

Meet Jason, a DMRF Canada Volunteer and dystonia Sufferer. We sat down with Jason to ask him about how dystonia has changes his life, and why research is such an important key to changing the lives of the 50,000 Canadians who are living with dystonia today.

DMRF: Thanks for sharing your story with us Jason. Can you tell us, when did you first experience your dystonia symptoms?

Jason: In late Summer, early Fall of 1999 I was living the life of a normal 25-year-old. I was a Volunteer Fire Fighter, I worked two jobs, was in a relationship with Amber, the woman who was to be my wonderful wife. Soon after waking one morning I felt the sensation of somebody tugging or flicking my face. There was nobody there doing this so I observed and grew nervous as this tugging and flicking feeling began to affect my hands and my feet, eventually leading to my arms and legs. At this point I called to Amber as I was unsure as to what was going on or how to fix it. We immediately drove to the local Emergency Room.

We were finally seen by a Doctor who was convinced I was stressed and said I should go home and sleep it off. Convincing him it wasn't stress he then pushed the "Drug Induced" responsibility on me which was nonsense as i had never touched the stuff in my life. After some time, he finally agreed to try to help stop the posturing which had been going on now for hours by giving me under the tongue Ativan. Eventually this stopped the posturing.

DMRF: And when were you officially diagnosed with dystonia?

Jason: After some days and then some quick testing by a very interested young Neuro and his experienced "Yoda" in Halifax, they diagnosed me with PNKD and determined Clonazepam would be the drug of choice for my treatment. Shortly after having side effects from the Clonazepam they moved me to Diazepam

DMRF: How are your day to day symptoms? Are the medications and other regimens helping?

Jason: For the first 11 years my symptoms remained fairly consistent with the odd anomaly. My episodes were typically every 3-5 days with some bouts of daily episodes and the odd week-long reprieve. In 2010 my youngest Daughter was taken to a Children's Hospital after a year of repeated hospital stays during which varied testing by Doctors could not determine what was wrong. She was showing signs of highly stressed organs, including her heart due to weight loss, repeated bouts of vomiting, which was leading to malnutrition. Thankfully they quickly diagnosed her with Celiac Disease (a Gluten allergy). It turned out that she and her Sister suffered from it.

At that time, we decided as a family to completely change our household making it a 100% gluten free zone. Even our cats were fed a gluten free diet. With this change in my diet as well I began to see changes. I felt better, stronger, and I could get up to two weeks without having an episode. Avoiding Gluten was actually helping my symptoms.

Then, in late 2011 to early 2012 I saw a drastic change in my symptoms. I was still eating gluten free and nothing else had changed but my body began developing tremors which were somewhat new to me. These tremors were not tight episodes that I was used to, they were constant, tiring movements that would last for hours until multiple doses of medication forced me to sleep. We tried twice over a number of days to see a Doctor but my Diagnosing Neuro was no longer practicing in the area and I did not know I was without a Neurologist.

During my first trip to the ER, the attending physician drew the conclusion that I was a drug addict suffering withdrawal symptom, I was told to deal with it and go home. Upon our second visit after days long battles and using Valium in the fruitless attempt to hold the movements at bay, I was repeatedly asked by a different attending physician how much alcohol I drink daily and when I was able to mutter the word, "none", he pulled my wife aside to inform her I was lying to her about my alcohol consumption. During all of this, we carried and offered a CD containing a text file and videos showing Dyskinesia and explaining what it was and how it was typically treated. Not only did they refuse to look at it, they refused to even ask the Neurologist who was in the ER at the time to come and assess me.

For days, I suffered... badly. Until my wife finally called an ambulance to take me in.

Upon arriving at the hospital, this time by ambulance, the paramedics made sure to talk to the attending Doctor to ensure I was looked at properly. When they did not know what to do we handed our trusty CD and files over to help. Trust me when I say that most Nurses were watching as well.

After years of trial and error, weaning off pills, and experimenting with treatments. I have been able to successfully become functional and productive. I no longer drive nor work. I have issues with numerous things but other than pain, I am learning to work around my symptoms.

The medications (I am down to using just Ativan, Propranolol and Baclofen or Nabilone when needed. I also have a local Chiropractor who has been researching Dystonia and how it may relate to his field and he has been invaluable to me these last few years.

DMRF: How do you feel about dystonia? Why is it important to you that we invest in research?

Jason: We Dystonia sufferers refer to the life-cycle of Dystonia as a Journey. I was very fortunate back in 1999 to have had a young, fresh, open-minded Neurologist working with a very experienced Neurologist, thus receiving a very quick diagnosis of Dyskinesia. Other than the initial hospital visit I did not experience a lot of the indignities that a large percentage of Dystonia sufferers content with. I did not know my original Neurologist had left the area until after my symptoms became worse in 2011/2012, which was when I felt the frustration and disappointment that so many of us must go through.

It took 3 visits to ER, the final one by ambulance, before my symptoms were taken serious. Even armed with a previous diagnosis of Dyskinesia as well as a cd of information and videos we had

provided ourselves, my Wife and I still had to fend off allegations of drug abuse and alcoholism by uninformed medical practitioners. During all three visits the two local Neurologists were either not contacted or were unwilling to even assess me. It took an ER Doctor calling a larger hospital 500 km away to get some info on how to try to help stop my movements. It still angers me to think that people may still have to walk this path due to a lack of awareness.

I use the analogy of a playbook when referring to some Neurologists as one can gather the image of a professional attempting to place you into a box that fits the symptoms put forth. When it is discovered there is no suitable box, the Neurologist can no longer follow the playbook as would happen with a Parkinson's patient, etc. Because of this we see a wide array of medications, diagnosis, and treatments being offered. There is no playbook for Dystonia because there is as yet not enough knowledge of the disorder.

For each and every person who battles Dyskinesia, there is an important reason for You to invest in research. For the fearful man who has no idea why he cannot control his movements and has lost his job and now is being accused of being a drug addict by his Doctor, it is important; for the lonely woman who suffers from so much pain from her Dyskinesia that she can barely get out of bed and is referred to as lazy, it is important; and for the child who has completely torn her feet apart because she had an episode while in the bathroom and uncontrollably kicked the door and radiator while her parents desperately tried to open the door to help her; it is important. These may sound like farfetched examples but I was that Man, I have a friend who is that Woman, and a parent sent me a picture of her daughters' feet which were full of cuts and bruises but thankfully no breaks. I cried thinking about how painful it must have been for their daughter and for how frightening that must have been for her Parents. This is not okay. Please, we need to change this any way we possibly can.

DMRF: What do you want to say to others with dystonia?

Jason: To those with Dystonia, I say, keep fighting. Continue to be the warriors you have always been. Be true to yourself and do not give up hope. We need to help one another, be there for one another, be strong for one another. Together our "Twitchy Family" will increase awareness, improve research, raise the level of knowledge, create new options for treatments, shorten the timeline for diagnosis, and most importantly, blaze a path for those who will follow our footsteps. For those who are newly diagnosed, please know that you are not alone, there are many others who understand what you are going through. There will be tough days so make the best of the good days and do not be afraid to push yourself.

DMRF: What do you want to say to researchers of dystonia?

Jason: To Researchers, I plead with you to please leave no idea on the table. Think outside of the box. There is no playbook for Dystonia and there may never be. I have heard dozens of people discuss a wide array of triggers as well as possible ways to stop or cut back episodes and or movements. Many of us end up misdiagnosed.

We miss out on a lot of things in life, such as the freedom of driving, leaving us to rely on others. Our afflicted kids have difficulty attend school, or attending most birthday parties, and miss out on a lot of typical childhood memories most take for granted.

Dystonia/Dyskinesia is more than the twisting, jerking movements professionals use to define it. It is also pain, depression, anxiety, frustration, fear, financial hardship, confidence and independence crushing, relationship altering, and isolating. Not just for those diagnosed with the disorder, but also for their partners, children, parents, and friends. We live and fight this battle on a daily basis. And sadly, it is not always just the disorder we fight, it's the ignorance, lack of knowledge and awareness.

Again, I plead with you to not leave any proverbial stone unturned. There is a wealth of untapped experience, knowledge, ideas, suggestions, and determination just waiting to be explored. It lies within Dystonia/Dyskinesia patients. Who better to provide insight than those living and breathing the disorder. We are more than willing to help, we just need be asked and given the opportunity to help.