

DEEP DIVE

The seekers: Why parents try fringe therapies for autism

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When her daughter was diagnosed with autism in 2004, Ariane Zurcher threw herself into researching a condition she knew nothing about. Everything she read indicated a bleak future for Emma, then a toddler. It led Zurcher to believe Emma would never form deep relationships, and would probably lack empathy. She might have compulsive behaviors and meltdowns or try to harm herself. She might never speak or be toilet-trained, and, once Zurcher and her husband died, she might have to be institutionalized. Zurcher says she felt as though she were “descending into hell.”

“I was desperate to save my daughter,” says Zurcher. “We went to everybody. We tried everything.”

She and her husband took Emma to neurologists, gastroenterologists, behavioral, speech and occupational therapists, nutritionists, naturopaths, a shaman and homoeopath, a craniosacral therapist and a Qigong master. A developmental pediatrician — who didn't take insurance, charged at least \$200 per visit and had a months-long waiting list — recommended they call a psychic in Europe; the psychic, ironically, refused payment because she didn't pick up a 'signal' from them. They tried dozens of treatments that claimed to have 'recovered' children with autism, including numerous vitamin supplements, topical ointments, restrictive diets, chelation, hyperbaric oxygen

therapy, brain scans, a so-called detoxification system and stem cell therapy.

Zurcher is hardly alone in her pursuit for something — anything — that might alleviate symptoms of autism in her child. Up to **88 percent** of boys and girls with autism in the United States **receive some alternative treatment**, according to **various studies**. Parents are enticed by alternative therapies that promise to do everything from improving social interactions to restoring speech. But there's no scientific evidence to support these purported benefits. Few of these therapies have been adequately tested for safety or efficacy, many come with a hefty price tag, and some are downright dangerous.

“Once you start down that road, it's hard to stop,” says Zurcher. As each intervention failed to help — much less ‘cure’ — Emma, Zurcher searched for the next one, feeling a surge of hope with each new possibility. “The allure of that one magic thing was so strong,” she says, “rational thinking was suspended again and again.”

The dilemma:

When it comes to alternative interventions, there's a seemingly endless array of diets, supplements, **high-tech therapies** and other options. This abundance is a reflection of both the huge **spike in autism diagnoses** in recent years and the lack of good treatment options.

Scientists have uncovered tantalizing clues about the underpinnings of autism, but those findings haven't translated into drugs to treat key aspects of the condition. “We do not have treatments that relate in any way to what causes autism spectrum disorder, or that really relate to what's happening in the brain,” says **Jeremy Veenstra-VanderWeele**, a child and adolescent psychiatrist and associate professor of psychiatry at Columbia University. “There are no quick fixes.”

The list of treatments with a solid evidence basis is short. Behavioral interventions for young children, which teach social skills **through repetition and reward**, have proved to be somewhat effective. The therapy is pricey, at up to \$70,000 a year if insurance doesn't cover it, requires 20 or more hours per week, and does not help all children with autism. Many also undergo speech and occupational therapy, to the tune of \$10,000 or so each year. On the pharmaceutical side, the U.S. Food and Drug Administration (FDA) has approved two drugs, risperidone and aripiprazole, to treat irritability in autism. The drugs are not approved to treat **repetitive behavior** or social deficits, and both have **significant side effects**, including weight gain, fatigue and anxiety.

Given those options, it's not surprising that parents seek out alternatives. They don't have to look

far. Internet searches turn up treatments in troves, each one accompanied by anecdotes of children who improved or were even “cured.” Facebook groups dedicated to unproven interventions are legion. Dozens are dedicated to **alternative therapies in general**; others focus on a specific treatment, such as **marijuana** or **essential oils**. And at massive conventions, sellers present what they call “breakthrough” treatments.

These unproven treatments do not come cheap, and some are harmful. There is zero evidence that **chelation therapy** (roughly \$4,000 for 30 sessions) — which removes heavy metals and minerals from the body — helps people with autism, and it carries a risk of heart failure. **Hyperbaric oxygen therapy** (about \$10,000 for 80 sessions), in which individuals inhale pure oxygen in a pressurized chamber, can bruise eardrums and cause sinus pain and seizures. **Miracle Mineral Solution** (\$20 per bottle) is a chemical drink that turns into the same compound used to bleach textiles when mixed, as directed, with its citrus juice activator (an additional \$20 per bottle). Side effects of ingesting the bleach (sodium chlorite) include nausea, vomiting and kidney failure, according to **Health Canada**.

The FDA has **warned** a number of companies, including those selling treatments listed above, that they may face legal action if they continue making false or misleading claims about treating or curing autism. In May, LearningRx agreed to pay the U.S. Federal Trade Commission a **\$200,000 fine** for making false and unsubstantiated claims that its “brain training” program (reportedly \$2,500 and up) can improve cognitive symptoms of autism.

“It’s a cottage industry of false hope,” says **Paul Offit**, professor of pediatrics at the Children’s Hospital of Philadelphia and author of **“Autism’s False Prophets,”** a book about dubious causes and cures. “To me, taking advantage of parents’ desperate desire to do anything to help their children is the lowest form of quackery.”

To an expert, dismissing pseudo-scientific alternatives or weighing the risks of potentially promising yet unproven treatments may be second nature. For parents, it’s much more complicated.

Emma’s journey:

Born in 2002, Emma grew into a rambunctious, social toddler who adored being around lots of people. When she started to speak, words often came out grouped together. “Chase me” was a near-constant demand.

When Emma was about 2 and a half, the family went on vacation to Cape Cod, Massachusetts, and spent time with two other families who had young children. Weeks before, Zurcher and her husband, Richard Long, had begun noticing Emma’s language falling away. As the couple

watched the gaggle of kids, Zurcher turned to Long.

“When was the last time Emma said ‘chase me?’” she asked.

He paused. “When was the last time she said anything?” he said.

“That was the moment everything changed,” recalls Zurcher. After they returned home to New York City, Emma was quickly diagnosed with autism. Zurcher stopped working as an art director at an ad agency to focus on Emma full-time.

“You’re told there’s this window to help your child, and it’s closing fast,” she says. “You feel like if you don’t hurry and try anything that might help, you’re a negligent parent.”

Emma was receiving behavioral and speech therapy, though neither seemed to help. She also suffered from gut problems. So Zurcher was encouraged when she found stories claiming that **gluten-free, casein-free diets** dramatically improve gastrointestinal (GI) issues, cognition and speech in some children with autism. Some parents reported remarkable improvements in their children’s behavior.

Zurcher cleaned out the kitchen, placed the long list of off-limits foods on the counter, and introduced Emma to the diet. Emma refused nearly everything. Zurcher would bake until 2 a.m. testing out new recipes, to no avail. Emma’s eye contact slightly improved — maybe. (Zurcher later realized it actually hadn’t.) But after just three months, Emma had lost a “frightening” amount of weight. So Zurcher brought back everything she had cut out. Now, Emma wouldn’t touch many foods she had loved before, including chicken, eggs and vegetables.

“We were worse off than before the diet,” says Zurcher. But she was undeterred in her quest to combat Emma’s autism: “I thought of it as a war.”

The war lasted seven long years. During that time, Emma took more than a dozen plant extracts to help her gut issues. They didn’t. Nor did a half-year of craniosacral therapy, a form of massage intended to relieve pain and pressure in the skull and the rest of the body. The Qigong master who promised to cure Emma by regulating her ‘energy flow’ was one of many who failed to deliver. Sticking detox pads to Emma’s feet to supposedly draw toxins from her body as she slept made no difference. Brushing therapy to reduce her sensitivity to touch riled her up and disrupted her sleep. Auditory integration therapy, aimed at quelling her hypersensitivity to sound, didn’t help or hurt.

Emma underwent one round of chelation before Zurcher and Long spoke to specialists at the Albert Einstein College of Medicine in the Bronx and learned the treatment is dangerous. (In fact, it had reportedly **killed a child with autism**.) They interrupted hyperbaric oxygen therapy — no improvement after a few sessions — to take her to Central America for stem cell therapy. After

making three trips and seeing no effects, a conversation with experts in the U.S. convinced them not to return. The experts told them how risky and invasive the approach was, says Zurcher. “They literally begged us to stop.”

The couple didn’t always agree. Zurcher was more intent on finding and trying treatments than Long was, and he was more skeptical. When she decided to try another diet in 2011, he said, “I’m not okay with this, but I’m not going to stop you,” she recalls.

She had read that soy and spelt — two foods she hadn’t cut out of Emma’s diet before — were problematic. “I thought, I didn’t do it right,” she says. “Let me do it again.” Under the guidance of a naturopath, Zurcher scoured farmers’ markets for the right goat cheese. She ordered goose eggs from Minnesota. She baked homemade fruit leathers in the oven for 10 hours. Again, Emma refused most everything; she lost 15 percent of her body weight in six weeks. “I came across her facing the wall. She’d stuffed a piece of goat cheese in her pocket and was eating it like a wild animal,” recalls Zurcher. “It was horrifying.” She stopped the diet.

“For so long, I thought any treatment was better than doing nothing at all,” Zurcher says. She’d had doubts about almost everything they’d tried, but she had pushed down her queasiness. Feeling perhaps greater despair than ever before, she began to seek out adults with autism. She hoped they might have insights that everyone who had tried to sell her something did not.

“I was desperate to save my daughter. We went to everybody; we tried everything.” Ariane Zurcher

Sounds like science:

The tricky thing about unproven treatments is that they sound scientific.

Take, for example, single-photon emission computed tomography, or SPECT. For around \$3,500, **Amen Clinics** — brain health centers named for founder and doctor Daniel G. Amen — will scan a child’s brain to deliver an autism diagnosis and create targeted treatments. “We use brain SPECT scans plus clinical data to make diagnoses,” says Amen, adding that the clinics have scanned more than 1,000 people with autism.

Autism experts interviewed for this story say these scans are far from — and may never be — ready for use to diagnose autism. Some say it’s pretty much hocus-pocus. “These extremely expensive ‘evaluations,’ which are almost never covered by insurance, are best described as a scam perpetrated on families who are being preyed upon by false hopes,” says Columbia’s Veenstra-VanderWeele. **Brain scans can’t reveal autism**, because researchers haven’t yet definitively

identified autism-specific brain activity patterns or structures. And scans certainly can't indicate which treatment would work.

For most parents, who have little understanding of how science is done, wading through claims made about alternative treatments can be befuddling. Even when someone knows to search **PubMed**, an online database of journal abstracts, she might not understand that obscure journals tend not to be taken seriously, and might not pick up on the difference between types of studies. A case report about a single child may be of purely scientific interest as an avenue for further investigation, for instance, whereas results from a rigorous randomized controlled clinical trial with a large number of participants can provide solid information on whether a treatment works.

What's more, media outlets often exaggerate the significance of findings. Take secretin, a peptide hormone that stimulates the secretion of digestive fluids from the pancreas. In the late 1990s, three children with autism were reported to **improve dramatically after taking secretin**. Word spread, parents heard about it on the news, and demand for secretin skyrocketed. But more than a dozen subsequent double-blind studies — in which neither the families nor the researchers knew which participants were in the placebo arm — found no evidence of effectiveness.

“As a scientist, you can end up on the front page of the science section of The New York Times with a new link to autism, but not really know if it's causal,” says **Catherine Lord**, a clinical psychologist who heads the Center for Autism and the Developing Brain at New York-Presbyterian Hospital in New York City. In other words, just because researchers find a connection between autism and a gene or some other factor does not mean that it causes the condition — or that blocking it can reverse the effects of autism. “I think it's probably very confusing for parents. So when someone says, ‘I can take what that scientist said and make it meaningful for you right now,’ that's incredibly appealing.”

At the **AutismOne** conference in Chicago this year, more than 150 practitioners and company representatives pitched therapies to hundreds of attendees in talks modeled on scientific presentations. Several presentations focused on the gut microbiome, reflecting findings suggesting that **disturbances to gut microorganisms** cause the GI problems that plague many children with autism. At last year's conference, a physician called Zach Bush explained, using slides of the gut viewed through a microscope as visual aids, how his plant-derived mineral supplement, RESTORE (\$49.95 for a one-month supply), strengthens cell membranes in the gut to keep toxins from leaking out. Bush told the parents in the audience that he was “excited to just be a piece of your puzzle” in the parents' quest to “rebirth that child into a state of health.” The company did not respond to multiple requests for comment.

The microbiome connection is in fact under investigation by multiple respected research groups. One hypothesis being explored is that disruption to gut microorganisms causes a '**leaky gut**' that allows bacteria to escape into the body, altering brain function and contributing to autism behaviors.

But promises such as Bush's are way ahead of the research, says **Ruth Ann Luna**, director of medical metagenomics at the Texas Children's Microbiome Center in Houston. "Right now, we're trying to characterize the gut biome in kids with autism who have significant GI problems," she says. Doing so could help pave the way for treating people who have both autism and gut issues. This is an intriguing **avenue of investigation**, but RESTORE and probiotic drinks marketed as autism treatments aren't yet backed up by research.

An even more aggressive approach, says Luna, is parents doing fecal microbiota transplants at home — although the transplants are worth investigating in clinical trials, she says. These parents mix a stool sample from a neurotypical family member with saline, strain the concoction, and then give the resulting liquid via enema to a child with autism. Instructions are readily available on YouTube. "It's very experimental and certainly risky to do without the oversight of a physician," she says.

When unproven treatments target the same links to autism being explored in serious research, it's that much more difficult for parents to evaluate the claims. "These so-called 'experts' are so confident, and they sound so convincing," says Zurcher.

Someone searching for information on, say, toxins that might have a link to autism could come across the "**IonCleanse by AMD for ASD**" Facebook group, where more than 3,300 members exchange information about a footbath made by a company called AMD. "As children's bodies begin to detox, the systems that were energetically blocked or shut down can start to function normally again," the **AMD website** says.

"We don't claim to treat autism," says owner Neill Moroney, who estimates 1,000 to 1,100 people with autism have used the \$1,995 footbath. Moroney says he would like to conduct a blinded trial with 30 children over 90 days to determine whether the gadget truly alleviates symptoms of autism. But he says the funding is difficult to find. "What I'm looking for is someone with the resources to give it the shot it deserves," he says.

Testing the untested:

Stem cell therapy is **getting that shot**, with two **trials underway** in the U.S. In animal models, one type of stem cell has been shown to alleviate inflammation in several types of tissue, including that from the **brain, bowel and bone**. Postmortem studies of children with autism have revealed **inflammation of brain tissue**. Stem cell therapy isn't approved in the U.S., but several foreign clinics offer it for around \$10,000. Sarah Collins credits the adult stem cell injections her two children received in Panama City, Panama, with the "recovery" of her older son and improvement in her younger son, both of whom were diagnosed with autism. Her experience led her to co-found

the “**Stem Cell Therapy for Autism**” Facebook group. She says one reason parents might not want to take part in clinical trials in the U.S. is that their child might end up in the placebo arm of the trial. “They won’t mess with that,” Collins says. “They’ll go right to Panama instead.”

But experts say without knowing more about whether and how the therapy works, those are costly, potentially risky ventures. The overseas clinics offer “hope, not a proven treatment,” says **Emanuel DiCicco-Bloom**, a child neurologist and neuroscientist at Rutgers Robert Wood Johnson Medical School in New Brunswick, New Jersey. DiCicco-Bloom’s team is taking blood cells from children with autism and their unaffected siblings and converting them into stem cells. The team then turns those cells into neurons and studies them at different stages of development, in hopes of identifying the differences between the siblings. “We’re seeing differences in the numbers of cells, kinds of cells, synapses, which suggests what might be contributing to autism,” he says. “But at this point, it’s not like we can say: ‘You’re missing these specific cells, let’s put them back.’”

Stem cell treatments could also be dangerous. Even though the **clinic in Panama**, for instance, states on its website that it tests for viruses and bacteria, “until a year ago, nobody would’ve looked for Zika,” DiCicco-Bloom says.

Knowing the risks, Karen Shearer decided to try stem cells anyway. After all, she says, almost nothing has helped her 13-year-old daughter, Skye, who is nonverbal, cannot dress herself and wears a diaper. To cover Skye’s first treatment in Tijuana, Mexico, in 2007, the family cashed in a life insurance policy; Shearer says it “was probably a scam.” Last year’s \$10,000 therapy in Panama, partly funded by a GoFundMe.com campaign, also failed. Then Shearer discovered a **clinic in Cancun, Mexico**, on Collins’ Facebook group that infuses cells via lumbar puncture, which the clinic says ensures the cells reach the brain. The only improvement Shearer has seen is that Skye is no longer terrified of the swimming pool.

Once she pays off her \$11,000 credit card debt from Cancun, Shearer knows what’s next: the **Plasticity Brain Centers**, which claims to reconnect neural pathways after their proprietary diagnostic technology pinpoints “the exact brain functions that need treatment.” Skye has tried other brain-related treatments, but this one, Shearer says, seems to take a different approach.

At this point, she says, her dream is that her daughter will dress herself and use the toilet. “Skye’s getting older but still functioning like a 2-year-old, and I’m getting more desperate,” she says. “How will I function 10 years from now? How will she?”

Better advice:

Given the dizzying profusion of alternative treatments, parents can find it a challenge to navigate the options and weigh the risks. A few **websites** provide parents with the right questions to ask: Does this practitioner or vendor promise miracles that no one else seems to achieve? Is the person promising the outcome also asking me for money? Do I find any scientific research supporting their claims, or are there only individual (often emotional) testimonials?

Many medical professionals may not take the time to talk through the potential risks or flaws of alternative therapies. But **Antonio Hardan**, a child and adolescent psychiatrist at Stanford University who specializes in autism, makes a point of it. “I’ve been in this field for 15 years, and seemingly every month you have something that people get excited about, and then it dies out,” he says. If whatever the latest is seems unsafe, he cautions against it — “though parents don’t always follow our recommendations,” he notes.

If the treatment seems safe, he helps families figure out how to include it in their schedule and budget, and instructs them to try it for three months, then stop and see what happens. Even with these guidelines, it’s difficult to connect an improvement to an intervention, he says: “You don’t know if it’s the drug or the child’s natural maturity process.”

Parents often combine multiple approaches, making it even more challenging to track cause and effect. “I saw a kid last week who is taking 80 different supplements,” says Hardan. More commonly, children take about 10 to 15 supplements, he says. “You could be the smartest person on earth and not understand how they are working together.”

He emphasizes that parents should discuss all the treatments they try with medical professionals — for safety reasons, but also because something they’re doing might warrant scientific investigation. Hardan himself has launched **studies into unproven therapies** he’s learned of from the families he works with. He is testing whether the neurosteroid pregnenolone alleviates irritability in children with autism. His group is also considering a study into the current “big thing:” cannabis. After seeing how cannabidiol — derived from marijuana — helps children with **epilepsy**, some parents have begun **giving it to their children with autism** and reporting drops in anxiety, aggression and self-injurious behavior.

“It’s possible there may be something beneficial out there,” says Hardan. “But currently, we don’t know if these are safe and effective, much less the appropriate dose and duration.” In this case, parents are far ahead of medical research, which can’t yet offer any answers.

“It’s a cottage industry of false hope.” Paul Offit

Finally, peace:

When Zurcher went looking for adults with autism who might offer insight into what the future holds for Emma, an intense internet search led her to Julia Bascom's blog, **Just Stimming**. As she read every post and clicked through to every site linked from Bascom's site, she found people who saw autism as an integral part of their identity. "It was as though I'd been living my life believing in this one universe, and then I was shown this alternate universe," she says. "My entire focus changed. Instead of fighting against Emma's neurology and trying to cure this heinous disorder, I started finding ways to help her flourish."

One major focus was giving Emma a means of communication other than speech, which is difficult for her. Ask her name, and she might respond, "You may not spit." Ask her age, and she might tell you she's 10. (She's 14.) Hand her a keyboard, though, and she'll type the correct answers — and much more. **She goes slowly**, picking out one letter at a time, all by herself. A single sentence can take a couple of minutes to craft, but the effort allows her to express herself. "There's not a direct line between my brain and my mouth," she **wrote** for an English assignment in May.

Lord says that for those children who can and want to type, it can be beneficial. But there's no guarantee that all children with autism can learn to type. "There are a very small number of people with autism who you'd think could never type, who do become able to type independently," Lord says.

Today, Emma takes three classes at her brother's school and is otherwise homeschooled. She wants to get her high school diploma someday, which looks like a real possibility. She still gets occupational therapy, but quit speech therapy after deciding she didn't like it. She loves to listen to music, dance, wear frilly dresses and write for the **blog** she's taken over from her mother.

Typing has been a boon; last year, for instance, Emma told her mother she was having stomach pains, something she couldn't have easily conveyed before. Still, she continues to face serious challenges. She struggles, for instance, with the **inability** to control things she feels compelled to say, and bites down on her arm to help dispel stress, even though she knows others find the behavior disturbing. "I cannot sit quietly unless I am able to twirl my string, softly murmur to myself and have a timer nearby. I cannot read aloud or answer most questions verbally, but I can type," she **wrote** in February. "I have an incredibly large capacity to listen, learn and feel."

Zurcher says the money they spent on their quest for a cure was "insane." She refuses to tally up the total. "My daughter has a disability, she is challenged, absolutely," says Zurcher. "And we make it so much harder by stigmatizing people with autism for having a different neurology." What still haunts Zurcher is the thought that she might have exposed her daughter to treatments that harmed her, perhaps in ways they'll never know.

The family no longer takes those risks with Emma's health. These days, Emma decides which, if any, interventions to pursue. "It's much more sensible, I think," says Zurcher. "But I'm also not living in terror anymore."

When asked, Emma has said that aside from occupational therapy, none — not one — of the interventions helped her, Zurcher says. But she doesn't seem to hold a grudge. In fact, she appears to forgive her mother more readily than Zurcher forgives herself. During a **conversation in 2014** about past treatments, Emma seemed to understand exactly why her mother pursued so many therapies over the years. "You thought my autism was hurting me and that you needed to remove it, but you did not understand that it is a neurological difference," she typed. "Fear caused you to behave with desperation."

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