. Drawing on studies pertaining to health outcomes, researchers argue that infants need vaccines most because their young immune systems are more susceptible to lifethreatening infectious diseases than older children.<sup>37</sup> They also have found that vaccines are safe and are becoming even safer as manufacturing technologies have improved and that multiple vaccinations do not overwhelm infants' immune systems. Although the

<sup>&</sup>lt;sup>36</sup> Augustina Ursino, "Your Child. Your Choice.," VacTruth.com, November 23, 2017, accessed February 23, 2019.

<sup>&</sup>lt;sup>37</sup> United States, Center for Disease Control and Prevention, *Immunization*, March 17, 2017, accessed March 22, 2019.

anti-vaccination movement shares the view that infants' systems are underdeveloped, my research supports that they perceive this as making infants too fragile for vaccines and that multiple in one doctor's visit an overwhelm the their system and cause injury or death. This is not grounded in scientific research but rather is falsely supported through repetition of anecdotal qualitative evidence gathered from non-expert parents desperately seeking answers to their children's tragedy. Additionally, the movement provides "evidence" through vaccine-injury narratives that parents should fear possible adverse effects of the vaccine more than the diseases vaccines prevent.

This discourse perpetuates ableism, or a set of beliefs and practices that promote certain abilities over others. The anti-vaccination movement perpetuates and mobilizes ableism by stigmatizing vaccine injury, particularly, autism. Although, the connection between vaccines and autism is unfounded, the anti-vaccination movement incites fear in parents of raising a non-neurotypical child, instead of embracing neurodiversity. Rather than accepting and celebrating autistic children, this frame depicts autism as a tragedy to fear and avoid at all costs, even by rejecting commonly accepted medical advice. Many anti-vaccination groups underscore an ableist view that autistic people will be unable to contribute to society without stable employment and thus will be unable to live meaningful and productive lives, a discourse which within itself that promotes neoliberal and capitalist priorities. The anti-vaccination movement vastly focuses on the ability expectations of autistic individuals and stresses their lack of abilities rather than their positive ones. My data supports that the vaccine refusal groups promote a skewed image of autism and perpetuate these ableist stereotypes to maintain a cultural standard of what is considered "normal" and "species typical" in order to

instill fear of vaccinations. Although it has been repeatedly scientifically disproven that vaccines cause autism, the fear that one's child may develop autism is in of itself playing into a harmful ableist framework.

The anti-vaccination movement seems to disperse unresearched and unfactual personal accounts of vaccine injury in order to spread their movement through fear and misinformation to create distrust in vaccination and medicine as a whole. Ethan Lindenberger is a teenager who rose to prominence after choosing to vaccinate himself against the beliefs of his mother. On March 5, 2019, the United States Senate Committee on Health, Education, Labor, and Pensions hosted a hearing "Vaccines Save Lives: What is Driving Preventable Disease Outbreaks?" At this hearing, Lindenberger testified that the organizations which I examined for this project, "instill fear in the public for their own gain, and they know their information is incorrect. For my mother, her love, affection, and care as a parent was used to push an agenda to create false distress."<sup>38</sup> The non-profit groups I examined utilize the power of narrative to take advantage of the deepest human fears of suffering and death in order to scare parents into refusing vaccination.

#### **Distrust in Expert Opinion**

The modern world is becoming more and more technically complex and full democratic participation in this society requires deliberation on complicated issues affecting everyday lives. This becomes a dilemma as citizens often do not possess enough knowledge to participate meaningfully in technically oriented policy decisions.

<sup>&</sup>lt;sup>38</sup> U.S. Congress. Senate. Committee on Health, Education, Labor, and Pensions. Vaccines Save Lives: What Is Driving Preventable Disease Outbreaks?. 116th Cong., 1st sess., March 5, 2019.

Simultaneously, it is difficult and unconstitutional in a democracy to legitimately deny citizens a role in that decision-making, particularly in issues that impact the health and wellbeing of themselves and their family members. Societal participation requires citizens to be equipped and provided with the best possible information act on their preferences.

However, the anti-vaccination movement encourages parents to treat medical professionals as consultants and not experts in their child's healthcare. From the data I collected, I can infer that the movement pressures individuals to dismiss the vaccine schedule created by governmental advisory bodies and promoted by medical organizations and scientific research. The movement encourages parents to conduct their own research online and view their children as unique and outside of the "one size fits all" vaccination schedule. In a newsletter published by the National Vaccine Information Center titled, "Class and Race Profiling in the Vaccine Culture War," NVIC suggests that parents restrain from "blindly trusting and relying on someone else to do their thinking from them."<sup>39</sup> NVIC encourages parents to perform their own research, often suggesting additional readings promoted by other anti-vaccination organizations. Additionally, government agencies like the Center for Disease Control are made out to be phony and fraudulent organizations that are part of a larger conspiracy against the health and well-being of American citizens.

In another newsletter by NVIC, "From Nuremberg to California: Why Informed Consent Matters in the 21st Century," NVIC discredits scientific consensus on vaccinations stating that "the stark reality is that the scientification of every branch of

<sup>&</sup>lt;sup>39</sup> Barbara Loe Fisher, "Class and Race Profiling in the Vaccine Culture War - NVIC Newsletter," National Vaccine Information Center (NVIC), July 17, 2017, accessed March 18, 2019,

philosophy has elevated prominent scientists and physicians promoting "consensus science" into positions of authority, whose judgment should never be questioned."<sup>40</sup> Additionally, NVIC discredits scientists as overextending their authority by controlling the moral compass of society, "those who practice and submit to the authority of science insist that not only must science be used to define *all* truth, but leaders in science and medicine are authorities who should define "the good," that is, define moral behavior and what kind of cultural values we should have."<sup>41</sup> The anti-vaccination movement portrays vaccination as a moral debate rather than simply a scientific or medical matter. By portraying it as such, the movement is able to discredit medical experts and scientists as unqualified to dive into matters of morality, ethics, and parental choice.

This is part of a larger trend toward the distrust of experts and science. From flat earthers to advocates against genetically modified food, to climate change denialists, there is an overarching movement towards severely doubting the validity of peerreviewed scientific findings on both sides of the political spectrum. Additionally, this distrust in experts extends past the scientific realm into matters of domestic policy and foreign affairs. Kellyanne Conway, advisor for President Trump famously coined the term "alternative facts" during the 2016 election, citing that the Trump team had not only different opinions but a different set of truths.<sup>42</sup>

<sup>&</sup>lt;sup>40</sup> Barbara Loe Fisher, "Why Informed Consent Matters in the 21st Century - NVIC Newsletter," National Vaccine Information Center (NVIC), October 24, 2017, accessed April 23, 2019.

<sup>&</sup>lt;sup>41</sup> Barbara Loe Fisher, "Why Informed Consent Matters in the 21st Century - NVIC Newsletter," National Vaccine Information Center (NVIC), October 24, 2017, accessed April 23, 2019.

<sup>&</sup>lt;sup>42</sup> Blake, Aaron. "Kellyanne Conway Says Donald Trump's Team Has 'alternative Facts.' Which Pretty Much Says It All." *The Washington Post*, January 22, 2017. Accessed February 20, 2019.

In his book *The Death of Expertise*, Tom Nichols discusses the phenomena in which growing numbers of people claim their personal opinions hold equal weight to the opinions of experts. He writes, "I fear we are witnessing the death of the ideal of expertise itself, a Google-fueled, Wikipedia-based, blog-sodden collapse of any division between professionals and laypeople." He goes on to write that "the death of expertise is more like a national bout of ill temper, a childish rejection of authority in all its forms coupled to an insistence that strongly held opinions are indistinguishable from facts."<sup>43</sup>

Although the "death of expertise" is not new, it is immensely magnified by the accessibility of the internet. It is now possible to decide beforehand what one believes and then look for a source on the internet that confirms that view. This is called "confirmation bias," a phenomenon in which one only reads news sources, reports, blogs, and other online material that only supports rather than challenges their original hypothesis. Nichols writes, "You click your way to validation, confusing the presence of a website with the plausibility of an argument."<sup>44</sup> He continues to paint an extremely grime view of society in which people Google more and knows less. "Society is dumbing down," Nichols writes. Empowering people through the diffusion of knowledge made easily accessible through the internet could enable them to make the informed decisions. However, the internet is plagued by falsified knowledge, misinformation, intentionally misleading material, which can also be disseminated quickly and cost-effectively through the internet.

<sup>&</sup>lt;sup>43</sup> Tom Nichols, Death of Expertise: The Campaign Against Established Knowledge and Why It Matters (Oxford University Press Press, 2019).

<sup>&</sup>lt;sup>44</sup> Tom Nichols, Death of Expertise: The Campaign Against Established Knowledge and Why It Matters (Oxford University Press Press, 2019).

Many anti-vaccination nonprofits send newsletters arguing one view of the vaccine debate. They support their view through quasi-scientific research and qualitative anecdotes and then urge their readers to "conduct their own research" if they are not convinced. This statement then encourages confirmation bias, as readers then investigate online to find a spiral of nonprofits and blogs that add to and support their view. Furthermore, their demonizing of medical experts is part of a strategy to discredit sources that directly counter the information they are promoting.

#### Aversion to the Medical-Industrial Complex

Furthermore, in coordination with promoting distrust in experts, the antivaccination movement fosters an aversion to pharmaceutical companies and the medical-industrial complex as a whole. Based on the data I collected, the movement seems to suggest a direct connection between pharmaceutical companies, which push pro-vaccine agendas in order to create revenue and policy-makers who pass mandatory vaccination legislation. Pharmaceutical companies are portrayed as profit-driven parasites who promote their own self-interested agenda without concern for the health and well-being of patients. VacTruth wrote in a newsletter from November 2017 titled "The Business of Birth." They write, "To the massive and deeply corrupt pharmaceutical industry, she, and every other man, woman, and child on the planet are seen as merely an endless source of revenue."<sup>45</sup>

The National Vaccine Information Center stresses in many publications that in 2011 the United States Supreme Court ruled that licensed vaccines by the United States

<sup>&</sup>lt;sup>45</sup> Phil Silberman, "Your Child. Your Choice.," VacTruth.com, November 26, 2017, accessed April 9, 2019.

Food and Drug Administration are "unavoidably unsafe."<sup>46</sup> In the opinion of NVIC, this ruling "effectively granted vaccine manufactures a full liability shield, even when there was evidence a company could have made a vaccine safer" and thus widely expanded the power of pharmaceutical companies to manufacture and sell vaccines that they know may cause side effects.<sup>47</sup> NVIC writes in a newsletter from July 1, 2018, that "doctors no longer have to worry about getting sued for being militant enforcers of vaccine policies and laws that punish children for genes they were born with and leave too many of them disabled and chronically ill for the rest of their lives."<sup>48</sup> Based on the data I collected, the movement seems to emphasize that not only are vaccines erroneously prescribed, but the companies that develop and manufacture the vaccines also are not liable in event of a vaccine injury.

This hesitation to embrace the medical-industrial complex is not unfound or particularly radical. Advocates for universal healthcare such as Medical-for-All and other populist healthcare movements have often demonized pharmaceutical companies as profit-driven, capitalist enterprises, who are responsible for driving up costs of necessary life-saving drugs like insulin in order to pay for expensive advertising and marketing. On the presidential campaign trail in 2016, Senator Bernie Sanders repeatedly accused large pharmaceutical companies of overpricing drugs and acting out

<sup>&</sup>lt;sup>46</sup> National Vaccine Information Center, "National Vaccine Information Center: Public Hearings on \ Measles Outbreaks and Vaccine Laws Provide Opportunities for Americans to Voice Concerns," news release. January 25, 2010, accessed March 2, 2019.

<sup>&</sup>lt;sup>47</sup> National Vaccine Information Center, "National Vaccine Information Center: Public Hearings on Measles Outbreaks and Vaccine Laws Provide Opportunities for Americans to Voice Concerns," news release, February 25, 2010, accessed March 2, 2019.

<sup>&</sup>lt;sup>48</sup> Barbara Loe Fisher, "Zero Tolerance Vaccine Laws in America: Will You Defend Vaccine Freedom? – NVIC Newsletter," National Vaccine Information Center (NVIC), July 1, 2018, accessed April 13, 2019.

of "greed" causing the "exploitation of the American people."<sup>49</sup> the Democratic Party has accepted populist rhetoric accusing Big Pharma of being an enemy of the American people and dozens of congressional candidates pushed this rhetoric during the 2018 midterm elections.

Additionally, due to the prominent media coverage of the Opioid Crisis devastating rural America, greater attention has been given to the influence of Big Pharma in influencing and persuading physicians to over-prescribe opioid drugs, which, if not managed, can lead to prescription drug addiction, heroin and fentanyl addictions, death, and other health concerns. Because of the already present and widely dispersed media and political rhetoric describing pharmaceutical companies as greedy and parasitic, it should not come as a surprise that the anti-vaccination movement has simply taken these themes and applied them to their own cause.

From my research, I found that the Children's Defense Fund, a nonprofit organization started by Robert F. Kennedy Jr., often mentions the amount of special interest money pharmaceutical companies have funneled to political campaigns and political action committees (PACs). Again, this attack is not new or radical. Politicians and political action committees consistently convey their opponents as "being in the pocket of special interests" by accepting money from pharmaceutical companies.<sup>50</sup> In the 2018 elections, the Democratic Congressional Campaign Committee (DCCC), made outside money, particularly from pharmaceutical companies, a key campaign issue across a variety of congressional districts and encouraged many Democratic candidates

<sup>&</sup>lt;sup>49</sup> Bernie Sanders, "Sanders: Big Pharma a Hazard to Our Health | Opinion," *LeHigh Valley Live*, April 23, 2016, accessed April 23, 2019.

<sup>&</sup>lt;sup>50</sup> Democratic Congressional Campaign Committee, "Mike Bishop Is "At Home" With Washington Special Interests," news release, March 26, 2018, DCCC.org, accessed April 23, 2019.

to refuse special interest and outside PAC money. The DCCC rolled out several attack ads against Republican candidates. For instance in Michigan's 8th Congressional District, the DCCC emphasized that incumbent Congressman Mike Bishop could "try to distance himself from the Washington swamp, but he's voted time and time again to line the pockets of the wealthy donors who bankroll his campaign. In D.C., he's cozy with pharmaceutical companies, big banks, and oil companies, while voting against the interests of his own constituents."<sup>51</sup> This line of attacks was extremely successful as Bishop was unseated by first-time candidate and former CIA analyst Elissa Slotkin.

However, the anti-vaccination movement takes the mainstream and widely accepted themes of special interest money to an extreme, elevating the rhetorical themes to a borderline conspiracy theory. Unlike the pharmaceutical companies pressuring medical professionals to prescribe increased doses of opioids, which has been wellresearched and documented, there is no evidence of politicians accepting special interest money from large pharmaceutical companies in exchange for reducing philosophical vaccination exemptions in any particular state. From the data I collected, I can infer that the anti-vaccination movement uses these commonly accepted frames of political corruption and Big Pharma's greed to further distrust in the pharmaceutical companies that produce the vaccines as well as increase distrust in elected officials and governing bodies that mandate compulsory vaccinations.

<sup>&</sup>lt;sup>51</sup> Democratic Congressional Campaign Committee, "Mike Bishop Is "At Home" With Washington Special Interests," news release, March 26, 2018, DCCC.org, accessed April 23, 2019.

#### Libertarianism, Anti-Authoritarianism, and Bodily Freedom

The vaccine refusal movement draws upon themes of bodily freedom associated with civil liberties grounded in the American founding documents. The movement views federally sanctioned mandatory vaccination a gross abuse of government authority. Vaccine refusal groups frame vaccine choice as a matter of freedom or enslavement by an authoritarian regime. These groups advocate that vaccination is forced medical attention and is an infringement of individual liberty.

In a filmed press release, Barbara Loe Fisher, the founder of NVIC, said, "Every July, Americans celebrate the day in 1776 when we declared our independence from a monarchy and began to create the Constitutional Democratic Republic to secure liberty and justice for all. Today, we are witnessing the erosion of core values that our constitutional democracy was founded upon."<sup>52</sup> Fisher suggests vaccine choice is an expression of American liberty that needs to be protected, along with the rights to life, liberty, and property enshrined in the United States founding documents. NVIC often quotes The Federalist Papers and the Founders, particularly Thomas Jefferson's view that, "the minority possess their equal rights, which equal laws must protect, and to violate would be oppression."<sup>53</sup> As a self-designated oppressed minority, NVIC asserts that mandatory vaccinations is legislation parallel to the draft and requires "all healthy children to risk their lives in a war that doctors declared on microbes two centuries ago."<sup>54</sup> The anti-vaccination movement encourages parents to refuse vaccination as a

<sup>&</sup>lt;sup>52</sup> Barbara Loe Fisher, "Zero Tolerance Vaccine Laws in America: Will You Defend Vaccine Freedom? -NVIC Newsletter," National Vaccine Information Center (NVIC), July 1, 2018, accessed April 11, 2019.

<sup>&</sup>lt;sup>53</sup> Barbara Loe Fisher, "Zero Tolerance Vaccine Laws in America: Will You Defend Vaccine Freedom? -NVIC Newsletter," National Vaccine Information Center (NVIC), July 1, 2018, accessed April 11, 2019.

<sup>&</sup>lt;sup>54</sup> Barbara Loe Fisher, "Zero Tolerance Vaccine Laws in America: Will You Defend Vaccine Freedom? -

right protected under the Constitution. NVIC invites parents to "stand up and defend freedom in America." By framing routine vaccinations as a matter of liberty, vaccine refusers effectively end the conversation and silences the debate in favor of government intervention in infectious disease prevention.

In a newsletter titled, "The New Internet Police Protecting You from Freedom of Thought and Speech," published in December 2018, NVIC emphasizes that mandatory vaccinations are not just an infringement on personal freedom, but are un-American. "It's your health, your family, your choice and our mission continues: No forced vaccination. Not in America."<sup>55</sup> NVIC portrays compulsory public health interventions that benefit the common good as unpatriot and against the American promise of freedom.

The anti-vaccination movement emphasizes that parents need to resist government overreach and wrestle control back from the state to regain authority of their child's health and wellbeing. From the research I conducted, I could infer that the anti-vaccination movement seems to equate mandatory vaccinations with authoritarianism. The movement frames mandatory vaccination as a slippery slope to the dictatorship of Nazi Germany in order to appeal emotionally to questioning parents and cause them to act rashly. In a newsletter from November 2017, NVIC describes the physicians' trials at Nuremberg in which doctors performed horrific scientific experiments on children and adults in concentration camps, including vaccine experiments. NVIC upholds the Nuremberg Code, which requires voluntary consent of

NVIC Newsletter," National Vaccine Information Center (NVIC), July 1, 2018, accessed April 11, 2019.

<sup>&</sup>lt;sup>55</sup> Barbara Loe Fisher, "The New Internet Police Protecting You From Freedom of Thought and Speech," National Vaccine Information Center (NVIC), December 3, 2018, accessed April 17, 2019.

human subjects as the most important document for vaccine choice and bodily freedom from unwanted medical attention and scientific study.<sup>56</sup> Additionally, at a screening of a documentary which pushed the scientifically disproven link between vaccines and autism, Robert F. Kennedy Jr., a celebrity leader of the anti-vaccination movement, equated mandated vaccines with the Holocaust, "They get the shot that night and they have a fever of a hundred and three, they go to sleep, and three months later their brain is gone... This is a holocaust, what this is doing to our country."<sup>57</sup>

This fear of government overreach and authoritarianism has ties to the libertarian movements as well. During the United States Committee on Health, Education, Labor, and Pensions hearing on vaccinations, Senator Rand Paul, a selfproclaimed libertarian from Kentucky said:

I'm not a fan of government coercion, yet given the choice, I do believe that the benefits of most vaccines vastly outweigh the risks. This may be the only medical procedure in today's modern world where informed consent is not required. As we contemplate forcing parents to choose this or that vaccine, I think it's important to remember that force is not consistent with the American story, nor is force consistent with the liberty our forefathers sought when they came to America." I do not favor giving up on liberty for a false sense of security.<sup>58</sup>

<sup>&</sup>lt;sup>56</sup> Barbara Loe Fisher, "Why Informed Consent Matters in the 21st Century - NVIC Newsletter," National Vaccine Information Center (NVIC), October 24, 2017, accessed April 9, 2019,

<sup>&</sup>lt;sup>57</sup> Brandy Zadrozny, "Robert F. Kennedy Jr. Compared Vaccines to a Holocaust—and Now Trump Wants Him to Investigate Their 'Safety'," *The Daily Beast*, January 10, 2017, accessed March 23, 2019.

<sup>&</sup>lt;sup>58</sup> U.S. Congress. Senate. Committee on Health, Education, Labor, and Pensions. Vaccines Save Lives: What Is Driving Preventable Disease Outbreaks?. 116th Cong., 1st sess., March 5, 2019.

In this sense, the vaccine refusal movement seems to align with certain threads of libertarianism. Vaccine refusers and libertarians do not believe that the state has the right to restrict individual liberty in order to promote welfare, such as by mandating vaccines to ensure herd immunity.<sup>59</sup> The vaccine movement champions vaccine choice as a human right to bodily integrity, which must be protected from authoritarian government overreach.

#### Individualism, Choice, and Self-Determination

The vaccine refusal movement draws upon narratives of individual optimization and consumption. The rhetoric of choice as an individual preference proliferates the anti-vaccination movement. The National Vaccine Information Center's slogan is "Your Health. Your Family. Your Choice."<sup>60</sup> Through this rhetorical framework, NVIC promotes vaccination as a personal decision, in which one should prioritize their and their children's own needs and manage individual risk rather than a collective social responsibility to public health and the betterment of the community. NVIC wants parents to reject a major tenet of public health, that healthy individuals should assume the minimal risk for the wellbeing of the most vulnerable.

The emphasis on individual choice encourages challenging mainstream medical advice. The vocabulary of choice permeates the rhetoric of the anti-vaccination movement. Vaccine policy promotes a uniform healthcare intervention in which vaccines are administered at the same time and in similar doses for all people. This

<sup>&</sup>lt;sup>59</sup> Justin Bernstein, "The Case against Libertarian Arguments for Compulsory Vaccination," Journal of Medical Ethics 43, no. 11 (2017).

<sup>&</sup>lt;sup>60</sup> "National Vaccine Information Center - Your Health. Your Family. Your Choice.," National Vaccine Information Center (NVIC), accessed February 23, 2019.

makes the distribution relatively cost-effective allowing for inexpensive government subsidy programs to promote herd immunity and public health. Individuals gain personal immunity, but also protect members of the community who are unable to receive the vaccinations due to medical reasons or age through herd immunity.

Prioritizing individual choice and autonomy raises questions about the intersection of personal freedom and social responsibility. When, if, and how should individuals sacrifice their own personal freedom for communal health and well-being? The anti-vaccination movement recommends individuals refrain from absorbing minimal risk for their child and reject the collective movement towards public well-being.

The sources I studied encourage parents to view their role as protecting their children's bodies from harm at any cost, even above the health and well-being of others. Parents are encouraged to perform their own research, to become experts in their behavior, above the expert advice of medical professionals, and resist government oversight and authoritarianism. However, mandatory vaccination legislation was created to drastically improve public health and herd immunity. By treating vaccination as optional and chosen after carefully calculated risks, healthy individuals opt out of vaccination and undermine public health by choice.

Physicians for Informed Consent (PIC), a nonprofit coalition of medical professionals dedicated to vaccine freedom published in a newsletter from December 2016, "Parents and doctors—not politicians—should be making medical decisions for children, PIC is committed to protecting the rights of parents to make medical decisions

for their children."<sup>61</sup> PIC included testimony from a vaccine refusal parent, "The only people who should be making vaccine decisions for children are their parents and physicians, not politicians."<sup>62</sup>

The movement advises parents to become shoppers selecting among options in the marketplace, without concern for herd immunity, public health, or the collective. In this sense, public health stands in direct opposition to neoliberalism. Wilkins writes, that neoliberalism "insists that citizens should be 'empowered' to pursue their own selfinterest as a condition of their rights as consumers of public resources."<sup>63</sup> Antivaccination groups subscribe to the neoliberal ideology that encourages parents to become managers of risk and seek to make the best decisions for their child's success, based on the information they consume and the resources they have available to them.

The individualistic nature of vaccines, should not come as a surprise. We have long lived in a country that frames healthcare as a commodity to be bought by consumers and sold by providers. The American medical system is no more a "free marketplace" than the American economy as a whole. Overall, this discourse of individualism and choice stems from an economic shift in the 1980s from welfare state to neoliberalism, in which free market rationalities have become entrenched in social policy, emphasizing principles of individualism, privatization, and decentralization over social rights and collective wellbeing.<sup>64</sup> This viewpoint was reflected in all aspects of

<sup>&</sup>lt;sup>61</sup> Physicians for Informed Consent, "Doctors and Scientists Unite to End Mandatory Vaccination Laws," news release, December 20, 2016, accessed March 8, 2019.

<sup>&</sup>lt;sup>62</sup> Physicians for Informed Consent, "Doctors and Scientists Unite to End Mandatory Vaccination Laws," news release, December 20, 2016, accessed March 8, 2019.

<sup>&</sup>lt;sup>63</sup> Andrew Wilkins, Affective Practices and Neoliberal Fantasies: Mothers' Encounters with School Choice (Ontario: Demeter Press, 2014).

<sup>&</sup>lt;sup>64</sup> Elaine Power and Jessica Polzer, Neoliberal Governance and Health: Duties, Risks, and Vulnerabilities Montreal;; Kingston; London; Chicago: McGill-Queens University Press, 2016).

policy frameworks. In healthcare, this transformed the way in which healthcare systems view and represent patients as consumers of health services rather than recipients of care. This shift towards neoliberalism also supported a model of citizenship in which individuals are expected to be good citizens by managing and maintaining their health through free choices and informed decision-making. This ideology promotes the view that individuals should feel motivated to manage themselves, behave morally, work hard, and avoid calculable risk through informed decision-making.

Furthemore, from the data I collected, I can infer that the anti-vaccination movement encourages parents to expend significant amount of time and resources to controlling their child's health by monitoring their health. Vaccine refusal groups want parents to believe that their lifestyle choices, such as nutrition or social monitoring, are enough to prevent infectious diseases. Furthermore, parents are encouraged to protect their children from outsiders who are perceived to carry disease and view those who share their values and lifestyle choices as unlikely to possess a threat to their child's health and safety. Parents are encouraged to manage social exposure from foreign bodies outside of their social networks and seek to protect their children by building what Jennifer Reich describes as "imagined gated communities."<sup>65</sup> This is an inherently a racist, classist, and xenophobic ideology and completely disregards the epidemiological data that a majority of disease outbreaks originate with other unvaccinated children in the United States and those who have traveled to Northern Europe. This rhetoric of choice is only made possible from immense social and economic privilege, as families that seek philosophical exemptions are predominately

<sup>&</sup>lt;sup>65</sup> Jennifer A. Reich, "Neoliberal Mothering and Vaccine Refusal," *Gender & Society* 28, no. 5 (2014)

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white and upper class.<sup>66</sup> Additionally, this framework completely disregards the way in which their children pose a risk to others, particularly children without the resources or access to vaccines, such as the undervaccinated. By ignoring this risk, the anti-vaccination movement encourages parents to re-establish risk management as an individual choice.

These "choices" exist within a politicized context with structured requirements, vaccinations are legally required for school attendance but can be avoided through adherence to paperwork and completing bureaucratic processes for exemption. These regulations are enacted to the benefit of the entire community but allow individuals with resources and knowledge of the system to exercise choice. Vaccine choices, like many decisions about children's health and education, reflect greater meanings of class, education, and access. While some parents are able to make vaccine decisions for their child, they do so from a place of privilege.

## CONCLUSION

This project sought to explore the narratives and rhetorical themes that permeate the anti-vaccination movement. Mass media has portrayed vaccine refusal groups as stupid, as conspiracy theorists, and as radically selfish. However, the data I analyzed supports that although these themes may appear to be radical, in reality, each seems to be congruent with already present societal frameworks. My data supports that the antivaccination movement perpetuates a belief that vaccines are not fully tested and are dangerous, encourages distrusting and questioning experts, scientists, and doctors and a

<sup>&</sup>lt;sup>66</sup> Jennifer A. Reich, "Neoliberal Mothering and Vaccine Refusal," *Gender & Society* 28, no. 5 (2014)

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rejecting of consensus-based medicine. Additionally, it supports an aversion to pharmaceutical companies and the medical-industrial complex, an embrace of American Constitutional civil liberties, a rejection of government overreach and authoritarianism and an acceptance of libertarianism, and finally, a preoccupation with the individual and self-determined health care rather than utilitarian or collective action.

In particular, rhetorical themes of individualism and informed choice are directly tied to neoliberal economic and social ideologies that have permeated the 20th century. Neoliberalism is more than a political or economic reality. Instead, it is a "technology of the self" and creates a path for creating a beneficial life for oneself and their dependents.<sup>67</sup> Neoliberal biopolitics holds individuals accountable for their lives, including optimizing their bodies, minds, and wellbeing in order to climb the social ladder in a competitive world. AnaLouise Keating calls these beings "self-enclosed individuals" or a form of "hyper-individualism" which "focuses exclusively on the human and define this human self very narrowly, in non-relational, boundaried [sic], terms."<sup>68</sup> Self-enclosed individuals constantly manage risk, gather information, and calculate odds for personal benefit. Self-enclosed individualism positions the self in opposition to other humans and is inherently anti-collective and anti-public good. Individuals are removed from their community and evaluate their actions in egocentric terms, "what is in it for me?," "how will this event or situation affect me and my future?," and "what can you do for me?" Neoliberal biopolitics also encourages individuals to view their relationships and daily decisions in economic terms to be

<sup>&</sup>lt;sup>67</sup> Julie Wilson, *Neoliberalism* (New York: Routledge, 2017).

<sup>&</sup>lt;sup>68</sup> Jennifer A. Reich, "Neoliberal Mothering and Vaccine Refusal," *Gender & Society* 28, no. 5 (2014)

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assessed as a series of gains and losses to create some sort of discernible future. Additionally, this discourse rejects government intervention as a personal failure, rather than a societal obligation for social wellbeing. This stands in direct opposition to mandatory vaccination, which requires socialist frameworks of collective action and public health. In this sense, I argue that vaccine refusal is an extreme side effect to already present and widespread neoliberal cultural and economic theories.

Discourses of health come and go, but not arbitrarily. They emerge and gain acceptance specifically because they are parallel to the social, political, and economic context in which they are produced and maintained. In this sense, discourses of health, particularly communication surrounding vaccines and vaccine refusal, are a mirror of our societal interests and agendas. The way in which we conceptualize and discuss health displays our beliefs about human nature, reality, and the kind of society we imagine creating and how to achieve it.

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	Rhetorical Themes	Individualism, "Informed Consent," Choice, Anti-Utilitarianism	Constiutional Freedoms, Civil Liberties, Human Rights, Bodily Autonomy	Libertarianism, Government Overstep, Anti- Authoritarianism	Vaccines are untested/dangerous, vaccine injury narratives	Big Pharma, Medical-Industrial Complex, monopolies, transparency	Distrust in Doctors, Scientists, Government Officials, Medical Experts
National Vaccine	Information Center - Newsletters		ratoriony	, lation and include	handaroo	lanoparonoy	Experte
	Taking No Prisoners in the Vaccine						
3/13/2019	Culture War	Х	X	X	X	Х	Х
2/17/2019	More Than 100 Bills Proposed in 30 States To Expand, Restrict or Eliminate Vaccine Informed Consent	x					
2/15/2019	NVIC's "No Forced Vaccination" Message Back Up in Times Square As Americans Fight for Human Rights	x	x	x	x	x	
2/10/2019	US Government Will Focus on Marketing HPV Vaccine for 2019	x	x		x	x	
1/27/2019	WHO, Pharma, Gates & Government: Who's Calling the Shots?	x		x	x	x	x
12/10/18	AFM Compared to Guillian-Barre Syndrome				x		
	The New Internet Police Protecting You						
12/3/18	<b>3</b> 1	Х	X	X		Х	
9/18/18	Eroding Freedoms: Pinterest Removed NVIC's Boards	x	x				
	If Vaccines Injure Pregnant Women or Their Unborn Babies, What Will the						
	Vaccine Court Do?	х	х		х		
9/12/18	The Pertussis Vaccine Blame Game	х			X		X
9/12/18		x	x				x
7/24/18	Back to School - Prevent Vaccine Bullying	х	x				
	Zero Tolerance Vaccine Laws in America: Will You Defend Vaccine						
7/1/18	Freedom?	х	Х	X			X
12/19/17	Chronic Inflammation in Alzheimer's Disease State Vaccine Legislation in America				Х		
10/25/17	2015-2017	х	x	х	х	х	
10/24/17	From Nuremberg to California: Why Informed Consent Matters in the 21st	x	x	x	x	x	x
	The Prospect of a Third Dose of MMR	X	X	~	x	X	~
	Odds of Vaccine Harm are One in a						
9/15/17					Х		
9/5/17	Foreced Vaccination Judged Unconstitutional in Colombia	x		x			
9/4/17	Texas Parents: Know Your Vaccine Choice Rights During Hurricane Harvey Flood Emergency	x	x	x			
	Intelligent People Who are Stupid About						
8/7/17	Vaccines? Class and Race Profiling in the Vaccine	Х					
7/17/17	Culture War	х					х
6/28/17	Why is Informed Consent to Vaccination a Human Right?	x	x		x		
6/12/17	The Smallpox Vaccine Was No Silver Bullet				x		x
		x					x
	America's Vaccine Injured Warriors Deserve More		x	x		x	x
E/00/47	What's the Difference Between Companies Selling Cigarettes and Companies Selling Vaccines					x	
	The Vaccine Revolution for Truth	x			X	x	X
	Privacy Ranks Low in Federal Vaccine Data Gathering	x	x			~	~
	Knowledge is the Antidote for Vaccine		~				
	Orthodoxy	х			Х		Х
VVIC Press Rele							
2/25/2019	Public Hearings on Measles Outbreaks and Vaccine Laws Provide Opportunities for Americans to Voice Concerns		x	x	x	x	
9/25/2018	During Vaccine Awareness Week, NVIC Calls on Health Officials to Protect Babies in US from Toxic DPT Vaccine				x	x	
5/20/2010	During Vaccine Awareness Week, NVIC Reports No Loss of Vaccine Exemptions		x			X	

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	Rhetorical Themes	Anti-Utilitarianism	Autonomy	Authoritarianism	narratives	transparency	Experts
12/8/16	NVIC Calls for 21st Century Cures Act "A Wolf in Sheeps Clothing" and Urges Presidential Veto to Protect Public Health	x				x	
	NVIC Renews Call for End to Protect Liability Shield for Vaccine Manufactures						
10/14/16	During 2016 Vaccine Awareness Week NVIC Calls US Proposal to Apprehend and Involuntarily Quarantine Travelers	X			X	X	
9/13/16	for Rashes and Cough a "Violation of Civil Liberties" NVIC Calls for Repeal of 1986 National		x	x			
	Childhood Vaccine Injury Act NVIC Questions FDA Fast Tracking of	X				X	
9/16/15	Squalene Adjuvanted Flu Vaccine				Х		
7/22/15	NVIC Says Proposed 21st Cenutry Cures Act Will Endanger the Public Health by Lowering FDA Licensing Standards NVIC Says New California Law	x			x	x	
	Threatens Human and Civil Rights in						
	America	Х	Х				
acTruth Newsle							
	UK Scientist Speaks Out About the Dangers of Aluminum Adjuvants in Vaccinations				x		x
8/30/18	Vaccine Induced Autism and the Fallout: What Now? How Scientists Use Statistical Deception				Х		x
8/10/18	to Fake Influenza Vaccine Effectiveness Fertility-Regulating Vaccines Being	Х			X	X	X
5/30/18	Tested in India The Big Divide: Why Chiropractors			X	X	X	
5/3/18	Oppose Vaccinations Whle Medical Doctors Embrace Them	x			x		x
5/2/18	Four Months of Critical Information is Missing from Alfie Evans' Timeline	х			X	х	
4/24/18	5	x	x	x			
4/9/18	New Jersey's New Vaccine Bill Attempts to Remove Religious Exemption	х	x				
3/8/18		х			x		
	Why Claims of Unvaccinated Flu Deaths are Highly Deceptive					х	x
2/2/18	DDT and the Polio Fallout			х	X		
1/22/18	Vaccine Supporter Threatens Mass Shooting"I'm gonna kill as many of you f#cks as I can before I go down."			x		x	
1/15/18	Daily Beast Senior Writer: "People Trust MeBut They Shouldn't"						
1/6/18	Vaccination, the Poisonous Paradigm	х		х			х
1/5/18	CMSRI Wins Award for Outstanding Research on Dangers of Vaccination						x
12/15/17		x	x	x			
12/5/17	New Research Proves Brains of Children with Autism are Loaded with Aluminum				x		x
12/3/17	Protecting Vaccine Choice in Colorado: Part 1	x		x		x	
11/26/17	Business of Birth	х				х	
11/22/17	Reclaiming Ancient Wisdom	х				х	х
11/18/17	How the MMR Vaccine Caused My Son's Encephalopathy, AKA Autism				x		
11/10/17	-			x	x	x	x
10/28/17	Forever Damaged From An Untested 8- in-1 Vaccine, Help Needed As Jodie's Legal Battle Continues				x		
	•	х			x		
	Baby Foreskin Is Being Used to Make Vaccines	~			x	x	
8/21/17	Why You Should Never Sign the Refusal to Vaccinate Form	x	x		x		

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	What Every Parent Needs to Know		,, <b>,</b>			,	
8/16/17	About Back to School Vaccine Threats and Exemptions			х	x		x
	The Dangerous Reasons You Should Never Give Your Baby Tylenol After						
8/9/17	Vaccines UNICEF Vaccinates African Refugee				X		
7/31/17	Children with Combination OPV/IPV Vaccines as Part of Vaccination Experiment	x		x		x	
7/28/17	How Do US Vaccines Rates, Policies and Children's Health Compare to Other Countries?	x	x	x	x	x	
7/25/17	The Failed MMR Vaccine Policies on College Campuses	x					
	Vaccines Ingredients: America's Dirty Little Secret				x	x	x
	The Autism Epidemic and How to Stop It	х			X		
	The True Causes of Sudden Infant Death Syndrome	x			x		
	A 7-Pound Premature Baby Died After Receiving 8 Vaccine Doses, Her Death Was Blamed On Co-Sleeping Instead of						
	Toxic Vaccines Is It Time for Your Flu Shot or Extra				X		
1/10/17	Nutrition? 13 Year Old Boy Permanently Disabled	X			X		
12/30/16	from Chicken Pox Vaccine Wins His Case in Vaccine Court				x		
12/20/16	A New Billboard Reminds Parents Vaccines Can Kill Their Baby				x		х
11/26/16		х			x		
11/20/16	Anti-Vaccinators and their Brave Fight Since the Smallpox Vaccine	x	x				
11/17/16	Aluminium Adjuvants Have Never Been Approved For Use In Vaccination				x		x
10/22/16	4 Month Old Baby Donates Organs After Recieving 7 Vaccine Doses				x		
9/13/16	Life With Vaccine Injury: A Mother's Perspective	x	x		x		
9/10/16	The Dangerous Expansion of Adult Vaccinations	х			x		
	8 Ways to Safely Take Charge of Your Health While Avoiding Toxic Vaccines	x					
9/1/10	How to Protect Yourself if You are	^					
8/27/16	Force-Vaccinated Aggressive Hospital Vaccine Policies:	Х	X		x		
8/13/16	Get Vaccinated or Lose Your Job	х	х				
8/11/16	Back to School Shots: How Your Child is Being Programmed	х		х		х	
8/6/16	8 Reasons Why Your Child's Doctor Pushes Vaccines				x	x	x
7/27/16	Vaccines: The Exception to Medical Coercion	x			x		x
7/19/16	How Congress Allowed Vaccine Manufactures to Dismantle the Constitution	x	x	x		x	
6/21/16	How to Find a Physician to Support Your Vaccine Choice	x			x	x	x
5/9/16	How Rhode Island Parents Are Winning Back Their Rights to Vaccine Choice	x					
4/27/16	Why the Documentary Vaxxed is so Controversial and Important to Support				x	x	
	How Healthcare Was Bought Out, Resulting in Today's Focus on Vaccinations and Pharmaceuticals					x	
3/22/16	Why Do Most Medical Doctors Blindly Recommend Vaccinations?	х				x	x
	formed Consent						
	PIC Opposes SB 276: Letter to California Legislators	x		x	x		
0440	Critical Calculation Error in Background Information for Hearing on "Vaccines Save Lives: What is Driving Preventable Disease Outbreaks?" on March 5, 2019			x	x		

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	Rhetorical Themes	Anti-Utilitarianism	Autonomy	Authoritarianism	narratives	transparency	Experts
2/25/19	Errors in Memorandum for the hearing on "Confronting a Growing Public Health Threat: Measles Outbreaks in the U.S." on February 27, 2019			x	х		
2/14/19	Physicians for Informed Consent to Host Workshop & Luncheon in Southern California	x			x		
	Physicians for Informed Consent Releases Information Statement About Vaccines and Immunocompromised						
7/2/18	Schoolchildren	Х					
12/20/17	Physicians for Informed Consent Finds MMR Vaccine Causes Seizures in 5,700 U.S. Children Annually						
10/10/17	Physicians for Informed Consent Publishes Scientific Finding on the MMR Vaccine				x		
12/20/16	Doctors and Scientists Unite to End Mandatory Vaccination Laws	x	x				x
Generation Reso	cue						
April 2017	Vaccine Safety: Making the Most Informed Decisions for Your Family	x	x	x	x	x	x
Children's Heath	Defense						
3/29/19	Four Billboards in Toronto Trigger A Public Airing Of Mandatory Vax In Canada: And the Politicians Respond 'NO', For Now	x	x		x		
	Vaccines: Gateway Drugs by Design				х	х	х
3/28/19	The Disturbing Increase in Colorectal Cancer in Young Adults				x		
3/27/19					x	x	
3/26/19	CDC's Infant Hep B Vaccine Recommendations—No Proof of Safety?	х	x	x	x	x	
3/25/19	Anatomy of a Science Study Censorship					Х	Х
3/21/19	CDC's Recommendation for Hepatitis B Vaccination in Infants. Are There More Risks Than Benefits?			x	x	x	x
3/19/19	Yale Press Conference and "Science of Vaccine Forum" Features Robert F. Kennedy, Jr.	x	x	x	x	x	
3/19/19	Real-Life Data Show that the CDC Vaccine Schedule is Causing Harm			x	x	x	x
3/14/19	One Vaccine Size Does Not Fit All—and Researchers Know It	x					
3/12/19	The Impact of Vaccines on Mortality Decline Since 1900—According to Published Science				x	x	
2/28/19	The Reality of Vaccine Injury: A Much Needed Lesson for Carly Weeks	x					
2/22/19	Maintaining Medical Freedom: Urgent Action Required!	x	x	x			
1/24/19	Why You Can't Trust the CDC on Vaccines			x			x
1/14/19	Robert F. Kennedy, Jr. Demands the Office of the Inspector General and Congress Investigate Department of Justice for Fraud and Obstruction of Justice			x	x	x	
	Vaccines Induce Bizarre Anti-Social Behaviour in Sheep				x		
7/0 · · · ·	Aluminum and Mercury Synergy: A	Y	v	v	V	V	Y
	"Perfect Storm" Could Goldman Sachs Report Be Exposing Pharma's Real End Game of Drug Dependency vs. Curing Disease?	x x	X	X	X	X	X
	The Vaccine Program: Betrayal of Public Trust & Institutional Corruption			x	x	x	
	Bill Gates, are vaccines a "miracle" over disease and a "fantastic investment"			^	^	^	
	Who Does the Childhood Vaccine Injury	v	v	v	v	×	
12/12/17	Act Protect? Campaign to Restore Child Health:	X	X	X	X	X	
11/27/17	Campaign to Restore Child Health: Behavioral-Developmental Disabilities & Vaccines	x					

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11/08/17	Why We All Don't Get Sick in the Same Way	x					
8/29/17	Fast-Tracking Mandatory Vaccination While Government and Media Muzzle Scientists					x	x
7/12/17	Mercury and Autism Relationship Confirmed in Longitudinal Study	x					
1/20/17	CDC Knew Its Vaccine Program Was Exposing Children to Dangerous Mercury Levels Since 1999				x	x	x
1/6/17	Mounting Evidence Links Lead, Mercury and Arsenic to Autism				x	x	x
12/20/16	Should I Get the Flu Shot? CDC Data Raise Concerns	x			x		
10/11/16	Is the Autism Epidemic Real?				х	х	х