



**Edmonton Dystonia Support Group**

November 2024

Dear Friend,

You're receiving this letter as a valued donor to our annual campaign. With your help, the funds raised over the last 25 years have contributed significantly to furthering groundbreaking research and improving quality of life for those living with dystonia.

This year we write to you with the hope you are able to continue your financial contribution and also to thank you for being a part of our community. Often one of the most difficult parts of dystonia is obtaining the correct diagnosis. Raising awareness is an integral part of our mission so that we can shorten the timeline to diagnosis and therefore proper treatment. Growing a supportive community that *understands* dystonia is a vital part of this goal.

Many of you have a personal connection to either Connie's or Brenda's families. You have seen one way in which dystonia can look. That is why this year we are sharing the stories of two others living with dystonia. The benefit they have received from proper diagnosis has been life changing, yet in both cases, took more than a decade to come to.

Just by being aware, you have become a vital part of our supportive community.

Thank you for continuing to give generously.

Warm regards,

Connie Zalmanowitz  
Chair, DMRF Canada Board of Directors

Brenda Currey  
President Edmonton Dystonia Support Group

P.S. If you'd like to support our research cause by donating to DMRF Canada online, please visit:  
[www.dystoniacanada.org/edmontonsupport](http://www.dystoniacanada.org/edmontonsupport)

## Jenn Ashton, Xwesam (Roberts Creek) British Columbia

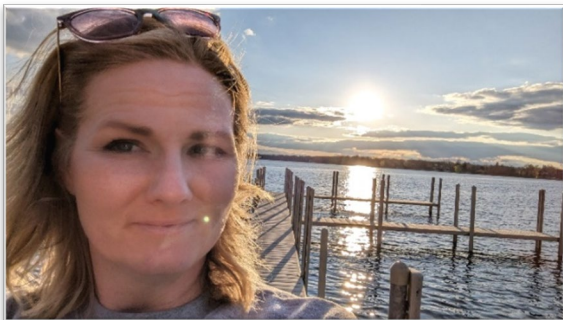
Jenn is a Squamish First Nations award-winning author and visual artist. Jenn's journey with dystonia began nearly 20 years ago, filled with uncertainty and misdiagnoses. Originally diagnosed with Multiple Sclerosis, her journey took a dramatic turn in February 2020 when she was finally correctly diagnosed with cervical dystonia after nearly two decades of being misdiagnosed and given incorrect treatment. With her new diagnosis, Jenn discovered a sense of relief mingled with the weight of her new reality.



As a lifelong learner, having attended the University of Oxford and the University of Edinburgh, Jenn immediately sprang into action to learn more about dystonia and connect with a community of individuals affected by the disorder. *“When I first received my diagnosis, I immediately sought out support groups and discovered Dystonia Medical Research Foundation (DMRF) Canada. Joining their local Facebook page connected me with individuals who shared similar experiences. It was incredibly relieving to engage with a community that understood what I had gone through. The dystonia community is welcoming, active, and proactive, providing invaluable support during challenging times.”*

Her journey reminds us all of the struggle to be heard in the medical community. Through her connection with DMRF Canada, Jenn found a supportive community that echoed her own experiences, transforming her pain into advocacy and hope for others. *“My hope for the future is that more people, including primary care physicians will recognize the symptoms of dystonia. A decade or more is a long time to await a proper diagnosis, and from what we already understand about dystonia, it doesn't have to be that way. I hope nobody has to wait as long as I did.”*

## Vanessa David, Steinbach Manitoba



Despite living thousands of kilometers apart, Vanessa's story mirrors Jenn's journey. As an elementary school vice principal, her health challenges spanned nearly two decades, filled with misdiagnoses and relentless symptoms. *“Reflecting on my health journey over the last 20 years, I've faced a multitude of misdiagnoses, including scoliosis, restless leg syndrome, and even arthritis. Throughout my twenties, I struggled with what I believed to be tension headaches, which I managed with Tylenol and Advil. However, in 2021, these headaches intensified, culminating in a visit to the emergency room where doctors were uncertain how to proceed. This prompted my primary physician to refer me to a movement disorder specialist.”*

Her eventual diagnosis of cervical dystonia, blepharospasm, and oromandibular dystonia in 2022 was both a relief and a source of anxiety about her future. With her husband and children by her side, Vanessa learned the power of self-advocacy, discovering DMRF Canada through her neurologist and became a fierce advocate for spreading awareness and understanding. Her diagnosis also became a catalyst for change, inspiring her to pursue her goals with renewed focus. Today, she is on the path to completing her master's in education, determined to make the most of every opportunity.

These journeys are not just tales of personal struggle; they are a testament to the strength found in community. Their stories highlight the urgent need for increased awareness, compassionate healthcare, and resources that empower individuals to navigate their own paths with dignity and hope.

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