

# The Refusers

Getting your shots used to be as American as motherhood and apple pie. Now a small but vocal group is saying no—with deadly consequences.

By **Tim Gihring** - December 15, 2011

Porter has autism, there's no doubt about that. He's 18 and still wears a diaper. A cloth around his neck catches the drool caused by his medication.

Around dinner time, his mother, Sarah Bridges, removes the white helmet he wears to protect him from himself, and he sits on the carpet of their Richfield home, smiling and staring.

"Where's Pocahontas?" he asks. Bridges, a psychologist and executive coach with the golden hair and easy manner of a displaced California girl, laughs—she's heard this one before, a reference to the Disney movie. "Pocahontas is with John Smith," she says. A few minutes later, he asks again: "Where's Pocahontas?" He says it until he gets an answer, and he expects the same answer. "He's got seven or eight of these questions that he moves between," Bridges says. "It's like he's in a loop."

Until he was four months old, Porter was developing normally. Then he got his immunization shots: diphtheria, tetanus, pertussis (whooping cough)—you name it, he got it. The night of his pertussis shot, Porter woke up screaming with a fever. Then he became unconscious. After a two-hour seizure, he returned to normal—only he wasn't the same kid.

By age 3, he had been hospitalized 14 times for seizures. He began regressing, losing his skills as if a video of his childhood was playing backward. He wouldn't sit still. He wouldn't speak except in non sequiturs: "Tigger's stuck in a tree!" over and over. He was soon diagnosed with brain damage and severe autism.

Bridges filed a lawsuit. Americans can't sue vaccine makers directly—the federal government, which presumes a steady flow of vaccine to be in the national interest, is too concerned that pharmaceutical companies would stop producing vaccines if they were hit with expensive personal-injury lawsuits. So, in 1986, as the country was generally becoming more litigious, Congress established the National Vaccine Injury Compensation Program, often called vaccine court, to handle any claims against vaccine makers. In the 1990s, when Bridges sued, three-quarters of the claims were related to the combined DTP (diphtheria, tetanus, pertussis) shot. Bridges alleged in her 1994 suit that the pertussis vaccine had led to Porter's brain damage and autism.

Years passed. Doctors contracted by the government would examine Porter, and then Bridges would hear nothing for long stretches. She chose not to vaccinate her other kids.

In the meantime, a highly publicized study suggesting that vaccines could in fact trigger autism, overseen by British researcher Andrew Wakefield and published in 1998, came and went—it was declared fraudulent by the *British Medical Journal* in early 2011. The supposed vaccine-autism link, said many other scientists, was a myth: vaccines have occasional side effects, like any other drug, but autism is not one of them.

Then, in May of last year, Bridges was invited to speak at a press conference in Washington, D.C., and revealed that years earlier she had reached a multi-million-dollar settlement with the government. "The idea that there's no link between vaccines and autism is a complete red herring," she said. Bridges was

interviewed on FOX News and the clip went viral on the Internet. For the millions of Americans who had never stopped believing in a vaccine-autism link—who thought the government was hiding the truth—here was the proof.

**Patsy Stinchfield** sits in her office at Children's Hospital and Clinics, in downtown St. Paul, surrounded by charts showing Minnesotans' relative risk for measles, mumps, polio, and other diseases that seem, as with bomb shelters and bobbysoxers, like relics of an earlier, scarier time. Yet the diseases are still around. They've just been held at bay by vaccinations. "The only disease we've ever eradicated is smallpox," Stinchfield says. "There was a time when we thought we'd eradicated measles, but obviously we haven't." She shows a recent newspaper clipping, framed beside her desk, of a tiny Minnesota boy hooked up to myriad tubes in the hospital, a victim of measles.

Officially, Stinchfield is the Children's director of infectious disease immunology, staying on top of trends in infection and prevention. Unofficially, she is the state's greatest vaccine evangelist, promoting the drugs wherever and whenever she can. She's done this since 1987, when most people never questioned vaccines. She has two kids—fully vaccinated. "For that five minutes of pain and poking, you get a lifetime of immunity," she says, her standard pitch.

Increasingly, the pitch has fallen on deaf ears. Though vaccinations have long been required in order to receive public education in Minnesota—no shots, no school—exemptions are made for religious, medical, or philosophical reasons. All you need is a notary to witness your refusal request.

"Look at this," Stinchfield says and pulls up a graphic on her computer. It's a square divided into four quadrants, representing different attitudes toward vaccination. In one corner, marked "action," fear of disease meets no fear of vaccines—this is the majority of Americans: getting their shots without protest. The opposite corner, where no fear of disease meets great fear of vaccines, is marked "refusal." Stinchfield circles the word with her finger. "This is the population that's been growing," she says. "The refusers."

Last spring, a survey showed that Minnesota, usually as good about vaccinating as it is about voting, had dropped several percentage points in its immunization rates, falling from seventh to 20th among the states. Around the same time, the largest measles outbreak in years hit Minnesota, sending more than a dozen kids to the hospital with near-fatal complications. In about half the cases, the children were too young to be vaccinated. In the other cases, however, the children were old enough to be vaccinated but had not been—their parents had refused. The reason was almost always the same: fear of autism.

**If you're like most Americans**, you probably fear infectious diseases about as much as you fear shark attacks. Maybe less. You've been vaccinated. You're out of the woods. Game over. But you're never completely safe: no vaccine is 100-percent effective. Flu vaccines are only about 59-percent effective in adults. You get by because of "herd immunity," the fact that if most of the people around you are vaccinated, you'll encounter few people who can give you the disease. This is how America has avoided a major epidemic for decades. But it only works, of course, if most people fear disease enough to get vaccinated.

Stinchfield, in her office, displays another chart: historical disease outbreaks overlaid with historical immunization rates. When diseases are down, sure enough, so are vaccinations. "We're a victim of our own success," Stinchfield says of public-health officials. "If we do a good job, nothing happens and people get comfortable. If you've never seen polio or measles, you don't fear them."

Polio, a once-widespread disease that causes muscle weakness and paralysis (President Franklin Roosevelt was famously afflicted with it), was the impetus to start a national vaccine program in the first place, in 1955. Mass inoculations are generally credited with reducing polio infections in the United States from a high of 58,000 in 1952 to zero within a couple of decades. Vaccines for other diseases were rapidly refined and distributed, subsidized by the government. The World Health Organization now estimates that some 3 million lives around the world are spared each year by vaccines.

The last time infectious diseases were widespread in the United States was in 1990. Measles had struck again—nearly 28,000 cases, more than 500 in Minnesota. When that was under control, the anti-vaccine movement began to take root, spurred by a rise in autism diagnoses that has yet to be conclusively explained.

One of every 160 American kids is now believed to fall somewhere on the autism spectrum, meaning the child shows, to various degrees and in various ways, the telltale signs of difficulty in communication and social interaction. The term "autism" has been around for a century, drawn from the Greek word *autos*, meaning "self," a reference to the self-absorption often indicative of the disorder. But it wasn't until the 1940s that the first cases were diagnosed. Starting in the 1990s, autism diagnoses increased radically—by some measures more than five-fold.

Suspicion of vaccines began when it was noticed that the spike in autism diagnoses roughly corresponded to an increase in the number of required vaccinations. Anyone who remembers the simple cards showing the required course of childhood shots in the 1970s or '80s would be surprised to see today's large tri-fold immunization schedule, covering 14 diseases, that Stinchfield readily admits has become much more complicated. "People see so many vaccines on this list," she says, "and they think there's no way that can be safe."

Early proponents of a link between vaccines and autism were dubbed "mercury moms" for focusing suspicion on a mercury-based preservative called Thimerosal that was used for decades in vaccines—and still is in certain flu vaccines. This trace amount, the government said, was harmless. But a few years ago, when vaccine makers began taking out Thimerosal, the result of an EPA effort to banish mercury wherever possible, the mercury moms felt justified. If Thimerosal is harmless, why take it out? "We thought the removal would reassure people," Stinchfield says. "Well, that backfired."

Autism rates appear to have held steady, despite the scaling back of Thimerosal. So refusers are beginning to focus on other factors: aluminum in vaccines, the age at which vaccines are given, the number of vaccines administered at once. They're also questioning the assumption that autism rates *have* continued to rise. They've asked for statistics from the federal Centers for Disease Control, and

when the agency has been slow to respond, because of the size or nature of the request, they become even more suspicious.

Minnesota, with one of the highest rates of autism diagnoses in the country (as high as one in 65 children), has become ground zero for refusers. A diverse, generally well-educated community, they range from stockbrokers to teachers, lawyers to nurses, comprising an unusual intersection of libertarians who want the government off their backs and natural-health adherents who want the industrial food and drug complex out of their bodies. They'll do baby yoga, they'll put their kids on vegan diets, but they won't do vaccinations.

Many refusers are simply scared or cautious—"vaccine hesitant" in the parlance of public health. Some don't believe vaccines are necessary: "Grew up perfectly fine in a nicer, more civil world with measles, mumps, and chickenpox a common occurrence," one refuser has posted online. "No deaths, no autism." Others are hard-core opponents of immunization. They're writing books, like a forthcoming critical study of the vaccine court. They're contributing to blogs like *Age of Autism: The Daily Web Newspaper of the Autism Epidemic*, a hotbed of anti-vaccine commentary. The Vaccine Safety Council of Minnesota, recently organized by parents of children with autism, frequently questions government-sponsored studies, citing perceived conflicts of interest, inadequate methodology, and occasional malfeasance by researchers, implying collusion between vaccine makers and the government. Last year, Minnesotans helped form a national political organization, the Canary Party, advocating for vaccine safety—and easier exemptions from vaccinations.

There are even examples of vaccine terrorism—threats to public-health workers and their children. "I was once offered \$750,000 to drink the entire childhood course of vaccines to prove it was safe," Stinchfield says. "My husband said to do it—we could use the money—but I won't respond to that sort of thing."

**To Sarah Bridges** and other refusers, her settlement in vaccine court is proof that the government quietly acknowledges a vaccine-autism link. But the settlement wasn't exactly for Porter's autism—the court has a list of injuries for which it will compensate, and autism isn't one of them. Porter was compensated for encephalopathy: brain damage. Bridges says you can call it what you want—brain damage, encephalopathy, autism—the result is that vaccines changed Porter.

This is certainly possible. In rare cases, perhaps one in a million, vaccines seem to trigger an underlying neurological disorder. "In some metabolically vulnerable children," says a recent report from the Institute of Medicine, "receiving vaccines may be the largely nonspecific 'last straw' that leads these children to reveal their underlying [problems]." Bridges says her pediatrician advised against vaccinating the children she had after Porter, playing it safe given Porter's medical history.

Still, the current science holds that brain damage isn't the same as autism—you can have one without the other, or both in the case of Porter. And the compensation proves little. The vaccine court offers compensation for temporal associations—the injury could happen within six months of the vaccination and you could win your case. "You don't have to prove cause and effect," says Dr. Greg Poland, a vaccine specialist with the Mayo Clinic in Rochester. "Your toe could fall off a day after the shots and you might still be compensated."

This tenuous link between vaccines and injuries has been exploited, says Poland, by anti-vaccine groups who point to compensated cases as evidence of harm. And they've cast enough doubt to recruit some influential sympathizers. Julie Gerberding, a former director of the Centers for Disease Control, has said the medical community needs to have "an open mind" regarding a possible vaccine-autism link. Secretary of State Hillary Clinton has similarly stated, "We don't know what, if any, kind of link there is between vaccines and autism, but we should find out." President Barack Obama has called for more investigation. "The science right now is inconclusive," he said recently, "but we have to research it."

Such equivocation is frustrating to public-health officials—in their minds the science *is* conclusive. There has never been a mainstream scientific report linking vaccines to autism that wasn't revised, retracted, or otherwise rejected.

Seeking to end the debate once and for all—the scientific equivalent of Obama releasing his birth certificate—the vaccine court came out with a decision in 2009 clearing the deck of some 5,000 lawsuits alleging a vaccine-autism link. The verdict, dismissing all claims, was almost demeaning, describing the petitioners as "victims of bad science" and suggesting that "an objective observer would have to emulate Lewis Carroll's White Queen and be able to believe six impossible (or at least, highly improbable) things before breakfast" to decide in the petitioners' favor.

The decision ended nothing. Last August, the Institute of Medicine issued the most comprehensive report yet on vaccine side effects, declaring the majority to be very rare or very mild. Autism was not among them. That same day, the Vaccine Safety Council of Minnesota released a critique of the report, declaring the research insufficient.

**There is no cure for autism.** No guaranteed treatment. No end in sight to solving the mystery of its manifestation. Suspicion of something as simple and material as vaccines has given parents an enemy to focus on and a belief that the means to control autism are within our grasp.

Wayne Rohde believes potential autism triggers are all around us. One afternoon, at his home in Woodbury, he watches his son Nick, who is 14 but looks about 10 and acts about 2. Tip-toeing around

the house, Nick makes a steady drone while slapping his chest. Occasionally he'll walk up to a guest, stare a while with little expression, and continue on his way. "He's checking you out," Rohde says.

Rohde lived in Oklahoma City until 2010, when he moved his family here—to a "more autism-friendly state," he says. He and his wife and two kids live about half a mile from the Minnesota Autism Center. But they couldn't escape the mercury, fluoride, aluminum, genetically modified food, and other manufactured menaces that Rohde believes are ruining an entire generation. "There is an environmental assault on our kids," he says.

When Nick was diagnosed with autism, the family got "a 1-page Xerox and a prescription for Ritalin," Rohde says. No explanation. So Rohde began searching the Internet for clues and landed on vaccines. He now calls the concept of herd immunity a "convenient excuse" to benefit vaccine manufacturers, and he and his wife opted not to vaccinate their second child.

"Money and power are driving vaccine policy today," Rohde says. On his coffee table, he has a copy of Andrew Wakefield's book and calls the defamed researcher wrongly accused. "I don't think we're going to find all the causes of autism," he says. "The powers that be don't want us to."

Both Nick and his brother were born very prematurely—Nick was just 3 pounds, 11 ounces. Still, at 13 months he was seemingly healthy and had language skills. Then, around the same time as his MMR (measles, mumps, rubella) shots, he started retreating. After Nick was diagnosed with autism, Rohde and his wife sold everything the family had of value and cashed in their retirement plans to pay for Nick's treatments, including dietary supplements, organic meals, and intensive therapy.

Rohde became known in Oklahoma for proposing "Nick's Law," which would have made it difficult for insurers to deny coverage of treatments for children with autism (the proposal failed in the state legislature). Last year, after helping start the Minnesota branch of the Canary Party, he lobbied here for a similar law.

"The older generation of autism parents have told me, 'Just deal with it,'" Rohde says. "No! Our son was stolen from us. We'd do everything we could to help Nick."

Rohde, a big guy who bears a passing resemblance to John Goodman, stiffens on the couch, suggesting a man not easily moved. "Over the past five to seven years, there's been a new generation of parents unwilling to accept autism as it is," he says. "I'm never going to accept the autism that Nick has. I'm going to defeat it. Period."

**The refuser movement** may be symptomatic of the broader distrust of experts, evident in everything from climate-change discussions to medical self-diagnosis, that has grown alongside the Internet. Websites and blogs, publishable by anyone with a modem, have turned laypeople into experts in their own minds—and increasingly in the minds of others. Jenny McCarthy, the former *Playboy* model, has a son with autism and has become a hero of the anti-vaccine movement through her Twitter feed and columns on the *Huffington Post* website, in which she asserts a vaccine-autism link. She has said she came to her conclusions through Internet research, attending the “University of Google.”

Mark Blaxill, one of the founders of the *Age of Autism* website as well as the Canary Party, makes his living as a high-powered business consultant in the Boston area. When his daughter was diagnosed with autism, he pulled strings to arrange an appointment that same week with a well-known neurologist at Harvard University. In the meantime, he hit the Internet and began connecting with parents. By the time he met with the neurologist, he says, “It was immediately clear that the people at Harvard had no idea what they were talking about and the parents were light-years ahead. Everything the parents were saying—about diets and the whole body—made infinitely more sense.”

Blaxill is now teaching himself anatomy and medicine by ordering textbooks and journal articles online. “People think that experts have to have degrees from Harvard, that they need to have a white coat,” he says. “That attitude is an attempt to turn our movement into some kind of anti-science, anti-rational thing that couldn’t be further from the truth. The scientists aren’t the heroes, they’re the chickens. They’re intimidated by the pharmaceutical industry, and the consumers are the only ones standing up.”

Stinchfield shakes her head at statements like this. “People used to ask a question like, ‘Should I get the HPV vaccine?’ of an expert, their doctor,” she says. “Now they’re asking that on a blog and getting a reply from someone named Jellyfish. Why aren’t we relying on the people who do this for a living?”

Public-health leaders have been slow to counter the erosion of their authority. “People around here are like, ‘What’s Twitter?’” says one official at the Minnesota Department of Health. So vigilantes are filling the void—parents like Ashley Shelby of Hopkins, who decided to fire back against anti-vaccine advocates by starting her own blog, *Moms Who Vax*. “We believe in using science honestly, telling the truth, living by the social contract, and protecting our kids and yours,” reads the blog subtitle. “So yeah, we vaccinate.”

Shelby, the daughter of former WCCO anchorman Don Shelby, has her father’s striking eyes and strong convictions. “We shouldn’t have to explain vaccines,” she says one morning in a coffee shop, firing up her laptop. “That’s like explaining why the earth goes around the sun.” She has also followed in her father’s journalistic footsteps—she used to write a blog called *Science for Sale* documenting the pharmaceutical industry and environmental toxins, which she feels should allay suspicion that she’s in cahoots with vaccine makers.

She’s also a former refuser. “I got totally duped,” she says. A self-described granola mom, breast-feeding and buying organic food, she put off her son’s MMR vaccination for months over concerns about autism. Then, in the middle of the night, it hit her: her son could die from a vaccine-preventable disease, and it would be her fault. “That word ‘death,’” she says. “Doctors don’t like to say it, but they probably should. I can say it on my blog and I do, because it’s time to play hardball.”

In an opinion piece published last year in the *Star Tribune*, Shelby proposed making it more difficult to refuse vaccinations. “I don’t believe in forcing people to vax,” she says, “but make it a bigger consequence if you don’t. Maybe your insurance premiums go up. Maybe schools can more easily turn away kids.”

But few officials, Shelby says, have echoed her arguments without sounding like government overlords. “The Department of Health has been blindsided—they don’t know how to talk about this issue,” she says. “It’s a failure of storytelling. They need to speak up like parents instead of doctors. I will talk to anyone anytime about vaccinating—doctors could give out my e-mail if they want, call me a parent ambassador.”

She thinks for a moment. “It’s the new parents I’m worried about—they don’t know what to believe,” she says. “But I’ve given the hardcore anti-vaxers up for dead. Doctors wouldn’t say this, but I will: would you rather your child be dead than have autism? Think about it—that’s essentially what these people are saying, and how offensive is that?”

**Last year**, the Minnesota Department of Health finally took action, forming a Vaccine Hesitancy Subgroup to explore ways to win over the wavering masses. Ashley Shelby was asked to join, along with doctors and public-health officials. On a Tuesday evening, in a conference room at the health department building in St. Paul, several members sit around a rectangle of folding tables eating salad and tossing out strategies. “The rise in vaccine-preventable disease—can this statistic be used to influence people?” a woman asks. “It’s pretty powerful.”

A doctor demurs, shaking his head. “For most parents against vaccines, it’s an emotional issue,” he says. “They’re not making a decision based on facts and I can’t talk to each patient for 20 minutes trying to convince them.”

Overseeing the discussion is Kris Ehresmann, the director of Infectious Disease Epidemiology at the health department. As everyone in this room knows, she has a son with Asperger’s syndrome, a form of autism. Afterwards, in her office upstairs, she says of anti-vaccine advocates, “They think we’re all heartless bureaucrats with no real life. But I understand how distressing it is not to have a cause to point to.”

Ehresmann remembers, several decades ago, when some people thought vaccines caused SIDS—Sudden Infant Death Syndrome. “In time, people learned more about SIDS and that theory went away,” she says. “We need to learn more about autism.”

Her sympathy, however, only goes so far. A note on her wall says, “Leading in totally screwed-up times.” She applauds thoughtful parents, but when they “start asking about things that have never been questioned,” she says, “it’s a recipe for disaster.”

Ehresmann pulls a *LIFE* magazine from 1965 out of her desk. Inside is a story on German measles, known as rubella—a disease then afflicting 20,000 people. “I don’t want an epidemic where lots of people die,” she says. “I don’t want that to be the way we finally get people’s attention.” She shrugs, smiles cautiously, and says, “We’re going to keep working toward a happy ending.”

*Tim Gihring is a senior editor for Minnesota Monthly.*

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