

FOR IMMEDIATE RELEASE

Eighteen Month wait for Diagnosis of Rare Neurological Disorder, Now Raising Awareness Nationwide

Toronto, Ontario, (May 13th, 2026) - At just 27 years old, Laurence Guénette-Rochon knew something wasn't right. What began as a vague sensation in her neck gradually worsened—but for nearly 18 months, she was left without answers.

After months of escalating symptoms, physiotherapy, and multiple medical consultations, Laurence was diagnosed with cervical dystonia, a neurological movement disorder that causes painful, involuntary muscle contractions.

Dystonia affects an estimated 50,000 Canadians, yet awareness remains low and delays in diagnosis are common. Based on a recent community survey¹:

- 59% of respondents wait more than one year for a diagnosis
- 31% wait five years or more
- Nearly 1 in 5 wait a decade or longer

“Early on, I couldn't quite explain what I was feeling, I just knew something wasn't right,” says Guénette-Rochon. “By the time I received my diagnosis, we had already shifted into finding solutions.”

Determined to find support and community, Laurence travelled from Quebec City to Toronto in 2025 to attend an event hosted by the Dystonia Medical Research Foundation (DMRF) Canada. The experience marked a turning point.

“What I was really looking for was hope and I found it,” she says. “Meeting others who understood what I was going through made all the difference.”

Now, Laurence is sharing her story as the 2026 Ambassador for *Freedom to Move: Run, Walk and Wheel for Dystonia*, a national awareness and fundraising campaign taking place throughout June. Participants across Canada can join virtually or attend the in-person event on June 14 at Downsview Park in Toronto.

Following last year's success, which raised more than \$50,000, the annual event has now generated over \$1 million in support of dystonia research and patient programs.

“We are excited to bring our community together once again, both in-person and virtually,” said Archana Castelino, National Director of DMRF Canada. “This event continues to be a powerful reminder of what we can achieve together—raising awareness, funding research, and strengthening support systems for people living with dystonia across the country.”

Dystonia is the third most common movement disorder, after Essential Tremor and Parkinson's disease, yet it remains widely misunderstood.

As this year's Ambassador, Laurence hopes her story will encourage others to seek answers sooner and feel less alone.

“If sharing my story helps even one person get diagnosed sooner or feel less isolated, it's worth it,” Guénette-Rochon says.

DMRF Canada is the only national organization solely dedicated to supporting Canadians living with dystonia, funding research, and providing education and community support.

Freedom to Move runs from June 1–30, with a flagship in-person event on June 14 in Toronto.

To find out more about the Dystonia Medical Research Foundation Canada, and to register for Freedom to Move, visit: www.freedomtomove.org

Contact:

Archana Castelino
National Director, DMRF Canada
archanacastelino@dystoniacanada.org

¹: DMRF Canada (2025). *The 2025 Dystonia Canada Survey Key Findings*.