



Article Link: <http://www.webmd.com/brain/autism/features/mission-to-get-son-better>

Autism Spectrum Disorders Health Center

I'm on a Mission to Get My Son Better — and Help Others

WebMD Feature from "Redbook" Magazine

By Nancy Rones

As Ryan faces new and frightening setbacks in his struggle with autism, his parents search for answers and find both purpose and peace in their new life.



For the past several months, REDBOOK has followed the Kalkowski family as it grapples with the challenges of battling 3-year-old Ryan's autism. In our last installment, Ryan's parents had a lot to celebrate: his birthday, his placement in a preschool class for the upcoming fall that would include both typical children and those with developmental delays, and the major strides he was making in intensive one-on-one therapy sessions at home. This month, the Las Vegas family is filled with mixed emotions as it faces the long-term reality of Ryan's disorder.

The day after Nicole Kalkowski's son, Ryan, took his first dose of medicine to treat an overgrowth of yeast in his little body, he woke up crying and extremely cranky. Nicole, 36, was worried but continued rushing around the house to get her two girls, Ciera, 9, and Ella, 7, ready for school.

Suddenly, Nicole heard a door slamming upstairs and ran toward the sound to investigate. What she saw made her heart sink: Three-year-old Ryan was standing at the entry to her bedroom, methodically opening and closing the door. Nicole was shocked — and scared. This was the type of repetitive behavior Ryan had started to display when he was a little older than 2, while in the grip of what's often referred to as a regressive autism; by that time he had also lost some developmental skills, such as responding to his name and waving. But thanks to intensive treatment, Ryan had managed to regain several of those skills, and many of his repetitive behaviors, including spinning and door slamming, had vanished — until now.

Nicole tried to redirect her son's attention. "Let's have breakfast," she said in a cheerful tone, gently pulling him away from the door. Ryan cried and refused to budge. Nicole grabbed a nearby toy and handed it to him. He couldn't be distracted. Finally, she pried him off the door and carried him downstairs as he screamed angrily.

After a few minutes of watching television, Ryan calmed down, but in the tense days that followed, a worried Nicole and her husband, Tim, 39, noticed that their son was moody and lethargic — plus, he wasn't talking much. They were also unnerved when they observed that Ryan was flicking his fingers in front of his face with increasing frequency. (This flicking is an example of "stimming," a behavior that a child with autism is thought to use to soothe himself or express his wants, such as the desire to be left alone.) Another disconcerting setback: Sometimes Ryan would lie down on the floor, pushing on his gassy stomach and screaming, "Ouch, I hurt" — a scene that was common before he'd started on his gluten-free, casein-free diet a year earlier. (This regimen is believed by some medical experts to alleviate symptoms of autism.) Ryan's therapists voiced concerns too. During their sessions with the little boy they'd nicknamed "Mr. Giggles," he now seemed less motivated to follow directions and perform tasks.

Ryan's new yeast-fighting regimen had been prescribed by his doctor, Geoffrey P. Radoff, an M.D. and a doctor of homeopathy who practices the Defeat Autism Now! (DAN) treatment approach. DAN doctors look for underlying medical issues that may be triggering autistic symptoms and remedy them primarily through supplements and dietary changes. Radoff had warned Nicole that the anti-yeast drug might temporarily trigger some problematic symptoms as Ryan's body adjusted to the new medication, but he also explained that this treatment was vital, because an overgrowth of yeast often leads to inflammation of the bowels and other medical conditions that could potentially fuel autistic behaviors. Still, Nicole couldn't ignore the guilty voice in her head that kept asking, "Did I make a mistake by giving him the medicine? Could I be jeopardizing all of the progress Ryan has made?"

Toxic Clues

Ryan's overabundance of yeast was only one of several issues his doctor wanted to address. After reviewing

the results of tests that analyzed Ryan's blood, stool, and urine, Radoff had found a number of irregularities, including high levels of aluminum, mildly high amounts of mercury and lead, a lack of some key vitamins and minerals (children with autism often have trouble absorbing various nutrients), and an infection in his digestive system. "All of these issues can lead to symptoms of autism, such as sleeplessness, head banging, and digestive problems," Radoff told Nicole and Tim, who listened to the report in disbelief.

"I was thrilled to finally get answers," says Nicole, who was hungry for clues about what may have been behind her son's symptoms. "But I was also so angry about the amount of metals in Ryan's body," she adds. "I wondered where they came from and what I might have done to cause those problems. I felt like in some way I hadn't protected my son enough."

With tears in her eyes, Nicole grilled Radoff about possible sources of the metals — particularly the aluminum, which was very high. (Some studies in mice have shown that overexposure to aluminum can damage the nervous system, and, though the results have been mixed, some research in humans has found that high levels of the metal in the body may cause Alzheimer's disease.) Radoff explained that there are many sources of aluminum in the environment, from certain types of cookware to tap water to canned food. Nicole shook her head, saying that her family barely used any of those things.

Then Radoff mentioned that some vaccines contain aluminum. According to the Centers for Disease Control and Prevention (CDC), the small amount of this metal included in vaccines has been used safely for 75 years and makes immunizations more effective; without it, a child might need more shots or have less protection from disease. But when Nicole heard the word *vaccines*, her stomach dropped. "Ryan's regression began right after he had five shots at 17 months," says Nicole. "I do believe my son has genetic differences that are partially to blame for autism, but my gut always told me that vaccines were connected too. Now, I was finally confronted with that fact. Since Ryan's diagnosis, I've had friends and even strangers who see the 'Think Autism, Think Cure' bumper sticker on my car ask me what I think about vaccines and whether they should get their child immunized. My answer is: 'I'm not anti-vaccine, but you just might want to ask your doctor about a slower vaccine schedule so your child doesn't have to get so many at once.'" (See "Do Vaccines Cause Autism?" on Redbook.com for more information on the controversy around kids' immunizations.)

Toxic Clues continued...

Radoff agreed that the metals in Ryan's body might be the result of vaccines. He added, though, that typical children may also have metals in their body; the buildup is just less likely to cause symptoms in those kids than in children with autism, who are more sensitive to environmental pollutants, including metals. Once these irregularities were removed from Ryan's system, he'd be happier and healthier, Radoff promised. The first step: the anti-yeast medicine, plus supplements to provide nutrients Ryan was lacking. Next, Radoff will treat the infection in the boy's digestive system with antibiotics, and finally, he'll work on getting rid of the metals through a process called chelation (which can take a year or two and, in Ryan's case, will involve suppositories).

Though relieved to have a plan in place, Nicole couldn't stop thinking that she was partly to blame for Ryan's shocking test results. When she learned from a DVD about autism that dust from construction can contain lead, she panicked — her mind flashed back to the summer of 2006, when the Kalkowskis were renovating their home. Nicole remembered that her curious little boy was always in the middle of things, surveying all the action. For days, she kept asking Tim, "Did we harm our son?"

When Nicole and Tim brought their concerns to Radoff, he said that based on the building materials that were used as well as the newness of their home, the construction was unlikely to have been a cause of Ryan's autism. But Nicole's guilt still lingered. She obsessed about the fumes from her newly varnished cabinets and about the large amount of pesticides they had sprayed to get rid of all the insects that came out during construction. "Thoughts of Ryan being exposed to those poisons haunt me now," says Nicole. "It's an absolutely horrible feeling."

After two agonizing weeks, Ryan's body did adjust to the anti-yeast medicine; except for occasional gassy stomachaches, his regressive symptoms faded. He even had a couple of breakthroughs following the hurdle: He said his longest sentence to date, "No, I no wanna do, Mama." And for the first time, he pointed on his own — to four cars, one at a time, on his train table at home, as Nicole and one of his therapists watched in excitement. "It was tough for a while, but this is huge," says Nicole.

She and Tim, who owns a contracting business, are now making an effort to rid their home of some potential toxins that could irritate Ryan or exacerbate his symptoms. Nicole has traded her regular cleansers for those with natural, nontoxic formulas; bought mattress covers to limit the family's exposure to dust mites; tossed out pajamas treated with flame-retardant chemicals; and avoids the use of pesticides. "I'd say that we've gone 'mint green' so far, but we're looking into more ways for our family to live in a cleaner, safer environment," she explains.

Mom Turned Advocate

Resolving to finally stop obsessing over what role she may have played in Ryan's condition, Nicole decided to direct her energy toward something far more productive: using her experience to help others who are in her situation. "At first, I just didn't want to accept autism, and I didn't have much interest in making friends with women in the [autism] community," she says. "I was strictly on a mission to get my son better. Now, I'm proud to say that I'm an active member of this community."

Nicole has joined the board of Families for Early Autism Treatment (FEAT); she pitches in at fund-raisers and volunteers with programs that provide emotional support to families. "To see a big group of people who care so much about fighting autism makes me feel that change will happen," says Nicole, who has gained her own incredible support group through FEAT. "Many of these women have been on the journey longer than I have, and they have taken me under their wing," she says. "These amazing, involved mothers really celebrate their children, and they continue to give me so much strength."

Her work with FEAT has given Nicole validation and hope, but her participation in another group, the education committee of the Autism Coalition of Nevada, has given her a voice. Nicole, formerly a special education teacher, is now able to put her background to work, brainstorming with prominent local politicians, medical experts, educators, and fellow parents during teleconferences about ways to improve early intervention and the educational system for those with autism in Nevada. "Instead of just screaming in my kitchen about things that are wrong with the system, I can give meaningful feedback and hopefully make it better for families," she says. "It's also a good feeling to have these important people in the state listening to what I have to say."

Less than a year after she learned that Ryan had autism, Nicole now also talks one-on-one with mothers whose kids have just been diagnosed, explaining to these women what to expect and reviewing treatment options. "Considering how depressed I was at one point about autism, I'm sometimes shocked by how encouraging and positive I am when I speak to mothers about it," says Nicole. "I feel my own spirit lift during those talks."

Tim is proud of his wife for giving so much of herself, and recently he, too, met with a dad whose two sons had been diagnosed. "When Nicole and I were feverishly looking for answers, one gentleman who had a son with autism took 45 minutes out of his busy day to talk to me about what to expect," says Tim. "He talked to me from the guy's perspective, and he didn't sugarcoat things. I remember how much that talk meant to me, and I was happy to help the next person. It's a horrible thing to admit, but before this was all happening with Ryan, I never really did anything to help people beyond my family and friends. Our experience with autism has put us in give-back mode."

A New Attitude

One day, after Nicole hung up the phone with a desperate mother who was searching for information about autism, Ryan ran over to give his mom a hug — and a feeling of gratitude about her life rushed over her. Holding her son tightly, she broke down in tears. "I had always imagined the perfect family as the commercial version — the one with the white picket fence," says Nicole. "So when Ryan was diagnosed, I was not only hurting for my son, but it also felt like my own dreams were shattered. I wondered, *How could I ever have joy and a 'normal' family life with autism?* It's something that I wrestled with inside."

But in that moment, Nicole felt incredibly happy. She was thankful for her loving husband, her two beautiful girls, and an adorable son who has made unbelievable progress in a relatively short period of time. And she was thrilled to have found *herself* in helping other families facing autism. "I never would have believed that the worst thing to happen to me could actually bring me to my purpose," she says.

As Nicole finally begins to embrace her complex and demanding new life, she is also learning to rely on help from others to keep that life running as smoothly as possible. Ryan undergoes intensive Lovaas Applied Behavioral Analysis (ABA), which involves tutors who work with him at home for about 40 hours a week on various developmental skills — and Nicole puts that time to very good use. "While Ryan is getting the attention he needs, I can take care of chores, occasionally have lunch with a friend in another room, or spend time focusing on my girls, whom I've really missed during all this," says Nicole. She has even started a sweet ritual with her daughters to reconnect with them: Every day, she writes a little loving note in each girl's journal. Her daughters write sweet notes back to their mother and rush to place their journals on her pillow.

While autism tears some families apart, the Kalkowskis have become even closer, cherishing their time together. They all go together to the girls' soccer games on Saturdays (Ryan claps and cheers for his sisters), and after church services on Sunday, the family looks forward to their hikes in nearby Red Rock Canyon. "Autism has definitely forced us to adjust our lives," says Nicole, "but now I know that I can find happiness in it all."

Originally published on September 1, 2008

Related content on redbookmag.com

- [What Autism Does to a Mother](#)
- [5 Symptoms Moms Can Relax About \(and 4 to Never Ignore\)](#)
- [Do Vaccines Cause Autism?](#)
- [3 Perspectives on Treating Autism](#)
- [Living with Autism: Losing My Little Boy](#)

Reprinted with permission from Hearst Communications, Inc.

SHARE [What is this?](#) | [Digg submit](#) | [facebook](#) | [del.icio.us](#) | [More...](#)

©2005-2007 WebMD, Inc. All rights reserved.
WebMD does not provide medical advice, diagnosis or treatment.

My Notes:



Check your symptoms and more on the go with your iPhone. **Free Download**

4 Must-See Articles

- [What It's Like to Have Autism](#)
- [Gluten-Free Diets for Autism](#)
- [On a Mission to Get My Son Better](#)
- [Is the Just the Blues or Something More?](#)



For more visit [redbookmag.com](#)



Try Something New: The Sex-Life Road Tests
Thousands of Recipes from Redbook, Good Housekeeping,
and Country Living
Mah Jongg, Sudoku and More for Free

Try An Issue Free