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Darryl Borsato and his wife, Chrissy. ***SUPPLIED***

Patients fight to advance ALS treatment through advocacy, research and trial

By Darryl Borsato

My name is Darryl Borsato and I have ALS. To those who understand the devastating effects of ALS, these are incredibly chilling words. ALS is essentially 100 per cent terminal. I am 52 years old and I have been dealing with this disease for almost six years now. I am one of only two per cent of ALS patients that are born with an SOD1 gene mutation that makes it hereditary for me. It was my destiny from birth to have this disease affect my life, just like it was for my birth mother, my uncle and my grandfather who all died from ALS.

My ALS started in my right foot. I had ankle surgery in 2014 and I never fully recovered the strength in my foot or ankle. I tried every kind of treatment available and nothing worked. Then one day, I went to the neurologist and discovered that there was denervation in both of my legs.

Gradually ALS has taken my legs, bit by bit and muscle by muscle. It has slowly strangled my motor neurons and left muscles to atrophy. Today I get around with the use of ankle foot orthotics, or as I like to call them, my bionic legs. I have to use a cane for balance since I have lost most of the muscles that stabilize my legs. I endure sleepless nights filled with cramping and muscle fasciculations. And lately, I have started to see the same things happening in my hands. That is how ALS works. It slowly and methodically takes from you until there is nothing left.

While ALS is a horrific disease, it also teaches you a lot about the many blessings in life. It gives you a new perspective on what is truly important. My wife Chrissy and I try to live life to the fullest every day because we know the value of time. We have learned through the struggles of ALS that we are blessed to have a life filled with experiences and that the biggest blessing of all is that we have each other.

ALS is incurable and fatal. The biggest difference for me is that I have real hope. My hope comes in the form of a new unapproved drug called Tofersen that uses mRNA technology to turn off the SOD1 gene mutation and has the potential to stop my progression through a monthly injection of the drug directly into my spinal fluid. While this drug may only benefit a small number of ALS patients today, it provides an immeasurable leap forward in the understanding of the disease and the opportunity for future generations of non-familial patients to benefit from its research. In fact, this treatment is only available because of years of research, advocacy and clinical trials. Without any one of these components, this would not be possible.

Most people with ALS live for two to three years on average. That is a terrible statistic but one that has been representative of this disease for many decades: people with ALS progressed so quickly that they almost seemed to disappear. Over the last few years this ideology has changed dramatically. Today, patients are stepping forward. They are demanding treatments. They are taking on massive drug companies to get access to revolutionary new treatments in hopes of making this disease treatable. They are putting voices and faces to this disease in hopes of raising awareness.

The new ALS landscape looks very different now. You have societies like ALS BC that are raising money and supporting patients every day. With 40 per cent of all fundraising going towards research and the remaining 60 per cent going to their stellar — and essential — equipment loan program, they are an essential part of the journey. You have patients who are fighting to participate in clinical trials and becoming human guinea pigs for new drugs and treatments with hopes that something will work. Then you have the advocates. With ever growing numbers and determination, there are groups across B.C., Canada and the world that are made up of patients, caregivers, friends and families of these fighters. You have groups like #IamALS that have paved the way for Canadian groups like ALS Action Canada. Without their unwavering resolve and their tireless efforts to get drugs into patients, treatments like Tofersen would not be possible.

When it comes to ALS, people truly are dying waiting, and with advocacy comes change. With change comes belief. With belief comes hope. For those of us facing a relentless terminal disease, hope is perhaps our most valuable commodity.

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