Anatomy of a Scare

When one study linked childhood vaccines to autism, it set off a panic. The research didn't hold up, but some wounded families can't move on.

Sharon Begley
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Like many people in London on that bleak February day in 1998, biochemist Nicholas Chadwick was eager to hear what the scientists would say. The Royal Free Hospital, where he was a graduate student in the lab of gastroenterologist Andrew Wakefield, had called a press conference to unveil the results of a new study. With flashbulbs popping, Wakefield stepped up to the bank of microphones: he and his colleagues, he said, had discovered a new syndrome that they believed was triggered by the MMR (measles, mumps, rubella) vaccine. In eight of the 12 children in their study, being published that day in the respected journal The Lancet, they had found severe intestinal inflammation, with the symptoms striking six days, on average, after the children received the MMR. But hospitals don't hold elaborate press conferences for studies of gut problems. The reason for all the hoopla was that nine of the children in the study also had autism, and the tragic disease had seized them between one and 14 days after their MMR jab. The vaccine, Wakefield suggested, had damaged the intestine—in particular, the measles part had caused serious inflammation—allowing harmful proteins to leak from the gut into the bloodstream and from there to the brain, where they damaged neurons in a way that triggered autism. Although in their paper the scientists noted that "we did not prove an association" between the MMR and autism, Wakefield was adamant. "It's a moral issue for me," he said, "and I can't support the continued use of [the MMR] until this issue has been resolved."

That's strange, thought Chadwick. For months he had been extracting genetic material from children's gut biopsies, looking for evidence of measles from the MMR. That was the crucial first link in the chain of argument connecting the MMR to autism: the measles virus infects the gut, causing inflammation and leakage, then gut leakage lets neurotoxic compounds into the blood and brain. Yet Chadwick kept coming up empty-handed. "There were a few cases of false positives, [but] essentially all the samples tested were negative," he later told a judicial hearing. When he explained the negative results, he told NEWSWEEK, Wakefield "tended to shrug his shoulders. Even in lab meetings he would only talk about data that supported his hypothesis. Once he had his theory, he stuck to it no matter what." Chadwick was more disappointed than upset, figuring little would come from the Lancet study. "Not many people thought [Wakefield] would be taken that seriously," Chadwick recalls. "We thought most people would see the Lancet paper for what it was—a very preliminary collection of [only 12] case reports. How wrong we were."

The next day, headlines in the British press screamed, DOCTORS LINK AUTISM TO MMR VACCINE AND BAN THREE-IN-ONE JAB, URGE DOCTORS AFTER NEW FEARS. That was mild compared with what followed. Hysteria over childhood vaccinations built to such a crescendo that Wakefield's nuanced warning—that it was specifically the triple vaccine, not single-disease vaccines (even measles), that posed a threat—was drowned out. In 2001, Prime Minister Tony Blair and his wife, Cherie, refused to say whether their son, then 19 months old, had received the MMR; rumors swirled that they had gone to France so the child could receive the measles vaccine alone. In 2003, a docudrama about Wakefield ran on British TV, depicting him as having his files stolen and his phone tapped by evil pharmaceutical companies intent on protecting their vaccines. As one reviewer described the show: "The MMR vaccine is coming to get our kids."

The MMR vaccine is the same on both sides of the Atlantic, so fears of childhood vaccines (of which U.S. health officials recommend 35 by age 6) started a backlash in the United States, too, fueled in no small part by the fact that the incidence of autism was rising for reasons scientists could not fully explain. In California, for instance, the incidence of autism had risen from 6.2 per
10,000 births in 1990 to 42.5 in 2001. Groups of parents began refusing vaccines for their children. Within a few years of Wakefield's announcement, rates of MMR vaccinations in Britain fell from 92 percent to below 80 percent. Although there was no comparable nationwide decrease in the United States, pockets of resistance to vaccination appeared throughout the country, laying the groundwork for a sevenfold increase in measles outbreaks. Looking back from the perspective of 11 years, the panic seems both inevitable and inexplicable. Inevitable, because legitimate scientists publishing in respected journals produced evidence of a link between vaccines and autism, and because the press as well as politicians and even public-health officials stoked the mounting hysteria. Inexplicable because, by the early 2000s, scientific support for that link had evaporated as completely as the red dot on a baby's vaccinated thigh.

Scientists and government officials who defended the safety of childhood vaccines were not shy about attributing the fears to the science illiteracy of the public and the fearmongering of the press. In truth, however, after Wakefield's announcement there was a steady drumbeat of studies—not from kooks in basement labs but from real scientists working at real institutions and publishing in real, peer-reviewed journals—that backed him up. In 2002, pathologist John O'Leary of Coombe Women's Hospital in Dublin reported that he had found RNA from the measles virus in 7 percent of normal children—but in 82 percent of those with autism, suggesting that some children are unable to clear the vaccinated virus from their systems, resulting in autism. That same year, a Utah State University biologist reported finding high levels of antibodies against the measles virus in the blood and spinal fluid of autistic children; the MMR, he postulated, had triggered a hyperimmune response that attacked the children's brains. In 2003, gastroenterologist Arthur Krigsman, then at New York University School of Medicine, reported finding what Wakefield had: that the guts of 40 autistic children were severely inflamed, lending support to the idea that leaks allowed pernicious compounds to make a beeline for the brain.

But these studies and others supporting the link between autism and the MMR were nothing compared with an extraordinary step that had been taken by the U.S. government and by one of the country's leading medical organizations. On July 7, 1999, the American Academy of Pediatrics (AAP) and the U.S. Public Health Service issued a warning about the preservative in many vaccines. Called thimerosal, it contains 49.6 percent ethylmercury by weight and had been used in vaccines since the 1930s, including the diphtheria/tetanus/pertussis (DTP) and Haemophilus influenzae (Hib) vaccines (but not the MMR). The experts tried to be reassuring, saying in a statement there are "no data or evidence of any harm" from thimerosal. But, they continued, children's cumulative exposure to mercury from vaccines "exceeds one of the federal safety guidelines" for mercury. (By 2003, most childhood vaccines did not contain thimerosal, though flu vaccines still did.) The AAP statement did not mention autism.

But on April 6, 2000, Rep. Dan Burton did. Burton had previously distinguished himself by his support for laetrile, the quack cancer remedy. Now he was chairing a congressional hearing on the link between vaccines and autism. His own grandson, Burton told an overflow audience filled with antivaccine activists, was perfectly normal until he received "nine shots on one day," after which he "quit speaking, ran around banging his head against the wall, screaming and hollering and waving his hands." Witnesses testified about their own tragedies, such as a child's "journey into silence" soon after receiving the MMR vaccine. Wakefield, too, testified. Since his Lancet paper, he said, he had studied scores more children, identifying almost 150 in whom MMR had triggered autism. O'Leary, the Irish scientist who had confirmed Wakefield's finding of measles virus in the guts of children with autism, pronounced himself "here to say that Wakefield's hypothesis is correct." Now there were two explosive theories about the dangers of childhood vaccines: Wakefield's, that the MMR caused gut inflammation and the release of autism-causing proteins into the blood and brain, and the thimerosal theory, that the mercury in childhood vaccines damages the immune system and, possibly, the brain.

Burton's hearing was widely covered in the press, but the attention was nothing compared with the flood of stories that were about to be unleashed. That November "60 Minutes" aired a segment featuring children who "appeared normal" until getting the MMR. On Nov. 10, 2002, The New York Times Magazine ran an article on "The Not-So-Crackpot Autism Theory," about thimerosal. It included news of an August 2002 study by the father-and-son team Mark and David Geier, who combed a federal database of reported "adverse events" after vaccinations. They found "increases in the incidence of autism" after children got thimerosal-containing vaccines compared with thimerosal-free vaccines. The following spring, the Geiers published another study: the more mercury in their vaccines, the more likely children were to develop autism.

By this time, mistrust of the scientific establishment—and of anyone defending vaccines—had mushroomed into something decidedly uglier. When pediatrician Paul Offit, a vaccine expert at the Children's Hospital of Philadelphia, testified before Burton's panel, he said that he had had his own children vaccinated, and gave their names. At a break, a congressional staffer pulled him aside and said, "Never, never mention the names of your own children in front of a group like this."
The following year he received an e-mail threatening to "hang you by your neck until you are dead." The FBI deemed it credible and assigned him an armed guard during vaccine meetings at the U.S. Centers for Disease Control and Prevention.

The first cracks in the vaccine theories of autism appeared in early 2004. An investigation by British journalist Brian Deer in The Sunday Times of London revealed that the children Wakefield described in the Lancet study had not simply arrived on the doorstep of the Royal Free. At least five were clients of an attorney who was working on a case against vaccine makers alleging that the MMR caused the children's autism. In addition, two years before the Lancet paper Wakefield had received £55,000 from Britain's Legal Aid Board, which supports research related to lawsuits. After meeting with Deer, Lancet editor Richard Horton told the British press, "If we knew then what we know now, we certainly would not have published the part of the paper that related to MMR … There were fatal conflicts of interest." On March 6, 10 of Wakefield's 12 coauthors formally retracted the paper's suggestion that the MMR and autism were linked.

Wakefield did not join them. Now executive director of a Texas nonprofit called Thoughtful House, which offers treatments for autism, he admits he was retained and paid by the lawyer for the parents of autistic children but denies that posed a conflict of interest. "At the time the children were referred to the Royal Free, none of the parents were involved in litigation, though some went on to do so," he says. The legal board's payment supported other vaccine-autism research he was conducting, Wakefield says, not that in the Lancet paper. "I will not be deterred from continuing to look after these children and research their problems," says Wakefield.

In 2005 Britain's General Medical Council, which licenses physicians, began a hearing in which Wakefield was charged with professional misconduct for, among other things, the alleged financial conflict of interest in the Lancet study. The investigation has since expanded, with new charges by journalist Deer that Wakefield or his coauthors misrepresented the children's medical records. In particular, Deer reported that the children's gut and autism symptoms appeared long before their MMR rather than, as the 1998 Lancet study reported, right after. Wakefield denies doing anything improper, saying he "merely entered the documented findings into the Lancet paper."

The charges against Wakefield were the least of what was undermining the vaccine theory of autism. What would eventually become an overwhelming body of evidence showing that childhood vaccines did not increase the risk of autism began to pile up. In 2002 scientists led by Brent Taylor of the Royal Free reported that their study of 473 children had found no difference in the rates of autism between those who had received the MMR and those who had not, providing "further evidence against involvement of MMR vaccine in the initiation of autism," they wrote. Scientists in Finland, studying 2 million children, reached the same conclusion in a 2000 paper. So did scientists at Boston University, studying the medical records of 3 million children, in 2001. In 2004 a study of the medical records of 14,000 children in Britain found that the more thimerosal the children had been exposed to through vaccines, the less likely they were to have neurological problems. Also that year, the Institute of Medicine (IOM) in the United States, having reviewed 200-plus studies, rejected the vaccine-autism hypothesis. Not only did it find no evidence of a link—and, indeed, evidence against the existence of a link—but it took aim at the original 1998 Lancet paper by Wakefield's group. Because autism symptoms typically appear at the same age that children get the MMR, the panel said, it was inevitable that some children would first show symptoms of autism soon after being vaccinated. Coincidence is not causality.

If the IOM panel thought that would be the end of it, they were naive. From the halls of Congress to the airwaves to the pages of leading newspapers, true believers went at the vaccine-autism link more passionately than ever. After the IOM released its report, Rep. Dave Weldon of Florida, a physician, took to the House floor to denounce the CDC for its vaccine-autism research. The agency, Weldon charged, was guilty of "selective use of the data to make the associations [between vaccines and autism] disappear" and had engaged in "a public-relations campaign [on behalf of vaccines] rather than sound science."

The following year, a story by environmental lawyer Robert F. Kennedy Jr. called "Deadly Immunity" made the case against thimerosal in Rolling Stone. Activists used large chunks of the money they were raising from terrified parents to spread their message. On June 8, a full-page ad for Generation Rescue, which had been founded the month before to push the thimerosal theory, ran in The New York Times, proclaiming, "Mercury Poisoning and Autism: It Isn't a Coincidence." It included quotes from several politicians, with Burton stressing research that "indicated a direct link between exposure to mercury and autism," and Sen. John Kerry saying "mercury has been linked to autism." Later that year, a book titled "Evidence of Harm: Mercury in Vaccines and the Autism Epidemic," by journalist David Kirby, got huge attention in the media. Kirby appeared on "Imus in the Morning" several times, as did politicians supporting his thesis. Sen. Joseph Lieberman, citing the growing incidence of autism coupled with the increase in the number of required vaccines, said, "Make sure your kids are getting vaccines without thimerosal."

Throughout this saga, the "vaccines cause autism" side could claim more powerful persuaders...
than the dry-as-dust scientific papers and even drier scientists trying to reassure parents. On Sept. 18, 2007, model and actress Jenny McCarthy appeared on "The Oprah Winfrey Show" to promote her new book, "Louder Than Words," in which she describes curing her son Evan's autism—which she blames on the MMR—with diet and chelation, a process that chemically binds heavy compounds in the body so they can be excreted. Asked about the CDC statement that science does not link vaccines to autism, McCarthy said, "My science is Evan." Researchers were dumbfounded that so many parents rejected the conclusions of the CDC, the Institute of Medicine and the American Academy of Pediatrics (which after its thimerosal debacle had put itself foursquare behind childhood vaccines). "The issue for people like Jenny McCarthy isn't that doctors and scientists and public-health officials haven't listened to parents," writes Paul Offit in his 2008 book "Autism's False Prophets: Bad Science, Risky Medicine and the Search for a Cure." "It's that they've been unable to find any evidence to validate parents' concern."

The anti-vaccine campaign was having an effect. As parents postponed vaccinating their children, or refused vaccines entirely, children were suddenly catching preventable diseases, and some were dying. The number of measles cases in the United States reached 131 in 2008, the highest in decades. Last month five children in Minnesota became infected with Hib. Four developed serious complications; the fifth child died. Other parents, believing that yanking mercury out would cure a child's autism, opted for chelation. Unfortunately, it can pull out vital metals such as iron and calcium as well as toxic mercury and lead.

An overwhelming majority of vaccine and autism experts were convinced that parents were putting their children at real risk over a phantom fear. But perhaps no one understood that the MMR theory was a house of cards better than molecular biologist Stephen Bustin of the University of London. In 2004 the U.K. High Court asked him to inspect the Dublin lab that had reported measles genes in the guts of autistic children right after they received the MMR, an important confirmation of Wakefield's theory. It was an uncomfortable situation, Bustin recalls, playing cop at another scientist's lab. But he discovered a number of problems. The genetic material the lab had found was DNA, but measles genes are made of RNA. The equipment was so poorly calibrated that its results depended on where in the machine the sample was placed. Wakefield defends his collaborator, saying that a later test confirmed "the fidelity and high quality of [the Dublin lab's] methods ... The original results that found measles virus genetic material in intestinal biopsies in 75 percent of the autistic children compared with 6 percent of the nonautistic controls still stand."

Under U.S. law, families who believe their child has been injured by a vaccine have their claims heard by a special "vaccine court." Since 1999 some 5,000 families had filed claims asserting that vaccines caused their child's autism. That is too many to try individually, so in 2004 they were combined into three test cases. One would represent the claim that MMR caused the children's autism, one that thimerosal in vaccines other than MMR did and one that the combination did. The last theory was tested with the case of Michelle Cedillo, a 12-year-old with severe autism; hearings began on June 11, 2007. Before it was over, the evidence would include 99 papers from journals and textbooks and testimony running thousands of pages. One of those testifying was Bustin, who explained that the finding of measles genes in autistic children rested on shoddy science. "Normally it hardly matters when a scientific paper gets it wrong," Bustin says. "But in this case, it matters a great deal."

On Feb. 12 Special Master George Hastings Jr. announced his decision in the Cedillo case. Every study conducted to test Wakefield's MMR hypothesis, he concluded, "found no evidence that the MMR vaccination is associated with autism." And the evidence "falls far short" of showing a thimerosal connection.

That is hardly the end of the legal cases. All three sets of parents in the test cases say they will take their claims against the manufacturers to civil court, hoping to convince juries—through the emotional power of tragically damaged children—of what they failed to prove to the vaccine court. And if those cases, too, absolve vaccines? In postings on antivaccine sites such as GenerationRescue.org and SafeMinds.org, parents have made clear that they think the system is rigged and that vaccines condemned their children to a lifetime of being barricaded behind the impregnable wall of autism. Perhaps it should not be a mystery why people refuse to believe science, with its tentative hypotheses, zigzag pathway to finding answers and a record of getting some things wrong before getting them right (see hormone-replacement therapy). On the day the court announced its decision, Offit pointed out that "tens of millions of dollars have been spent trying to answer these questions [about vaccines and autism]," but many people "refuse to believe the science." Perhaps, he mused, that's "because while it's very easy to scare people, it's very hard to unscare them."

And it's impossible to prove a negative such as "vaccines do not cause autism." The slim hope of finding a link—perhaps only children with specific genetic variants are at risk of developing autism as a result of vaccines; perhaps the vaccine is dangerous only in combination with other environmental triggers—keeps activists at the barricades. (They received some support in 2007,
when the federal government settled the case of Hannah Poling, admitting that a vaccine had exacerbated a rare underlying cellular disorder and, as a result, brought on autistic symptoms.) Wakefield, unrepentant, slams the vaccine-court decision for "not being based on any definitive science." One powerful advocacy group, Autism Speaks, said after the decision that it will continue to support research into whether certain children with "underlying medical or genetic conditions may be more vulnerable to adverse effects of vaccines." Chief science officer Geraldine Dawson says they "owe it to the parents to listen and address their concerns. We don't want to close the door." Not even a door that, since it was opened 11 years ago this month, has let through such demons. It is bad enough that the vaccine-autism scare has undermined one of the greatest successes of preventive medicine and terrified many new parents. Most tragic of all, it has diverted attention and millions of dollars away from finding the true causes and treatments of a cruel disease.

With Jeneen Interlandi

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