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Jenn Krawchyk – Personal NF Story

When my son Kyle was officially diagnosed with NF1 at 6 months old, my husband Dave & I were devastated. I remember our first specialist telling us, “whatever you do, don’t Google it. All you will find are the scary & negative stories.”

Being a librarian, I did just that & found those awful stories. Our emotions have ranged from confusion, to denial, then anger, still more confusion, and finally acceptance. A lot of our confusion and anger with NF came from a place of not truly knowing WHAT NF is. In my research, I’ve read countless articles that say how NF is one of the most common genetic disorders around, but you would never know it, because no one truly KNOWS about it. That is why we advocate so hard for NF research and funding for this disorder. We need funding not just so we can find a cure; we need funding for NF research so we can educate. So we, parents, advocates, & people with NF can look others in the eye when we are asked, “What exactly is NF?”, and give them more than just textbook facts or a blank stare.

Funding is so important to me, and my family, because it’s personal. It’s about my son. It’s about running my son, a 4 year old Lightning McQueen/Buzz Lightyear loving boy, to endless therapies almost everyday to make sure he is on track with his peers. It’s about fighting for his right to a fair education because he’s not quite “on par” with the rest of his classmates at his age. And most importantly, it’s about letting him be a typical 4 year old that shouldn’t have to worry about anything more than playing & getting dirty.

NF has created a lot of setbacks for our son Kyle, but he has come such a long way since that nine word anvil was dropped on us. We are always fighting insurance companies to make sure he can get the speech, occupational, and physical therapies he needs, but it never seems like it’s enough. In addition to his schooling, he also receives therapies through pediatric specialists in our area. Kyle also wears two types of braces to help correct & protect his right leg (due to bowing) and back because of scoliosis; both conditions of NF. As one can guess, this too, leads to more fighting with insurance companies to make sure he can receive what he needs.

I remember thinking upon first hearing Kyle’s diagnosis, how my vision of the kind of parent I wanted to be was now different than what I imagined. Different in that we would always have to fight for him; to be heard, educated, & whatever else came our way. It became more than just reading stories, writing first letters, and speaking first words. It wasn’t going to be cut and dry and easy, like it is for other kids who are younger than Kyle that can do so much more than he can. Kyle’s successes and milestones were (and still are!) huge celebrations in our house, even though I’m pretty sure others think we’re nuts for celebrating the small things. It’s because there are no small things with NF. Every success is a victory.

That is why we are such strong advocates for NF funding. NF funding allows for more education and support that is desperately needed. This funding is just as important as cancer research and every other social/medical cause there is, but without this funding, NF continues to be the “silent” disorder. The one you hear about, but never really understand, because you either find all of the bad information out there, or you don’t find anything at all.

Please help us continue to fight the good fight. Thank you for your time.

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