

# SHATTERING MYTHS

*When it comes to autism, don't believe all you're told...*

BY MARCIA HINDS

**Y**our child has autism. Now what? As parents, we find ourselves in a unique, select group, the “Autism Club.” No one asks to become a member, but because of our kids, we were forced to be in the A-Club. Autism isn't just a medical crisis; it is a family crisis that affects everyone. Only another parent understands what it is like to live with autism, day in and day out. It's beyond exhausting. And in spite of everything, we love our children too much to ever give up on them.

When it comes to autism, you can't believe all you are told! And never accept that an autism diagnosis means “game over”. The first step is to learn what autism really is. Many dedicated doctors and “autism experts” still mistakenly believe it is a psychiatric or developmental disorder. We need to stop looking at this backwards. Autism is not the cause of the medical conditions with which our children suffer. In reality, it is the other way around. Our children have immune systems that don't function properly.

The good news is that means autism is treatable. If the load on the immune system can be lifted, recovery becomes a possibility. The bad news is that it is difficult to find doctors who actually know how to treat it. Don't be surprised if your pediatrician gives you a strange look when you ask about medical treatment for autism. They didn't learn about this in medical school.

There is nothing simple about autism. It is difficult to treat, and the treatment is different for every child. Far too often, children with complex medical issues like severe sleep disorders, limited speech, nutritional deficiencies, stomach problems, severe allergies, and many other medical issues aren't taken to a pediatrician but instead are sent to psychiatrists or psychologists. Why? When autism is a part of the picture, underlying medical conditions are sadly and inexplicably attributed to an ASD diagnosis. Is it really okay that our children do not get medical treatment for the same conditions as other kids?

## SEARCHING FOR ANSWERS

My son Ryan was diagnosed at age four. My husband and I walked into the psychiatrist's office ready to find the answers to explain why Ryan was different from other children his age. But our “autism expert” didn't have answers. The specialist we waited months to see ripped away every dream we had for our child.

The doctor said there was no recovery from autism. There was no cure. There was no hope.

She finished by adding that most of these kids end up in institutions or jail. On the way home, without any discussion, we both knew we would never be going back. If your “expert” was anything like ours—do not walk—run, and find someone else.

The grief parents experience when receiving the diagnosis is paralyzing. Each of us is overwhelmed by the fear we have for our children's future. But you can't feel sorry for yourself or your child for too long. You don't have time. Your kid needs you, and you have too much work to do.

## GETTING PAST THE GRIEF

Only parents have the determination, stamina, and commitment to take on the seemingly insurmountable task of recovery. We will keep working to help our children no matter how tired or discouraged we feel. No one else ever volunteers to do this job for you. And your child will not



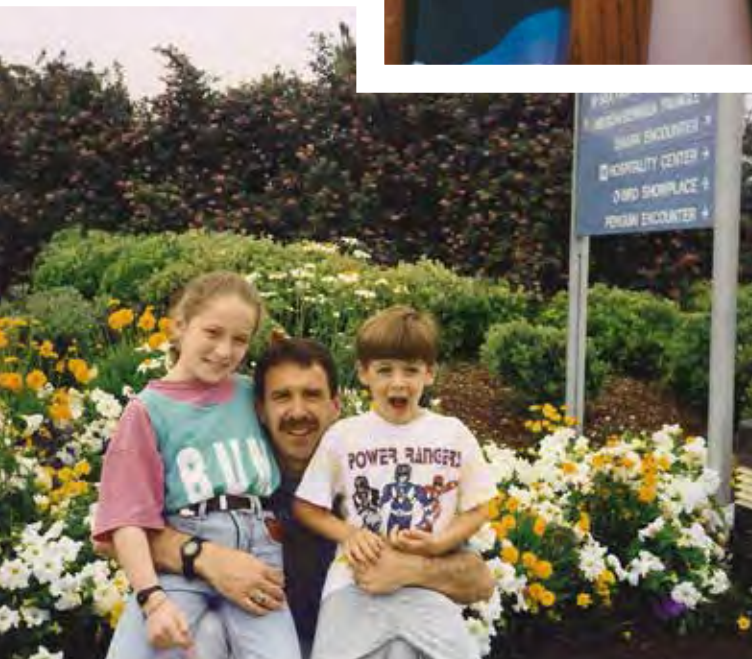
### ► ROAD TO RECOVERY—

(Top to Bottom)

Ryan's family never gave up in their efforts to communicate with him despite the lack of response.

In the beginning, Ryan had to be taught to do what most consider routine such as smiling for the camera.

Ryan's sister Megan was in charge of pretend play, becoming one of his most effective therapists.



come out of this by himself; you have to go in there and get him. So roll up your sleeves, trust your instincts, and do what needs to be done.

At the beginning of this nightmare, I had trouble putting one foot in front of the other. Some days I was so discouraged, I wasn't sure I could get up to face another day filled with autism. It wasn't only Ryan's behavior that was extreme, at times mine was worse.

The thought of our family always living this awful existence, the personal and family energy needed to work relentlessly to help Ryan day and night, and the frustration that came from only seeing gradual changes sometimes sent me to the ledge, ready to jump. It created a lot of stress in our marriage, and we almost didn't make it.

Sometimes, it felt as if we were caretakers of an absent soul. Since Ryan didn't respond, it was difficult to continue talking to him. I wanted some inkling that I was getting through to him, or that he was listening to me. He gave me *nothing*. Not a look, not a smile. It was hard to recognize any sign of intelligence when it was overshadowed by his odd, intense, and unpredictable behavior. What I didn't know at the time was that my son was still learning—but it was in stealth mode so therefore difficult to realize and appreciate.

### ONE-SIDED CONVERSATIONS

Since I was the only one talking, we never really had a conversation at all. Most of the time, all I got was that blank stare. I continued to constantly talk for both of us, even though my son lacked the communication skills to respond or nod his head in understanding. And I hadn't yet realized the profound and positive effect this one-sided interaction had on my son's future development.

Some parents stop talking to their children because they think the lights are out and nobody's home. I thought that too at first. It was only later after he recovered, that I came to see he had been *in there* all along listening to every word.

### SLOWLY BUT SURELY

When Ryan entered kindergarten at almost six years of age, he was in trouble developmentally and we were in trouble as a family trying to cope with his

intense and confusing behavior. He was in the third percentile for speech and language, and that was just one of his many developmental problems.

After medical treatment, supported by behavioral and educational interventions, Ryan tested in the eighty-fifth percentile for speech and language by the fourth grade. By fifth grade, he seemed to do well academically, but he still was still different and “weird”. To get kids to notice him, he repeatedly



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poked them. He still spoke in scripts about the same thing over and over again until all of us wanted to scream. He wanted friends, but didn't know how to make them.

Any social situation Ryan hadn't been specifically taught was confusing to him. And it was impossible to follow him around and teach him every circumstance he needed to learn. Although my kid no longer looked severely autistic and was ahead academically, he still wasn't *typical*. Ryan loved to repeat obscure facts about

## A MULTI-FACETED TREATMENT PLAN

*While medical interventions are paramount to recovery, the behavioral and educational components are equally important to the process*

I get frustrated when I hear about how we need to accept our children with autism as they are. Of course we accept them as the individuals they are, but would we accept cancer and not treat it? I don't think so. Our children have immune systems that don't function properly. The brain cannot function when the body is ill. This illness causes the behavioral symptoms that are diagnosed as “autism”. And when it is possible to correct what is medically wrong or even remove some of the stress on their systems, they are healthier, and their autism symptoms lessen over time.

Most children improve with medical treatment, but that only makes them able to learn what they couldn't before. Medical intervention alone is not enough. Our children still need an intensive rehabilitation program to catch them up on all they missed. That's why programs like Applied Behavior Analysis (ABA), Floortime, Son-Rise, or RDI need to be implemented at the same time as the medical components. Parents, behaviorists, educators, and medical professionals must work as a team to help kids get better. Each of us has a piece of the puzzle.

The common belief among most conventional doctors continues to be that autism is a dead-end developmental or psychiatric disorder. This couldn't be further from the truth. It is medical and I believe caused by an immune system that is sometimes over and/or underactive. It shouldn't be a life sentence of special education classrooms that lead eventually to a group home. For me, the word “autism” and all the numerous labels we use like PANS, PANDAS, Lyme Disease, ADHD, etc., try to define a collection of symptoms that look different in every child. Maybe we should just stop calling it “autism” and instead call it what it is: a dysfunctional or “messed-up” immune system.

Although this is a difficult medical condition to treat, no parent should ever accept there is nothing they can do. And we need more doctors trained in how to treat this. Good doctors are very hard to find and sometimes even when you find a dedicated doctor, they don't understand that our kids need medications long term to help their immune systems continue to function properly. Our children's condition might be compared to the diabetic who needs insulin for life. My view is that the symptoms of autism can be reversed, but the dysfunctional immune system still requires treatment.

My son still is on antivirals and antifungal medications and has been since he was very young. I used to worry about the effects the pharmaceuticals could have on his body and potential growth. My concerns were relieved when I realized that was why my kid had frequent blood tests to make us aware of any potential liver or kidney stress. Some individuals have been able to stop the medications when the immune system starts to function better, but as of yet, my Ryan is not one of them.

Then there is the other problem that parents incorrectly assume the medical isn't working when their children don't start speaking in full sentences after treatment. Remember it takes three years for typical kids to learn speech. Even if we could wave a magic wand and correct all the medical issues our children have, they still wouldn't act typical. Their strange behaviors have become engrained, and they must be re-taught how to act and speak.

Children are individuals and will respond in their own way to both the medical and behavioral interventions. Since they have been ill for a long time, getting better takes time. That often doesn't work well for parents like me who wanted my son fixed before lunch. **And equal effort does not guarantee equal outcome.** I know many families that worked as hard as we did, but never made it off Autism Island. Some kids are just too sick and their immune systems are too broken to completely recover. This highlights the need for a rapid and appropriate medical response to the diagnosis. The faster these kids can get good medical attention, the better.



## TOP TEN TIPS FOR PARENTING A CHILD WITH AUTISM

**#1 Treat your children like they are “typical.”** Keep talking to them even if it seems like the lights are out and nobody’s home. It was only after Ryan was better that I knew he was in there and hearing every word I said.

**#2 Don’t speak negatively when they’re around.** Many of our kids have supersonic hearing and can hear us even though they are not in the same room. Our children need to know their parents believe in them and would do anything to help them.

**#3 Don’t avoid stressful situations or meltdowns.** Our kids need to follow the same rules as the rest of the world. When they do meltdown (and we all know they will), don’t make excuses for them. It may be embarrassing, but get over it. Don’t worry about what other people think and always do what is best for your child.

**#4 Don’t try to fix everything at once.** Pick the one thing they do that drives you out of your mind and only work on eliminating that behavior. When that’s mastered, pick another. Correcting too many inappropriate behaviors at the same time gives them the message that they can’t do anything right.

**#5 Learn to ignore most of what they do wrong and notice what they do right.** I know this is difficult because so much of what our children do can be inappropriate. But find that one thing they do correctly and reward that behavior. Consistency and positive reinforcement are the keys to success. Reinforcement must be immediate for all kids. Most can’t be rewarded at the end of the day or given a prize at the end of a good week. We used what Ryan loved or obsessed about to motivate him. That meant everything my son needed to be taught had to include elevators, cars, computers, technology, sharks, electric plugs, or light switches as part of the lesson.

**#6 Don’t get so engrossed in the medical care and therapy that you forget your children are kids.** Sometimes we cancelled whatever we had scheduled for a few days and just had fun. That way, instead of being “Dr. Mom” who interpreted lab tests, and served as his chief therapist and caseworker, I got to be his mommy. I needed that, and Ryan needed it too.

**#7 When you’re at the end of your rope, feel that there is no hope, and have trouble continuing—fake it.** That’s when I’d crank on the rock and roll and make the entire family dance. I pretended to be happy and eventually my “fake it” method of therapy started to work. Another tactic was to load everyone in the car and change the scenery. Sometimes we’d go to the park, the McDonald’s play place, or just for a walk.

**#8 Listen to all the experts, do your research—but trust your gut.** No one knows your child like you do. I had Ryan’s tonsils out when the doctor who helped us most said I shouldn’t. After, my son’s constant strep throat was gone and he was no longer sick all the time. When that same physician told me NOT to do Applied Behavior Therapy (ABA), I did it anyway.

**#9 Stop feeling sorry for yourself and your child.** It’s frustrating that you have to teach your child what most kids learn easily and naturally. You don’t have time to worry about that. There is too much work to be done.

**#10 Don’t ever give up or accept their condition.** You need to be more stubborn than they are. And never ever negotiate with terrorists or kids with autism!

sharks, electricity, and airplanes over and over again. He had no idea how to decipher social situations, and he was the perfect victim for any bully.

### THE ROAD AHEAD

Following years of intense medical and behavioral interventions (*see sidebar*), Ryan is now employed as an engineer at a major aerospace company. But more importantly, he has friends and is happy. One of his bosses recently complimented him on his great people skills. Ryan and I had a good laugh over that one. My son is now the liaison between his company and their customers. Before medical and behavioral interventions, he didn’t have friends, spoke in the same scripts over and over again, and had to be taught what other kids just “knew”. Who could have predicted that one day he would have a career that required advanced social skills?

His favorite thing to do is going surfing with friends. Surfing requires coordination. I used to have to hold Ryan’s hand to make sure he didn’t fall when he walked down the street. He was also very sensitive to sounds and touch. He had to have every tag cut out of his clothes and he covered his ears every time a bell rang at school. But all of that is gone now.

Ryan now does all the things the “experts” said could never happen. Recently, he vacationed in Bali with one of his best friends from college. He also went to Panama with another friend he stole from his sister. His life would have been very different if we had accepted his autism or embraced it. And I’m pretty sure it wouldn’t involve surfing in Bali or Panama.

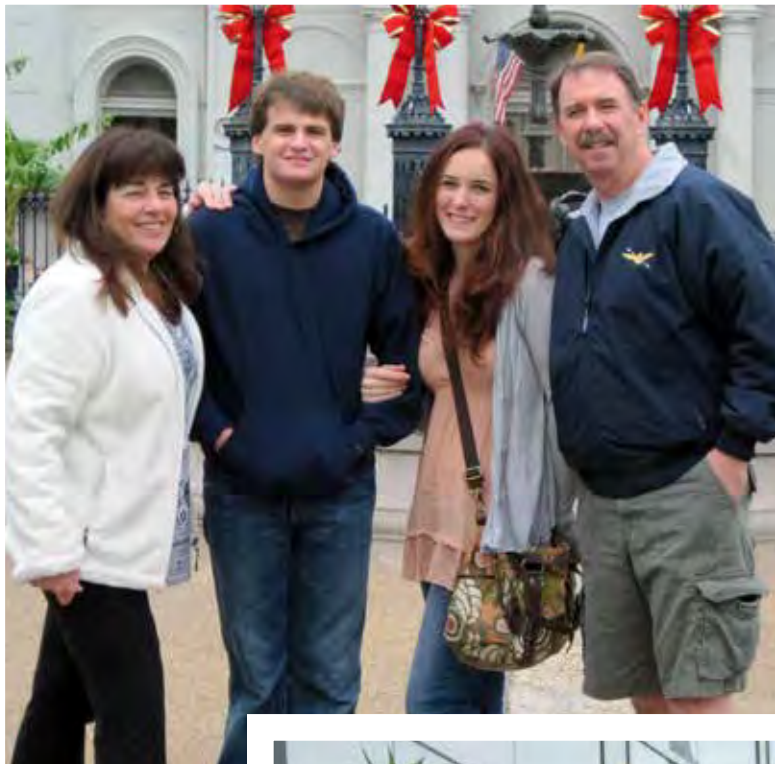
The loneliness my son experienced was the hardest part. He was “with it” enough to realize he was not accepted by his peers, but not enough to know what to do socially. Sometimes Ryan was the only boy in his class not invited to a birthday party. We’d cry together about that. He had very few friends and was rarely invited anywhere until college.

I questioned if our family's sacrifices and efforts were actually accomplishing anything. I worried about the impact of Ryan's issues on my daughter. At times, I wasn't sure if I had the strength to be more stubborn than my son. My fear for Ryan's future continued past the awkward school years and into the beginning of college. It wasn't until then that Ryan finally started to understand the social piece of the puzzle and could figure things out on his own. Yet, he wasn't "fully cooked" until after he started working. One question parents often ask me is, "When did you know Ryan would be okay?" It wasn't until after his bosses and coworkers still liked him after a year at his job that I knew things were finally all right.

Helping my son recover was the hardest thing I have ever done! I made many mistakes along the way. But the one thing I did right was to never give up no matter how hard things got. We couldn't give up because sometimes we got a glimpse of the kid that was *in there*. ◀

### FIND OUT MORE

*I Know You're In There: Winning Our War Against Autism* is the story of Ryan's recovery. Although most kids improve when you combine medical treatment with behavior and educational interventions, not all can reach full recovery as Ryan did. We need to change that so what happened for Ryan is no longer the exception. The book can be previewed on the website [www.iknowyourinthere.com](http://www.iknowyourinthere.com) and is also available on Amazon, iTunes store, barnesandnoble.com, smashwords.com, and kobo.com.



### ◀ FUN & FAMILY— (Top to Bottom)

Ryan today doing what he loves most. He travels to other countries with his friends in search of that perfect wave.

It took the entire family—and then some—to make Ryan's recovery from autism possible.

Ryan graduated with a master's in engineering management in 2012.

