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How to Have a Rare Disorder

Cora Yoesting

Step one of having a rare disorder is to have a rare disorder.

Step two of having a rare disorder is realizing you have a rare disorder.

This is where things get complicated. Ever since I was very young, I remember thinking, “Does everyone breathe like this?” But I didn’t think to ask any follow-up questions. When I was in the fourth grade, I started furrowing my eyebrows. I thought it was because I wore my ponytail too tight. I did it so often that my friends began to notice. One friend offered to help by slapping me on the forehead anytime I did it, regardless of the situation. We tried that for a couple of weeks, and it seemed to work. I didn’t think any more of it for years.

Scratch that – step two is realizing you have something.

Over the years, my symptoms very slowly, almost imperceptibly, worsened. I had my first big tic attack – or what we called a tic attack at the time – in August of 2019. Maybe it was the stress of beginning my senior year. Maybe it was random. All I know is that one day I was a normal teenager who sometimes had twitches, and the next day I was disabled. Now, it wasn’t just my eyebrows furrowing. My whole face would morph into what looked like a silent scream. Silent because, at the same time, my throat would close so that I couldn’t breathe. Over and over, these spasms continued throughout the day, and by the evening, I was utterly exhausted. My chest was tight. I was lightheaded. My throat hurt. I could barely function. This was when my mother caught a candid video of my spasms for the very first time. Finally, I had something I could show to a doctor. I soon received my first diagnosis: Tourette's syndrome.

Step Three: Adjust to living with your new diagnosis.

Throughout my senior year of high school, I slowly grew more comfortable with having a visible disability. For a while, every time I talked to someone new, I would preface

The Barn

Nicole Bellin





Butterfly and Pink Flower

Ann Tilger

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whatever I had, it was rare.

our interaction with a disclaimer that I had tics. Eventually, however, I learned that it was best to simply let people be confused. When I stopped explaining myself and started presenting myself confidently, I found that the frequency of the questions decreased significantly. At the same time, I developed a very laid-back personality and sense of humor, which is often necessary for survival when you have such a potentially isolating condition. In response to this, people seemed less worried about walking on eggshells around me, and the previously concerned questions turned to curious ones. Just as I began to feel really comfortable in my skin, it was time to move on to step four.

Step Four: Wait, what was that thing about breathing?

In mid-December of 2021, following a period of stress and sleeplessness, I experienced another attack, this time significantly more severe than the last. I quickly became extremely lightheaded and weak. I simply had to lie down and focus on trying to breathe, eventually being hooked up to an oxygen machine. For days, I was completely incapacitated. It took me months to feel somewhat normal again, but I don't think I ever truly recovered.

At this point, I knew something was very wrong. I had heard of extreme cases of Tourette's, but this felt different somehow. So, I began researching. For hours, I scoured medical journals describing dozens of different movement disorders. Only a few sounded anything like what I had been experiencing. Hours turned into days which turned into weeks. My brain was constantly rotating through a list of potential leads and keywords: myoclonus, dystonia, myokymia, dyskinesia, ataxia. It became clear very quickly that, whatever I had, it was rare.

Eventually, I came across an article about something called, "Meige syndrome." For the first time, I felt like I was reading about myself. Finally, I had a name for what I had been experiencing for what, in retrospect, seemed to be my whole life. Upon reading further, it seemed that I had an incredibly rare presentation of this already rare disorder; therefore, my journey from here on out would not be a simple one.

Step Five: Start treating yourself like a case study.

With this newfound information in hand, I made an appointment with a neurologist. During the months in which I waited for an initial evaluation, I began regularly filming my symptoms. In the few previous videos I had taken of my "tics," I was laughing at myself and at the absurdity of the situation. In these, however, I was sometimes calm and casual, but never laughing. Some were taken after my symptoms had kept me awake and constantly fighting to breathe for all hours of the night, my hair greasy and eyes puffy. In a few videos, I broke down crying. During this time, it felt like my symptoms would never stop worsening. I felt like I was going to die, and never had I wanted to live so badly.

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Frozen Heart
Jayna Burch

Step Six: Get comfortable with needles.

When I finally saw a neurologist for the first time, he approved me for the one available treatment option—botulinum toxin, or Botox, injections throughout my face and neck. The first time I received Botox, I got fourteen total injections. The second time I got seventeen at a higher dose. It caused my eyebrows to look somewhat Vulcan but had no effect on my spasms.

I felt like no one was listening to me.

After my first appointment, I had to come back for an MRI. The nurse poked me six times, trying to get my IV, and blew out the vein on one arm. Once I was finally in the machine, I prepared myself for the noise level I had been warned about and focused on staying as still as possible despite my spasms. What I didn't expect was for the machine to sound more like something out of a goofy sci-fi movie than a printer. My laughter ended up being a greater hurdle for staying still than my spasms.

**Step Seven: Don't let disillusionment become discouragement.**

When I saw an ENT for my throat spasms, she stuck a camera down my nose, declared that I had vocal cord dysfunction, and referred me to a voice therapist. I told her that I had looked into vocal cord dysfunction, and I was sure that it wasn't what I had. Nevertheless, she said I would have to attend at least a few therapy sessions before she would consider treatment with Botox.

Six months later, I nearly broke down during my last voice therapy appointment. We had seen no improvement. As it turns out, you can't do breathing exercises when your throat is closed. Meanwhile, some of my symptoms relaxed for a while, others worsened, and I was now in chronic pain. I felt like no one was listening to me. When I finally saw the ENT again, she once again stuck a camera down my nose and told me I had vocal cord dysfunction. Still, she conceded that we could try Botox injections into my vocal cords. She told me, as I already knew from my extensive research months prior, that the outlook for injections here wasn't nearly as positive as in other muscles and negative side effects were much more likely. The only other potential options if Botox failed were experimental deep brain stimulation or a full laryngectomy and tracheostomy. I left her office on the brink of tears, feeling like I was fighting a very expensive losing battle.

Step Eight: Pull yourself up by your bootstraps.

At this point, it had been nearly a year since the major episode that had sent me down this spiraling path of appointments. I now knew that what I had been calling a "tic attack" was really a "dystonic storm," but I was seemingly no closer to

Standing

Davis B. Lyle

relief. I once again began doing my own research. This time I came across a group of people with the same condition. Their website was a wealth of information, all compiled by people like me who had been forced to become their own advocates.

I attended a support group meeting and was by far the youngest person there and the only person visibly spasming, as everyone else seemed to be much farther in their treatment journey. They were all brutally honest and extremely open about their personal medical history. They had to be. If we didn't help each other, no one would. It was refreshing. I learned more at that meeting than at any appointment I had ever been to. They knew all the best and worst providers in the country. They very bluntly told me that I needed to leave my current neurologist and go see an expert down in Houston. I made an appointment the next day.

I'm incredibly young for my diagnosis, so they were very worried about how my condition might affect my well-being. They gave me all the advice they had and got my contact information so they could personally help me. I felt like I had been newly adopted by several loving and supportive grandparents. With a comforting and cheerful smile, one of my new grandmothers sent me off with their favorite saying, "Keep your eyes open!"

**For the first time in a long time,
I was hopeful. I was excited.**

Afterward, it was like a weight had been lifted off my shoulders, and I couldn't stop smiling. For the first time in a long time, I was hopeful. I was excited.

Step Nine: Keep your eyes open.

Step Ten: See step one.

Who Sits in That Empty Chair

Amanda Duncan

