

# WHEN FACTS AREN'T ENOUGH

Infectious disease specialists are struggling to find a way to convince parents vaccines are safe. But how can you conquer doubt when data doesn't seem to do the trick?



ILLUSTRATIONS: ALLISON+CAM

**IF YOU'VE** ever held a flailing infant down while a doctor pushed a vaccine-loaded syringe into her soft, unblemished baby skin, you might recall feeling stressed, anxious or even afraid. Maybe you took comfort in the thought that it was for her own good. Maybe the fact that your doctor told you that she had to be vaccinated was enough reassurance. Or, maybe you're part of the 15 to 20 percent of parents who have some serious doubts about immunization.

Trust is a fragile thing—hard to earn and easily broken. Lately, it seems more tenuous than ever. From fake news to government computer hacking, the events of the past year have done little to repair our eroding trust in the institutions designed to protect us. This is especially true when it comes to science. Last September, researchers at the Ontario Science Centre found that one in five Canadians trusts their intuition over science when it comes to forming opinions about things like GMOs. A 2015 Angus Reid poll of more than 1,500 Canadians revealed that 40 percent question the science behind vaccines.

This mounting mistrust has led many parents to put off immunizing their children, while some are choosing not to do it at all. As a result, diseases we haven't seen in years—measles, whooping cough (pertussis), mumps—have returned. In the 1970s and '80s, there were fewer than 2,000 cases of whooping cough in the United States. In 2012, the Centers for Disease Control and Prevention reported more than 48,000 instances. The situation is serious. "Because we don't frequently see these diseases anymore, we don't perceive the risk of not getting vaccinated," says Julie Bettinger, a vaccine safety scientist at BC Children's Hospital. "But the diseases we developed vaccines for—like polio, which killed or crippled thousands of children—were selected precisely because they're so severe."

Bettinger was the lead author of a recent study that looked at how many Vancouver kindergartners are up to date with their immunizations. She was disheartened by the results. Her team discovered most schools no longer have the 90 percent immunization rate necessary for "herd immunity," which means not enough kids are being vaccinated to protect those who can't be immunized for health reasons. Some schools' rates were as low as 60 percent—troubling, considering how contagious some of these illnesses are. (If a kid goes to school with the flu, he might

infect up to three others. If he gets measles, he could spread the disease to between 12 and 18.)

Because Canada doesn't have a national vaccine registry, we don't actually know what our immunization rate is. It's estimated that about three percent of parents are deciding against immunization, while another 15 to 20 percent fall into the "vaccine-hesitant" group. It's these parents Bettinger is most interested in: Like undecided voters in an election, they're the ones who make all the difference. They could take us from a few isolated incidents of illness to widespread outbreaks.

"It's hard to change the minds of the small percentage of parents who have already decided not to vaccinate," Bettinger says. What's more important is to address the concerns of those who are wavering because they don't know who—or what—to believe. "Parents have a lot of questions about the immunization process, and even parents who chose to vaccinate have concerns," she says. "It's often an emotional decision, so just providing facts isn't enough. It's about establishing trust." The question is how, exactly, to build that trust.

## A MOUNTAIN OF MISINFORMATION

The good thing about the common cold, pink eye and ear infections (viruses most kids have at least once) is that they tend to cause just a day or two of misery and are soon forgotten. But when it comes to polio, pertussis and measles, doctors can't always cure kids. Measles is responsible for thousands of deaths worldwide each year—134,200 in 2015. Severe cases of mumps can lead to male infertility later in life. And before the vaccine became available in the 1940s, whooping cough killed about 9,000 people in the United States every year. Back then, no one questioned the benefits of immunization. In fact, Noni MacDonald, an infectious disease specialist at the IWK Health Centre in Halifax, says her mother's generation was "breaking down the door" to get their children immunized.

"Vaccines are like seat belts for disease," she says. "The thing about seat belts is they don't do any good after an accident." Nowadays, parents don't think twice about buckling babies into car seats, but when it comes to a doctor approaching their infant with a needle, it's another thing entirely. "Parents are out to do what's best for their children, and they want to make the best decisions, but they don't always get the best information," MacDonald says. It doesn't help that the messages getting across aren't always the most truthful.

If you're a parent worried about your baby's intro to immunization at her two-month checkup, chances are you've already hit the Internet for information—only to discover that anti-vaccination sites tend to pop up first in Google searches. MacDonald says the key is to search for "immunization" instead of "vaccine," but how many parents know to do that? She recommends sticking to sites affiliated with well-respected agencies, like the Canadian Paediatric Society or Immunize Canada. In theory, it should be simple, but finding information can be frustrating. Earlier this year, if you visited the Public Health Agency of Canada's website and actually found the vaccine safety link "Will My Child Have an Adverse Event?" you'd click to find "HTTP Error 404—Not Found." After a site redesign, things haven't improved much. It's not surprising, then, that many parents are having second thoughts. "I'm not against vaccinations," says Maria Klyuev, a chartered accountant from Toronto who speaks softly into the phone to avoid waking her 14-month-old son, Ben. "I'm just not completely comfortable with them, so I want to learn more." Concerned about potential side effects, she began researching immunization online. "The more I read, the more questions I had."

Even when she landed on the Canadian Paediatric Society's Caring for Kids—a site recommended by vaccine experts—she was frustrated by how vague the information was. She wasn't reassured by sweeping statements like "studies show that combination vaccines are safe and effective" or "there is no evidence linking thimerosal to autism or any other developmental disorder." (Though thimerosal is still used in some flu vaccines, it hasn't been used in routine childhood vaccines in Canada since 2001.) Klyuev then found a study that suggested the CDC used flawed research to promote thimerosal's safety. "I don't know who to believe anymore," she says.

The study Klyuev is referring to is called "Methodological Issues and Evidence of Malfeasance in Research Purporting to Show Thimerosal in Vaccines Is Safe," which was published in *BioMed Research International* in 2014. (The title alone shows just how confusing a lot of the information is.) It looks legit enough—until you dig deeper. It turns out all of the investigators in the study have been involved in vaccine litigation, and the research was funded by a dubious organization whose founder had his medical licences revoked.

Klyuev's paediatrician told her not to worry, that vaccines are safe. "My paediatrician is great, but everyone just says, 'It's safe, shut up,' and that's just not good enough," she says. "I'd rather they said, 'Here are a bunch of good links. Read this and let's talk at your next appointment.'" For now, she has decided to wait to vaccinate Ben. "At this point, we're pausing," Klyuev says. "I don't know what the answer is for us. All I want is to have my concerns addressed and for someone to put my mind at ease."

### THE PROBLEM WITH LABELS

Paediatricians often don't have time for even a quick conversation about vaccines, leaving parents feeling like they've been given the brush-off. There's also a misconception that parents are only worried about autism, which makes paediatricians even more reluctant to talk about it. (The myth that there's a link between vaccines and autism has been so resoundingly debunked that some doctors are frustrated by the mere mention of the word.) Mark Largent, a professor of social relations and policy at Michigan State University, has studied parents' concerns and how most of them have nothing to do with autism at all. From worries about side effects to efficacy in general, the questions parents have are wide reaching. Unfortunately, public health officials are too quick to focus on old autism fears, which oversimplifies the issue.

"Pro-vaccine types think the people they label 'anti-vaxxers' are ignorant and just need to be educated," Largent says. In fact, the majority of vaccine-hesitant parents are upper-middle class, educated women. But Largent says there's plenty of research to show that just presenting people with scientific evidence isn't enough and that it even reinforces vaccine myths. "Throwing information at people isn't what changes their minds." Doctors need to remember that it's reasonable for parents to be worried, he says. "There are side effects to all medications, and in this case you're giving drugs to a healthy child—there are only two prescription meds we give to people who aren't already sick: vaccines and birth control."

Danielle Gajewski, a business owner in Edmonton, has stopped talking about her concerns because she's afraid of the stigma. She doesn't believe vaccines cause autism; she was once pro-immunization. Her daughter, Gabriella, had her shots when she was two

## SKIP A GENERATION?

Some infectious disease specialists think it might be more effective to explain immunization to kids than their parents. Ontario has included child and youth vaccine education in its 2020 immunization plan.

Kumanan Wilson, a senior scientist in clinical epidemiology at the Ottawa Hospital Research Institute, likes the kid-focused approach. When he gave a talk on immunization to his son's grade five-six class, he used a space adventure analogy to explain the role of viral invaders and white blood cell defenders. It went over so well that Wilson created a new comic book to help children learn about the cool science behind immunization. (You can check it out at [immunitywarriors.com](http://immunitywarriors.com).)

months old and again at four months. Then Gajewski started reading about alternative schedules and asked her doctor about them. "She bit my head off," Gajewski says. "I got the sense she was thinking, *Oh, first-time moms are so annoying*. She completely dismissed my fears." Gajewski switched doctors—and how she felt about vaccinations.

She'd been worried that getting too many vaccines too soon might increase the risk of side effects, but the negative experience with her paediatrician led her to question everything. Many parents wonder whether the push from doctors to immunize is influenced by pharmaceutical companies—corporations they believe are less interested in their children's health than they are in turning a profit, which only adds to their skepticism.

Gabriella, now four and a half, is behind in her shots, and Gajewski hasn't decided what she's going to do. "I recently booked an appointment and then cancelled it the next day," she says. "I don't talk about it with anyone. It seems like there's always someone barking their opinion in your face, and you feel like you're being attacked all the time. You get disregarded as an anti-vaxxer or a nut or a conspiracy theorist."

This tendency to stop partway through the immunization process is what prompted Devon Greyson, a post-doctoral fellow at BC Children's Hospital Research Institute, to study why parents change their minds about vaccines. In a study Greyson conducted last year, she found that those who initially accepted vaccines but became hesitant often experienced a lack of support from their healthcare providers. "Either they didn't get adequate information at the outset or there was an adverse event, such as a fever, and the doctor failed to reassure them," she says. "Fever aren't uncommon, but to a parent, they can be scary."

For those who were initially hesitant, what changed their minds in favour of immunization was having positive, trusting relationships with their healthcare providers and getting consistent, verifiable vaccine safety information. "Most parents vaccinate," Greyson says. "But because we need almost everyone to be immunized, we need to figure out how to build better relationships of trust." For one mother in Greyson's study, it took a year of her paediatrician providing information and answering questions before she decided to vaccinate. If that's what it is required to get parents to trust the science, Greyson says it's worth it—especially when the alternative could be more very sick kids.

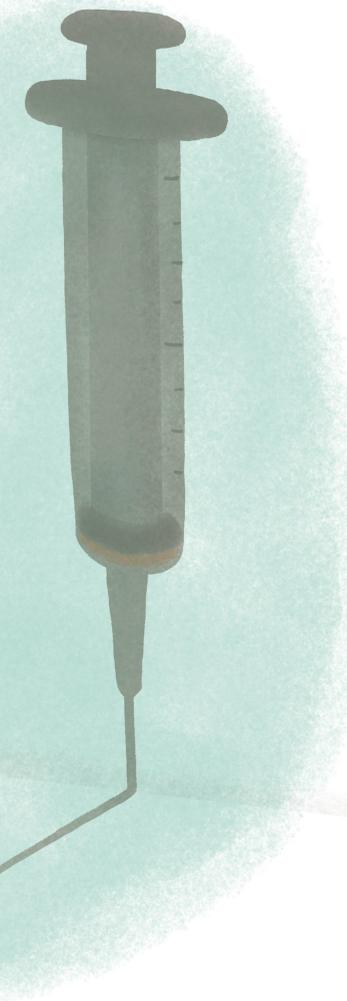
### WHAT THE SCIENCE SAYS

Vaccines are like actors playing the roles of infections, only their performances are so believable that the body thinks they're real and mounts an immune response. (They're made from weakened versions of disease-causing viruses—modified so the part that does harm has been removed. They stimulate the immune system to produce antibodies, which stick around for future protection.) By age six, the average Canadian child will have received roughly 14 vaccines, which means for a few years it can feel as though your child is being stuck with a needle at every checkup, because many vaccines require several doses.

Some parents worry that all these vaccinations are too much for immature immune systems to handle, especially newer vaccines that have been combined into a single shot (such as Pediarix, which combines DTaP, hepatitis B and polio). A US survey from 2011 found 50 percent of parents believe these vaccines are less safe, a fear researchers sought to address in the journal *Pediatrics*. The authors noted that today's vaccines

contain fewer than 100 antigens—the substances that stimulate an immune response—in comparison to the thousands of antigens children are exposed to every day. (The original smallpox vaccine contained about 200 antigens, whereas all 11 US-recommended childhood vaccines contain fewer than 130 in total.) "Our immune systems weren't built to only handle one thing at a time," Bettinger says. "If you take your kids to one of those play areas filled with plastic balls, a vaccine is nothing compared to that."

Both Klyuev and Gajewski had heard that spacing out vaccinations is easier on the immune system and reduces side effects. But there's no actual evidence to support that practice, Bettinger says, and delaying vaccines only puts kids at risk. "We vaccinate infants because they're at the highest risk for getting these diseases and have greater complications if they get sick." Not sticking to the schedule also makes it harder for parents—and doctors—to keep track and increases the chances that a child will miss the shots they need and won't be fully protected.



understandable that these symptoms might worry parents, and clinicians are sometimes too dismissive—we need to make them aware that parents are concerned and that they should have a conversation about it."

### REBUILDING TRUST

There is no easy way to address vaccine hesitancy. In 2016, Ontario's health minister introduced a bill that would require parents to take an education course before they could exempt their children from immunizations. (Manitoba, Ontario and New Brunswick have enacted legislation that requires children to be immunized before attending public school.) Canada has lower immunization rates than many other countries, but that's partly due to democracy, says Joan Robinson, divisional director of paediatric infectious diseases at the University of Alberta. "We give people an opportunity to make personal decisions," she says. "We believe vaccination is the right thing to do versus something you have to do." Plus, there's no evidence that forcing people increases vaccination rates—if they feel strongly enough, they will home-school.

Overcoming vaccine hesitancy requires a collaborative, sympathetic solution, Largent says. Instead of telling parents they need to vaccinate for the public good (which sends the message other people's children are of more concern than their own), he says it's important that healthcare providers be more thoughtful in their approach. "We need to frame it differently so parents can weigh their options. We need to say, 'You and I want your child to be as healthy as possible, so let me tell you what to watch for if you choose not to vaccinate.'"

Despite the risk vaccine hesitancy poses to children's health, there has yet to be a single effective strategy for countering it. In 2015, researchers from Quebec reviewed 15 studies on various approaches, from financial incentives to increasing awareness through media campaigns, and determined none of them were all that beneficial. Isabel Rossen, a research associate at Curtin University in Western Australia, is fascinated by the psychology of the debate. Last fall, she was the lead author on a study in *Frontiers in Psychology* that addressed the failure of current strategies, all of which are based on approaching the problem logically. She believes a psychological approach might be more effective. She says the biggest problem is that immunization conflicts with many people's beliefs.

“My recent research shows two major values underpin vaccine hesitancy: a preference for personal liberty and a preference for purity,” Rossen says. The idea that vaccines are somehow impure means parents aren’t easily convinced it’s a good idea to inject them into their infants. “People tend to hear what they want to hear and disregard anything that doesn’t fit with their beliefs,” she says. So for those who think vaccines are unnatural or introduce harmful chemicals into the body, Rossen suggests framing vaccination as something that triggers a natural process—the immune response—that can help people fight disease on their own.

In November, Australian researchers evaluated an immunization campaign that targeted the vaccine-hesitant community. The I Immunise campaign incorporated testimonials from six community members who embraced home birthing, babywearing and eating whole foods. (In one poster, a father wore his infant son in a wrap made by his artisan wife.) The survey found the campaign had a positive response with 77 percent of those who viewed it. One respondent who decided to immunize afterwards said, “It made me realize vaccination is compatible with ethical parenting.”

### FROM ANTI TO PRO

Sometimes it takes a crisis to change people’s minds. Like so many parents, Kristen O’Meara had her concerns about vaccines shrugged off. A teacher in Chicago, she intentionally sought out vaccine-resistant sites when she was pregnant with the first of her three daughters. “I’m a skeptical person by nature,” she says. “I was slightly suspicious of government and pharmaceutical companies, and—I realize now—the arguments against vaccination fit with my pre-existing biases.”

O’Meara says she figured the pro side would naturally say vaccines were safe, and she wanted to hear the opposing view. It didn’t help that when she told her paediatrician she was having second thoughts, he rolled his eyes. “He was really condescending,” O’Meara says she left the feeling ashamed and embarrassed—and having made the decision not to vaccinate.

“If I’d encountered someone who made me feel more embraced, more understood,

it might have been different,” she says. For a while, O’Meara felt superior to parents who had simply followed the herd and vaccinated their babies. “I had this sense of pride—I’d done the research and figured it out.” Then, when her daughters were five and three, the entire family got rotavirus, a severe gastrointestinal infection that causes fever, vomiting and diarrhea—and can be prevented by vaccine. “It was terrible,” O’Meara says. “But I just felt grateful that that’s all it was. We were lucky it wasn’t something worse.” She was already having doubts, but her family’s illness—and the measles outbreak in California that occurred around the same time—changed everything. She talked to a different paediatrician about getting her daughters caught up.

All three of O’Meara’s girls are now fully vaccinated. “I honour the good intentions of parents on both sides of the issue,” she says. “It’s an age of high-stakes parenting. You feel like you have one shot and if you make a mistake, it’s the end of the world.” Still, she says, in the end you have to trust somebody. “It’s OK to be confused about it—there’s so much conflicting information out there—but I learned you have to be aware of your own personal biases, too.”

O’Meara says rebuilding trust in immunization programs might require parent advocacy groups to be the intermediaries for the scientific community. Like patient advocacy groups, they could become more involved at a decision-making level around education, research and policy-making. Instead of just saying, “It’s OK, trust us,” O’Meara says you need people involved who understand parents’ concerns and can spend time addressing them. “I take full responsibility for my decisions,” she says. “But if I’d talked to someone I trusted and who I didn’t feel was judging me, I might have changed my mind sooner, before my girls got sick.”

As with O’Meara’s family, there is still time for re-establishing that trust on a larger scale, before more children fall ill. Maybe then, instead of going backward and treating children for old diseases that should have disappeared years ago, we could direct our energy toward developing vaccines that will protect them from new ones. —SYDNEY LONEY

## COMMON QS

Infectious disease specialist Noni MacDonald answers parents’ most common concerns about vaccines.

### What’s the logic of giving a two-month-old a tetanus vaccination. Wouldn’t it be better to wait?

Tetanus is in the dirt, and kids start crawling at around seven months. But because you need three immunizations to be protected, we need to start vaccinations early.

### I’m concerned about the role of Big Pharma. For instance, why does Merck have a monopoly in Canada for things like the mumps vaccine?

There are several different mumps vaccines, but we use the Merck one because its mumps strain has a very good efficacy and safety profile—it’s safer than the Leningrad-Zagreb vaccine strain. And it comes as a three-component vaccine (measles, mumps and rubella), so kids require fewer needles.

### Is it true that babies need booster shots because they can’t effectively produce antibodies to vaccines, so they wear off quickly?

It’s not an age issue. For example, the tetanus vaccine requires three doses and a booster—whether you’re two months or 30 years old—to build full immunization. Even having tetanus isn’t enough to make you immune; you still need to be vaccinated.

### I got the shot for pertussis. Could I have infected my daughter, who is too young to be vaccinated?

The pertussis vaccine isn’t a live vaccine. It’s made up of small pieces of the bacteria. It can’t multiply in you, so there’s nothing that would spread. The good news is you were immunized, which helps protect your child.

### When we vaccinate babies, are we transferring what would have been a mild childhood disease into a more serious case in adulthood?

Some vaccines do require booster doses in adulthood. We vaccinate kids because generally the disease is far worse for them. In contrast, rubella is usually a mild disease in prepubescent children but can cause arthralgia (chronic joint pain) in teens and adults. And if a pregnant woman gets rubella, it can damage her unborn baby, so we immunize kids to protect everyone. Then there’s chicken pox, which people don’t think is dangerous but is the number one predisposing factor for group A streptococcus (flesh-eating disease)—and if a child does get chicken pox, they’re at risk of developing a more serious shingles infection later in life.