

Curing Jamie Handley

BY ANGELA VALDEZ
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One Portland family pushes a fix for the autism "epidemic."



Jamie Handley, 3, began showing the symptoms of autism at 18 months.
IMAGE: STEPHEN VOSS

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The ritual begins the same way, every other morning, in J.B. and Lisa Handley's Southwest Portland home. They roust their 3-year-old son, Jamie, from their bed, take off his pajamas and squeeze 23 drops from a tiny white bottle onto his inner thighs. They rub in the liquid and, triggering a wave of giggles, blow his skin dry.

"It's like a spiritual moment because of the utter magnitude of what we're actually doing," J.B. says. "We're literally altering the course of his life."

Jamie is autistic, and his parents blame the disorder on mercury poisoning. They treat him with a \$180-a-bottle tincture of amino acids that binds to mercury and other heavy metals in his body and flushes them out with his urine.

The Handleys have faith that the treatment, called chelation ("key-LAY-shun"), will eventually cure their son, halting his disruptive, repetitive behavior, social disinterest and inability to communicate. They see their morning routine as a small victory in a battle being waged by thousands of parents against a perceived epidemic, and against the medical establishment, which insists that chelation is not a cure and may actually put children at risk.

In less than a year, the Handleys have become leaders in a growing national movement, investing hundreds of thousands of their own dollars to launch a nonprofit called Generation Rescue, print full-page ads in *The New York Times* and *USA Today*, and hire a San Francisco PR firm to run a media campaign. The couple, both Stanford graduates, makes a formidable team: Lisa, 38, is a Hering, long a prominent Oregon surname, and J.B., 36, runs an investment-capital firm based in San Francisco.

But in recent months, the Handleys and their movement have come under assault. In August, a 5-year-old autistic boy in Pennsylvania died of cardiac arrest following an intravenous chelation treatment in his doctor's office.

The death prompted renewed warnings from parents and doctors worried about chelation's potential side effects, including liver failure

and allergic reaction. But the Handleys have not backed down. J.B. said the death, though tragic, was an opportunity to "to bring this issue to the top of the national health agenda." He blames the government for failing to recognize the virtues of chelation, which is not covered by insurance when used to treat autism.

While conventional medicine holds that autism stems from an abnormality in the brain, alternative theories have long sought an external cause for the devastating disorder. In the 1940s, psychologists denounced "ice box mothers" who left home for work and neglected their children. Today, parents like the Handleys blame mercury and a corrupt medical establishment. Perhaps more than any other historical nostrum—from the shark-cartilage cure for cancer to magnetic therapy for pain—the theories about mercury poisoning and autism convince more parents each day, despite a lack of clear scientific evidence.

The problem, J.B. says, "is that we're painted as blind to reason because we're doing something that the mainstream hasn't put a stamp on. I say that's horseshit."

In 2004, the Handleys were living comfortably with Jamie and his older brother, Sam, in Lafayette, a wealthy community 10 miles east of San Francisco, in a ranch-style home on a hill shaded by groves of eucalyptus and oak trees.

As the spring wore on, their blue-eyed, 18-month old son began to slide backward in development. His newly acquired words—"mamma," "daddy," "night-night"—evaporated into a silence soon filled with frantic screams. He began to obsess over repetitive actions, like running back and forth—for minutes—along the kitchen counter, his eyes averted to the side, or walking on his toes.

While Lisa suggested autism as an explanation, J.B. says he resisted, finding excuses like a recent cold or a new playmate to explain their son's behavior. But during a visit with Lisa's family in Portland, they watched Jamie play alongside a cousin four months his junior. The younger boy seemed far more advanced than their son. "The contrast was so stark it shocked us out of any denial we may have had," J.B. says. "It changed everything."

Like many parents, the Handleys went online before venturing into a doctor's office. They learned that autism fell amid a spectrum of developmental disorders, with symptoms including social dysfunction, speech delay and repetitive behavior. The condition presents a paradox: Normal-looking children lose their ability to speak while growing socially aloof and emotionally vacant—yet they obsess with uncommon concentration on tasks as simple as pacing back and forth and as complex as building a train set. As they read, the Handleys became convinced that Jamie suffered from autism. The disorder promised to rob them of the central joys of parenthood—watching their son mature, form bonds and develop his own personality. "It meant being locked in a dungeon for life," J.B. says.

The Handleys were shocked to read that U.S. autism rates had skyrocketed in recent years, from 1 in 10,000 in the 1980s to as many as 1 in 166 today. Mainstream medicine downplayed the existence of an epidemic and offered parents little hope. According to the Centers for Disease Control and Prevention website, the cause of the disorder was unknown—maybe genetics, maybe an environmental contagion—and a cure was not on the horizon.

In addition to the mainstream descriptions, the Handleys couldn't miss the abundance of online testimonials linking autism to mercury poisoning.

In countless articles, parents and a handful of doctors attested to a direct connection between thimerosal, a mercury-based preservative once common in childhood vaccines, and the onset of autism. With growing anger, the Handleys read parents' accounts of autistic symptoms emerging around the same time their children received vaccines. The websites offered compelling epidemiological evidence: The spike in autism coincided with an increase in the number of childhood vaccines, both beginning in the early 1990s.

Their conclusion seemed obvious. Jamie had gotten a flu shot just weeks before his symptoms began; before that, he had received several other vaccines that may also have contained thimerosal.

In the ether of the Internet, the Handleys had stumbled upon the biomedical movement, an alliance of parents united by local autism foundations and a national organization called Defeat Autism Now! (DAN!). In addition to the vaccine link, the movement draws a causal relationship between autism and disorders in the digestive tract and vitamin deficiencies.

They also offer a cure: a regimen of chelation, special diets, and vitamin and mineral supplements. Often, adherents discourage parents from vaccinating their children.

Even though most medical institutions—from the CDC to the American Academy of Pediatrics—reject the theories and treatments as junk science, the thimerosal argument made sense to the Handleys. They believed that science could explain Jamie's sudden deterioration. J.B. says his distrust of bureaucrats, a skepticism he learned from his father, and his wife's "truth compass" made it easy to believe that the CDC and vaccine manufacturers would hide a deadly secret from parents.

"That was the only thing that made sense to us for what was wrong with Jamie," J.B. says. "It was so simple. We thought, 'We have got to get the mercury out of this child as quickly as we can.'"

When they visited their pediatrician, however, he dismissed their beliefs. "That was the last visit we had with our moronic mainstream pediatrician," J.B. says.

In June 2004, the Handleys found a naturopathic physician in San Francisco named Lynne Mielke. Mielke prescribed a liquid chelation agent and recommended a wheat- and dairy-free diet. She also offered advice on choosing the right supplements, helping the Handleys fill a kitchen cabinet with a \$1,000, three-month supply of chemicals and vitamins.

Early this year, the Handleys launched a nonprofit dedicated to compiling information on biomedical theories and helping parents find resources. Their ads in *The New York Times* and *USA Today*—costing at least \$300,000—stated: "Mercury poisoning and autism. It isn't a coincidence." The Generation Rescue website provides the names of sympathetic parents, or "Rescue Angels," and doctors who will prescribe chelation treatment.

"It's the slickest Web page out there," says Darryn Sikora, a psychologist and head of the Oregon Health & Science University autism clinic who is highly critical of the biomedical movement. "It's so well-written. It's so convincing. Who wouldn't want to do that?"

This summer, nearly a year after their journey began, the Handleys moved to Portland to be closer to Lisa's family. They have treated Jamie with a lotion-based chelating agent for nearly a year—and recently began applying the cream to their own bodies, in anticipation of trying for a third child.

Lisa, a slender blonde with easygoing poise, speaks with heartfelt honesty about her faith in the thimerosal theory. She feels hurt that so many people dismiss her beliefs. "To have to meet all these experts who say that you're crazy, that you're wrong, that you're desperate," she says, "it's really hard."

J.B. is more forceful. He has an intense presence, with loose locks of strawberry-blond hair and a jagged scar on his upper lip from getting cleated in a rugby match. When Lisa begins to talk about the science behind autism, he often interjects, saying, "I'll explain." Although he is open with the press, he is also hostile toward journalists who've taken a critical view of the biomedical movement, especially "two a-holes from *The New York Times*."

The Handleys say evidence that their cure is working can be seen in Jamie's behavior, although they admit an outsider might not see the difference.

"We've already got our proof," J.B. says. "A year ago, he was on Pluto."

Jamie's moods progress fluidly from joy to concentration to panic. He has full run of his parents' sprawling home, a hypoallergenic realm with wool carpets, insulation made from blue jeans and HEPA filters to clean the air.

One afternoon this summer, Jamie dragged his father by the finger to a mattress in the middle of the basement floor and, holding onto both of his hands, began jumping up and down, lofting higher and higher with each leap. The game was an autistic obsession. The blond boy sprang up again and again, never tiring, his face frozen in an expression of total joy.

Jamie eventually moved from the mattress to his train set, another obsession, and later to the table, where he covered reams of paper with spiraling circles, using his teeth to uncap each pen in the box until all the lids and pens lay on the floor where he cast them aside. All the while, he didn't speak a word.

Three months later, Jamie had learned to point at things he wanted and to wave goodbye. He still screamed shrilly, ran back and forth, and didn't speak in front of a reporter. His parents have augmented the biomedical regimen with other treatments—speech and occupational therapy and applied behavioral analysis, an intensive program that teaches autistic children to mimic "normal" behaviors, like waving goodbye.

While the Handleys still insist chelation is making their son better, they admit they don't have an easy answer for the death this August of 5-year-old Abubakar Tariq Nadama, whose parents had moved to the United States from England in search of a cure for autism.

Jim Laidler, a Portland anesthesiologist with two autistic sons, has a less equivocal opinion about Nadama's death. Although a medical examiner in Pennsylvania was unable to make a direct link between chelation and the death, Laidler says he believes the treatment killed the boy.

"It was terrible," Laidler says. "This is what I've been holding my breath hoping wouldn't happen."

Jim and his wife, Louise, also an anesthesiologist, once agreed with the Handleys about the cause of autism. After their two sons were diagnosed with autism in 1997, the Laidlers found hope in the promises of the biomedical movement.

Their pediatrician recommended the traditional route: speech therapy, early-intervention classes. "That didn't seem very satisfying," Jim says. "You want bells and sirens, you want big intervention." The Laidlers put their boys on a wheat-and dairy-free diet, bought supplements of B vitamins and zinc, and, later, tried chelation. Thinking the treatment was promising but potentially dangerous, Jim eventually wrote guidelines for its safe use.

"We started doing these things, and it was very tantalizing," Jim says. Especially when their sons made improvements. But when one of the boys lost new skills or failed to improve, he says, they were told that setbacks were part of the process.

The Laidlers' doubts began in 2001. On a trip to Disneyland, David grabbed a waffle from the buffet table in their hotel. A wheat waffle. According to their doctors, eating wheat would reverse all the progress they'd made. Jim and Louise watched in horror, thinking, "Oh, my God! What's going to happen?" They waited. "Nothing happened."

Still, the Laidlers continued to use biomedical treatments on their older son, Ben. The regimen was exhausting. "We were spending so much time working on our kids, working ourselves to a frazzle, and we weren't spending enough time with our kids."

Jim went on thinking they should just stick with the program. When he got home one night, his wife asked him how he thought Ben was doing. "About average," he said.

Louise confessed that she'd stopped everything—the chelation, the diet, the supplements—for an entire month. Instead of getting angry, Jim felt foolish. "The light came on," he says. "I felt really stupid."

David, 9, has improved with traditional therapies and now attends regular classes at Capitol Hill Elementary. Ben, 12, still struggles with severe disabilities and participates in a life-skills class at Jackson Middle School.

Over the past three years, Jim Laidler has become nearly as zealous as J.B. Handley arguing against the biomedical movement. Jim often directly challenges J.B. in online forums and websites devoted to debunking bad science.

Laidler says the increase in the incidence of autism corresponds not to the use of thimerosal, but to a widening of the definition for the disorder—effectively allowing thousands of additional cases to be diagnosed. He also cites five international epidemiological studies that show no link between autism and thimerosal. The scientific studies behind the biomedical movement, he says, are rife with errors.

Laidler also points out that the symptoms of autism often change—and improve—as development proceeds. Traditional therapies, including ones used by the Handleys, have been shown to encourage such improvement, making it hard to separate one "cure" out of a jumbled handful of treatments.

Scoffing, J.B. refers to Laidler as "the one guy from the FBI who defected to the KGB."

But Laidler is not alone in criticizing the Handleys.

"I get the impression that Handley has responded to his son's diagnosis as he might respond to any business challenge," says Kathleen Seidel, a Massachusetts parent who runs an autism website. "He thinks: Let's grab this bull by the horns and ride it to victory."

Seidel believes the Handleys are "prematurely announcing to the world that all autism is mercury poisoning and that [a] magic cream can cure it." She thinks their efforts encourage parents to ignore the reality of their children's condition.

Darryn Sikora of OHSU understands why the biomedical movement has an appeal. "We [doctors] can't say, 'If you do X, Y and Z, your kid's going to get better.'"

Because they can offer hope where science has none, the Handleys seem to be winning the battle for parents' minds.

The biomedical movement has thrived in Oregon, perhaps because of a local openness to alternative medicine. The multimillion-dollar business supporting the biomedical regimen includes an Oregon company, Kirkman Labs, which sells many of the pricey vitamins and supplements used by parents. The DAN! website lists nine Oregon practitioners—including MDs, naturopathic physicians and acupuncturists—willing to prescribe a range of biomedical treatments.

The state board of medical examiners has investigated at least two of the doctors on the list. Because of strict confidentiality rules, it is often unclear why the inquiries were initiated.

Silvia Townsend, a San Diego lawyer, brings her son to visit Dr. Green in Oregon City every three months for intravenous chelation treatment. Townsend sees the investigation as a sign of Green's embattlement. "All of the doctors who try to help detox our children have been scrutinized from time to time," she says. "Dr. Green is a saint."

Townsend is also among hundreds of parents who count the Handleys—especially J.B.—among their heroes. "I have yet to see another parent dedicate themselves so fully to the issue," says Silvia. "It's just amazing."

J.B. and Lisa say they will not stop chelating their son until he gets better. They have no doubt that he will recover, and refuse to consider the possibility that their theory might be wrong.

"You've gotta understand," J.B. says, "if we're wrong...." He shakes his head, stops speaking and starts over. "We feel like we're working in facts."

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Generation Rescue's website: www.generationrescue.org

Centers for Disease Control and Prevention: www.cdc.gov/ncbddd/dd/ddautism.htm

DANI and the Autism Research Institute: www.autism.org