

# On Autism's Cause, It's Parents vs. Research

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Kristen Ehresmann, a Minnesota Department of Health official, had just told a State Senate hearing that vaccines with microscopic amounts of mercury were safe. Libby Rupp, a mother of a 3-year-old girl with autism, was incredulous.

"How did my daughter get so much mercury in her?" Ms. Rupp asked Ms. Ehresmann after her testimony.

"Fish?" Ms. Ehresmann suggested.

"She never eats it," Ms. Rupp answered.

"Do you drink tap water?"

"It's all filtered."

"Well, do you breathe the air?" Ms. Ehresmann asked, with a resigned smile. Several parents looked angrily at Ms. Ehresmann, who left.

Ms. Rupp remained, shaking with anger. That anyone could defend mercury in vaccines, she said, "makes my blood boil."

Public health officials like Ms. Ehresmann, who herself has a son with autism, have been trying for years to convince parents like Ms. Rupp that there is no link between thimerosal - a mercury-containing preservative once used routinely in vaccines - and autism.

They have failed.

The Centers for Disease Control and Prevention, the Food and Drug Administration, the Institute of Medicine, the World Health Organization and the American Academy of Pediatrics have all largely dismissed the notion that thimerosal causes or contributes to autism. Five major studies have found no link.

Yet despite all evidence to the contrary, the number of parents who blame thimerosal for their children's autism has only increased. And in recent months, these parents have used their numbers, their passion and their

organizing skills to become a potent national force. The issue has become one of the most fractious and divisive in pediatric medicine.

"This is like nothing I've ever seen before," Dr. Melinda Wharton, deputy director of the National Immunization Program, told a gathering of immunization officials in Washington in March. "It's an era where it appears that science isn't enough."

Parents have filed more than 4,800 lawsuits - 200 from February to April alone - pushed for state and federal legislation banning thimerosal and taken out full-page advertisements in major newspapers. They have also gained the support of politicians, including Senator Joseph I. Lieberman, Democrat of Connecticut, and Representatives Dan Burton, Republican of Indiana, and Dave Weldon, Republican of Florida. And Robert F. Kennedy Jr. wrote an article in the June 16 issue of Rolling Stone magazine arguing that most studies of the issue are flawed and that public health officials are conspiring with drug makers to cover up the damage caused by thimerosal.

"We're not looking like a fringe group anymore," said Becky Lourey, a Minnesota state senator and a sponsor of a proposed thimerosal ban. Such a ban passed the New York State Legislature this week.

But scientists and public health officials say they are alarmed by the surge of attention to an idea without scientific merit. The anti-thimerosal campaign, they say, is causing some parents to stay away from vaccines, placing their children at risk for illnesses like measles and polio.

"It's really terrifying, the scientific illiteracy that supports these suspicions," said Dr. Marie McCormick, chairwoman of an Institute of Medicine panel that examined the controversy in February 2004.

Experts say they are also concerned about a raft of unproven, costly and potentially harmful treatments - including strict diets, supplements and a detoxifying technique called chelation - that are being sold for tens of thousands of dollars to desperate parents of autistic children as a cure for "mercury poisoning."

In one case, a doctor forced children to sit in a 160-degree sauna, swallow 60 to 70 supplements a day and have so much blood drawn that one child passed out.

Hundreds of doctors list their names on a Web site endorsing chelation to treat autism, even though experts say that no evidence supports its use with

that disorder. The treatment carries risks of liver and kidney damage, skin rashes and nutritional deficiencies, they say.

In recent months, the fight over thimerosal has become even more bitter. In response to a barrage of threatening letters and phone calls, the centers for disease control has increased security and instructed employees on safety issues, including how to respond if pies are thrown in their faces. One vaccine expert at the centers wrote in an internal e-mail message that she felt safer working at a malaria field station in Kenya than she did at the agency's offices in Atlanta.

### **An Alarm Is Sounded**

Thimerosal was for decades the favored preservative for use in vaccines. By weight, it is about 50 percent ethyl mercury, a form of mercury most scientists consider to be less toxic than methyl mercury, the type found in fish. The amount of ethyl mercury included in each childhood vaccine was once roughly equal to the amount of methyl mercury found in the average tuna sandwich.

In 1999, a Food and Drug Administration scientist added up all the mercury that American infants got with a full immunization schedule and concluded that the amount exceeded a government guideline. Some health authorities counseled no action, because there was no evidence that thimerosal at the doses given was harmful and removing it might cause alarm. Others were not so certain that thimerosal was harmless.

In July 1999, the American Academy of Pediatrics and the Public Health Service released a joint statement urging vaccine makers to remove thimerosal as quickly as possible. By 2001, no vaccine routinely administered to children in the United States had more than half of a microgram of mercury - about what is found in an infant's daily supply of breast milk.

Despite the change, government agencies say that vaccines with thimerosal are just as safe as those without, and adult flu vaccines still contain the preservative.

But the 1999 advisory alarmed many parents whose children suffered from autism, a lifelong disorder marked by repetitive, sometimes self-destructive behaviors and an inability to form social relationships. In 10 to 25 percent of cases, autism seems to descend on young children seemingly overnight, sometime between their first and second birthdays.

Diagnoses of autism have risen sharply in recent years, from roughly 1 case for every 10,000 births in the 1980's to 1 in 166 births in 2003.

Most scientists believe that the illness is influenced strongly by genetics but that some unknown environmental factor may also play a role.

Dr. Tom Insel, director of the National Institute for Mental Health, said: "Is it cellphones? Ultrasound? Diet sodas? Every parent has a theory. At this point, we just don't know."

In 2000, a group of parents joined together to found SafeMinds, one of several organizations that argue that thimerosal is that environmental culprit. Their cause has been championed by politicians like Mr. Burton.

"My grandson received nine shots in one day, seven of which contained thimerosal, which is 50 percent mercury as you know, and he became autistic a short time later," he said in an interview.

In a series of House hearings held from 2000 through 2004, Mr. Burton called the leading experts who assert that vaccines cause autism to testify. They included a chemistry professor at the University of Kentucky who says that dental fillings cause or exacerbate autism and other diseases and a doctor from Baton Rouge, La., who says that God spoke to her through an 87-year-old priest and told her that vaccines caused autism.

Also testifying were Dr. Mark Geier and his son, David Geier, the experts whose work is most frequently cited by parents.

### **Trying to Build a Case**

Dr. Geier has called the use of thimerosal in vaccines the world's "greatest catastrophe that's ever happened, regardless of cause."

He and his son live and work in a two-story house in suburban Maryland. Past the kitchen and down the stairs is a room with cast-off, unplugged laboratory equipment, wall-to-wall carpeting and faux wood paneling that Dr. Geier calls "a world-class lab - every bit as good as anything at N.I.H."

Dr. Geier has been examining issues of vaccine safety since at least 1971, when he was a lab assistant at the National Institutes of Health, or N.I.H. His résumé lists scores of publications, many of which suggest that vaccines cause injury or disease.

He has also testified in more than 90 vaccine cases, he said, although a judge in a vaccine case in 2003 ruled that Dr. Geier was "a professional witness in areas for which he has no training, expertise and experience."

In other cases, judges have called Dr. Geier's testimony "intellectually dishonest," "not reliable" and "wholly unqualified."

The six published studies by Dr. Geier and David Geier on the relationship between autism and thimerosal are largely based on complaints sent to the disease control centers by people who suspect that their children were harmed by vaccines.

In the first study, the Geiers compared the number of complaints associated with a thimerosal-containing vaccine, given from 1992 to 2000, with the complaints that resulted from a thimerosal-free version given from 1997 to 2000. The more thimerosal a child received, they concluded, the more likely an autism complaint was filed. Four other studies used similar methods and came to similar conclusions.

Dr. Geier said in an interview that the link between thimerosal and autism was clear.

Public health officials, he said, are "just trying to cover it up."

### **Assessing the Studies**

Scientists say that the Geiers' studies are tainted by faulty methodology.

"The problem with the Geiers' research is that they start with the answers and work backwards," said Dr. Steven Black, director of the Kaiser Permanente Vaccine Study Center in Oakland, Calif. "They are doing voodoo science."

Dr. Julie L. Gerberding, the director of the disease control centers, said the agency was not withholding information about any potentially damaging effects of thimerosal.

"There's certainly not a conspiracy here," she said. "And we would never consider not acknowledging information or evidence that would have a bearing on children's health."

In 2003, spurred by parents' demands, the C.D.C. asked the Institute of Medicine, an arm of the National Academy of Sciences and the nation's most

prestigious medical advisory group, to review the evidence on thimerosal and autism.

In a report last year, a panel convened by the institute dismissed the Geiers' work as having such serious flaws that their studies were "uninterpretable." Some of the Geiers' mathematical formulas, the committee found, "provided no information," and the Geiers used basic scientific terms like "attributable risk" incorrectly.

In contrast, the committee found five studies that examined hundreds of thousands of health records of children in the United States, Britain, Denmark and Sweden to be persuasive.

A study by the World Health Organization, for example, examined the health records of 109,863 children born in Britain from 1988 to 1997 and found that children who had received the most thimerosal in vaccines had the lowest incidence of developmental problems like autism.

Another study examined the records of 467,450 Danish children born from 1990 to 1996. It found that after 1992, when the country's only thimerosal-containing vaccine was replaced by one free of the preservative, autism rates rose rather than fell.

In one of the most comprehensive studies, a 2003 report by C.D.C. scientists examined the medical records of more than 125,000 children born in the United States from 1991 to 1999. It found no difference in autism rates among children exposed to various amounts of thimerosal.

Parent groups, led by SafeMinds, replied that documents obtained from the disease control centers showed that early versions of the study had found a link between thimerosal and autism.

But C.D.C. researchers said that it was not unusual for studies to evolve as more data and controls were added. The early versions of the study, they said, failed to control for factors like low birth weight, which increases the risk of developmental delays.

The Institute of Medicine said that it saw "nothing inherently troubling" with the C.D.C.'s adjustments and concluded that thimerosal did not cause autism. Further studies, the institute said, would not be "useful."

## **Threats and Conspiracy Talk**

Since the report's release, scientists and health officials have been bombarded with hostile e-mail messages and phone calls. Dr. McCormick, the chairwoman of the institute's panel, said she had received threatening mail claiming that she was part of a conspiracy. Harvard University has increased security at her office, she said.

An e-mail message to the C.D.C. on Nov. 28 stated, "Forgiveness is between them and God. It is my job to arrange a meeting," according to records obtained by The New York Times after the filing of an open records request.

Another e-mail message, sent to the C.D.C. on Aug. 20, said, "I'd like to know how you people sleep straight in bed at night knowing all the lies you tell & the lives you know full well you destroy with the poisons you push & protect with your lies." Lynn Redwood of SafeMinds said that such e-mail messages did not represent her organization or other advocacy groups.

In response to the threats, C.D.C. officials have contacted the Federal Bureau of Investigation and heightened security at the disease control centers. Some officials said that the threats had led them to look for other jobs.

In "Evidence of Harm," a book published earlier this year that is sympathetic to the notion that thimerosal causes autism, the author, David Kirby, wrote that the thimerosal theory would stand or fall within the next year or two.

Because autism is usually diagnosed sometime between a child's third and fourth birthdays and thimerosal was largely removed from childhood vaccines in 2001, the incidence of autism should fall this year, he said.

No such decline followed thimerosal's removal from vaccines during the 1990's in Denmark, Sweden or Canada, researchers say.

But the debate over autism and vaccines is not likely to end soon.

"It doesn't seem to matter what the studies and the data show," said Ms. Ehresmann, the Minnesota immunization official. "And that's really scary for us because if science doesn't count, how do we make decisions? How do we communicate with parents?"

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