



November 2023

Dear Friend,

Dystonia is often cited as a “rare” disorder. **Did you know that Dystonia is the 3rd most common movement disorder**, behind Parkinson’s and essential tremor?

Why does there continue to be so little awareness of dystonia, especially within the medical community?

When Connie’s son, Laurie, was diagnosed 26 years ago, she had knowledge of dystonia from working as a speech-language pathologist with people affected by spasmodic dysphonia (dystonia in the voice box) and neurological disorders. She was able to bring the information about dystonia to doctors. Due to lack of awareness, it is not uncommon for dystonia to go undiagnosed for years, resulting in negative physical and psychological effects. This is why the story of our fellow Canadian support group leader, Jennifer Lovell, resonated so much with us.

Jennifer is the current Winnipeg Dystonia Support Group leader. She is a mother of two and is completing a Masters focusing on population health and wellness. There was a time in Jennifer’s life when she would not have thought this was possible for her. From the time she was a young child, Jennifer remembers a variety of symptoms: cramping legs, headaches, neck pain and fatigue. Her jaw joints and spinal cord were worn down by the pressure of tightened muscles, requiring surgery. Her eyes spasmed shut. Moving from one specialist and unsuccessful treatment to another, **Jennifer was finally diagnosed with dystonia at the age of 48**. By this point it had affected her physical and mental health to the point that she was socially isolated and unable to work. She asked her neurologist **“Where did I go wrong? Why did it take me so long to get diagnosed?”** The neurologist had this simple answer for her: **“It’s not you. Many doctors just don’t know about dystonia.”**

Jennifer had dopa-responsive dystonia, so after a short trial of Levodopa, her symptoms eased remarkably. Botox alleviated some of the struggle with her eyes and jaw. A lifetime of strange symptoms could suddenly be explained and treated effectively by her diagnosis of dystonia.

Education within the medical community and research for effective treatments are two of the major goals of the Dystonia Medical Research Foundation Canada’s fundraising efforts. Donations are an essential part of ensuring those with dystonia do not have to wait a lifetime to find answers.

We are very grateful to you, our local donors who have been supporting us for many years. Thank you for giving generously.

Warm regards,

Connie Zalmanowitz
Chair, DMRF Canada Board of Directors

Brenda Currey
President Edmonton Dystonia Support Group

DMRF Canada 2023 Highlights and Accomplishments

DMRF Canada is comprised of a wonderful community of supporters, volunteers, and donors dedicated to empowering affected individuals and their families to thrive and live their best lives with dystonia. With a full time staff of just two and thanks to your incredible support, the following achievements were made possible this year:

Innovative Research, Investments, and Breakthroughs

- Awarded the first year of our ***Two-Year Clinical and Research Fellowship for Movement Disorders with a Specialty in Dystonia***, valued at **\$110,000**. The selected Fellow, **Dr. Talyta Grippe, Krembil Research Institute, University Health Network, Toronto, ON** research will focus on developing the design of a novel non-invasive neuromodulation treatment protocol tailored to different types of dystonia, of which some may have the potential to be used as a diagnostic tool.
- Launched a multi-centered research project led by **Dr. Laura Cif, LRENC Montpellier, France** partnered with **Dr. Alexandre Legros, Western University** and **Dr. Gabriella Horvath, University of British Columbia** valued at **\$100,000**. This project will aim to validate a clinical and deep learning-based tool for recognition assessment and monitoring of complex movement disorders in dystonia patients.
- Continued to partner with the DMRF in the United States to fund the best research world-wide. Since 1976, this collaboration has funded over 400 grants awarding over \$22 million in research funding.
 - This includes a grant to **Dr. Jean-Francois Nankoo, University Health Network, Toronto, ON**. His project, ***“Theta Burst Transcranial Focused Ultrasound as a Novel Treatment for Cervical Dystonia”*** aims to explore the effects of a novel non-invasive brain stimulation technique that has the potential to be a safer, less costly, and more accessible alternative to deep brain stimulation.

Tailored Support for a Connected Community

- Expanded our online resource bank for health professionals to include resources and best practices for physiotherapists to incorporate in their treatment of people with dystonia. A top request from our community, the online resource bank has been accessed **over 300 times** this year.
- Implemented **7 recommendations** from our **Support Advisory Group Committee**, comprised of members with lived experience of the condition from diverse geographic locations in Canada, into our support programming ensuring that the lived perspective of people with dystonia is fully integrated into our model of care.
- With continued emphasis on removing barriers and improving accessibility we offered several new resources including self-advocacy tools and resources, and enhanced patient care packages.
- To bolster community support and engagement, we offered one-on-one, personalized phone and online support as well as a mix of **virtual and in-person support meetings**, providing a **more customized approach for peer support**. Hundreds in the dystonia community benefitted from meetings on swimming with dystonia, quarterly national meetings, local in-person meetings, and dystonia-specific support meetings offered through our international collaboration with the Benign Essential Blepharospasm Research Foundation and Dysphonia International.

Amplifying our Collective Voice to Raise Awareness

- Published **two newsletters, five e-newsletters**, and supported the community through our **digital and print resources** that have been **accessed close to 165,000 times**.
- In September, we celebrated Dystonia Awareness Month, and connected with over **30,000 people online** – our most successful campaign to date. We lit up **11 major landmarks** to show solidarity with the dystonia community.
- In June, we hosted our nation-wide, hybrid in-person and virtual event: *Freedom to Move: Run, Walk and Wheel for Dystonia*. Across **9 provinces**, we raised over **\$50,000** for research and patient support programs.

P.S. If you'd like to support our research cause by donating to DMRF Canada online, please visit:

www.dystoniacanada.org/edmontonsupport