



In an earlier post, I mentioned that I believe in [finding your community](#) to help you adjust and thrive as a special needs parent. For my family, that has taken the shape of a local special needs support group, and we also do a lot of volunteering with [JDRF](#). This post expands on some of our experiences with JDRF, and how much it has meant to us.

Starting Out with JDRF

The diabetic nurse educator that worked with us in the hospital when Daniel was first diagnosed with type 1 diabetes—the one tasked with teaching us all the lessons we needed to learn so rapidly—was a volunteer with her local JDRF chapter. JDRF was formerly the Juvenile Diabetes Research Foundation, but as the disease is no longer known as “juvenile diabetes,” the organization simply uses the initials, and it is the largest private funder of type 1 diabetes research worldwide. She talked to us about the support found in the JDRF community, and before we had left the hospital, my husband had signed us up to do our first JDRF One Walk.

That first year, 2016, we participated in one walk and volunteered at three others. One of those was so wet and so cold, and our boys were only 3 and 5 at the time, and they were the stars of the show: dancing in the rain in their little Batman raincoats, making friends with the photographers, basically charming everyone who met them. We became friends with the staff at our home chapter, and began to get more involved, attending several events over the next year, making connections with other families affected by type 1 diabetes, hearing research updates from the professionals, and more.

Launching Our Own Events and Awareness Endeavors

For the 2017 season, we again participated in one walk and volunteered at three others. There was more rain, more laughs, more fun, and more networking. We hosted a golf outing and a ghost walk as our own fundraisers, and we launched our own Facebook page ([Team Danny X](#)) where we update about our advocacy efforts and post tidbits about type 1 diabetes, autism, ADHD, and sensory issues – in other words, all the issues that affect Daniel and our family as a whole. It’s a unique insight into our family life, to say the least! Because of our efforts, Jim was asked to speak to other One Walk team captains, encouraging and offering



support to families new to One Walk, and we became mentors to families newer than us to the world of diabetes.

What Helping Out Means to Us

The JDRF community has become an extension of our family, providing much-needed emotional support, and so much more. Several weeks ago, we attended an event, the Type One Nation Summit, where we spent the day with several hundred others who are somehow, in some way, also affected by type 1 diabetes. While we were originally meant to simply attend the event, we ended up volunteering instead, staffing the One Walk information table. This wound up being an excellent opportunity for us as a family, and I came away from the day quite touched.

For my children, the day was simply “fun.” My little guy, just shy of five, has been referring to it ever since as the “JDRF party at the hotel.” He sat at our information table briefly, but as soon as the kids’ room was open, that’s where he wanted to be. The event was held at a local hotel and conference center, with one of the conference rooms being set aside as the “Kids’ Korner.” It was staffed by counselors from an area diabetes camp, as well as a nurse and JDRF staff. Crafts, games, and fun were the order of the day. Owen made a new friend almost immediately, and every time I ran over to check in on them, Owen and this other young boy were together. Most importantly for him, Owen got to just be “Owen,” something that is so important for the siblings of children with extra needs or chronic illnesses. Most importantly for *me* with regards to Owen was this: every time I went over there, I was told how well-behaved he was, and how even though Owen was doing his own thing, they’d catch him looking up every now and then to see where his brother was. We work very hard to make sure that Owen does not feel *responsible* for Daniel, but we do want him to be aware of Daniel’s differences and to know that if Dan needs help, to get an adult. It’s always nice to hear from others that our lessons have taken root in his little brain! Empathy is SO IMPORTANT in this world of ours!

For Daniel, the day was fun, but it was taxing. Because of his autism, it’s difficult for us to tell



sometimes how much he is struggling to cope or how much he is enjoying himself. He knows that JDRF means other people with diabetes, and of course he knows that he has diabetes. We have explained that it's important for him to meet people like himself, and it is my hope that by being involved from such a young age, he will grow up in a community of people who share such a huge part of who he is. By 10 a.m. however, he was already asking to leave, and the event ran for several more hours. I was so proud of him, though, because he didn't fuss, he didn't tantrum, and he didn't melt down; he just participated when he felt up to it, retreated with his tablet to a corner when he was overstimulated, and he was just a boy doing his thing.

For my husband and I, the day was all about service and connection. We got to hear several very motivated speakers, including the Chief Mission Officer for JDRF, Dr. Aaron Kowalski. When I got to shake his hand and personally thank him after, I felt like I was meeting a rock star. He was kind, patient, and infinitely intelligent, but spoke in a way that made everyone feel like they knew exactly what he was talking about – and with the science of immunology and autoimmunity, it's not easy making that “accessible.” Other speakers were extremely inspiring as well, and it has been my habit to listen intently, introduce myself after the fact, and immediately connect on social media. Being acquainted with these superheroes in the battle against type 1 diabetes has vastly shifted my perspective, taking me from victimhood to advocate in a fairly short time. I want to be one of those voices in the future, speaking and inspiring others the way these folks have done for me.

I have to say, the best part of the event for me was meeting other families. We connected with one family whose daughter had only been diagnosed a few weeks earlier, and other families who had been affected by type 1 for decades. We got to see folks we'd met at the walks, and folks we only knew from the “Diabetes Online Community.” The singular most important connection for me was meeting another family who also had a son with both type 1 diabetes *and* autism. It's a very rare combination – so rare, there's hardly any scientific research denoting an overlap – and the two issues combined provide some unique challenges, so to find another family with a little boy so close in age to Dan, and so similar, it was like we could hear the chant, “One of us, one of us,” and choirs of angels singing all at



once, and we're looking forward to creating more of a personal relationship with them!

Participation is a privilege, and a gift, and so, so good for healing wounded hearts. We are so lucky to have been a part of such a wonderful day, and look forward to being a part of many, many more.

Related Reading:

- [Parent Support Groups](#): HIE and Pediatric Disability
- [Jennifer McCue](#): Our Journey to Acceptance



Jennifer McCue

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