

# My Family's Experience With Autism and MS



**Imagine how scary it would be if you were sick and couldn't tell anybody—a booming headache, blurred vision, numbness in your hands, a tingling sensation in your feet or your favorite blanket suddenly feels like a million thorns.**

**It is very likely that's the world my daughter, Irene, lives in.**

In her 30s, Irene has autism and is mostly nonverbal. As an infant, she consistently missed milestones, such as sitting up and holding her bottle. Ultimately, a neurologist diagnosed her as developmentally delayed. It was her first diagnosis and the motivation for my first acts of advocacy: researching appropriate programs and enrolling her in early intervention.

In those early years, Irene exhibited behaviors very common in autism, which were treated with speech, occupational, and physical therapy. She was the first child in our large immediate family to have special needs and we were all learning together how to care for her. I had a great support network and we actively participated in community-based awareness events. The goal was to stay engaged and informed about resources and programs designed to benefit individuals with autism.



Irene has always been reasonably healthy, very sweet, calm and happy. So we were concerned when she started behaving differently.

Irene began having screaming episodes, pulling at her ears and hair, leaving bloody scratches. She had become noise-sensitive—the car radio or conversation at the dinner table would also trigger the ear-pulling. Next, we noticed she had developed a fear of the stairs, stepping hesitantly and clinging to the banister. Then, there was the eating with her hands, something she had never done before.

December 2018, I noticed Irene's irises were stuck in the corners of her eyes and took her to an emergency room. The entire experience was traumatic for us both. Irene was admitted and I watched helplessly as a team of hospital staff struggled with her to insert an IV. Later, Irene and I were both crying as another team tried to immobilize her to send her through the MRI machine. She was screaming and begging for my help with her eyes. Through my tears, I tried to assure her everything was going to be okay. Little did I know, our lives were about to change.

The following afternoon, Irene was asleep, and I was watching TV. I sat slouched in a hospital chair with my feet under her covers, rubbing softly against her leg. A doctor came in and told me Irene had several lesions on all parts of her brain. She was certain they were caused by multiple sclerosis.

My heart broke for my baby girl. How frightened and confused she must have been when the symptoms flared, trapped in her own world, unable to explain what she was feeling.

After allowing myself room to come to terms with the newness of the diagnosis, it was time to get busy doing all the things I know Irene would ask me to do if she could talk: "Mom, make sure I have the best medical care, research appropriate treatments for me and please

tap into resources for emotional and spiritual support because we're both going to need it."

I immediately connected with advocacy groups and sought information in online forums. I asked a lot of questions and although the symptoms of MS are very individualistic, people openly shared their experiences, which gave me some insight into what Irene might be feeling.



There were certainly more questions than answers but advocating for Irene was familiar territory for me. What was unfamiliar was the complexities of a disease that is mostly invisible. The painful symptoms and side effects of treatment need to be verbalized but my daughter cannot tell me her hands and feet are numb, her vision is blurred, or her insides are on fire. **This is the intersection of autism and MS where my worry resides.**

Irene's receptive language is high. She can answer most "yes" or "no" questions, but she is unable to communicate intricate feelings. For example, prior to her diagnosis, our family went on a summer vacation. We were out sightseeing when Irene became upset. We stopped at a pizzeria to take a break and cool off in the air conditioning, but she was inconsolable. We had a bit of a walk back to our hotel and by the time we got there, she was in full meltdown. She slept for almost 24 hours and then she was back to her cheerful self. After she was diagnosed, we learned heat can bring on extreme fatigue. That was likely the symptom Irene was experiencing on that hot day.

Irene is being followed by an MS neurologist. Treatment is proving to be difficult because of

her fear of needles and the MRI machine, both of which would be routinely required once on medication. We also have to consider her inability to verbalize whether she's experiencing painful side effects.

Today marks the last day of World Autism Month. Although I've never met anyone in our situation, I believe there are other families affected by similar combined diagnoses. MS has brought on a range of emotions for me but one of the strongest is isolation. The feeling that no one understands what we're going through. **That's why it's so important to share Irene's story, to let others know: you are not alone.**

It has been quite a journey for us, but my sweet Irene and I are blessed to have so many wonderful people who love and support us as we learn how to live with the challenges of autism and MS.

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Editor's Note: Everyone has their own unique journey with MS, and The National MS Society blog strives to amplify the diverse perspectives of people in the MS movement. While the content of this blog may be sensitive to some, the author is sharing her personal, authentic journey with MS.

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