

# Misinformation about Vaccines

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## ABSTRACT

Erroneous information about vaccine safety (misinformation) has existed since the dawn of vaccines and its dissemination is permitted by the freedom to express an opinion—no matter how incorrect.

Because of the increasing number and timing of vaccines, they are easy scapegoats for adverse events which occur coincident with vaccine administration, particularly those outcomes that are incompletely understood. In addition, vaccine-preventable disease activity has been greatly reduced by immunizations, causing parents to fear what they perceive might be complications of vaccines more than the actual diseases that the vaccines prevent.

It may require years to collect the data necessary to meet the rigorous standards that permit scientists to emphatically reject a vaccine safety concern. During the time needed to collect the evidence, however, those claims can evolve into misinformation.

Misinformers may be unintentional (they are uninformed) or intentional, in which case many have profit incentives. The most effective misinformers, however, are parents who truly believe that their child has been injured by vaccines.

Misinformation about vaccines can—and is—aggressively disseminated. Presented as fact by prominent individuals, it is often featured in publications, expounded on by the news media, discussed on popular TV and radio talk shows, and made the subject of TV dramas and docudramas. Because these compelling stories often feature prominent people, it is little wonder that other parents become confused. Unfortunately, there are barriers in responding to misinformation including innumeracy on the part of the public and poor communication skills on the part of vaccine spokespersons.

Confused parents may delay or refuse immunizations for their child. Many parents have many misperceptions about disease risks and vaccine safety, both those parents who permit their child to be immunized and those who do not. Health professionals can also become confused and some have helped perpetuate misinformation about vaccine safety.

The consequences of misinformation about vaccine safety can be declines in immunization acceptance and coverage followed by disease outbreaks with global consequences.

Countering misinformation about vaccines has become an urgent priority to assure the continued success of immunization programs. Fortunately, parents continue to seek information as well as the means to validate what they find. They also are seeking to identify trusted health providers to give them more information and guidance.

## INTRODUCTION

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In the 20th century, infectious diseases in the United States and other developed countries began to be better controlled as a consequence of clean water, pest control, and especially because of vaccines (Table 17.1). National immunization programs were successful because of effective childhood vaccines and a broad societal consensus that rare serious side effects—such as vaccine-associated poliomyelitis—were tragic but were tolerable for the benefit of the general public health. Of course, serious vaccine misadventures during the past century led to the vaccine industry being one of the most closely regulated of all US industries (Parkman, 2002).

While the immunization programs have been remarkably successful, they have had to deal with many challenges some of which are consequences of misinformation about vaccines and vaccine safety (Gust et al., 2004, 2005). For example, there have been recent measles outbreaks in the UK (Jansen et al., 2003; Ashmore et al., 2007), the Netherlands (Lernout et al., 2007), Germany (van Treeck, 2006; Bernard et al., 2007; Steart-Freedman and Kovalsky, 2007), and Switzerland (Richard and Masserey Spicker, 2007), attributable to inadequate rates of immunization coverage, at least in part related to the impact of misinformation about the safety of measles-containing vaccines. Similarly, recent outbreaks of mumps in the US seem likely to have been imported from the epidemic in the UK (Centers for Disease Control and Prevention, 2006a),

also related to decreased vaccine coverage due to the measles misinformation.

Seventy seven percent of US children 19–35 months of age are fully immunized with all the universally recommended vaccines (Centers for Disease Control and Prevention, 2007)—of course, that also means that 33% of children are under-immunized. In 2001, it was estimated that 3 children per 1000 had never received any vaccines (Smith et al., 2004); thus many others must be incompletely immunized. Under-vaccinated children are consequences of limited health-care access as well as financial and other barriers to immunization, although some are also a consequence of confusion about the importance of vaccines and misperceptions about vaccine safety (Gust et al., 2004). In contrast to under-immunized children, unvaccinated children's families tend to oppose immunization, cluster in communities, and their parents tend not to consider the advice of physicians or other health professionals (Smith et al., 2004; Salmon et al., 1999). Many parents are uninformed about the risks of vaccine-preventable diseases as well as misinformed about the safety of vaccines (Gust et al., 2004).

People opposed to immunization have been present since immunizations began. Cotton Mather's home was bombed (fortunately the bomb did not detonate) for preaching support for variolation, having convinced Zabediel Boylston, a physician, to variolate people in Boston in 1721 (Best et al., 2004). Admittedly, variolation was a practice with severe side effects, including 2% of patients dying, but the risk was less

TABLE 17.1 Vaccines and vaccine-preventable diseases—a remarkable outcome

Diseases	Number of cases before vaccine was widely used <sup>1</sup>	Year vaccine recommended for routine childhood vaccination	Number of cases	
			2005	2006
Smallpox	48,164	Early 1900s	0	0
Diphtheria	175,885	Mid-1940s	0	0
Pertussis	147,271	Mid-1940s	25,616 <sup>a</sup>	15,632 <sup>a</sup>
Tetanus	1314	Mid-1940s	27	41
Paralytic poliomyelitis	16,316	1955	0 <sup>c</sup>	0
Measles	503,282	1963	66	58
Mumps	152,209	1967	314	6584
Rubella	47,745	1969	11	11
Congenital rubella	823		1	1
Invasive <i>H. influenzae</i> , type b <sup>b</sup>	20,000	1985	9	29
Invasive <i>S. pneumoniae</i> <sup>b</sup>	17,240	2000	1495	1861
Hepatitis A (acute)	26,796	1995	4488	3579
Hepatitis B (acute)	26,107	1986	5119	4713
Varicella	About 4,000,000	1995	32,242	48,445
Deaths	105		3	ND <sup>d</sup>

Source: Adapted from Myers and Pineda (2008) with permission of the publisher.

<sup>a</sup>Numbers of cases of pertussis were at a historic low of 1010 in 1976.

<sup>b</sup>Children less than 6 years of age.

<sup>c</sup>In 2005, there was one case of imported, vaccine-associated paralytic poliomyelitis.

<sup>d</sup>ND, no data are available for 2006 yet.

than the mortality of smallpox in the unimmunized that developed smallpox (14.9%). Initial concerns about the safety of variolation led Benjamin Franklin to decide to not have his 4-year-old son, Franky, immunized by variolation, with tragic consequences:

In 1736 I lost one of my sons, a fine boy of 4 years old, by the Small Pox... I long regretted bitterly and I still regret that I had not given it to him by inoculation; This I mention for the sake of parents, who omit that operation on the supposition that they should never forgive themselves if a child died under it; my example showing that the regret may be the same either way, and that therefore the safer should be chosen (Hastings Weld, 1859).

## MISSING INFORMATION

### Missing Community Fear

How can communities knowingly put their children at risk from vaccine-preventable diseases? Of course, communities do not realize that their children may be at risk. In the absence of the vaccine-preventable diseases, parents do not recognize that their communities remain at risk of these infections and that these

diseases can be introduced and quickly spread within communities. This loss of societal fear represents one of the extraordinary ironies of the success of immunization programs. Except for smallpox, the vaccine-preventable diseases are still present. Tetanus spores persist in soil and, with global air travel, diseases like measles, mumps, rubella, diphtheria, and poliomyelitis remain just a plane ride away.

Decades ago, when thousands of children (and adults) in the United States contracted these diseases, parents feared these diseases. Successful immunization programs, however, have remarkably lowered disease rates for many of these illnesses. Presently, most parents (and many physicians) have never seen a child with paralytic poliomyelitis, asphyxiated by a diphtheric membrane, or brain damaged by measles, congenital rubella, or *Haemophilus influenzae*, type b (Hib). Some parents even believe that some of the vaccine preventable diseases are “not so bad” (Benin et al., 2006).

Although antivaccine opinions have been around for a long time, the majority of parents have maintained a collective consensus—largely driven by fear of the vaccine-preventable diseases—that vaccines and vaccine mandates are essential to the public health and the safety of children in a given community. In the

absence of disease visibility the collective consensus has begun to erode.

The challenge for vaccine policy makers is to communicate that the risks of disease introductions are real—even if they are largely unpredictable.

### Missing Data or “The Data are Insufficient to Accept or Reject the Hypothesis”

The timing of immunizations—beginning shortly after birth and then repetitively during the first 2 years of life with continuing immunizations throughout childhood—occurs at the ages when developmental and other problems are being recognized for the first time. Thus, the timing of vaccination—plus their widespread use—make vaccines the perfect “scapegoats” to be blamed for causing diseases of unknown or poorly understood causes.

When a vaccine concern is first suggested—particularly when the association is to a disease about which there is little understanding about etiology—there are often little or no data available to permit an honest scientist to state categorically that “vaccines do not cause that particular disease.” And then, as data accumulate, the lack of a demonstrated association does not assure coincidence, requiring multiple studies before scientific consensus is reached that the data “favor rejection of the hypothesized association.”

Compounding the issue of the time it takes to collect the needed data is the fact that many well-educated and intelligent people are innumerate—that is, they are unable to process information about risk assessments and measurements (Paulos, 1988). In addition, many suffer from availability bias (Poland and Jacobson, 2001). That is, they make intuitive judgments using readily available information. They base their estimates of how likely an event is based upon how easily they can imagine an example as well as its emotional impact.

Finally, when trying to communicate the complexities of demonstrating coincidence to an innumerate public, vaccinologists and public health officials often “speak in tongues”—using technical jargon as well as using expressions that have very different technical meanings than when they are used in everyday conversational English (Table 17.2). For example, when discussing vaccine safety, the vaccinologist uses the term “adverse event” to describe something that occurred temporally related to vaccine administration whereas many misconstrue that term to mean a “vaccine side effect.” For instance, fever is a common side effect of many vaccines, but febrile adverse events after vaccine receipt are not always caused by the vaccine. Similarly, when some serious condition

is recognized at about the time vaccines have been administered, the temporal association is difficult for parents to grasp as likely having been coincidental; particularly when public health officials only reassure with expressions such as “the data favor rejection of the theory.”

### The Uninformed as Misinformer

The uninformed or incompletely informed person may unintentionally disseminate misinformation. Parents rely on many sources for health information (Gellin et al., 2000; Paulussen et al., 2006) including family and friends but, unfortunately, many of these sources may also be uninformed misinformers.

## MISSING INFORMATION CAN EVOLVE INTO MISINFORMATION

Once evidence favors rejection of a vaccine safety hypotheses—such as has occurred with thimerosal- or measles-containing vaccines and autism (Institute of Medicine, 2004)—assertions about that vaccine safety concern are misinformation. The evolution of a vaccine safety concern into misinformation is complex but seems to follow a pattern which includes both unintentional and intentional misinformers (Table 17.3).

Consistently, there is a period of scientific uncertainty; a period of missing information where the scientist has difficulty being emphatic that the vaccine and the adverse event are unrelated, even if (s)he believes that the association is coincidental. People respond differently during these periods. Some parents do not immunize their children, perhaps believing that public health and health provider information was “one-sided” or “poor” (Smith et al., 2004); other parents express distrust of the medical community and perhaps a conspiracy by those advocating vaccines (Mills et al., 2005); while the majority, fortunately, trust that their physician or nurse will know what to do (Gellin et al., 2000).

A person’s perception of risk is based upon their experiences and knowledge. Someone who thinks that their child—or someone else’s child with whom they can empathize—had an adverse outcome because of a vaccine would likely think that vaccines are riskier than a person who has not. Conversely, a parent whose child has had a vaccine-preventable disease—or a physician who has treated that disease—will likely advocate for vaccines.

People respond better to some types of perceived risk than others (Reynolds, 2002). For example, natural

TABLE 17.2 Technical and conversational expressions that may confuse the public

Expression/word	Technical meaning	Conversational meaning
Vaccine adverse event	Something that occurred at about the same time as vaccination, which may or may not be caused by the vaccine	Something caused by the vaccine (vaccine reaction or side effect)
Bias	Systematic error that could lead to the wrong conclusion	Not having an open mind
Controversy	There are different but plausible interpretations of the same data within the scientific community	There is a difference in opinion
The patient “denies xyz”	The patient says she does not have them	The patient reacts defensively to an accusation
Epidemiology	The study of how disease is distributed in a population and of the factors that influence that distribution	Number crunching
Favors rejection of the hypothesis	The data suggest that the hypothesis should be rejected (but you can not prove a negative)	They still do not know
The finding would not go away	We could not find an alternative explanation	They are fudging the data
Inadequate to accept or reject the hypothesis	The data do not allow a definitive statement	They do not know
Naive	The person or animal has not previously been exposed to a particular infection, drug, or vaccine	Unsophisticated, lacking experience, or training
Paralysis	Loss of the ability to move a body part usually as a result of nerve damage	Inability to act, helpless inactivity
Plausible	Theoretically possible	Appearing worthy of belief, factual
Positive	The results of the study concur with the hypothesis; having a value greater than zero	Good
Power	The likelihood of a study finding an effect, if there was one; or, the number of times a number is multiplied by itself	Energy, strength, control
Probably a small risk	The association is likely real but very infrequent; or, uncertainty	Likely that it is a risk
Relative risk	The ratio of two rates of risks, often used to compare risks	The risks are related
Safe	Remote or insignificant risk	No risk or zero risk
Significant	This may not be a chance difference	Important
Not significant	Likely due to chance	Not important
Uncertainty	When the available scientific information is not sufficient to prove a relationship or is not sufficient to favor rejection of a relationship	They do not know

Source: Adapted from Myers and Pineda (2008) with permission of the publisher.

risks (such as infectious diseases) are better tolerated than man made risks (such as vaccine side effects) and risks that affect adults are better tolerated than risks affecting children. Risks that are perceived to have unclear benefits are less tolerated than risks where the benefits are clearly understood. For example, some parents believe that the risk of contracting measles could be lower than the risk of their child possibly experiencing a serious side effect being suggested by other parents who are convinced that their child was harmed following immunization. If they think that there is little benefit from immunizing their child,

they may conclude that there is no reason to take the risk of a possible adverse event, even if public health officials try to reassure them. If they are confused as to the risks, they may fail to immunize their child.

Stories about bad things happening to children after a vaccination circulate widely on the internet, are discussed on radio and TV, and described in magazines and newspapers. Despite the fact that serious vaccine safety risks are rare, perceived health risks are the center of attraction to the media, make effective sound bites, and may be egregiously inaccurate (Pribble et al., 2006).

**TABLE 17.3** The evolution of vaccine safety concerns into misinformation

A vaccine safety concern is suggested—usually by case reports of possible temporal associations of adverse events with vaccine administration or by an increase of reports of possible adverse events following vaccine administration.

- In the absence of any data making an association, and despite reassurances from the public health authorities, the media may declare that there “may be a problem.”<sup>a</sup>
- Some parents become frightened.

Vaccinologists respond that there are insufficient data to be able to state that the vaccine caused the adverse event or that it was just coincidental in time.

- This creates a sense of uncertainty which in turn causes some parents to become confused.

Public health officials compare the possible risk from the adverse event with the known risk of the disease, based on whatever available data there are.

- They make a recommendation.
- Some parents perceive a “cover-up.”

The media reports the scientific “uncertainty.”

- Parents who are convinced their child was harmed by vaccines want to warn other parents.
- The media often describe a controversy (difference of opinion) between public health officials and parents. True scientific controversy is rarely reported.
- Pseudoscience is promulgated; it is discounted by scientists but is often widely reported by the media.
- Intentional misinformers seek publicity.

Many parents become confused about vaccine benefits and risks.

- Parents see no disease, and reason “why take a risk?”

As data are collected, scientists reach a consensus that the data “favor rejection of the hypothesis.”

- Misinformers deny the data.
- Misinformers attempt to discredit the scientists.
- Those who are convinced, make up ad hoc hypotheses.

If community immunity has declined, outbreaks of disease may occur.

Ultimately—perhaps decades later—a cause for the coincidental disease is described.

<sup>a</sup>For example a BBC news headline reported (BBC News Online, 1998, [http://news.bbc.co.uk/2/low/uk\\_news/60510.stm](http://news.bbc.co.uk/2/low/uk_news/60510.stm)) “child vaccine linked to autism” following the initial case reports by Wakefield et al. (1998) about measles-containing vaccine and some cases of autism.

Media reports about the vaccines-autism theories, for example, continue to be published frequently. Although scientists say “the data suggest no association” (or, that “the data favor rejection of the theory”), parents want to hear a trusted source say “that vaccine does not cause that.” In contrast, some who believe that their child (or one that they know) was harmed by vaccine(s) insist that the theory has been established. Unfortunately, media reports often cite both opinions with equal credibility and emphasis;

generating uncertainty among parents, affecting their perceptions of risk, and their decision to vaccinate their child (Dannetun et al., 2005).

## IMMUNIZATION MANDATES

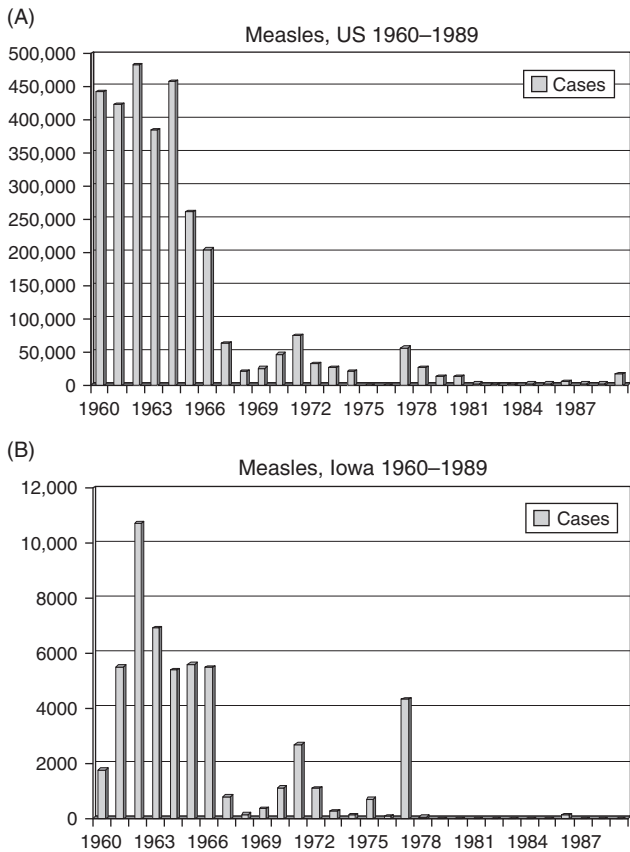
States require vaccines because they have a responsibility to protect both individuals and the entire population of their state. All states have immunization laws. However, other countries that also have very high levels of immunization coverage—such as Canada and Mexico—do not (WHO, 2007a).

School immunization laws were first established to control outbreaks of smallpox and in recent decades have been widely used to increase vaccine coverage and reduce outbreaks of vaccine-preventable diseases. Immunization requirements are set by states and currently all states have school immunization laws—although there are differences in what may be required in different states (see [www.immunizationinfo.org](http://www.immunizationinfo.org) for individual states’ requirements and exemptions).

Measles vaccine was licensed in the US in 1963; there was a rapid decline in the incidence of measles from about 438,000 cases/year (1960–1964) to about 42,700/year (1967–1971) in the United States (Centers for Disease Control and Prevention, 1995) (Fig. 17.1A). Both national and local epidemics continued to occur, however (Fig. 17.1A, B).

The constitutional basis for “a community to protect itself against an epidemic of disease” by immunization was established in 1903 (Parmet et al., 2005). This provided a means for states to expand immunization coverage. In the late 1960s and the 1970s immunization laws for school entry were enacted in many states largely on the demands of parents, because of continuing measles epidemics. For example, in Iowa, the creation of immunization requirements for school entry in 1977 (Iowa Administrative Code, 1977) was largely a response of parents to the recurring measles epidemics with the attendant mortality, cases of encephalitis, and overall morbidity (Myers, 1977, unpublished observations); the impact on measles activity was rapid (Fig. 17.1B) with cases dropping from 4333 in 1977 to none in 1981 through 1985 (Iowa Department of Health, 2007).

Parents who oppose vaccines for their children actively seek means to avoid immunizations, including home schooling and lobbying legislators for easier exemptions from immunization laws. Some parents oppose immunization mandates as a violation of their civil liberties. Both groups of parents try to recruit other parents to their “cause.”



**FIGURE 17.1** Measles in (A) the United States (Centers for Disease Control and Prevention, 1995) and (B) Iowa (Iowa Department of Health, 2007, [www.idph.state.ia.us/adper/pdf/cade/decades/pdf](http://www.idph.state.ia.us/adper/pdf/cade/decades/pdf)) 1960–1989. Measles vaccine was licensed in 1963. Mandatory immunization laws were enacted widely by states in the late 1960s and 1970s. Iowa enacted its immunization law in 1977 (Iowa Administrative Code, 1977).

All US states permit exemptions for children who have medical contraindications to immunization. However, most states also permit religious or philosophical exemptions. States permitting easy exemptions have many more unvaccinated children than do states that do not permit philosophical exemptions and unvaccinated children tend to cluster in communities (Smith et al., 2004; Salmon et al., 1999). Children who received exemptions were found to be 35 times more likely to contract measles and were more likely to spread measles to others (Salmon et al., 1999; Parker et al., 2006).

Washington State had school entry immunization exemption rates exceeding 5% in 2005–2006, six counties exceeding 10%, a substantial increase over 1999 (Bardi, 2007). Texas reported a school district with 19.05% conscientious exemptions for the school year 2003–2004, the first year after enactment of the exemption (Immunization Branch, Texas Department of State Health Services, 2003–2004, <http://www.dshs.state.tx.us/immunize/coverage/conscientious.shtm>).

## MISINFORMERS

Misinformation comes from many sources. Some who are uniformed or misinformed unwittingly misinform. Others are parents who honestly believe that their child was harmed by vaccines and they want to warn other parents. Still others are antivaccine activists many of whom may gain by disseminating and popularizing misinformation. For example, profits may come from contributions to organizations, book sales, movie rights, political support, tort precedents, court testimonies, speech making, inches of news space, or minutes of news time.

### Conflicts of Interest

Many organizations, government agencies, and universities require their employees (and their immediate families) to divulge potential or perceived financial and other conflicts of interest. Because of the nature of what vaccine researchers do, it is not surprising that some hold patents for their intellectual property, that they may be asked to consult for vaccine companies, or that a portion of their salary may come from grants or contracts with vaccine companies. While it is hard to imagine how an individual could otherwise become a vaccine expert, these types of relationships when active do in fact represent perceived—and at times real—conflicts of interest.

Misinformers make much ado about vaccinologists' real and perceived conflicts of interest. But they are aware of these conflicts of interest because the vaccinologists divulge these associations.

Misinformers may also have conflicts of interest, some obvious others less so. They have no obligation to divulge their own or their families' conflicts of interest. Book authors do not need to divulge their book sales income; investigative reporters (or their spouses) do not need to expose their retirement portfolios; pseudoscientists do not need to divulge their funding sources nor the income they receive from court testimony; and politicians only divulge conflicts of interest that are required by law.

### False Experts or “Experts” who Lack Expertise

No credible expert vaccinologist would claim to be expert in *all* the fields that relate to vaccine safety. For example, the IOM Committee on Immunization Safety included experts in pediatrics, neurology, immunology, internal medicine, infectious diseases, genetics,

epidemiology, biostatistics, risk perception and communication, decision analysis, public health, nursing, and ethics (Institute of Medicine, 2004).

Some who claim to be experts make claims outside their field of expertise. Such is the case of Dr. Mark Geier:

Dr. Geier's expertise, training, and experience is [sic] in genetics and obstetrics. He is however a professional witness in areas for which he has no training, expertise, and experience (U.S. Court of Federal Claims, 2003).

Another example would be "...Dr. Eric Ryndland who is considered one of the nations foremost experts on autism..." according to the reporter (Gillen, 2007). He<sup>1</sup> has no publications listed on the National Library of Medicine's Pub Med. It is unclear what, therefore, the reporter utilized to form her opinion of him as an "expert" in her article "To vaccinate or not to vaccinate."

### Journalists who have Written Articles or Books about Vaccine Safety

Although many journalists do a credible job writing about scientific and medical issues in ways that makes this information understandable and informative to the general public, they are usually specialized medical or science reporters at large news organizations. Good science journalists let the experts speak through their articles instead of purporting themselves to be experts.

Often times, however, stories—particularly published by smaller news organization and local TV stations—have not been checked for the reliability of the facts and present "controversies" that pit parents or others with an opinion against scientific experts, as if opinions and facts had similar value.

Others simply misinform. Media exposure and "controversies," of course, sell books and attract readers. For example, the journalist David Kirby—with apparently no scientific background or expertise in any field relating to vaccine safety or developmental disorders—wrote a book, *Evidence of Harm*, about thimerosal and autism which misinterprets scientific evidence and quotes out of context, attempting to imply a cover-up by respected scientists. Nevertheless, this book received an award for investigative reporting (Investigative Reporters and Editors, 2006, <http://www.ire.org/history/pr/2005ireawards.html>). Kirby is a frequent speaker at events for antivaccine and antithimerosal activists.

<sup>1</sup>Neither this spelling, nor Rindland, nor Ryndland.

Dan Olmsted, the author of *The Age of Autism*, once a regular columnist for United Press International (UPI), reported on his "research" that autism is less frequent among unvaccinated Amish children in Pennsylvania in contrast to other children. For a time, his articles attracted media attention despite the lack of any scientific content. His research methods included discussing his theories with a man who sells water purifiers in Amish communities (Olmstead, 2005).

### Politicians who Claim to be Experts

Many politicians bring together groups with differing interests and expertise—such as parents with opinions and scientists with expertise—in order to collect information and to understand the issues. However, there is little in a politician's training—including those with advanced education including a medical degree—that would qualify them as experts. Of course, politicians often seek support by taking on the causes of different interest groups.

Between 1999 and 2004 the Committee on Government Reform of the US House of Representatives held more than 10 hearings about vaccines, thimerosal, and autism. Rep. Dan Burton chaired this Committee from 1997 to 2002; his claim to expertise being that he is the grandfather of a child whom he believes has autism as a consequence of vaccines. When the IOM Vaccine Safety Committee said in 2004 that the body of scientific evidence favored rejection of a causal relationship between thimerosal-containing vaccines and autism (Institute of Medicine, 2004), Rep. Burton said in a press release:

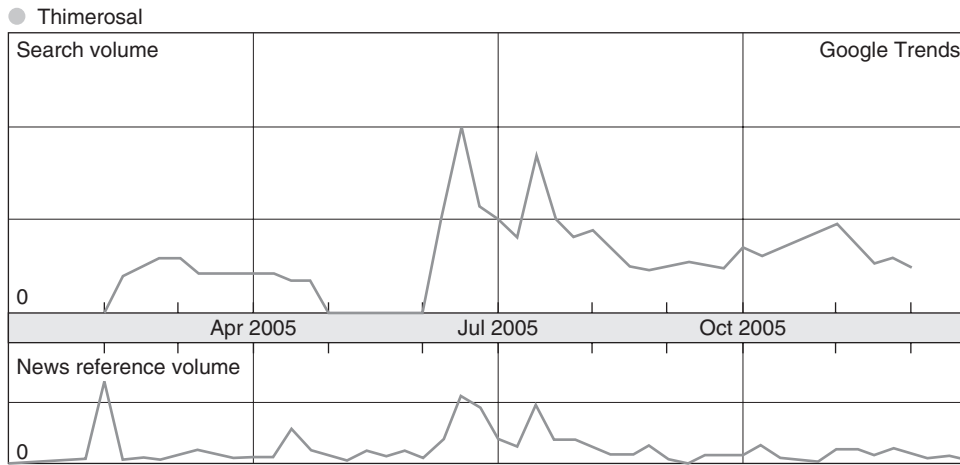
Unfortunately, I believe the findings announced in the May 18th IOM report are heavily biased, and unrepresentative of all the available scientific and medical research (Burton, 2004).

Politicians, lawyers, journalists, and others such as parents with an opinion contribute in a very positive way to the public discussion of immunization policy and vaccine safety but they are not authoritative scientific experts. Nonetheless, they are often quoted as if they were.

## DISSEMINATION OF MISINFORMATION

Unfortunately, misinformers can disseminate misinformation easily, especially employing the internet and other media.

More than two-thirds of US adults use the internet (Fox, 2005) and 80% of them use the Internet to



**FIGURE 17.2** Thimerosal misinformation events in March and June, 2005 were associated with increased news and search volume for thimerosal. “News reference volume” relates to news stories containing the search word that were accessed on Google News<sup>®</sup>. “Search volume” describes the volume of internet searches made using that search term.

find health information, including information about vaccines and immunization (Fox, 2006). There are disparities of access to the internet as well as the quality of internet access but those who access the internet (Fox, 2005) appear to have similar demographics to those who are antivaccine (Smith et al., 2004). Those who seek information online usually start at a search engine and do not often check on the source of the information (Fox, 2006). Internet search engines do not distinguish information from misinformation and most people are unable to distinguish reliable from unreliable information. In addition, one-third or more of streaming video on www.YouTube.com were critical of immunizations, with those videos higher rated than video clips favorable to immunizations (Keelan et al., 2007).

An example of how people use the internet in response to misinformation was shown by surges in search engine queries that included the word “thimerosal” following extensive publicity surrounding two misinformation “events”: the initial release of the book “Evidence of Harm” by David Kirby (St. Martin’s Press) in March, and the publication of the article “Deadly Immunity” by Robert Kennedy Jr. in Rolling Stone and Salon.com in mid-June, 2005. Google Trends<sup>®</sup> demonstrated both increased news volume and search engine searches for thimerosal in March (book release) and mid-June (article published) (Fig. 17.2) (Myers and Pineda, 2007).

The mainstream media reaches and influences all segments of society. For example, health stories must attract viewers because these account for more than 10% of air time in nightly TV news broadcasts. Unfortunately, these stories are usually unrelated

to public health priorities, they may be inaccurate, and provide misinformers with exposure. These reports may contain erroneous information (Pribble et al., 2006).

Unfortunately journalists may feel compelled to present a balance between opinions, reporting “controversies” (or “debates”) between the scientific community and misinformers, giving misinformers extensive media exposure and possibly credibility in the minds of the public. For example, on reporting the findings from a large comprehensive study that did *not* suggest any causal association between increasing exposure to mercury in thimerosal—neither prenatal or early in life exposure—and subsequent neuropsychological outcomes at 7–10 years of age (Thompson et al., 2007), Time Magazine in October, 2007 (Time Magazine, 2007), headlined an article “the vaccine debate goes on” and opened the article “Latest Findings. Thimerosal, a mercury-based vaccine preservative, has long been associated with neurological disabilities like autism.” The article continued by outlining Centers for Disease Control and Prevention and their “critics” positions.

## MISINFORMATION CONTENT

Misinformation content often consists of many of the following:

### **Pseudoscience**

Pseudoscience (“false knowledge”) is often presented to the media as “science” by misinformers. It is usually ambiguous, employs hard to comprehend methods,

may not be quantifiable, and the results can usually not be duplicated. In many cases, these reports are not subjected to peer review. Often, data may be represented to show one outcome when another is the case. Other times the methods that are used may be likely to give a predetermined outcome. Only data purporting to support the author's claims are presented while conflicting data are ignored or dismissed.

The peer review mechanism employed by most respected journals is intended to ensure that only carefully conducted science is published; but sometimes poorly run studies slip by the most careful editor. Because of the vetting process, however, most pseudoscientific claims about vaccine safety are not published in respected journals but are often published in obscure journals or in the "alternative medicine" press.

A number of studies implying a link between vaccines and neurodevelopmental disorders have been published by Mark Geier and his son David Geier. They often utilize data from the Vaccine Adverse Event Reporting System (VAERS) to try to establish causality (Geier and Geier, 2004). VAERS data cannot be used to establish causality. The purpose of VAERS is to tabulate possible adverse events in order to look for "signals" that should be explored systematically (Varricchio et al., 2004). In addition, the Geiers' reports also often failed to describe methods, important statistical figures were not defined accurately, and data sets overlapped (American Academy of Pediatrics, 2003, <http://www.aap.org/profed/thimaut-may03.htm>).

In addition to pseudoscience, misinformers often misquote legitimate research claiming that studies support their views, when in fact the original data do not. For example, the November 14, 2005 issue of the New York Times included a full-page advertisement by the group Generation Rescue thanking the researchers who did "groundbreaking research on the connection between mercury and autism" (The New York Times, 2005, <http://www.generationrescue.org/images/051114.gif>). The ad listed 19 citations of articles—including one by the Geiers. None of the 19 articles shows that mercury causes autism. Although some of them did look for a possible link between mercury and autism, others were about autism in general with no mention of mercury. One of the papers cited was by Andrew Wakefield, about MMR (which does not contain thimerosal) and autism.

### Invalid Assumptions

Some invalid assumptions often underlying misinformation claims are that illness in a vaccinated

person proves that the vaccine does not work, temporal associations establish causation, and epidemiologic studies are not real science.

### Logical Fallacies

Misinformers often use logical fallacies in their arguments. For example, the post hoc argument is common; that is, the temporal association of an adverse event is assumed to infer causality. It is especially seen online, where people report that a vaccine harmed a child because certain symptoms appeared a few days or weeks after vaccination. Also, VAERS reports are purported to be descriptions of vaccine side effects. Often they also make an *argument from ignorance*—claiming that a statement is true only because it has not been proven false, or that it is false only because it has not been proven true.

The ad hominem fallacy—attacking the person—takes many forms in discussions of vaccine safety, alleging cover-ups and conspiracy theories by which misinformers try to discredit those who do not agree with them. Indeed ad hominem arguments are recognized to be a frequent attribute of antivaccination Web sites (Davies et al., 2002) as well as media coverage about antivaccination topics (Leask and Chapman, 1998). Attacks of this type on members of the Institute of Medicine Vaccine Safety Committee and other reputable scientists were so serious that Senator Enzi (2007) filed an investigative report with the US Senate Committee of Health, Education, Labor and Pensions in 2007 refuting the charges. Similarly, the *guilt by association* fallacy claims that a theory or an argument must be false simply because of who else supports the argument.

Misinformers often use the ad misericordiam fallacy to frighten other parents, by featuring anecdotes about children that they claim have been killed or maimed by vaccines (Davies et al., 2002; Wolfe et al., 2002).

### Ad hoc Hypotheses

When misinformers find themselves in the position of believing something that becomes unsupportable based on the data, they will often resort to making an ad hoc hypothesis. Attorneys litigating vaccine injury claims do this not infrequently. When multiple studies found no causal association between measles- or thimerosal-containing vaccines with the subsequent development of autism, a new hypothesis was generated that together measles-containing vaccine and the preservative thimerosal in other vaccines cause autism (Office of Special Masters, 2007).

## THE CONSEQUENCES OF MISINFORMATION

Outbreaks of vaccine-preventable diseases often begin among the unimmunized and underimmunized and then spread to the fully immunized in the community (Salmon et al., 1999; Parker et al., 2006)—a portion of whom remain susceptible because no vaccine is 100% effective. Sustained transmission of infections within communities occurs when a sufficiently large proportion of the population is susceptible, the proportion differing among the different vaccine preventable communicable diseases (Fine, 2004). Immunization coverage is often utilized as a surrogate marker for the proportion who is immune.

Following periods of intense misinformation, decreases in immunization coverage may occur and disease outbreaks may occur. For example, because of the concerns about whole-cell pertussis vaccine possibly being associated with severe neurologic developmental problems, immunization rates in Great Britain in 1978 had fallen from 80 to 30%. Epidemic pertussis soon followed: between 1977 and 1979 there were 102,500 cases of whooping cough with 36 deaths (Cherry et al., 1988).

In Japan, because of concerns about the whole-cell pertussis vaccine's safety and claims that it was no longer necessary to immunize because pertussis was not present in the community, the age for immunization was changed and immunization coverage for infants fell from about 85% in 1974 to 13.6% in 1976 (Cherry et al., 1988). In 1979, Japan reported 13,105 cases of pertussis with 41 deaths. In the early 1980s Japan re-introduced acellular pertussis-containing vaccines with a reduction in the number of cases (Gangarosa et al., 1998). Similarly, after discontinuing pertussis vaccine, rates of whooping cough returned to the levels seen in the prevaccine era in Sweden. Of 2282 who were hospitalized for whooping cough in 1981–1983, 4% had brain injury from the illness (Cherry et al., 1988).

The specific contribution that misinformation played on these pertussis outbreaks is hard to define because it is not clear when missing information about whole-cell pertussis vaccine safety evolved into misinformation. However, countries whose immunization programs were disrupted by whole-cell pertussis antivaccine movements (Sweden, Japan, the UK, Ireland, Italy, Australia, the former West Germany, and the Russian Federation) experienced ten to 100 times higher pertussis incidence than did countries in which the antivaccine movement had a limited impact on pertussis vaccine coverage (Hungary, the former

East Germany, Poland, and the US) (Gangarosa et al., 1998).

Two decades later, another vaccine scare began in the UK. In 1998, Wakefield and others published a series of case reports suggesting that some children who had received measles-containing vaccine suffered bowel injury, permitting absorption of substances that caused brain injury and thus autism (Wakefield et al., 1998). Although Wakefield's report did not provide any evidence of a link between measles vaccine and autism, media coverage was extensive, giving his hypothesis credibility in the eyes of many in the public; the headline in London's *Daily Telegraph* read, "Vaccination may trigger disease linked to autism" (Daily Telegraph, 1998, <http://www.telegraph.co.uk/htmlContent.jhtml?html=/archive/1998/02/27/nmmr27.html>). Many national and international news outlets carried the same story. Both the initial report and subsequent claims of evidence for measles virus in children with autism have now been dismissed (D'Souza et al., 2006; Doja and Roberts, 2006; Murch et al., 2004; Horton, 2004) but many frightened parents, not surprisingly, feared the vaccine more than the diseases. In the following years MMR vaccination rates fell from 93 to 79% by 2003, with measles (Gust et al., 2005) and mumps (Centers for Disease Control and Prevention, 2006b; WHO, 2007b) (Fig. 17.3) outbreaks as a consequence. The outbreak of mumps in 11 states in 2006 and the epidemic in the UK in 2005 were both caused by mumps virus, genotype G (Centers for Disease Control and Prevention, 2006a), suggesting they may have been epidemiologically related.

Misinformation confuses many. For example, in an unpublished random digit dial telephone survey, almost half the parents with children less than 6 years of age reported that they believed vaccines can cause

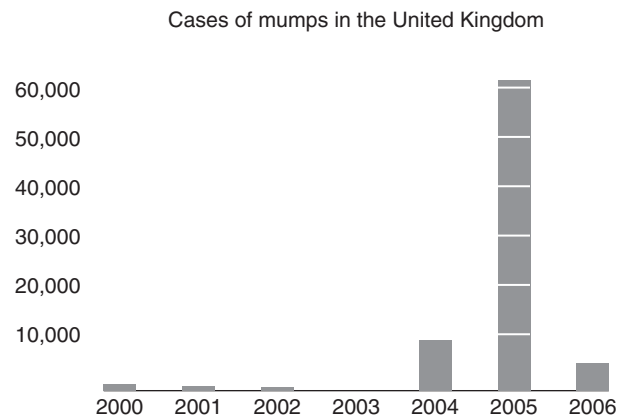


FIGURE 17.3 In 2005, there were more than 63,500 cases of Mumps in the United Kingdom (WHO, 2007b) (Adapted from Myers and Pineda (2008) with permission of the publisher.)

autism (APCO insight, 2006). Misinformation can also confuse health providers, including school personnel overseeing immunization programs (Salmon et al., 2004). In 2006, a 23-month-old asthmatic child with influenza A pneumonia was admitted to a hospital in Texas requiring ventilator support. Two weeks previously she had been denied influenza immunization because the provider believed the child should only receive influenza vaccine without thimerosal preservative, which the practice did not have in stock (Patel, 2006, personal communications).

Misinformation impacts parental decision-making. For example, 13 of 33 mothers interviewed postpartum were vaccine hesitant or outright rejected vaccine for their newborns (Benin et al., 2006). A couple in Tennessee, confused about vaccine safety because of what a friend had told them, decided to delay their daughter's vaccinations. The girl developed Hib meningitis (Snyder, 2000).

Misinformation can have serious consequences for individual families as well as for communities.

### **VACCINE MISINFORMATION IS A GLOBAL PROBLEM**

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Misinformation about vaccine safety is a problem that affects developing as well as developed countries. False allegations in Nigeria that oral polio vaccine could cause sterility—thought to be intended to limit the Muslim population size—or that it could cause AIDS, resulted in a resurgence of wild-type polio viruses transmission, cases of polio, and the spread of wild-type virus into 19 previously polio-free countries (Centers for Disease Control and Prevention, 2005–2006). Similar rumors have plagued the introduction of other vaccine programs in other countries. For example, the introduction of a maternal and infant tetanus immunization program necessitated Egypt to train community guides to dispel these types of rumors—and one immunizer had to immunize herself to prove the vaccine safe (U.S. Fund for UNICEF, 2004, [www.who.int/entity/immunization\\_monitoring/diseases/06\\_fall\\_2004.pdf](http://www.who.int/entity/immunization_monitoring/diseases/06_fall_2004.pdf)).

In contrast to developed countries, antivaccine activities in developing countries focus on national immunization days, religious and political arguments against vaccines, and concerns about “western plots,” especially that vaccines could cause involuntary contraception or sterilization (Eastern and Southern Africa Regional Office, United Nations Children's Fund, 2001).

Part of the difficulty of dealing with misinformation about vaccines in developing countries is resistance to change (Regional Office for South Asia, United

Nations Children's Fund, 2005, [http://www.unicef.org/rosa/Immunisation\\_report\\_17May\\_05\(final\\_editing\\_text\).pdf](http://www.unicef.org/rosa/Immunisation_report_17May_05(final_editing_text).pdf)) as well as the recognition that some vaccines and immunization practices have in fact in the past been unsafe (Simonsen et al., 1999). Because the foundations of an effective immunization program are safe and effective vaccines which are delivered in a safe manner, the WHO has put in place systems to try to ensure the safety of the vaccines used in all national programs (Ducloso, 2004; Clements et al., 2004).

To measure the impact of a vaccine and to be able to evaluate adverse events following immunization require surveillance of vaccine coverage and disease activity as well as the monitoring of adverse events. Many developing countries have not integrated these components into their national immunization programs (Ducloso, 2004). Countries that do have these tools in place, such as the US, still have difficulty dispelling concerns about vaccine-associated anecdotes; in the absence of such an infrastructure, it is little wonder that health officials have difficulty reassuring the public about coincidental associations.

The historical impact of antivaccination rumors on the introduction of immunization programs have led to the development of strategic communication plans for national immunization programs that include the assumption that misinformation and negative reactions will occur as part of the introduction of new vaccines (Regional Office for South Asia, United Nations Children's Fund, 2005, [http://www.unicef.org/rosa/Immunisation\\_report\\_17May\\_05\(final\\_editing\\_text\).pdf](http://www.unicef.org/rosa/Immunisation_report_17May_05(final_editing_text).pdf)).

### **FIGHTING WITH THE BOOGEYMAN: COUNTERING MISINFORMATION ABOUT VACCINE SAFETY**

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The vast majority of parents would not opt out of any vaccine and they also understand that school immunization laws protect their children (Gellin et al., 2000). However, there are also many parents who have great misperceptions about the risk and severity of vaccine preventable diseases as well as about the safety of vaccines (Mills et al., 2005; Dannetun et al., 2005; APCO insight, 2006; Salmon et al., 2004; Freed et al., 2004; Fredrickson et al., 2004). Misperceptions about disease risks and vaccine safety are similar among parents who refuse vaccines for their child and among those parents who permit their child to be immunized, although the proportions of parents with misperceptions are greater among those who withhold some or all vaccines from their children (Gust et al., 2004, 2005).

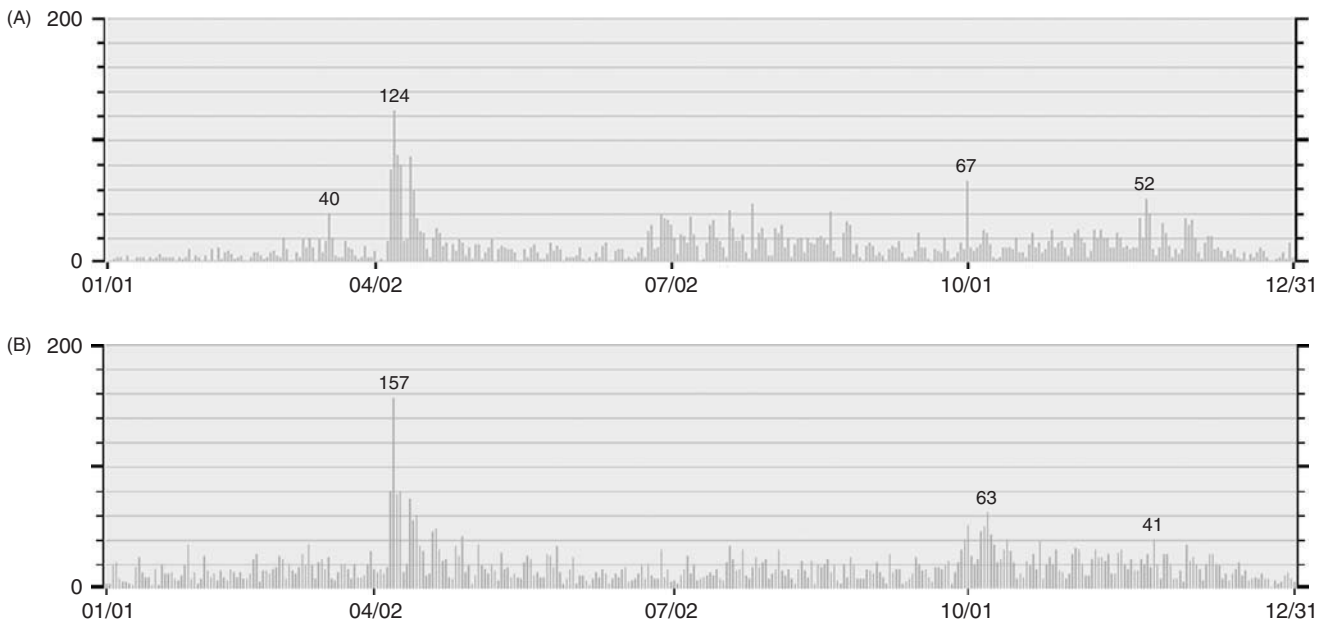
Parental refusal (either refusal or delay) of vaccine for their child is not uncommon (Benin et al., 2006; Fredrickson et al., 2004; Diekma and Committee on Bioethics, 2005; Flanagan-Klygis et al., 2005), most physicians who care for children have to deal with this problem at least once a year—the rate of refusal is estimated to be 7.2/1000 children less than 18 years of age (Fredrickson et al., 2004). Fear of pain, fear of serious side effects, plus the belief that the diseases are not harmful are common reasons for vaccine refusal. These are also common concerns among parents who do immunize their children.

Misinformation about vaccine safety comes in many forms and from many sources. Fortunately, most parents still obtain information about immunizations from trusted health professionals (Gellin et al., 2000). Unfortunately, some health professionals may be uninformed, some themselves may be confused by misinformation, and some (particularly alternative medicine providers) may be “anti-vaccine.”

Parents are actively seeking more information (Gust et al., 2004). The most important intervention for countering misinformation may be that a trusted provider addresses the parents’ lack of knowledge about the diseases as well as their concerns about vaccine safety. But this approach is limited by the time available to busy clinicians: discussions about vaccines comprising about 15s during the average visit (Davis et al., 2004).

We have observed increasing use of the NNii Website [www.immunizationinfo.org](http://www.immunizationinfo.org) over time—from 17,677 visitors per month in October 2005, to 32,553 in October, 2007 (Myers and Pineda, 2007). The entrance pages to the Web site are usually the Homepage or, if accessed by search engine, often directly to specific vaccines/diseases featured in the section “Vaccines and the Diseases they Prevent.” The next most popular section is Immunization Issues, consisting of essays about topical issues on vaccine safety (many suggested by viewers). We also have observed that during times of increased media activity surrounding misinformation events (Fig. 17.2), there is a corresponding surge in readership of archived essays on related topics (see Fig. 17.4A on our Web site. At about the same time, many visitors follow links to information about assessing the reliability of information found on the internet (Fig. 17.4B) (Myers and Pineda, 2007).

A large proportion of parents—whether vaccine hesitant or not—have been confused by misinformation publicized about vaccine safety. Although some parents have made up their mind to not immunize their children—and disregard data that do not support their views (Meszaros et al., 1996)—the majority of parents desire more information. They have many information resources available; unfortunately, they may frequently locate misinformation. However, in addition to seeking information, they also seem to want to confirm the reliability of what they found.



**FIGURE 17.4** Search activity at [www.immunizationinfo.org](http://www.immunizationinfo.org) coincident with increased media activity surrounding thimerosal-containing vaccines. (A) Daily pageviews of archived essays about thimerosal-containing vaccines. (B) Daily pageviews of archived essays about misinformation about vaccine safety, viewed largely by hyper links (Myers and Pineda, 2008). A pageview is a request for a page, enumerated by [www.urchin.org](http://www.urchin.org).

Parents need education about the risks and severities of the vaccine-preventable diseases; most do not recognize that they are uninformed.

There seem to be a number of favorable factors to counter misinformation: Most parents want to establish trusting relationships with health professionals; they are seeking more information; they are willing to utilize guidance; and many seek to validate information they locate. These openings would seem to provide the most effective means to sustain and expand confidence in immunization programs in the face of burgeoning misinformation about vaccines and vaccine safety.

In considering the introduction of new vaccines—including vaccines for biothreats and emerging infectious diseases—as well as vaccines developed employing new technologies and new delivery strategies, it will be important to employ communication plans for all the target populations, analogous to those being utilized for the introduction of new vaccines in developing countries (Regional Office for South Asia, United Nations Childrens Fund, 2005, [http://www.unicef.org/rosa/Immunisation\\_report\\_17May\\_05\(final\\_editing\\_text\).pdf](http://www.unicef.org/rosa/Immunisation_report_17May_05(final_editing_text).pdf)).

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