We Cured Our Son's Autism

By Karyn Seroussi

When the doctors said our son would be severely disabled for life, we set out to prove them wrong.

When the psychologist examining our 18-month-old son told me that she thought Miles had autism, my heart began to pound. I didn't know exactly what the word meant, but I knew it was bad. Wasn't autism some type of mental illness -- perhaps juvenile schizophrenia? Even worse, I vaguely remembered hearing that this disorder was caused by emotional trauma during childhood. In an instant, every illusion of safety in my world seemed to vanish.

Our pediatrician had referred us to the psychologist in August 1995 because Miles didn't seem to understand anything we said. He'd developed perfectly normally until he was 15 months old, but then he stopped saying the words he'd learned -- cow, cat, dance -- and started disappearing into himself. We figured his chronic ear infections were responsible for his silence, but within three months, he was truly in his own world.

Suddenly, our happy little boy hardly seemed to recognize us or his 3-year-old sister. Miles wouldn't make eye contact or even try to communicate by pointing or gesturing. His behavior became increasingly strange: He'd drag his head across the floor, walk on his toes (very common in autistic children), make odd gurgling sounds, and spend long periods of time repeating an action, such as opening and closing doors or filling and emptying a cup of sand in the sandbox. He often screamed inconsolably, refusing to be held or comforted. And he developed chronic diarrhea.

As I later learned, autism -- or autistic spectrum disorder, as doctors now call it -- is not a mental illness. It is a developmental disability thought to be caused by an anomaly in the brain. The National Institutes of Health estimates that as many as 1 in 500 children are affected. But according to several recent studies, the incidence is rapidly rising: In Florida, for example, the number of autistic children has increased nearly 600 percent in the last ten years. Nevertheless, even though it is more common than Down syndrome, autism remains one of the least understood developmental disorders.

We were told that Miles would almost definitely grow up to be severely impaired. He would never be able to make friends, have a meaningful conversation, learn in a regular classroom without special help, or live independently. We could only hope that with behavioral therapy, we might be able to teach him some of the social skills he'd never grasp on his own.

I had always thought that the worst thing that could happen to anyone was to lose a child. Now it was happening to me but in a perverse, inexplicable way. Instead of condolences, I got uncomfortable glances, inappropriately cheerful reassurances, and the sense that some of my friends didn't want to return my calls.

After Miles' initial diagnosis, I spent hours in the library, searching for the reason he'd changed so dramatically. Then I came across a book that mentioned an autistic child whose mother believed that his symptoms had been caused by a "cerebral allergy" to milk. I'd never heard of this, but the thought lingered in my mind because Miles drank an inordinate amount of milk -- at least half a gallon a day.

I also remembered that a few months earlier, my mother had read that many kids with chronic ear infections are allergic to milk and wheat. "You should take Miles off those foods and see if his ears clear up," she said. "Milk, cheese, pasta, and Cheerios are the only foods he'll eat," I insisted. "If I took them away, he'd starve."

Then I realized that Miles' ear infections had begun when he was 11 months old, just after we had switched him from soy formula to cow's milk. He'd been on soy formula because my family was prone to allergies, and I'd read that soy might be better for him. I had breast-fed until he was 3 months old, but he didn't tolerate breast milk very well -- possibly because I was drinking lots of milk. There was nothing to lose, so I decided to eliminate all the dairy products from his diet.

What happened next was nothing short of miraculous. Miles stopped screaming, he didn't spend as much time repeating actions, and by the end of the first week, he pulled on my hand when he wanted to go downstairs. For the first time in months, he let his sister hold his hands to sing "Ring Around a Rosy."

Two weeks later, a month after we'd seen the psychologist, my husband and I kept our appointment with a well-known developmental pediatrician to confirm the diagnosis of autism. Dr. Susan Hyman gave Miles a variety of tests and asked a lot of questions. We described the changes in his behavior since he'd stopped eating dairy products. Finally, Dr. Hyman looked at us sadly. "I'm sorry," the specialist said. "Your son is autistic. I admit the milk allergy issue is interesting, but I just don't think it could be responsible for Miles' autism or his recent improvement."

We were terribly disheartened, but as each day passed, Miles continued to get better. A week later, when I pulled him up to sit on my lap, we made eye contact and he smiled. I started to cry -- at last he seemed to know who I was. He had been oblivious to his sister, but now he watched her play and even got angry when she took things away from him. Miles slept more soundly, but his diarrhea persisted. Although he wasn't even 2 yet, we put him in a special-ed nursery school three mornings a week and started an intensive one-on-one behavioral and language program that Dr. Hyman approved of.

I'm a natural skeptic and my husband is a research scientist, so we decided to test the hypothesis that milk affected Miles' behavior. We gave him a couple of glasses one morning, and by the end of the day, he was walking on his toes, dragging his forehead across the floor, making strange sounds, and exhibiting the other bizarre behaviors we had almost forgotten. A few weeks later, the behaviors briefly returned, and we found out that Miles had eaten some cheese at nursery school. We became completely convinced that dairy products were somehow related to his autism.

I wanted Dr. Hyman to see how well Miles was doing, so I sent her a video of him playing with his father and sister. She called right away. "I'm simply floored," she told me. "Miles has improved remarkably. Karyn, if I hadn't diagnosed him myself, I wouldn't have believed that he was the same child."

I had to find out whether other kids had had similar experiences. I bought a modem for my -- not standard in 1995 -- and discovered an autism support group on the Internet. A bit embarrassed, I asked, "Could my child's autism be related to milk?"

The response was overwhelming. Where had I been? Didn't I know about Karl Reichelt in Norway? Didn't I know about Paul Shattock in England? These researchers had preliminary evidence to validate what parents had been reporting for almost 20 years: Dairy products exacerbated the symptoms of autism.

My husband, who has a Ph.D. in chemistry, got copies of the journal articles that the parents had mentioned on-line and went through them all carefully. As he explained it to me, it was theorized that a subtype of children with autism break down milk protein (casein) into peptides that affect the brain in the same way that hallucinogenic drugs do. A handful of scientists, some of whom were parents of kids with autism, had discovered compounds containing opiates -- a class of substances including opium and heroin -- in the urine of autistic children. The researchers theorized that either these children were missing an enzyme that normally breaks down the peptides into a digestible form, or the peptides were somehow leaking into the bloodstream before they could be digested.

In a burst of excitement, I realized how much sense this made. It explained why Miles developed normally for his first year, when he drank only soy formula. It would also explain why he had later craved milk: Opiates are highly addictive. What's more, the odd behavior of autistic children has often been compared to that of someone hallucinating on LSD.

My husband also told me that the other type of protein being broken down into a toxic form was gluten -- found in wheat, oats, rye, and barley, and commonly added to thousands of packaged foods. The theory would have sounded farfetched to my scientific husband if he hadn't seen the dramatic changes in Miles himself and remembered how Miles had self-limited his diet to foods containing wheat and dairy. As far as I was concerned, there was no question that the gluten in his diet would have to go. Busy as I was, I would learn to cook gluten-free meals. People with celiac disease are also gluten-intolerant, and I spent hours on-line gathering information.

Within 48 hours of being gluten-free, 22-month-old Miles had his first solid stool, and his balance and coordination noticeably improved. A month or two later, he started speaking -- "zawaff" for giraffe, for example, and "ayashoo" for elephant. He still didn't call me Mommy, but he had a special smile for me when I picked him up from nursery school. However, Miles' local doctors -- his pediatrician, neurologist, geneticist, and gastroenterologist -- still scoffed at the connection between autism and diet. Even though dietary intervention was a safe, noninvasive approach to treating autism, until large controlled studies could prove that it worked, most of the medical community would have nothing to do with it.

So my husband and I decided to become experts ourselves. We began attending autism conferences and phoning and e-mailing the European researchers. I also organized a support group for other parents of autistic children in my community. Although some parents weren't interested in exploring dietary intervention at first, they often changed their mind after they met Miles. Not every child with autism responded to the diet, but eventually there were about 50 local families whose children were gluten- and casein-free with exciting results. And judging by the number of people on Internet support lists, there were thousands of children around the world responding well to this diet.

Fortunately, we found a new local pediatrician who was very supportive, and Miles was doing so well that I nearly sprang out of bed each morning to see the changes in him. One day, when Miles was 2 1/2, he held up a toy dinosaur for me to see. "Wook, Mommy, issa Tywannosauwus Wex!" Astonished, I held out my trembling hands. "You called me Mommy!" I said. He smiled and gave me a long hug.

By the time Miles turned 3, all his doctors agreed that his autism had been completely cured. He tested at eight months above his age level in social, language, self-help, and motor skills, and he entered a regular preschool with no special-ed supports. His teacher told me that he was one of the most delightful, verbal, participatory children in the class. Today, at almost 6, Miles is among the most popular children in his first-grade class. He's reading at a fourth-grade level, has good friends, and recently acted out his part in the class play with flair. He is deeply attached to his older sister, and they spend hours engaged in the type of imaginative play that is never seen in kids with autism.

My worst fears were never realized. We are terribly lucky.

But I imagined all the other parents who might not be fortunate enough to learn about the diet. So in 1997, I started a newsletter and international support organization called Autism Network for Dietary Intervention (ANDI), along with another parent, Lisa Lewis, author of Special Diets for Special Kids (Future Horizons, 1998). We've gotten hundreds of letters and e-mails from parents worldwide whose kids use the diet successfully. Although it's best to have professional guidance when implementing the diet, sadly, most doctors are still skeptical.

As I continue to study the emerging research, it has become increasingly clear to me that autism is a disorder related to the immune system. Most autistic children I know have several food allergies in addition to milk and wheat, and nearly all the parents in our group have or had at least one immune-related problem: thyroid disease, Crohn's disease, celiac disease, rheumatoid arthritis, chronic fatigue syndrome, fibromyalgia, or allergies. Autistic children are probably genetically predisposed to immune-system abnormalities, but what triggers the actual disease?

Many of the parents swore that their child's autistic behavior began at 15 months, shortly after the child received the MMR (measles, mumps, rubella) vaccine. When I examined such evidence as photos and videotapes to see exactly when Miles started to lose his language and social skills, I had to admit that it had coincided with his MMR -- after which he had gone to the emergency room with a temperature of 106°F and febrile seizures. Recently, a small study was published by British researcher Andrew Wakefield, M.D., linking the measles portion of the vaccine to damage in the small intestine -- which might help explain the mechanism by which the hallucinogenic peptides leak into the bloodstream. If the MMR vaccine is indeed found to play a role in triggering autism, we must find out whether some children are at higher risk and therefore should not be vaccinated or should be vaccinated at a later age.

Another new development is giving us hope: Researchers at Johnson and Johnson's Ortho Clinical Diagnostics division -- my husband among them -- are now studying the abnormal presence of peptides in the urine of autistic children. My hope is that eventually a routine diagnostic test will be developed to identify children with autism at a young age and that when some types of autism are recognized as a metabolic disorder, the gluten and dairy-free diet will move from the realm of alternative medicine into the mainstream.

The word autism, which once meant so little to me, has changed my life profoundly. It came to my house like a monstrous, uninvited guest but eventually brought its own gifts. I've felt twice blessed -- once by the amazing good fortune of reclaiming my child and again by being able to help other autistic children who had been written off by their doctors and mourned by their parents.

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The Autism Network for Dietary Intervention (ANDI)

Fax 609-737-8453
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Publishes ANDI News, a newsletter containing recipes, research updates, and articles by parents and physicians.

The Autism Research Institute

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Provides information about autism research and treeatment, including alternative therapies. Organizes the annual DAN! (Defeat Autism Now!) Conference.