DYSTONIA
MEDICAL
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FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

Dystonia Canada Report

A Newsletter from
Dystonia Medical Research
Foundation Canada

Photo Credit: Lindsey Vogt

2025–2027
Clinical and Research Fellowship Awardee
Supported by Merz Therapeutics
Dr. Lindsey Vogt (L)
Pictured with Mentor Dr. Carolina Gorodetsky (R), SickKids

Fall/ Winter 2025

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PLEASE RENEW YOUR MEMBERSHIP FOR 2025

Support the dystonia community with a donation to DMRF Canada.
visit: www.dystoniacanada.org/donate
Thank you for your support.

Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation (DMRF) Canada is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRF Canada funds medical research toward a cure, promotes awareness and education, and supports the well-being of affected individuals and families. We work in partnership with the DMRF in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and with other like-minded research organizations to fund excellent dystonia research in Canada.

This Dystonia Canada Report is supported by
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Foundation Update

Dear members,

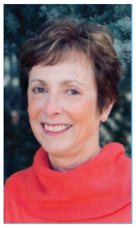
Behind the scenes, DMRF Canada has been hard at work, getting events and resources ready to launch for Dystonia Awareness Month in September. This year, to make it most meaningful to our community, we had the benefit of your input from our recent National Dystonia Survey. See page 3 for some preliminary insights into what you told us.

One thing that resonated with us, is that our community shares the focus we have on advancing research. Finding better treatments and ultimately a cure, is central to our mission. Fortunately for us, our community is also a key component in getting closer to this goal: you help us build our army of volunteers.

In this issue of the Dystonia Canada Report, you will find many resources and events that have been facilitated by volunteers. They help us raise funds, organize events, build partnerships and spread awareness. Volunteerism doesn't have to look formal or require a great time commitment. It may be raising funds by volunteering at a casino or bingo, or it may be requesting donations from your network by sharing your personal story. Our survey revealed that several people did not even know DMRF Canada existed before they filled out the survey. Perhaps you can make a difference by simply telling people about us to spread the word.

At DMRF Canada, we're committed to fulfilling all aspects of our mission by providing the resources for our volunteers to make them happen. With your support, we can make strides towards a cure, while making our reach go even further. We extend deep gratitude towards our dedicated community and include a humble ask for even more to reach out to generously offer their time. As evidenced by the examples in this fall issue, together, we can make a difference.

With gratitude,



Connie Zalmanowitz,
Chair, DMRF Canada,
Board of Directors
Connie

Archana Castelino,
National Director,
DMRF Canada
Archana Castelino

In Tribute

DMRF Canada extends our condolences and gratefully acknowledges the generous gifts received in memory of the following:

Jacqueline Bell *(Greater Toronto Area Support Group Contact)*

Dalila Murphy **Barbara Newton** **Ronald Stafford**

2025 Dystonia Canada Survey Results

We want to thank all those who responded to our National Survey. We had almost 400 respondents who took the time to answer 80+ questions about living with dystonia, each one giving us more insight into what our members would like to see. While a more detailed report will be completed, we wanted to share key insights from the results and how they connect with our strategies and efforts highlighted in this Dystonia Canada Report.

Research

Over 60% of respondents indicated that research was their number one priority when it came to DMRF Canada's mission.

We hear this! Advancing research is at the heart of DMRF Canada's activities. Significant efforts go into funding our Clinical and Research Fellowship Appointment (Pg 7), as well as the 2025 DMRF Grant and Fellowship Recipients (pg. 22). You can also continue to contribute by volunteering for research studies by searching our listings of available studies (Be Part of the Progress, Pg. 21).

Medical Community Education

Over 50% said they felt their symptoms were not taken seriously due to doctor's lack of knowledge about dystonia, or dismissed as stress, attention-seeking, or psychosomatic.

We take educating the medical community about dystonia seriously, so these circumstances happen less. See our sponsorship of the 2025 Pan American Movement Disorders Course (Page 21) and our September awareness partnership with Patient Voice (Page 15) as an example of how we're facilitating training and education.

Patient Advocacy

48% of respondents said they do not feel they have adequate strategies to communicate effectively with their doctor.

Finding the right healthcare providers can be difficult. Ensuring patients have the tools to collaborate with healthcare providers is an essential part of the support we provide. If you're looking for new ideas for navigating treatment and working with your healthcare providers, see Setting Treatment Goals with Your Health Care Provider (Page 4). New patient advocacy materials are available to support living with dystonia (Nonmotor Symptoms of Dystonia, Page 14).

Visit www.dystoniacanada.org/Survey2025 to explore key insights from this survey.

This survey was made possible through the support of the medical student volunteers from the Community-Based Service-Learning (CBSL) program, an initiative of the Health in Community (HC) team at the UofT Temerty Faculty of Medicine, and with thanks to our prize partner, AbbVie.

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Setting Treatment Goals with your Health Care Provider

The results of our National Dystonia Survey brought forward many goals we can help patients work towards. One of these is ensuring people with dystonia have a treatment plan. This includes setting goals and providing actionable steps towards achieving them. In our survey, 42% felt they received a dystonia treatment plan from their healthcare provider. This leaves 24% in the "sometimes" category and 34% with an absolute "no". While treatments for dystonia are not perfect, this doesn't mean that patients should be left without any plan for managing their symptoms.

To understand how patients can play an active role in striving towards better management of their dystonia, we spoke with Dr. Davide Martino, neurologist and director of the Movement Disorders Program at the University of Calgary. Throughout his extensive experience treating patients with dystonia, Dr. Martino has compiled some helpful advice for patients to ensure they have a path forward.

See a Movement Disorders Specialist

If there is one thing Dr. Martino encourages patients to advocate for, it is seeing a movement disorder specialist. He acknowledges that access to specialists can be a problem but highlights that these are the experts best able to manage dystonia. "I appreciate that there are regions where they need to drive and travel a lot or where there are waitlists but it's worth trying their best to get into a movement disorders clinic."

Dr. Martino emphasizes that in an ideal situation, your neurologist specializing in movement disorders is best suited to be your care coordinator. In addition to treating motor symptoms, he tries to help his patients navigate where they can obtain multifaceted support that will address the whole person.

Get to Know How Dystonia Affects your Social and Emotional Health

Along the same lines of treating the whole person, Dr. Martino notes that there are two major aspects of dystonia. One includes the **motor impact**. These are the uncomfortable movements that limit physical activities of daily life such as reading, driving, walking and sitting. The effort involved in executing these basic tasks can also lead to fatigue, providing further limitations. The second aspect is the **social impact**. Dystonia is visible. It can lead to avoidance of social activity as people may feel stigmatized.


Dr. Davide Martino

Increased effort in socializing means a person's overall social efficiency and fitness is reduced. This aspect also considers that movement disturbances create higher incidences of sleep disruption, pain and anxiety furthering the social-emotional impact.

"We cannot detach the motor features from the emotional aspect related to stigma and social changes," he emphasizes. Dr. Martino notes that healthcare providers should be asking about how dystonia is affecting patients' social connections and mental health and it's not a simple matter of fixing the motor component and then the social aspects will be taken care of. He notices that for many people having lived with dystonia for years, their whole perception of social life has changed and needs to be addressed. Dr. Martino encourages considering lifestyle elements that can improve quality of life: light exercise, social interaction, and consistency in routines. While these may not necessarily be "prescribed," they can be helpful in managing the physical, social and emotional impact dystonia all together.

Patients should be encouraged to recognize and address the social impacts in addition to the motor features of dystonia as they are valid and far reaching when it comes to quality of life. "Be open to discussing the nonmotor problems with your neurologist or family physician," he advises.

Become Knowledgeable about Treatment Options

A treatment plan doesn't always mean seeking only one type of treatment or one opinion. As an example, Dr. Martino points out that botulinum toxin injections are one of the most effective treatments for focal dystonia, results can vary. "If it doesn't help, I think it makes sense to ask for a second opinion. Usually movement disorders clinics have more than one injector and that can make a difference."

Article continues on page 5

Gathering knowledge about other possible treatments can also be part of your plan with your healthcare provider. Deep Brain Stimulation (DBS) can sound scary and unknown for patients. While not everyone is a candidate, you can help decide if it is a good choice for yourself by gathering information. "It's not experimental at all. It's routine and patients need education about it to make an informed decision," encourages Dr. Martino.

Dr. Martino cautions people to think carefully about treatments that come with high price tags. "I try to defend my patients from taking up offers of high-cost, evidence-less treatments," he says. "Information travels so fast and without filters. People with dystonia, more than other populations and groups of patients, are exposed to all sorts of potential treatments. [If we don't look for good evidence that a treatment works] pretty much anything can be slotted in as a form of treatment, and we have to be cognizant of that." He acknowledges that placebo effects can be high which means people can be at risk for spending excessive amount of money for treatments whose effects are largely anecdotal.

The bottom line is that there are treatments that have been shown to work. Sometimes these require time and different expertise to realize the full effect, but patients should not feel like they've run out of options for dystonia management.

Engage in Self-Reflection to Collaborate

There are two people involved in developing a treatment plan: a patient and their healthcare provider. The goal of treatment should be some improvement in any area that is contributing to quality of life. Dr. Martino suggests that before meeting with their doctors, patients ask themselves questions to reflect on whether they find improvements in things like pain, posture or general quality of life. He acknowledges the constraints of the healthcare system. "[Patients] should think about it before: I am happy because...I am not happy because... They have to help the efficiency of the system, because there's limited capacity and there's too many patients. Come prepared with the message because there isn't a lot of time for long interviews." People know themselves best so reflecting on aspects of their life where they have found success or would like to see improvements can help doctors offer the best information tailored to their patients.

For those in Alberta, you can hear more from Dr. Martino at the Alberta Dystonia Symposium, taking place in Red Deer on September 20, 2025.


Soreyea Apolzer

A Patient's Perspective

It's difficult as a patient to feel like you are being led through a healthcare system that isn't meeting your needs. We spoke with **Thompson/Okanagan support group leader Soreyea Apolzer**, who is living with cervical dystonia. She shared her experience in navigating healthcare to ensure she was an active participant in her treatment goals.

"With the first doctors I went to, I was either the first or the worst case they had seen. My initial GP (General Practitioner) didn't take the situation seriously. I found a new GP who is fantastic. He did his research and found ways to assist me. He helped connect me with my movement disorders specialist, who diagnosed me. The specialist has guided me through many life changes, providing me with literature to read and techniques to practice to take control of my symptoms to a certain degree. My specialist has helped change medications, ensuring we have follow-ups with what is working and not working. It's made all the difference to find doctors who are so hands-on and willing to work with me."

Steps to Creating a Treatment Plan with your Healthcare Provider:

- Advocate for seeing a movement disorders specialist even if it means traveling or being on a waitlist. They have the knowledge that is best suited to treat dystonia.
- Address the social and emotional impacts of dystonia. This can include discussing lifestyle changes like light exercise and keeping a regular routine.
- Educate yourself on different treatments your healthcare provider is offering. Do not give up because something hasn't worked. Be cautious of treatments that come with a high price tag.
- Engage in self-reflection to clearly communicate with your provider about what is currently working and what is not. Have goals for your own treatment plan and come prepared with a clear message for your health care provider.

For more information on talking to your doctor about treating nonmotor symptoms of dystonia, see our Community Education and Impact section to find a downloadable new resource entitled *Burden of Dystonia is More than a Movement Disorder.*

Moving Together, Making a Difference

Thank you to everyone who participated in this year's *Freedom to Move: Run, Walk and Wheel for Dystonia*! Whether you joined us in person at our Toronto event on June 8th or completed your run, walk, or wheel virtually between June 1st and 30th, your support made an incredible impact.

Together, **130 participants across 37 cities in 7 provinces** raised over **$50,000** for dystonia research and support programs. Every step taken, every dollar raised, and every story shared brings us closer to greater awareness and improved care for people living with dystonia.

Funds raised through this event directly support initiatives like the **Clinical and Research Fellowship at SickKids Hospital**. To learn more about this program and meet the 2025 Fellowship recipient, **Dr. Lindsey Vogt**, please see page 7.

Top Fundraisers

A special congratulations to our top three individual fundraisers, whose efforts helped raise over **$15,000 collectively**:

1. **Mary Guy**
2. **Oliver Jaakkola**
3. **Geoffrey Allan**

Your dedication and outreach made a remarkable difference—thank you!

Special Recognition: Lives in Motion Video Contest

A heartfelt thank you and congratulations to **Jirome De Castro**, winner of our *Freedom to Move: Lives in Motion* video contest! Jirome's inspiring submission captured the spirit of resilience, hope, and community that defines this event. Thank you for sharing your story and helping raise awareness in such a powerful way.

Ambassador Appreciation

Special thanks to our **Freedom to Move Family Ambassadors, Ken and Ruth Jenkins**, for their outstanding efforts in rallying more awareness for dystonia. Through their passion, personal advocacy, and community engagement, Ken and Ruth have helped shine a light on the lived experiences of those affected by dystonia. We are deeply grateful for their ongoing commitment and heartfelt leadership.

Thank You to Our Generous Sponsors and Partners

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Advancing Canadian Dystonia Care and Research: 2025 Clinical and Research Fellowship Appointment

We often hear from the dystonia community that while other types of support are helpful, working towards a cure should be the primary goal. At DMRF Canada we feel the same way! This is why funding research is a large part of our mandate. Over the summer we announced an exciting development in this area, with the appointment of Dr. Lindsey Vogt as the recipient of the 2025 Clinical and Research Fellowship. This is the first time since the program's inception in 2018, that the fellowship has been awarded to a specialist with expertise in pediatric neurology, expanding the impact of the program to dystonia care across all ages.

Dr. Vogt comes from a strong background in movement disorders where she has already made notable contributions to the field. The fellowship will allow her to further her expertise and research through the Hospital for Sick Children (SickKids) and Toronto Western Hospital, two of Canada's most esteemed institutions for movement disorder care and research. Through her fellowship, Dr. Vogt will participate in a wide range of specialized clinics including an integrated training experience through SickKids' Pediatric-to-Adult Movement Disorders Transition Clinic which ensures adolescents and young adults get the care they need when transitioning from pediatric to adult movement disorders specialists. This comprehensive, interdisciplinary training ensures that Dr. Vogt will develop advanced expertise in both interventional therapies, such as Deep Brain Stimulaton (DBS) and botulinum toxin injections, as well as the nuances of delivering care across diverse patient populations and life stages.

"I'm incredibly grateful to the DMRF Canada and their partners for supporting my training in pediatric movement disorders," says Dr. Vogt. "This fellowship gives me the chance to learn from world-class mentors and gain the skills I need to help improve the lives of children living with dystonia."

Your Advocacy and Volunteer Hours Can Keep the Momentum Going

If you're curious as to how fellowships are funded, they are the direct result of awareness, advocacy and volunteer opportunities through DMRF Canada. One of our main sponsorships comes from the generous support of Merz Therapeutics through partnerships built by our dystonia community and DMRF Canada.

2025-2027 Clinical and Research Fellow, Dr. Lindsey Vogt (left) with her mentor, Dr. Carolina Gorodetsky

"We are proud to partner with DMRF Canada in supporting this fellowship," said Mike Stone, Country Manager (Canada), Merz Therapeutics. "Supporting this program reflects our ongoing commitment to advancing medical education and enhancing access to expert care for individuals living with dystonia. By investing in the development of future healthcare professionals and leaders, we aim to help ensure patients receive the highest standard of care throughout their treatment journey."

The Clinical and Research Fellowship is also supported by Ontario Charitable *Gaming Association's fundraising program Charitable Gaming Community Good* with Bingo World and Gaming Richmond Hill, and the City of Richmond Hill. This is an excellent example of our community's volunteer hours contributing directly to funding new medical expertise and research. We could not do it without you.

To read more about Dr. Vogt and the fellowship program, visit our news section: www.dystoniacanada.org/news

Get Involved in Funding the Next Breakthrough in Dystonia Research

Consider volunteering your time or asking those in your network to volunteer at an upcoming Bingo (Ontario) or Casino (Alberta).

For more information and to sign up as a volunteer, visit www.dystoniacanada.org/volunteer or contact us at 1-800-361-8061

DMRF's New Chief Science Officer — Also Serving as Advisor to DMRF Canada

Thirty years ago, when the subspecialty of pediatric movement disorders neurology was still in its infancy, Jonathan W. Mink, MD, PhD was preparing for a career in adult neurology at Washington University in St. Louis, when he had the opportunity to spend a day with Philip R. Dodge, MD, one of the founders of American child neurology.

"(Dr. Dodge) was in his early seventies at the time, and I saw him get down on the floor and sing to children and examine them while playing with them," Dr. Mink recalled. "I thought, boy, I could make a living playing with children. And then I started to explore whether my interest in movement disorders could fit with my interest in pediatrics, and most people said, 'Well, probably not.' But I saw an opportunity there, and the rest is history."

After a distinguished career as a pediatric neurologist and researcher, most recently at the University of Rochester in New York, where he retired in 2023, last month Jonathan Mink officially stepped into the role of DMRF Chief Science Officer. He will assume the dystonia research grant review responsibilities from Chief Scientific Advisor Jan Teller, MA, PhD, as Dr. Teller becomes more focused on scientific meeting planning for the Foundation.

A Vision for Dystonia Research

In his new role as the Chief Science Officer of the DMRF, Dr. Mink stated that he is looking to capitalize on the organization's strengths.

"I'm looking to build on the success the DMRF has had, and particularly the success achieved with Jan Teller in the role as their Chief Scientific Advisor, at

Dr. Jonathan W. Mink: A Legacy in Pediatric Neurology

Jonathan W. Mink, MD, PhD, retired in 2023 from the University of Rochester after a distinguished career in pediatric neurology. He held multiple prominent positions, including the Frederick A. Horner Distinguished Professor in Pediatric Neurology, Professor of Neurology, Neuroscience, and Pediatrics, and Chief of Child Neurology. Dr. Mink's work in pediatric movement disorders, particularly dystonia and Tourette Syndrome, has left a lasting impact on clinical practice and research.

Early Life and Education

Dr. Mink, originally from St. Paul, MN, earned a BA in Biology-Psychology and an MA in Psychology from Wesleyan University. He completed his MD and PhD in Neuroscience at Washington University in St. Louis, followed by residency in Pediatrics and Pediatric Neurology at St. Louis Children's Hospital.

Academic and Clinical Career

In 1994, Dr. Mink joined Washington University's faculty, specializing in movement disorders. He moved to the University of Rochester in 2001, where he founded the Child Neurology Residency in 2003 and served as Program Director for 10 years. His clinical and research expertise in pediatric movement disorders, including Batten Disease and basal ganglia physiology, earned him international recognition.

Recognition and Achievements

Dr. Mink has authored over 150 peer-reviewed publications and co-authored Movement Disorders in Childhood (3rd edition). He served as president of the Child Neurology Society (CNS) from 2017 to 2019 and received the CNS Hower Award in 2021. He also received the first Dr. Oliver Sacks Award from the Tourette Association of America in 2015.

Service and Leadership

Dr. Mink has served on advisory committees for Tourette Association of America, the Batten Disease Support and Research Association, NINDS Advisory Council, the FDA Pediatric Advisory Committee, and the DMRF Medical & Scientific Advisory Council (MSAC). He was also an Associate Editor for Neurology and Continuum and contributed to the Taskforce on Pediatric Motor Disorders and the Tourette Association of America Scientific Advisory Board. He currently serves on the International Child Neurology Association Executive Board and on the FDA Genetic Metabolic Diseases Advisory Committee.

Legacy

Dr. Mink's career has advanced the understanding of pediatric movement disorders and shaped the future of neurology through his leadership and mentorship. His impact continues to resonate across the scientific community.

the same time coming in as a pediatric neurologist, someone who really has lived in the world of childhood-onset dystonia," he said. "I hope to be able to push the envelope of understanding about dystonia in children and treatment options in the world of medicine and neurology. Most of our treatments are developed for adults first and then we try to extend them to children, but there's a good reason to think that dystonia in children is different in some important ways from dystonia in adults."

Dr. Mink offered the example of adult onset dystonias that are focal dystonias which affect one part of the body and respond well to botulinum neurotoxin.

"Although children can have benefit from botulinum neuro-toxin, they usually involve much more of their body, and so it is not as great an option," said Dr. Mink. "But because of the genetics there may be targeted therapies that are critically important for treating children that may not be as relevant to adults. So, I'm hoping that there will be an opportunity to kind of push research forward targeting earlier treatment and developing better knowledge about the best way to treat dystonia in children."

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What Fuels Dystonia Research:
A Conversation with Jan Teller, MA, PhD

After almost twenty years as the DMRF Chief Scientific Advisor, and Advisor to DMRF Canada, Jan Teller, MA, PhD, will be transitioning away from overseeing the Foundation's grants program to focusing on scientific meeting planning and monitoring dystonia-related neurological research for the DMRF.

Over the years, Dr. Teller has brought together scientists and clinicians from a wide variety of research areas to advance our understanding of dystonia.

Dr. Teller noted that the DMRF has a long and exemplary history of leading the way in dystonia research and, among many achievements, was instrumental in the discovery of the torsinA/DYT1 gene and its pathogenic mutation as a cause for an inherited form of dystonia.

"In 1997, the torsinA gene mutation was discovered, which opened up not only opportunities to treat the DYT1 dystonia but also encouraged people to pursue other genetic studies in different inherited forms of dystonia," he said. "And now we have, by some accounts, several hundred dystonia-linked genes."

Bringing Together Researchers from Various Disciplines

Dr. Teller explained that genetic studies allowed some researchers to focus on the specific molecular and cellular mechanisms of dystonia resulting in breakthrough discoveries. At the same time, there has been emerging research on dys-tonia as a brain network disorder, which provides scientific basis for various forms of neuromodulation treatments, such as deep brain stimulation (DBS) or non-invasive methods that are gaining popularity.

"Over the years we've been organizing different workshops small meetings of scientists—and those meetings have always been designed to bring together people with new ideas, to critically discuss them—and not really to present and confirm what we already know," he said. "Even if the workshops were very small, when we had no more than ten or twelve people, we always wanted to invite a few who represented a different field, different way of thinking about the brain."

"In the early days it was a big challenge," Dr. Teller admitted. "There was—perhaps still is, to some extent—a long delay in accepting new research results and incorporating them into clinical practice. Now, clinicians are quite knowledgeable about the genetic and molecular aspects of dystonia, and, very often, they drive the discovery process by actively seeking genetic underpinnings of dystonia that runs in families. And that's why we discover new dystonia-related genes at such astonishing speed."

Dr. Teller said that bringing together researchers from different scientific disciplines has led to productive discussions and provided new, often surprising perspectives on dystonia.

"I love this type of interaction, because at small meetings you have an optimal number of people, no more than 20, so you can talk—and listen—to everyone," he said. "You can interact very easily during breaks, and talk about things which are not yet ready to be released to the public. You can tackle technical topics which typically are not suitable for a bigger international symposium."

During his time with the DMRF, Dr. Teller has initiated and helped organize close to 40 workshops and meetings, as well as several larger international symposiums to exchange new ideas and foster collaborations. One of the biggest ever symposiums dedicated exclusively to dystonia was held in Barcelona, Spain in 2011, and the most recent one was held in Dublin, Ireland in 2023. Dr. Teller is currently working with Antonio Pisani, MD, PhD, and Buz Jinnah, MD, PhD, to plan another international dystonia symposium in 2027.

"It's very important to build relationships," Dr. Teller explained. "As a foundation, we don't directly run studies, but we can certainly provide ideas and influence and support people, be it through grants or fellowships. And we always go beyond that. As a patients focused organization we try to see the bigger picture. We constantly monitor what's going on at the forefront of neuroscience, neurology, other movement disorders and science and engineering in general. Every so often we say, wow! There is something going on in cerebral palsy or Parkinson's disease, or Alzheimer's that could help us understand dystonia or design new treatments. And then we read about new technology that may revolutionize DBS. How can we get these people interested in dystonia? How can we attract them to the field? Another workshop idea is quickly born."

The Future of Dystonia Research

As Dr. Teller plans workshops for 2025 and beyond, he said that one area of research that requires more immediate exploration is the biological phenomenon of penetrance. In some genetic disorders, a genetic mutation always results in the disorder, but that is not the case with several genetic forms of dystonia.

"In DYT1 dystonia, the penetrance is only 30-40 percent—which means that out of ten people who have the disease-causing mutation, only three or four will get it," he said. "So, this is a phenomenal paradox that holds potential clues for treatment. We need to figure out if there are some unknown genetic factors or something environmental, which can either trigger or suppress the pathogenic mutation. Knowing this would help us treat or even prevent dystonia."

Other dystonia-related topics, such as non-invasive neuro-modulation, will be explored in the future and aided by new approaches and technologies. Dr. Teller added that while using Artificial Intelligence (AI) for data analysis in dystonia research is just beginning, once scientists figure out a way to use it in a way that makes data interpretation manageable, the progress will be "exponential."

The Power of Relationship Building

By building long-lasting relationships with scientists inside and outside of dystonia research field, Jan Teller and the DMRF have been able to advance dystonia research at an accelerated rate by recruiting both experienced and young investigators and funding their breakthrough research projects.

"Trust building is key," explained Dr. Teller. "We provide support that can range from fellowships or grants or invitations to workshops. We don't just invite the most senior, accomplished researchers. We always strive to invite young, emerging investigators, counting on their enthusiasm, energy and new ideas."

"The researchers who looked kind of interesting to us 20 years ago are now leaders in the field," he said. "They are a big asset to dystonia research and the DMRF and now we rely on them, as they become senior and influential people in the field of dystonia research."

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FOCUS ON Early Onset Childhood Dystonia

Like adult-onset forms of this condition, dystonia in childhood is a movement disorder that causes involuntary muscle contractions, which result in twisting, repetitive movements and abnormal postures. These movements and postures may be chronic or occur in episodes.

The chance that dystonia will affect multiple body parts is generally linked to the age of onset. The younger a patient is at the age of onset, the greater the chance that symptoms will spread. In contrast, the older a person is when the disorder begins, the more likely it is to remain moderate.

DMRF Chief Science Officer Jonathan W. Mink, MD, PhD, who spent his career as a pediatric movement disorder neurologist, noted that in many cases the children who were brought to him as patients had been developing completely fine before displaying symptoms of dystonia.

"(Parents would ask) What is this? Why is this happening? And then, of course, what can we do about it?" he said.

What are the Symptoms?

Signs of dystonia in children can include:

- A body part is flexed or twisted into an abnormal or fixed position.
- Repetitive and patterned body movements, which may resemble tremor.
- Movement symptoms worsen with voluntary action. (This can cause the incorrect perception that the child is "faking" the symptoms.)
- Symptoms may be present with some activity but absent with others. For example, symptoms may be present while walking forward but not running or swimming or walking backwards.
- Symptoms diminish or disappear during sleep.
- Attempting a movement task on one side of the body may activate dystonia symptoms on the opposite side.

Dystonic movements and postures may be temporarily relieved by a gentle touch or specific action called a sensory trick.

How is Dystonia in Children Diagnosed?

Diagnosing dystonia in children is complex and requires careful evaluation by experts in pediatric movement disorders. Dystonia can be the only movement symptom a child has or occur along with other movement symptoms—for example, myoclonus (jerking movements).

Dystonia in children is diagnosed primarily by observation of physical symptoms. The diagnostic work up may include blood tests, genetic testing, family history, testing for metabolic disorders (lumbar puncture), magnetic resonance imaging (MRI), and electroencephalography (EEG).

An expert in pediatric movement disorders can ensure dystonia is not mistaken for spasticity, weakness, bradykinesias, or other movement symptoms such as tics.

What Causes Dystonia in Children?

There are a number of inherited dystonias that affect children, many of which are attributed to a single gene variant. These genes include DYT1/TOR1A, DYT6/THAP1, DYT11/SGCE, and others. Several gene panel tests are available to screen for dystonia-causing genes.

Numerous underlying causes of dystonia in children are treatable, so careful investigation into the possible causes of dystonia is important. Possible causes include hypoxic brain injury, infections, autoimmune disorders, metabolic disorders, stroke, toxins, and certain medications.

Dyskinetic cerebral palsy is among the most common causes of dystonia in children. Dyskinetic cerebral palsy

Oral Medications Prescribed for Dystonia

All of these medications are commonly used for treating dystonic symptoms in children but they are used off-label.

- **Baclofen**
  Baclofen belongs to a class of medications called skeletal muscle relaxants. Baclofen is an antispasmodic agent that acts on spinal cord nerves and decreases the number and severity of muscle spasms in patients with certain conditions affecting the spinal cord. Baclofen is used in adults and children at least 12 years old to treat certain types of spasticity (muscle stiffness and tightness) and muscle pain in people with multiple sclerosis or a spinal cord injury or other spinal cord diseases.

- **Trihexyphenidyl**
  Trihexyphenidyl is used to treat symptoms of Parkinson's disease (stiffness, tremors, spasms, poor muscle control). Trihexyphenidyl is also used to treat and prevent Parkinson-like symptoms that are caused by using certain anti-psychotic medications.

- **Levodopa (Oral)**
  Levodopa is used alone or in combination with carbidopa to treat Parkinson's disease, sometimes referred to as shaking palsy. Some patients require the combination of medicine, while others benefit from levodopa alone. By improving muscle control, this medicine allows more normal movements of the body.

- **Diazepam**
  Diazepam is a benzodiazepine. It is thought that benzodiazepines work by enhancing the activity of certain neurotransmitters in the brain. Diazepam is used to treat anxiety disorders, or alcohol withdrawal symptoms. Diazepam is sometimes used with other medications to treat muscle spasms and stiffness, or seizures.

Source: www.hpr-rps.hres.ca

is characterized by a combination of involuntary movements including dystonia choreoathetosis (writhing, twisting movements), or both. Symptoms typically occur on both sides of the body and begin after the first year of life. Patients may also have spasticity (a specific form of muscle tightness).

Dopa-responsive dystonia is a group of diverse inherited disorders often misdiagnosed as cerebral palsy. Consensus among most clinicians suggests that children presenting with dystonia should be prescribed a trial of levodopa because dopa-responsive dystonias typically respond dramatically to this therapy and children with various additional types of dystonia may also benefit.

Dystonia acquired due to an insult to the brain such as a stroke or brain tumor may develop months or years after the incident.

What Type of Doctor Treats Dystonia in Children?

Treating dystonia in children may require a team of health care professionals, including a neurologist or child (pediatric) neurologist with special training in movement disorders.

Dr. Mink emphasized the importance of an early diagnosis for children presenting with the symptoms of dystonia.

"Early diagnosis can mean a lot," Dr. Mink explained. "First of all, it gives families information and can help give them some peace of mind that they know what is causing their child to have movement problems. It also can provide some useful information about what to expect. And if it's genetic, you know whether other family members are at risk of developing similar symptoms. The other thing is, we have good evidence now that early treatment is associated with better outcomes than delaying treatment."

What Treatments Are Available?

Although dystonia symptoms can be difficult to eliminate completely, treatments are available.

Treatment may include physical therapy, occupational therapy, adaptive equipment and devices, speech therapy, behavioral strategies such as relaxation techniques, oral medications, botulinum neurotoxin injections, deep brain stimulation surgery, or a combination.

Oral medications may include baclofen, trihexyphenidyl, levodopa, and diazepam (see sidebar article). Side effects are common. Children may be less likely to recognize or complain about medication side effects than adults.

Common concerns for children with dystonia include pain management, difficulties with daily tasks, trouble using the hands, difficulty with seating, mobility challenges, sleep difficulties, and sometimes communication issues. Children with dystonia, especially inherited dystonias, may have higher rates of anxiety and depression than children overall. While treatment for dystonia in children tends to focus on reducing the movement symptoms, these non-movement aspects of dystonia can have a significant impact on overall quality of life and should be considered as part of a comprehensive treatment plan.

Special Considerations in Infants and Toddlers

Not all dystonia symptoms in children indicate a chronic movement disorder. The following conditions, which should be diagnosed by a qualified physician, can typically be resolved within the first several months or years of a child's life:

- Benign idiopathic dystonia of infancy: Transient dystonic postures and/or movements may occur in infants. Symptoms appear during the first months of life and resolve without treatment.
- Benign paroxysmal torticollis: Recurrent head-tilting or twisting, often with vomiting and irritability. Episodes typically occur with some regularity and become less frequent as the child develops.
- Congenital muscular torticollis: A rare disorder characterized by shortening of muscle in the neck causing the neck to twist. It is seen in newborns or very young children. This is not a dystonic disorder. Treatment includes physical rehabilitation and sometimes surgery.
- Paroxysmal tonic upgaze: Recurring episodes of sustained eye movements in infants under one year of age. Symptoms may outwardly resemble epileptic seizure, but there is no loss of consciousness. Due to this resemblance, diagnosis is not made until seizures have been ruled out. The episodes eventually diminish.

Conversation Starters with Your Child's Doctor

Diagnosing dystonia in children can be a complex process, given its many manifestations and causes. The following questions and topics may be helpful to discuss with your child's doctor during the evaluation process once a dystonia diagnosis is made or suspected.

- How did you come to a dystonia diagnosis for my child?
- Are there additional movement or neurological symptoms?
- Could the dystonia have resulted from a reaction to medication?
- Could the dystonia be attributed to cerebral palsy, a brain lesion, autoimmune disorder, or infection?
- Is neuroimaging, such as MRI, recommended?
- Could the dystonia be attributed to a metabolic disorder? Do you recommend a lumbar puncture?
- Is genetic testing appropriate? Can you recommend a genetic counselor?
- What treatments do you recommend and why?
- What can be done to address specific symptoms? (e.g. pain, trouble sleeping, etc.)
- Who can help us develop strategies to assist in daily living? (e.g. mobility, self-care, communication, etc.)

Source: Pediatric Dystonia | Dystonia Medical Research Foundation
Adapted and reprinted with permission from DMRF Dystonia Dialogue
Spring 2025 Vol 48, N1

Community Education and Impact

Continued Success with Neurologic Music Therapy

Thanks to positive feedback from participants in the University of Toronto, Faculty of Music's complimentary Neurologic Music Therapy for Dystonia, online sessions will be resuming this fall. There are still spots available so don't miss out on this free opportunity to try music and movement-based strategies for managing symptoms of dystonia. www.dystoniacanada.org/events/NMT

To help others experience the benefits beyond the research program DMRF Canada has added a list of Neurologic Music therapists to our website. Thank you to the Academy of Neurologic Music Therapy for compiling this valuable resource. www.dystoniacanada.org/support.

New Advocacy Materials – Nonmotor Symptoms of Dystonia

Giving our community tools they need to understand and advocate for treatment is of utmost importance to us. Thanks to the DMRF, we have added a new brochure to help people with dystonia and their families understand the often-neglected nonmotor symptoms of dystonia. Covering topics like anxiety and sleep difficulties, the brochure entitled Burden of Dystonia is More than a Movement Disorder is available with several other dystonia educational materials on our website.

www.dystoniacanada.org/dystonia-information-materials

Alberta Dystonia Symposium

The Calgary and Edmonton dystonia support groups have come together to organize a symposium for people with dystonia and families. Guest speakers will include movement disorders specialists Dr. Akash Shetty from Edmonton, Dr. Davide Martino from Calgary and Jacquie Towsend BMR PT Physiotherapist. The symposium will take place in Red Deer on September 20, 2025 from 12:00 pm – 5:00 pm.

For full information, visit our website. www.dystoniacanada.org/event/2025AlbertaSymposium

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Support Group News

A variety of in person and virtual support group opportunities are available thanks to our dedicated volunteer leaders:

- National Virtual Support Group – September 20 and November 15, 2025
- Dystonie Partage Support Group (Montreal) - September 27, 2025
- Greater Toronto Virtual Support Group – November 30, 2025

For more information and up to date listings of upcoming meetings and events, visit our website. www.dystoniacanada.org/upcoming-events

This past August, those with a rare form of dystonia called Paroxysmal Dyskinesia, had the opportunity to meet and support each other through sharing their experiences. DMRF Canada support group leaders from Cape Breton NS, and Toronto ON organized the first online support meeting for this specific form of dystonia. We're grateful to our volunteers for providing the support needed!

Jonathan from Toronto, ON (left) & Jason from Cape Breton, NS (right)

In case you missed it, visit this page: www.dystoniacanada.org/about-dystonia/paroxysmaldyskinesias for the discussion summary and details on future meetings.

Volunteer as a support group leader! If you're looking to build community with people who truly "get it", or have ideas for ways to support others, there are still groups across the country that are in need of leaders. Visit our volunteer page to find your community. www.dystoniacanada.org/volunteer

We are grateful to our volunteers, who lead with generosity and put the needs of the dystonia community alongside their own — inspiring others to do the same.

Community Education and Impact (Continued)

Fundraising Volunteers Needed

Did you know that charitable gaming proceeds account for a large portion of our fundraising? Just one shift as a casino volunteer can raise up to $3,000 per person. If you're looking for an impactful way to donate, volunteer to work at one of our casino or bingo fundraisers. We're in search of volunteers for the following:

- **Bingo**: Richmond Hill, Ontario - www.dystoniacanada.org/bingovolunteer
- **Casino**: Calgary, Alberta - Chairperson and General volunteers www.dystoniacanada.org/casinovolunteers

Thank you to those who volunteered at the Bingo Hall in Richmond Hill and Edmonton casino over the summer to make it a fundraising success!

September is Dystonia Awareness Month

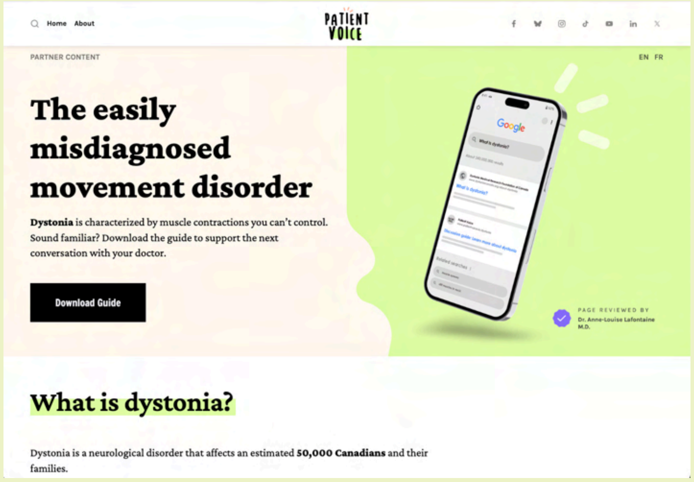
New Patient Voice Partnership Amplifies the Lived Experience of Dystonia and Improves Advocacy

In honour of Dystonia awareness month in September, DMRF Canada has joined forces with Patient Voice, a patient engagement and storytelling platform, with support from AbbVie Canada. Results of our survey indicated that almost half of respondents felt that at some point, their dystonia-related movements were not taken seriously by healthcare providers. The road to diagnosis remains long and isolating for many. This can especially be the case with the most common form of focal dystonia, cervical dystonia, where symptoms can present with similarities to other conditions.

The solution to a shorter path to diagnosis is two-fold: increase dystonia awareness amongst healthcare practitioners, and provide access to awareness and advocacy tools for the general public.

This is where initiatives such as the Patient Voice campaign come in. The campaign will offer a space where people can gain awareness of what living with dystonia looks like. It will invite Canadians to become familiar with dystonia and empower those who had previously never heard of it to bring the right information to their healthcare provider when seeking an accurate diagnosis.

Available by mid-September, Canadians can refer to www.patientvoice.io/dystonia to download a self-assessment guide as a tool to navigate a dystonia diagnosis. With input from movement disorder specialist Dr. Anne-Louise Lafontaine and support from AbbVie Canada, DMRF Canada contributed to the development of this resource to help individuals recognize potential symptoms and speak with confidence to their family doctors about next steps, including referrals to neurologists with experience in movement disorders.



The easily misdiagnosed movement disorder

Dystonia is characterized by muscle contractions you can't control. Sound familiar? Download the guide to support the next conversation with your doctor.

What is dystonia?

Dystonia is a neurological disorder that affects an estimated **50,000 Canadians** and their families.

Together, DMRF Canada, Patient Voice, and AbbVie Canada are working to ensure that people living with dystonia are not just seen and heard—but centered in the conversations that matter towards faster and more accurate diagnosis.

If you're looking for ways you can improve dystonia awareness, see our online resources and past successes available at: www.dystoniacanada.org/dystoniaawarenessmonth

Living in Harmony with Dystonia

How Meghan Fell finds community, opportunity and joy in music

Meghan Fell is a self-described "raging extrovert". This is apparent when you speak with her; Broad smile, sense of humour and overall natural performer energy. In a previous chapter of life, she played multiple instruments and sang, until she acquired dystonia secondary to a stroke at age 13. "It changed everything. I have dystonia on my left side, so piano, French horn, and guitar were all left-handed instruments. I lost them all, which was devastating, but I carried on with voice lessons."

Meghan spent her early adulthood in a career in marketing, communications and fundraising. Once she got married and had her son, Meghan found the energy required for being out of the house at work all day wasn't sustainable with the demands of dystonia and family life. So what does one do as an adult with an overabundance of extraversion and no outlet? This is what led Meghan to women's acapella show choir, Lions Gate Chorus. What started as an outing with a coworker, has become an 18-year weekly commitment. It has earned her bragging rights as winner of the 2024 Sweet Adelines World Championships (for those outside the singing world, this is THE competition if you're an acapella performer, specifically women's barbershop), an appearance on Canada's Got Talent, travel opportunities and a consistent source of joy.

Meghan is accustomed to a body that doesn't cooperate. If you're picturing a Lions Gate performance as a stuffy group of 100+ women belting out choral arrangements, think again. "We don't just stand there and sing. There's dancing," describes Meghan playfully. Because her left side has its own ideas, Meghan has adapted the choreography to suit her abilities. She also has the benefit of the group's choreographer that she can consult to ensure modifications fit well with the group's vision. Meghan performs from a riser chair that allows her to sit and still be at the same level as her fellow performers.

When asked what benefits singing and performance brings to her life with dystonia, Meghan emphatically describes the impact on her social and emotional well-being. "It fills my bucket, fills my soul, fulfills creative needs and social needs. They are my village. I am physically exhausted when I get home, but it's a good tired, like after you've done a really good workout." There is also the added benefit that singing and music bring to body awareness. Meghan is very aware of her posture, tension and breath. There's also the aspect that the focus involved in singing eclipses the focus she may typically have on her dystonic movements. "I just don't pay attention to it because I need to be in the musical moment. I acknowledge it and say, oh, how fascinating. Now, off you go. I'm not dealing with you right now."

Meghan adds that the regularity and structure of her participation in a group like Lions Gate Chorus, has become a necessary outlet through the pressures of life. "There are people counting on me. I'm going every Tuesday. I've been in the chorus for 18 years and I'm showing up for myself."

Thanks to Meghan for sharing a small bit of her star power with us at DMRF Canada. You can catch Meghan and the rest of the Lions Gate Chorus in their next "Pitch-Perfect" inspired big performance, *Aca-Stravaganza!* at the Queen Elizabeth Theatre on September 27 in Vancouver.

If you're looking for an easy way to see if music can make a positive impact on your life with dystonia, see our Community Education and Impact section for information on free Neurologic Music Therapy sessions through the University of Toronto. Visit our events section: www.dystoniacanada.org/upcoming-events

2025 Update for "Definition and Classification of Dystonia" Published in Movement Disorders

In May 2025, an updated definition and classification of dystonia was published in Movement Disorders. This update builds on the original 2013 consensus publication and incorporates important scientific advances made over the past decade, particularly in areas like genetics and cell biology.

Over time, the original classification had been interpreted in different ways, leading to inconsistencies in how it was used in clinical settings. To address this, an International Consensus Committee, consisting of investigators with years of experience in different aspects of dystonia, was formed with sponsorship from the International Parkinson Disease and Movement Disorder Society (MDS) Dystonia Study Group, the Dystonia Medical Research Foundation, the Dystonia Coalition, and Dystonia Europe.

The committee members reviewed and revised the definition, classification, and terminology of dystonia, to make them clearer and more practical for healthcare providers, while also creating a guide for future dystonia research. This updated consensus is designed to help doctors better recognize, diagnose, and treat dystonia, so patients can get more accurate care and support. It also helps ensure that people all over the world are using the same concepts and terminology when talking about and studying this condition.

Formal Definition of Dystonia

The authors decided to retain the definition of dystonia with only minor clarifications to the wording. Dystonia is defined as "a movement disorder characterized by sustained or intermittent abnormal movements, postures, or both. Dystonic movements and postures are typically patterned and repetitive and may be tremulous or jerky. They are often initiated or worsened by voluntary action and frequently associated with overflow movements."

How Is Dystonia Now Classified?

The system still uses two main "axes" to define and classify dystonia:

Axis I: Clinical Characteristics

These are descriptors that neurologists use to classify dystonia and guide testing during diagnosis. They include:

1. **Age of Onset of Symptoms –** can range from infancy to late adulthood

2. Family History – whether dystonia is likely genetic or appears sporadically
3. Body Areas Affected – e.g., just the neck (focal), or several body regions (generalized)
4. Timing and Course – how and when symptoms start, and whether they change or stay the same over time
5. Movement Features – how the dystonia occurs: Does it happen with movement? Is it tremor-like or jerky? Are there ways to ease it?
6. Other Symptoms – whether dystonia is the only issue or occurs alongside other movement disorders or neurological symptoms

Axis II: Causes and Biological Mechanisms

This axis focuses on what causes dystonia and how symptoms are expressed:

1. **Genetic Factors** – recognizing the genetic forms, whether inherited or not
2. **Acquired Causes** – like certain medications, toxins, or injuries
3. **Brain Imaging Clues** – identifying areas of the brain that might be damaged
4. **Biological Processes** – such as developmental factors, cellular or metabolic pathways, or immune reactions

What's New and Improved in the Updated Publication?

- More precise descriptions of symptoms and their timing
- New terms that reflect novel developments in genetics and molecular biology
- A clearer guide to help doctors connect symptoms with possible causes
- Useful for both everyday medical care and future research and treatment development

Impact of the New Definition and Classification

This new system recognizes that dystonia can affect people in many very different ways and originate from a variety of genetic and non-genetic causes. It offers a more detailed and clearer way to understand and classify dystonia. Ultimately, it is designed to help neurologists make better diagnoses and researchers explore more targeted treatments.

Meet the Authors

The authors of the 2025 Definition and Classification of Dystonia are movement disorder specialists with an expertise in dystonia, representing over three decades of experience across four continents.

- Alberto Albanese MD, IRCCS Neurological Institute C. Mondino, Pavia, Italy; Catholic University, Milan, Italy
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- Mark Hallett MD, National Institute o Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Bethesda, Maryland, USA
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- Marina A.J. Tijssen MD, University of Groningen, Groningen, The Netherlands; University Medical Center Groningen, Groningen, The Netherlands
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Adapted and reprinted with permission from DMRF Dystonia Dialogue Summer 2025 Vol 48. No 2

Source: Albanese, A., Bhatia, K.P., Fung, V.S.C., Hallett, M., Jankovic, J., Klein, C., Krauss, J.K., Lang, A.E., Mink, J.W., Pandey, S., Teller, J.K., Tijssen, M.A.J., Vidailhet, M. and Jinnah, H.A. (2025), Definition and Classification of Dystonia. MovDisord. https://doi.org/10.1002/mds.30220

Pain Management Options for Dystonia

Pain associated with dystonia can be variable—it can depend on what part of the body is involved, the severity of the dystonia, a person's age, and comorbidities, which are additional medical conditions.

Physicians who treat people with dystonia can provide several options to treat their symptoms and alleviate pain, ranging from botulinum toxin injections for focal and segmental dystonia, deep brain stimulation (DBS) for generalized dystonia, as well as physical/occupational therapies and complementary therapies as part of an integrative medicine approach.

Goals of Pain Management for Dystonia

"Any narcotic is not going to be good for chronic use," Dr. Perlmutter explained. "And it's not effective. It may cause substantial adverse effects and lead to addiction in some people, so we try to avoid that."

Dr. Perlmutter added that there are situations where certain drugs can be effective, combined with other therapies.

"If it's a person with dystonia and we haven't tried levodopa, then we should as dystonia occasionally can be dopa responsive," he said, explaining that patients can be started on a low dose of levodopa to see if the drug alleviates dystonia symptoms.

"Sometimes there are interventions that physical therapists can provide that may include various exercises and stretching to try to reduce the effects of wear and tear injuries," Dr. Perlmutter added. "Occupational therapists can work toward the same goal, but with a different perspective. They can look at how the person is positioned, for example, at their desk, working on their keyboard, and find better positions to reduce repetitive type injuries that may occur in people with dystonia. That approach helps reduce the impact twisting or unusual postures that contribute to pain and find a position that minimizes the effect of dystonia on a painful part of the body."

Complementary Approaches to Pain Management

Harini Sarva, MD, Chief of the Division of Movement Disorders at Weill Cornell Medicine, New York City, and a former DMRF clinical fellow, also supports finding a good physical therapist to relieve pain caused by dystonia, especially someone who is well versed in neurology and movement disorders.

"What they'll end up doing is working on is compensatory mechanisms—compensatory muscles, posture, and all of that is really important," she said.

Dr. Sarva has also referred dystonia patients to the integrative medicine center at her institution to explore complementary therapies, which are not a replacement for standard medical treatments but may be used in conjunction with other treatments.

These complementary therapies may include:

Acupuncture: A form of traditional Chinese medicine used for pain relief that involves needle insertion into the affected areas.

Reiki: A Japanese technique of hands-on therapy for stress reduction and relaxation.

Alexander Technique: A therapy for stress-related chronic conditions that focuses on improving posture.

Gentle massage: Rubbing of the soft tissues of the body. Transcutaneous Electrical Nerve Stimulation (TENS) device: A type of pain relief therapy that uses a low-voltage electrical current to block pain or change one's perception of it.

Yoga: A mind and body practice that involves movement, breathing exercises, and a focus on thoughts and feelings as they happen (mindfulness).

In Canada, many of these therapies can be provided by regulated professionals like massage therapists and physical therapist. This means coverage may be available through your province or health benefit plan (if applicable). Check with your local health authority to see if you qualify.

"Local pain acutely is an inflammatory response, but chronic pain is more of a neurological condition," explained Dr. Sarva. "They're perceiving pain differently, so there are other means of trying to get to that. That's where physical therapy and some complementary therapies like acupuncture, mindfulness, biofeedback—those mechanisms are really trying to work at altering the pain pathways in the brain and the way patients perceive pain. In the long run it's a lot more work, but they're more meaningful and have more meaningful change, although they're not always readily available for patients."

In addition to all these complementary therapies, getting enough sleep is an integral part of dystonia care as sleep disorders are very common and poor sleep can lead to pain aggravation.

Dr. Sarva advised that in addition to asking their medical practitioners about pain management options, dystonia patients can ask members of dystonia support groups—like those supported by the DMRF—for advice on pain relief methods that have worked for them as well.

Dr. Perlmutter noted that a sensory trick—a specific gesture or action that temporarily reduces dystonia symptoms— can also help reduce discomfort in dystonia.

"Sometimes a soft collar will be that sensory trick for that person...We ask the patient what feels best for them," he said. "They can try a soft collar. If just touching the chin and the soft collar gives that continuous input, then that may help that person."

Dr. Perlmutter added that a hard cervical collar (neck brace) that renders the neck completely immobile or splints that force muscles into place are usually not recommended for dystonia patients because the muscles will "fight" against the restraint and cause more irritation and problems than benefit for the patient.

Talking to Your Doctor About Pain Management

Dr. Perlmutter advises that patients with dystonia who have questions about pain management should arrive at their doctor's appointments prepared with details about the pain they have been experiencing, and it is helpful to have these details written down, such as answers to the following questions:

- A description of the pain: What does it feel like? What part of the body is affected?
- What movements tend to make the pain worse? What makes it better?
- Give a severity rating of the pain on a scale of 0 to 10, with 10 being the most severe.
- How long does the pain last?
- How was pain managed in previous treatments: If they're being treated with botulinum toxin, did that help that pain or not?

"These are things that if they can explain that to the clinician, then the clinician can help review what the proper options are for them," said Dr. Perlmutter. "If an option—or options—are presented, a patient should always ask, what's the pro and con of this option? What are the chances it'll help? What are the potential side effects? How long will this benefit last? Does it need to be repeated or is it a one-time deal? Is there something that we could do for the dystonia rather than going after the pain directly? All those are appropriate questions."

For pain clinics, workshops, or other helpful resources in Canada, visit
www.dystoniacanada.org/living-with-dystonia

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Photo Credit: Regina Annirood

2025 Pan American Movement Disorders Clinical Neurophysiology Course


Photo Credit: Regina Annirood

Training Tomorrow's Experts: DMRF Canada Supports Dystonia Education at 2025 Neurophysiology Course

This past May, medical professionals in Toronto hosted the 2025 Pan American Neurophysiology course, led by course director Dr. Robert Chen. While the event attracts specialists who research and treat many different neurophysiological conditions, this year's course featured content very relevant to dystonia.

Dr. Talyta Grippe and Dr. Karlo Lizarraga, past recipients of the DMRF Canada Clinical and Research Fellowship award, were among the speakers sharing their expertise in movement disorders. The sessions included training in using neurophysiology studies (tests that show how your brain, nerves, and muscles are working) to guide treatment with Deep Brain Stimulation (DBS) and Botulinum toxin injections. These treatments are some of the most effective for managing motor symptoms of dystonia and improving patient quality of life. With the addition of EMG and ultrasound, these can be administered even more precisely and effectively.


Photo Credit: Regina Annirood

DMRF Canada made it a priority to sponsor this event and support medical fellows in attending. Our strategy includes providing access to education for future dystonia specialists to ensure our community has increased access to high-quality treatments. DMRF Canada's support helped the course reach full capacity meaning there are now more medical specialists trained in gold-standard treatment techniques for dystonia.

We're proud to support the 2025 Pan American Neurophysiology course as a way of engaging with the medical community to ensure dystonia remains a priority in their training. These opportunities could not be provided without the funding, time and advocacy, you as our community, facilitate.

Be Part of the Progress: Dystonia Research Needs You

A better future for those with dystonia is dependent on research. By participating in studies, you are broadening access to information or resources for your own benefit while also advancing knowledge to support future treatments.

Did you know DMRF Canada keeps an up-to-date listing of research participation opportunities? While some opportunities are in person, others may be completed online. You can contribute to a better future with dystonia! Visit our website for a listing of clinical trials. www.dystoniacanada.org/clinical-trials-for-dystonia

You can also stay on top of the latest findings through our continuously updated research listings. www.dystoniacanada.org/latest-dystonia-research-news

2025 Grant & Fellowship Recipients

DMRF Canada is dedicated to advancing research for more treatments and, ultimately, finding a cure for dystonia. Our aim is to support the best and brightest minds in the field, both in Canada and internationally. Working with our sister organization, the DMRF in the US, DMRF Canada supports research aimed at expanding the knowledge of the genetic, molecular, physiologic and pathologic basis of dystonia. Congratulations to the newest award recipients and thank you to all DMRF Canada supporters for making this research possible.

Grant Recipients

Martin Piazza, MD University of Pittsburgh, Pittsburgh, PA
Neurosurgery in Pediatric Dystonia: A multimodal analysis of complex decisions

QUICK SUMMARY: Dr. Piazza will study how families make informed decisions about deep brain stimulation (DBS) surgery for children with dystonia by addressing two key gaps: understanding how families weigh the benefits and risks of DBS and comparing its long-term effectiveness and costs to standard medical care. Ultimately, the research will provide better support for families, guiding them through complex decisions about their child's care.

Mariangela Scarduzio, PhD University of Alabama at Birmingham, Birmingham, AL
A Role for Striatal Somatostatin Interneurons in Hyperkinetic Movement Disorders

QUICK SUMMARY: Dr. Scarduzio seeks to further explain why special cells called somatostatin-expressing interneurons (SOMs) found in certain brain circuits in the striatum become highly active when dystonia-like symptoms are induced. By testing ways to control these cells, she hopes to better understand how to treat movement disorders like dystonia.

Joaquim Alves da Silva, MD, PhD Champalimaud Foundation, Lisbon, Portugal
Striatal Neural Correlates of Overuse Dystonia

QUICK SUMMARY: Dr. da Silva aims to introduce a new mouse model where repetitive training of a skilled task triggers dystonia, hoping to better understand the brain circuits involved and test deep brain stimulation (DBS) as a treatment. By studying brain activity during dystonia development in the new mouse model, this project hopes will shed insights into the condition's mechanisms and uncover new pathways for therapeutic development.

Postdoctoral Research Fellow

Alexander Hodge, PhD University of Michigan, Ann Arbor, MI
Determining a mechanism of symptom severity in DYT1 dystonia

QUICK SUMMARY: Dr. Hodge intends to explore how changes in the neurotransmitters dopamine and acetylcholine in the brain's striatum contribute to the development and severity of dystonia. By tracking real-time interactions between these neurotransmitters in mice with different dystonia-related mutations, the research will provide insights into how these chemical changes affect motor behaviors and may lead to dystonic symptoms. The findings could help identify specific targets for improving clinical manifestations of dystonia. Dr. Hodge is a postdoctoral research fellow in the lab of Daniel Leventhal, MD, PhD—a DMRF grantee from 2010.

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DMRF Welcomes New MSAC Members

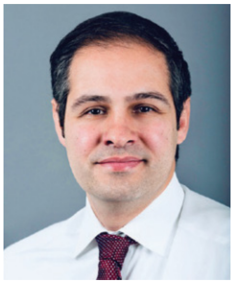
The Medical & Scientific Advisory Council (MSAC) is comprised of pre-eminent clinicians and researchers. The MSAC represents expertise in microbiology, genetics, brain circuitry, epidemiology, and related fields. These scientists conduct peer-review of research applications for recommendation to the Board of funding. Members set the directions of research and participate in focus workshops.

Meike van der Heijden, PhD
Virginia Tech University Blacksburg, VA

Aryn Gittis, PhD
Carnegie Mellon University, Pittsburgh, PA

Alberto Espay, MD
University of Cincinnati Cincinnati, OH

Robert Chen, MA, MBBChir, MSc, FRCPC
University of Toronto Toronto, ON, Canada



Darius Ebrahimi-Fakhari, MD, PhD
Boston Children's Hospital, Boston, MA

Mark Edwards, MBBS, PhD
King's College London London, United Kingdom

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TCS Toronto Waterfront Marathon

This October 18th, members of our **Greater Toronto Area Dystonia Support Group** are stepping up for something bigger than a finish line—they're taking on the **5K Charity Challenge** to raise awareness and funds for dystonia.

This is more than just a run. It is a powerful moment of visibility at one of **Toronto's largest events, drawing over 30,000 participants and 150,000 spectators**. Every dollar raised goes toward critical research, as well as programs that bring care, hope, and connection to the dystonia community.

Whether you run, walk, or cheer from the sidelines, your support matters. Full event details are available here www.dystoniacanada.org/event/TCSWaterFront

If you are unable to participate, please consider donating or share the message to support our runners.

DMRF Canada Needs Your Help - Please Give Generously

Each discovery builds toward the next – *all leading to the ultimate goal of a cure for dystonia.*

Your support matters. We exist, and our mission survives because of you. There are various ways to support DMRF Canada to have your impact felt today and ensure a brighter tomorrow for the 50,000 Canadians living with dystonia.

Legacy Giving: Leave a Gift that Lives On

DMRF Canada established the Legacy Society to recognize those who have made a lifetime commitment in the battle against dystonia by naming DMRF Canada in their estate plans. Through the Legacy Society, you can make a commitment of support today to ensure the continuation of dystonia research in the future.

Options Include: • Wills and Bequests • Life Income Gifts: Charitable Trusts and Gift Annuities • Qualified Retirement Plans • Real Estate

For more details on estate planning, please visit: www.dystoniacanada.org/legacy

○ **Yes, I want to join DMRF Canada's Legacy Society.**

Please provide an email address:____________________

Yes, I want to support DMRF Canada. Please add your selection below.

○ **Yes, I want to make a one time gift to invest in critical dystonia research. Here is my gift of:**

○ $250 ○ $150 ○ $75 ○ $45 ○ $ ______

I am sending my cheque made payable to the Dystonia Medical Research Foundation Canada.

Please note: DMRF Canada has removed mailed in credit card information as a payment method to help safeguard donor information. You can still make a credit card donation or sign up to be a member of our Monthly Giving Team by visiting our website ***www.dystoniacanada.org/donateonline*** or scan the QR Code. You can also call our office at 1.800.361.8061. **Charitable #12661 6598 RR0001**

DMRF Canada PO Box 1009, STN Toronto Dom, Toronto, ON M5K 1P2
e. info@dystoniacanada.org **t.** 416.488.6974 / **tf.** 800.361.8061

ADDRESS BOX

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