Dystonia Canada Report

A Newsletter from Dystonia Medical Research Foundation Canada

Dystonia Medical Research Foundation Canada
Fondation de Recherche Médicale sur la Dystonie Canada

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

Winter/Fall 2026

IN THIS ISSUE:

PLEASE RENEW YOUR MEMBERSHIP FOR 2026

Support the dystonia community with a donation to DMRF Canada.

visit: www.dystoniacanada.org/donate

Thank you for your support.

Foundation Update

Dear Friends,

This year marks 50 years that DMRF Canada has been funding research, promoting awareness, and supporting and advocating for the well-being of those with dystonia. As a small Canadian organization, we do not have the volume of membership or funding like the bigger charities or our global counterparts, but we recognize the need and benefit of having this local support for Canadians.

We also recognize we are a piece of a larger picture when it comes to working towards finding better treatments, and ultimately a cure. In the pages of this edition of the Dystonia Canada Report, we share information that explains our place in this global network and how being a part of this is bringing us closer to our goal.

This milestone year has also been marked by the passing of Frances Belzberg, who co-founded the Dystonia Medical Research Foundation (DMRF) with her husband, Sam. Their vision shaped both DMRF Canada and DMRF in the United States and helped build the lasting partnership and global network that continues today.

Read on to see how DMRF Canada contributes to this greater effort. You'll find the Canadian experts serving on the Medical and Scientific Advisory Council (page 7), DMRF Canada's participation in the Dystonia Coalition (page 3), as well as our long history of partnership with DMRF in the United States, working together toward better treatments and, ultimately, a cure (page 5).

Of course, there are also the many stories you'll see of our membership and volunteers putting in effort in their local communities. They distribute information, support others, and fundraise for our contributions to a future without dystonia. They make our small voice heard nationally, and therefore internationally.
As you read this edition, we encourage you to see how you can continue to play a role in keeping us strong locally, so we can be a source of knowledge and support to those within Canada, as well as furthering training and advancements in research for a future free of dystonia world-wide.

As always, we thank you for your past contributions and look forward to your continued support in making our community stronger.

Sincerely,

Catherine Mulkins,
Chair, DMRF Canada,
Board of Directors

Catherine Mulkins

Archana Castelino,
National Director,
DMRF Canada

Archana Castelino

It is the editorial policy to report on developments regarding all types of dystonia but not to endorse any of the drugs or treatments discussed. DMRF Canada encourages you to consult your physician about the procedures mentioned herein.

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.

You Can Help Shape Dystonia Research -Sign Up Today!

The goal of the Global Dystonia Registry is to support future dystonia studies, including clinical and research trials, through the collection of data on persons affected by dystonia. Although the focal dystonias have many different manifestations, most experts believe they share a common pathogenesis or mechanism that causes the disorder. The common causes may be a similar gene defect, similar lifetime experiences, or both. Collecting information from different patient populations may help us identify the common features that they may share.

The Global Dystonia Registry

Visit: www.globaldystoniaregistry.org to learn more and register

Dystonia Coalition

The DMRF Canada is proud to be a member of the Dystonia Coalition. The Dystonia Coalition is a collaboration of medical researchers and patient advocacy groups supported by the National Institutes of Health, a part of the US Department of Health and Human Services responsible for medical research.

The Dystonia Coalition is a groundbreaking collaboration of medical researchers and patient advocacy groups focused on accelerating clinical research in the field. Fifty-six research centers in North America, Europe, Asia, and Australia are currently participating. Due to the collaboration and infrastructure provided by the Dystonia Coalition out of the United States, scientists and researchers globally have access to natural history data to better understand dystonia progression and a network of experienced clinical sites and investigators.

DMRF Canada is encouraged to see some of the impact this infrastructure provides, which is available in a recorded presentation on www.dystoniacanada.org/dystonia-coalition.

In Tribute

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

Colleen Elaine Egan **Shirley Poirier** **Ed Welch**

Remembering Frances Belzberg, Co-Founder of DMRF Canada

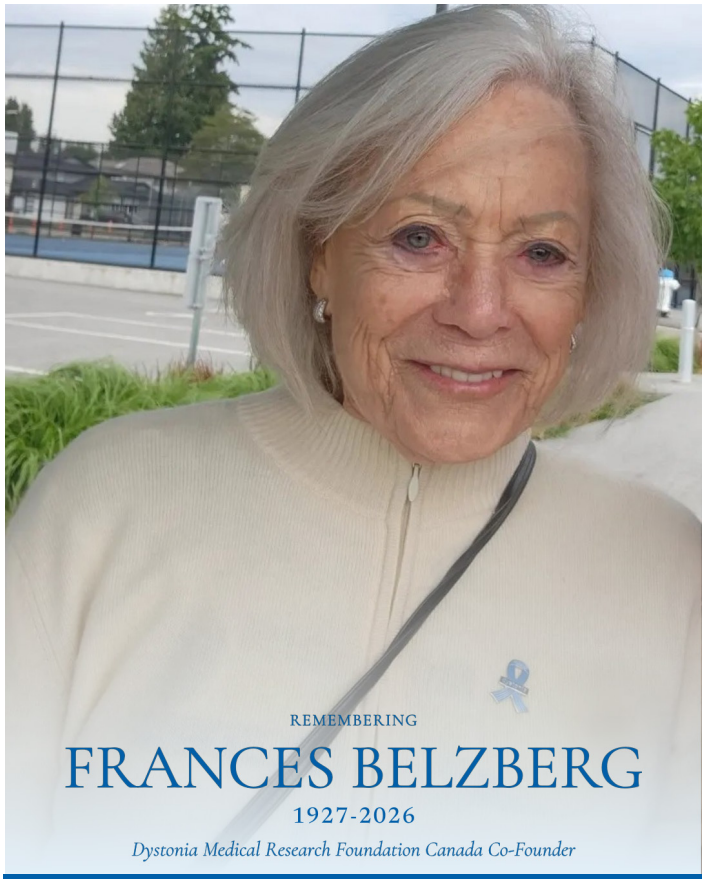
We are deeply saddened to announce the death of Frances Belzberg, co-founder and Honorary Chair of the Dystonia Medical Research Foundation (DMRF) Canada.

Fran and her husband, Sam, established the DMRF in 1976 after their daughter, Cheri, was diagnosed with dystonia. At a time when little was known about the disorder and few resources were available, they created an organization dedicated to advancing research, providing information and support, and raising awareness for individuals and families affected by dystonia.

They immediately recognized the importance of engaging dystonia experts to join with the DMRF to work on developing treatments and ultimately a cure. They worked tirelessly to engage researchers, with a focus on young investigators, to the field and ignited the global dystonia research effort. Fran and Sam pioneered the practice of having open meetings with scientific advisors reviewing grant applications and having scientific discussions with the lay leadership present. This practice was novel at the time and allowed members of the Foundation's Board of Directors to better understand the process and challenges of dystonia research.

Fran also understood the importance of providing accurate information so people could learn as much as possible about dystonia and the critical role support had for those living with dystonia. She participated in support groups in Canada and in the United States and would often volunteer to speak with other mothers whose children had dystonia.

Following Sam's death in 2018, the International Dystonia Symposia was named for him. Fran remained deeply engaged in the Foundation's mission, and gave the welcoming remarks at the first symposium held after his death, traveling to Dublin for the Samuel Belzberg International Dystonia Symposium in June 2023. In her remarks she said, "I want to thank each and every one of you for your efforts to ease the burden of dystonia and your search for a cure... but I also want to remind you that people are waiting. People like my daughter who was diagnosed so many years ago and people who have just been diagnosed... all waiting for scientific breakthroughs, for answers. No pressure, but we're counting on you!"



Fran at the 2023 Freedom to Move event in British Columbia. Picture Credit: Jirome De Castro

The extraordinary contributions of Fran were recognized through her appointment as a Member of the Order of Canada in 1995. She was later appointed to the Order of British Columbia in 2021, the province's highest form of recognition.

Fran worked relentlessly to promote the work of the DMRF and DMRF Canada and inspired so many to join this fight. She leaves a lasting legacy. It is with gratitude that we continue our work to achieve the mission she and Sam set out to do 50 years ago.

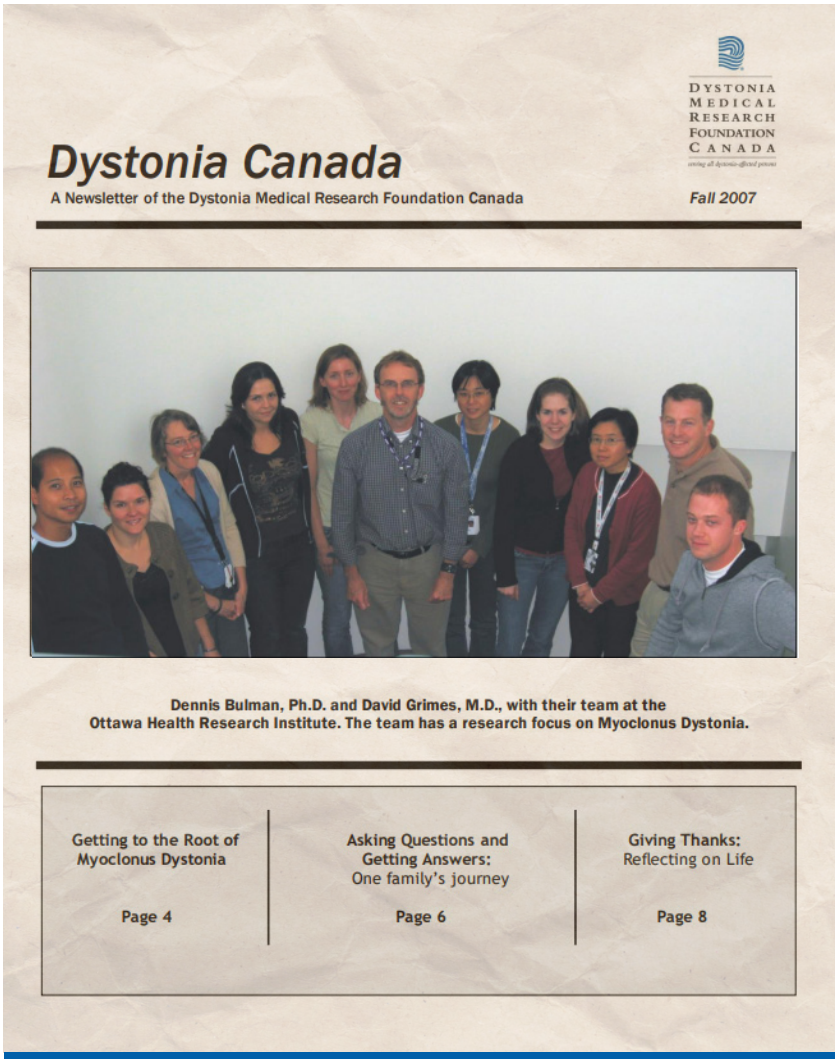
As DMRF Canada marks 50 years, Fran's vision remains at the heart of our work. The research, education, and support available today reflect the foundation she and Sam built and the determination they inspired in others.

50 Years of Progress Powered by Partnership

This year marks 50 years since the Dystonia Medical Research Foundation (DMRF) was founded by Samuel and Frances Belzberg. Since 1976, DMRF has worked with the same mission: to fund dystonia research, promote awareness, and support the well-being of those affected by dystonia. What many may not realize is the close partnership between DMRF in the United States and DMRF Canada and how this relationship benefits advancements in dystonia globally.

This partnership began as one organization. Vancouver-based Samuel and Frances Belzberg started DMRF. As DMRF began its work, this initial era saw the establishment of early support networks, as well as the formalization of the Medical and Scientific Advisory Council (MSAC, previously referred to as the Scientific Advisory Board), a vital component to ensuring resources are allocated towards the most promising advancements (for more on MSAC see Part 1 on page 15 of our series on the history of dystonia research support). Formalization of MSAC was especially notable as it created the first scientific network for dystonia, expanding the reach of DMRF outside its North American home.

DMRF Canada operates as an organization providing funding, awareness, and support across Canada. DMRF in the United States maintains their own infrastructure, continuing to share the same mission, as well as serving as a point of data collection to inform researchers in other parts of the globe.



Fall 2007 Dystonia Canada Newsletter Cover

As proud Canadians, we celebrate the fact that so many achievements have come from a Canadian-founded organization. This partnership has allowed access to a larger pool of resources for both patient support and funding sources. An American partner ensures access to National Institutes of Health (NIH) grants which has provided millions for medical research and funds the Dystonia Coalition (for more on this see Page 3), which makes global collaboration possible.

Having limited resources in Canada has not stopped us from continuing to make our mark in dystonia science and research here. In the last 20 years, DMRF Canada has invested nearly $1.5 million into more than 150 dystonia-related Canadian programs and activities. These accomplishments are a collaborative achievement of contributions from our generous donors, the expertise of our MSAC members, the Canadian experts who have helped advise on and drive dystonia research in Canada, the efforts of our Board of Directors, and the ability of our small staff to make those dollars stretch.

Read on for a breakdown of how the last 50 years have advanced our mission. While we cannot yet celebrate until there is a cure, we acknowledge the hard work, support, and partnerships that have resulted in significant progress.

Continued on page 6

50 YEARS OF PROGRESS AND IMPACT

FIFTY YEARS. STRONGER TOGETHER.

Dystonia Medical Research Foundation Canada
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serving all dystonia-affected persons
desservant toutes personnes atteintes de dystonie

COMMUNITY RESEARCH EDUCATION AWARENESS COLLABORATION

1976–1985

A Canadian-Founded Movement Begins

- Founded by the Vancouver-based Belzberg family.
- Established the foundational patient and family support networks.
- Formalized the Scientific Advisory Board (now MSAC), creating the first global scientific network for dystonia.
- In 1984, convened the first dystonia definition and classification consensus.

1986–1995

Research Connections & Shifting Paradigms

- Redefined dystonia from a psychological label to a neurological disorder.
- Expanded grassroots volunteer chapters across Canadian provinces.

1996–2005

Science and Discovery Grow

- Discovery of the DYT1 gene.
- Baseline dystonia genetics and brain circuitry are mapped thanks to the work of collaborative networks.
- Supported critical research work for DBS in dystonia, moving it from an experimental idea into a clinical reality.

2006–2015

Strengthening Science Through Partnership

- Funded nearly 50 DMRF Canada-supported science and research programs/activities, investing approximately $1.4M in efforts worldwide.
- Partnership with CIHR (since ended) to launch research funding in Canada and expand support for clinical fellowships.
- Supported the launch of patient data collection initiatives for global research pipelines.

2016–2026

Research, Education & Support Expand

- Funded 115+ DMRF Canada-supported science and research programs/activities, investing approximately $1.7M in global efforts (including planned 2026 programs).
- Built strategic partnerships to amplify funding and national advocacy.
- Expanded medical education, knowledge mobilization, trial participation, and national awareness initiatives.

Advancing Hope. Driving Discovery. Transforming Lives.

Series on the History of DMRF Research

At the heart of the Dystonia Medical Research Foundation's mission is the ongoing pursuit of scientific advancements that lead to the discovery of the causes of dystonia, earlier diagnosis, more effective treatments, and ultimately a cure. DMRF Canada shares this mission with DMRF USA, collaborating closely and actively supporting research efforts and initiatives. We're pleased to highlight this series from recent editions of the Dystonia Dialogue outlining how and why research is a critical component of our mission.

The History of the DMRF Medical and Scientific Advisory Council (MSAC)

To ensure information and research supported by DMRF is of the highest quality and benefit, the DMRF Medical and Scientific Advisory Council (MSAC) exists to provide guidance and advice on all scientific efforts. This includes the planning of scientific workshops and reviewing all grant applications for dystonia-related research based on scientific merit at the Foundation's Annual MSAC Meeting in February. MSAC's review and scoring of applications serves as a guide in providing funding recommendations to the Board of Directors. With up to 30 members serving a four-year term (approximately one quarter of the members rotate on and off each year) MSAC represents a diversity of scientific fields related to dystonia research, such as clinical neurology, molecular biology, genetics, neurophysiology, and neurochemistry.

The Dystonia Medical Research Foundation welcomed the following new members to the Medical and Scientific Advisory Council (MSAC) this year. Amongst the expertise of these new members, is Canadian movement disorders specialist Dr. Davide Martino who has been active in supporting members of our dystonia community our of Calgary.

Amy Bastian, PhD, PT
(Kennedy Krieger/Johns Hopkins)
Baltimore, MD, USA

Davide Martino, MD, PhD
University of Calgary
Calgary, Alberta, Canada

Kai Miller, MD, PhD
Mayo Clinic
Rochester, MN, USA

Jens Volkmann, PhD
University Hospital Würzburg
Würzburg, Germany

Katja Lohmann, PhD
University of Lübeck
Lübeck, Germany

Why Does the DMRF Fund Basic Research?

Basic research investigates the biological and genetic mechanisms of dystonia in laboratories to understand what causes it. This may include experiments with cell cultures, genetic sequencing, and rodent models to study dystonia pathogenesis—the biological mechanism and process by which the disease develops and progresses in the body.

The founding of the Dystonia Medical Research Foundation in 1976 came at a time when the study of movement disorders was transitioning from a loosely defined area to a recognized neurological subspecialty. Then, as now, the DMRF and DMRF Canada funded basic research related to drug targets, which are molecules in the body, usually proteins or nucleic acids, that are essential in a disease process and can be manipulated by a drug to correct or interrupt their function.

Identifying drug targets for dystonia has been critical to developing new medications and/or existing drugs that may be effective. This process takes time, and ongoing funding for basic research is essential to ensuring that the pace of discovery doesn't slow down.

The Importance of Clinical Research in Dystonia

Clinical research involves using human patients to study the disease's characteristics, develop diagnostic criteria, and test new pharmaceutical or surgical treatments. This may involve observational studies, patient registries and clinical trials involving patients. In the 1970s, the work of two key researchers helped change the way the medical community viewed the condition. Stanley Fahn, MD, and David Marsden, MD, showed evidence that dystonia was a neurological, not a psychiatric disorder.

For decades since then, clinical research in dystonia has evolved and in the last five years, has shifted from purely observational descriptions to more targeted interventions. The field has evolved with an overhauled classification system of dystonia, mapping the genetic causes of the disease, and refining precision treatments like botulinum neurotoxin and deep brain stimulation (DBS).

To read the full series, please visit
www.dystoniacanada.org/history/dmrfresearchsupport

Thank you to DMRF for permission to adapt and reprint for our Canadian audience. DMRF Canada shares the mission and works in partnership with DMRF in the United States to fund the best and most relevant dystonia research worldwide, including in Canada.

FREEDOM TO MOVE FOR DYSTONIA RUN WALK & WHEEL

Over $65,000 Raised

Thank you to everyone who participated in this year's event! Whether you joined us in Toronto on June 14 or participated virtually throughout June, your support made a meaningful difference. A special thank you to our support group leaders who organized community events in Kingston, Winnipeg, and Calgary, and to everyone who participated in them.

Freedom to Move in Winnipeg

Together, nearly 140 participants from 49 cities across six provinces raised more than $65,000 and surpassed our $60,000 fundraising goal! Every step, donation, and shared story helps advance dystonia research, strengthen support programs, and raise awareness for the more than 50,000 Canadians living with dystonia.

Celebrating Our Top Fundraisers

Congratulations to our top individual fundraisers and fundraising teams, whose incredible efforts helped make this year's campaign a success!

Top Individual Fundraisers

1. Mary Guy
2. JC for Team Wesley
3. Oliver Jaakkola

Top Fundraising Teams

1. Team Sudbury
2. Team Impact
3. Team Eli Konorti

Dwayne Backer Memorial Award for Excellence in Fundraising

Mary Guy is also the recipient of the *Dwayne Backer Memorial Award for Excellence in Fundraising*. The award honours Dwayne's remarkable legacy as a dedicated supporter of DMRF Canada and long-time Freedom to Move participant. Over two decades, he raised nearly $120,000 for dystonia research and support programs, and his generosity continues through his legacy gift.

Freedom to Move in Calgary

Toronto City Councillor James Pasternak officially starts the race in Toronto

Heartfelt Thanks

We are grateful to our 2026 Ambassador - Laurence Guénette-Rochon and her family for travelling from Quebec City to join us in Toronto at our June 14 Downsview Park event. Living with cervical dystonia, Laurence courageously shared her journey to raise awareness, reduce stigma, and inspire others.

Special thanks to volunteers Debbie and Helene Bauer for securing generous prizes for top fundraisers and for the Toronto event.

We also thank Toronto City Councillor James Pasternak, Ward 6 – York Centre, for attending, promoting the event, and offering words of support that helped shine a spotlight on dystonia and neurological health.

Thank You to Our Generous Sponsors and Partners

Whimsy Works · UNITED BAKERS DAIRY RESTAURANT · P&G · ONTARIO BRAIN INSTITUTE · INSTITUT ONTARIEN DU CERVEAU · AGO Art Gallery of Ontario · SPINCO LESLIEVILLE

Metro Lawrence and Bathurst | Metro Keele and Wilson | Metro Sheppard and Bathurst | Kiva's Bakery | Sobeys Hilda Thornhill | Fruit of the Land Bayview Village | No Frills-Bathurst and Wilson | Imagine Cinemas Promenade Thornhill

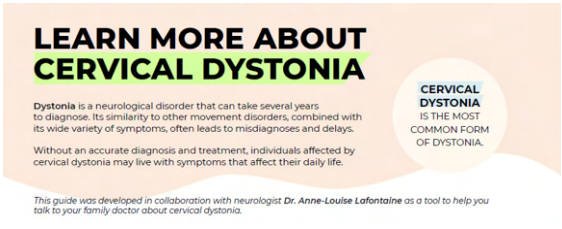
Shortening the Path to Cervical Dystonia Diagnosis

Help Us Share Our Resources!

Cervical dystonia is the most common form of focal dystonia. In some cases, it can take up to 10 years for an accurate diagnosis. Our goal is to ensure Canadians have all the tools to expedite their pathway to proper diagnosis and care.

In partnership with Patient Voice and AbbVie Canada, a downloadable guide to cervical dystonia is available to help people recognize symptoms and support conversations with healthcare providers.

Help raise awareness by sharing this resource with your family doctor and healthcare community. You may help someone receive an earlier diagnosis and access to appropriate care.



Download the guide:
www.patientvoice.io/dystonia

Personal Stories Help Spread the Word

In addition to the guide available on Patient Voice, a familiar face is also sharing her story on the site. Casey Kidson is well known in the dystonia community for her ongoing awareness and fundraising efforts through her "Dyfying Dystonia" campaign and now her story is featured on Patient Voice (in partnership with Abbvie Canada), providing that personal aspect that helps readers connect more with the information.

As a determined athlete Casey competes in races like triathlons and Ironman competitions all over the US and Canada. In the process, she raises funds and awareness for dystonia while also supporting her own well-being and mental health.

"Dystonia is a complicated illness and managing it is always going to come down to knowing your own needs and knowing your own body," she says. "That's been one of the great benefits of my fitness journey — the way it has helped me understand my health, accept my diagnosis, and always keep testing and pushing my limits."

You can access Casey's story and share it as part of your own awareness efforts at
www.patientvoice.io/shorts/defying-expectations-how-casey-outruns-and-outswims-and-outcycles-dystonia

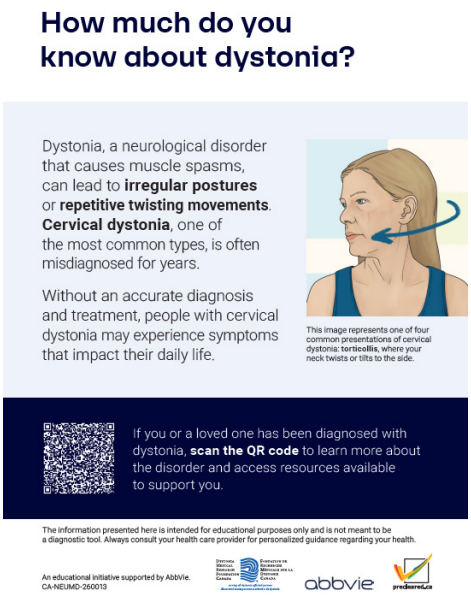
Lookout for a New Resource Offline

The internet is a vast source of information, however for those with dystonia, knowing where to find accurate information can be difficult. In order to support individuals who have recently been diagnosed Abbvie Canada has created a resource providing reliable information, introducing available resources and directing readers to DMRF Canada. AbbVie Canada will be distributing this resource to clinics for display.

Be on the lookout for this valuable resource at your local movement disorders clinic. You can help ensure this information is available to all patients by asking whether your family doctor or GP would be willing to have copies available in their offices.

Our Sincere Thanks to AbbVie Canada for their support.

abbvie



Building Canada's Next Generation of Movement Disorders Specialists

Meet Dr. Blanche Perraud, the 2026 Clinical Movement Disorders Fellowship Recipient

One of DMRF Canada's most effective strategies has been to partner with other movement disorders organizations to maximize our impact. In March, we announced the launch of the Clinical Movement Disorders Fellowship Program, a partnership between Parkinson Canada, the Huntington Society of Canada and DMRF Canada. This collaboration aims to address the shortage and train the next generation of movement disorder specialists providing support to communities across Canada.

This year's recipient is Dr. Blanche Perraud from the University of Sherbrooke. Dr. Perraud is currently completing her year-long fellowship in London, UK, at the National Hospital for Neurology and Neurosurgery (NHNN). As one of the oldest clinical neuroscience centers in the world, NHNN is at the forefront of therapeutic options for movement disorders.

Dr. Perraud's interest in movement disorders began during her undergraduate degree. She spent four months on a project dedicated to Parkinson's Disease and became fascinated with how neurological movement disorders could be better addressed. Then during her neurology residency, Dr. Perraud noticed that those with movement disorders like dystonia were often underrepresented in research, driving her to pursue training that could fulfill this need.

She has felt lucky that her training with the University of Sherbrooke allowed for hands-on experience with botulinum toxin injections. Dr. Perraud was struck by how much of a difference this treatment could make in terms of quality of life for patients. She enjoyed developing a rapport with her dystonia patients and working collaboratively with them to get the most benefit.

Her time spent in London will build on her experience in Canada, providing her with 5-days a week of clinical experience, access to a much higher volume of patients, and mentorship from world-renowned movement disorders specialists. Dr. Perraud sees this as an opportunity to bring this expertise back to Canada. "This training will transform my practice, allowing me to offer my patients the most modern therapies available globally." Specifically, she looks forward to gaining hands on experience with Deep Brain Stimulation and MRI-Guided focused ultrasound. "These are high-tech tools that can significantly improve a patient's quality of life," she says.

Dr. Perraud stresses that this opportunity could not have been made possible without the support of donors. "Your support is making an international bridge possible. Moving abroad for a year of specialized training is a significant personal but also financial commitment, as there is no institutional funding for this. Your grant is not just supporting my career; it is an investment in the health of Canadians."

That investment will be felt directly upon Dr. Perraud's return from her fellowship. She is already committed to joining a movement disorders clinic on Montreal's South Shore, doubling their capacity to see patients.

This impact does not stop with Dr. Perraud and her future patients. She has long-term plans to become a clinical leader and educator of movement disorders. "As a teacher within a university network, I also look forward to mentoring the next generation of neurologists, sharing the unique international perspective I gained during my time in London."

Celebrating Brenda Currey: Decades of Dedication

As we recognize 50 years of DMRF Canada, we're reflecting on the people who have made this milestone possible. We simply wouldn't be here without the dedication of our members and volunteers. One of those remarkable individuals is Brenda Currey, President of the Edmonton Dystonia Support Group and peer support contact for those living with dystonia and generalized dystonia specifically, who has spent nearly 40 years volunteering with DMRF Canada and has become a familiar and inspiring presence in our community.

Brenda has been living with generalized dystonia for most of her life. Her symptoms began in early childhood and affect most parts of her body. As a result, she has used a wheelchair for many years.

Seeking connection with others who understood their family's experience, Brenda's mother, Sheron contacted DMRF Canada when it was first founded. Brenda had been diagnosed the year before at age 7. They were looking for a community where they could share stories, exchange practical advice, and build relationships with people living with dystonia. It didn't take long for Brenda to become a leader. Edmonton founded their local support group in 1990 and a few years later when they were looking for a new president, Brenda stepped in to the role. She got to work organizing meetings and producing newsletters to raise awareness and keep members informed.

Brenda also recognized the importance of fundraising. Although she says she wasn't sure where to begin, she was always willing to say "yes" when help was needed. In 1999, DMRF Canada board member Connie Zalmanowitz, whose son has dystonia, approached Brenda with the idea of organizing an Edmonton Run, Walk and Wheel fundraiser in support of dystonia research. Brenda was quick to ask, "How can I help?"

That willingness to help has never faded. Over the years, Brenda has dedicated countless volunteer hours to the Edmonton Dystonia Support Group. Those early Run, Walk and Wheel events paved the way for other initiatives, including Edmonton's casino fundraisers and the group's annual letter-writing campaign.

For many years, Edmonton had two collaborative dystonia groups. One focused on peer support and awareness, while Brenda and Connie concentrated much of their energy on fundraising. "Research is important," Brenda says. "There could be a breakthrough, and the only way we can get one is if we keep raising money." She also points out that there are more researchers interested in studying dystonia than there is funding available. "If they're interested, the money should be there," she emphasizes.

More recently, Edmonton's two groups merged once again, with Brenda stepping into the role of President. She hopes to continue growing the group's membership and create more opportunities for people to connect in person. Just as she once sought out a community of people who understood her journey, she wants to ensure that same support is available to others. "I would love to hear what people want," she says.

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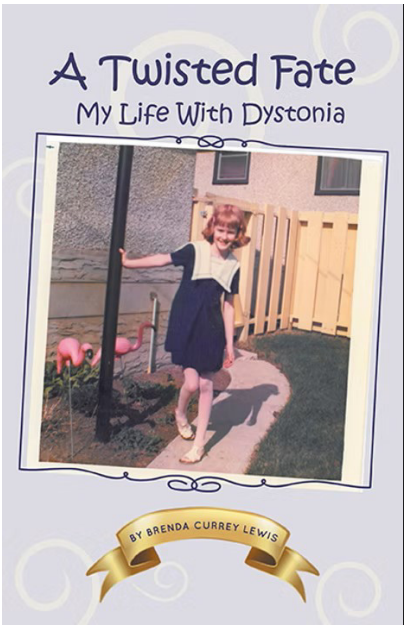
Celebrating Brenda Currey: Decades of Dedication (Continued)

Beyond her volunteer work with DMRF Canada, Brenda leads an active and engaged life. "I'm quite independent," she says. "People would probably be surprised at the things I can do." She does her own grocery shopping, cares for her loyal dog, Cooper, and regularly visits her mother, who continues to be one of her greatest supporters after volunteering alongside Brenda in the dystonia community for many years.

Exercise is also an important part of how Brenda manages her dystonia. She has attended programs at the Steadward Centre twice a week for nearly 40 years, focusing on maintaining flexibility while enjoying the friendships she's built there. "I've made a lot of friends there," she says. At the same time, she's learned the importance of listening to her body and allowing herself time to rest and recover when needed.

In 2013, Brenda shared her story in her memoir, A Twisted Fate: My Life with Dystonia. She wrote the book to raise awareness and to help others navigate their own journeys with dystonia. More than a decade later, it continues to reach readers around the world. Brenda still receives messages from people who say her story has helped them better understand dystonia and life with a disability. As one reviewer wrote, the book "inspires you to live your life to the fullest," a sentiment that perfectly captures Brenda's enduring optimism, resilience, and commitment to helping others.



As DMRF Canada marks its 50th year, we're proud to recognize volunteers like Brenda Currey, whose generosity, leadership, and unwavering belief in the power of community continue to strengthen our organization and inspire people living with dystonia across Canada.

More about Brenda and her ongoing efforts to raise awareness can be found on her book website www.atwistedfate.ca

Volunteer with the Edmonton Support Group

The Edmonton Support Group is currently looking for volunteers to fill two important roles:

- **Support Group Co-Leader**: Help organize and facilitate support group meetings, welcome participants, and work alongside Brenda to create a supportive and welcoming space for members.
- **Casino Chairperson**: Help coordinate the group's casino fundraising activities, including organizing volunteers and assisting with the planning and administration needed for the event.

If you are interested in either role, please contact info@dystoniacanada.org.

To connect with Brenda or learn more about support in the Edmonton area, visit: www.dystoniacanada.org/edmonton

Spotlight on the Stride Dystonia Study for Patients with Isolated Dystonia by Vima Therapeutics

New treatments are high priority in dystonia medical research. We're encouraged to see ongoing clinical trials looking at new treatments, especially for those types of dystonia that remain difficult to target with current methods. The Stride Dystonia Study by Vima Therapeutics, is one of these clinical research trials. While botulinum toxin injections remain one of the most widely used treatments for dystonia, surveys showed that many types of dystonia are not truly focal and affect more than one part of the body, which is difficult to target with localized injections. Founder and CEO, Bernard Ravina, and his team started looking at potential oral medications that could be used in more wide-spread dystonia.

This research study is testing whether an investigational oral medication (VIM0423) is effective in reducing the severity of dystonia symptoms in those with isolated dystonia. Currently, the study is running out of centres in the United States, following participants for approximately 32 weeks from consent to conclusion. Eligible participants are randomly assigned to one of two groups. One group receives the investigational drug and the other receives a placebo, both taking the medication twice a day. The random assignment and inclusion of a placebo group make the Stride Dystonia Study one of the highest-quality types of clinical research, helping scientists determine whether the treatment itself is responsible for any observed effects. For more information, visit www.stridedystonia.com

The study is being conducted at centres in the United States and is currently open only to eligible U.S. residents. Canadian residents are not eligible to participate at this time; however, the study is being highlighted to keep the Canadian dystonia community informed about emerging research.

Continue reading to learn more about Vima Therapeutics and how the Stride Dystonia Study is taking shape. Thank you to DMRF for permission to adapt and reprint this interview for our Canadian audience.

Q & A with Bernard Ravina, MD, MS, CEO of Vima Therapeutics

Bernard Ravina, MD, MS, is the founder and Chief Executive Officer of Vima Therapeutics, a clinical-stage biotechnology company based in Cambridge, MA, focused on developing new oral treatments for dystonia and related movement disorders. Dr. Ravina has over 25 years of cross-functional experience spanning government, academia, and the biopharmaceutical industry.

Q: You've spent much of your career as a neurologist treating people with movement disorders. What motivated you to found Vima Therapeutics and focus specifically on new dystonia treatment options?

When I had the opportunity to start a new company, I asked two main questions: 1. Is there a need for a new treatment? 2. Do we understand enough about the underlying science and biology to develop a new treatment? As I looked into this further it became clear that the answer to both was yes. There haven't been any new treatment approaches for dystonia, other than toxins and deep brain stimulation (DBS), since I was a movement disorders fellow 25 years ago. On the biology and science, we realized that there were common themes about neurotransmitter imbalances across different types of dystonia. That got us working on some initial ideas and experiments back in 2023 and set us on the path to develop a potential new oral treatment for dystonia.

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Q: You attended the 6th Samuel Belzberg International Dystonia Symposium in 2023. What stood out to you from the meeting?

That was a great meeting and showed me that there was energy, infrastructure like the Dystonia Coalition and natural history study, and a lot of talented scientists. What also stood out was some of the data from the Dystonia Coalition and DysTract German natural history data that showed that when you look closely, more people have more widespread dystonia or more parts of the body involved than previously thought. Not focal, or limited to one body part, but in two or more body parts that might not be addressed by toxin injections.

Q: How important are gatherings like this for connecting researchers and clinicians?

I can't overstate the value of the research and clinical community—it's where you get and share ideas and those groups become the people that run clinical trials and develop new treatments. You see it in every other field, and the research community grows along with the collaboration that comes from running clinical trials.

Q: Many current treatments for dystonia don't fully control symptoms or can be difficult to tolerate. From your perspective, where are the biggest gaps today?

Our goal is to develop a reliable, daily oral treatment that would work regardless of the body part or parts affected by dystonia. That just doesn't exist now. Toxins have fluctuating or variable effects over time and are only FDA approved (and Health Canada) for neck and eyes and are very dependent on the quality of the injection and skill of the clinician. DBS can have big effects in some, but of course it's still brain surgery and natural history data show that only about 3% of dystonia patients have DBS. In short, those treatments are helpful, but we need something that can treat more people more of the time.

Q: Your company is developing an oral medication, VIM0423, which is designed to target the underlying biology of dystonia. Can you explain, in simple terms, how it works in the brain?

The basic idea that comes from years of research is that there is an imbalance in key neurotransmitters that are involved in how the brain controls movement. More specifically, we think there is an excess of a brain chemical, acetylcholine, relative to dopamine, in a part of the brain called the striatum, that is basically a relay center for movement signals. Past studies and clinical trials suggest that blocking acetylcholine signaling may improve dystonia symptoms. However, existing medicines that block acetylcholine receptors are poorly tolerated due to side effects. So, we have designed our investigational drug, VIM0423, to work on that mechanism, reducing acetylcholine signaling, while improving safety and reducing the side effects, with the goal of having a potential new, oral medication for dystonia.

Q: You've recently initiated the Phase 2 STRIDE Dystonia trial. What is the main goal of this study?

The goal of any clinical trial including Stride Dystonia is to understand the potential benefits and the potential side effects. That's what we are trying to do here and specifically to understand what the best dose is to maximize benefit on dystonia and minimize side effects to make the drug as useful as possible. This is a process and the data from Stride Dystonia will help us to plan the next study and the path forward with the FDA, which is responsible for granting approval of all new medications.

Q: When might patients expect to see results from the STRIDE Dystonia trial, and what would success look like?

We are hopeful that we will complete the clinical trial in the first half of 2027. That timeline depends on everyone working together.

Q: How important is patient participation in advancing research like this?

Patient participation is the key ingredient. We started this company for people living with movement disorders. The trials that we conduct are a collaboration between people with dystonia and researchers. Trials don't happen without people enrolling, staying in the trial, taking the study drug, and relaying their objective and accurate experience in the trial. That's what becomes the data. It's also one of the reasons we call this trial Stride Dystonia, making progress and taking the next step together. Participating in trials is a contribution, it's not about a particular person getting treatment; it's about helping to develop future treatments. So, as we get started on this trial, I just want to say thank you for the time and effort to those people who are already participating, and for those who are interested, you can learn more about the trial at stridedystonia.com

Q: Are there forms of dystonia that may benefit most from this therapy?

Right now, we are focused on isolated or primary dystonia. This dystonia includes people who have dystonia not caused by another neurological disorders. We also want to study people who have dystonia in more than one part of the body —that allows us enough severity to measure any change in the clinical trial.

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We are hopeful that VIM0423 could work for people with many different kinds of dystonia regardless of the part of the body that's involved, but we have to start somewhere, and this trial needs to be successful for us to make progress.

Q: If VIM0423 and similar therapies are successful, how do you envision the treatment landscape changing over the next 5–10 years?

A first approved oral medication for dystonia could be a game changer. First, it would offer people an entirely different way of treating dystonia without injections or surgery. It will also set the stage for more new treatments to be developed. It will tell people who invest in research that dystonia is an area poised for progress; it will build that research community that we were talking about earlier, so that future trials can be even more efficient; and it will lay a path with the FDA for future treatments to follow toward approval. Having a defined regulatory pathway would encourage other companies and researchers to explore other new treatments. Changing that 5–10-year landscape starts with one successful trial, and so we are excited about Stride Dystonia and our collaboration with the DMRF and dystonia community to continue to move dystonia research forward.

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Participate in Clinical Trials and Dystonia Research Studies

Research participants play a vital role in advancing our understanding of dystonia and improving future care. A new **Alberta Idiopathic Dystonia Research Project** is recruiting adults with **adult-onset cervical dystonia** to help researchers better understand the condition and develop improved therapies. Your participation could help shape future treatments and improve the lives of others living with dystonia.

To learn more about this and other research opportunities, visit www.dystoniacanada.org/clinical-trials-for-dystonia.

You can also explore the research recruitment websites listed on the page. On each website, enter "**dystonia**" in the search box to find relevant studies.

"As a newly diagnosed person with cervical dystonia, I contacted DMRF Canada for information. I am very pleased with what was sent to me, and I was able to receive paper copies of the information"
- Karen

Advocacy

DMRF Canada is an active member of **Neurological Health Charities Canada (NHCC)**, working with other neurological charities to advance shared priorities and improve outcomes for people affected by neurological conditions.

Working together allows us neurological charities to share expertise, coordinate advocacy efforts, and maximize our collective impact. The **NHCC 2025–2026 Impact Report** highlights this collaboration and efforts, including engagement with federal decision-makers, advocacy planning, and work toward a national population-level neurological health survey.

The report available in English and French:
www.mybrainmatters.ca/education/reports-publications/

How Physiotherapy Can Help People Living with Dystonia

Last year, DMRF Canada surveyed people living with dystonia to better understand how they manage their symptoms. More than half of respondents reported participating in physiotherapy, making it the most commonly used complementary therapy. To learn more about how physiotherapy can help people with dystonia and how to find the right therapist, we spoke with physiotherapist Haseel Bhatt, founder of Neurology Rehab in Durham Region, Ontario.

Bhatt has spent his career treating people with movement disorders, including dystonia, Parkinson's disease, and Functional Neurological Disorder. His experience in movement disorders clinics has given him extensive knowledge of the challenges people with dystonia face, the treatments available, and the role physiotherapy can play alongside medical care.

Haseel Bhatt is a physiotherapist and owner of Neurology Rehab. He has extensive experience working in the area of movement disorders.

Why Consider Physiotherapy?

Although all people with dystonia are different, Bhatt has some general advice. "Anyone who hasn't tried physiotherapy for their dystonia could probably benefit," he says. "If you're a person living with a dystonia and trying to push through pain, or push through tightness, there's likely a better way."

Specifically, Bhatt suggests that those who are receiving botulinum toxin injections can especially benefit during a certain time in their treatment cycle. "There's a therapeutic window after [botulinum toxin] injections in which patients can do a lot of work to retrain muscle patterns," he says.

Dr. Jane, Liao, a movement disorders neurologist also shares this recommendation. "There have been good studies specifically looking at the role of physiotherapy in treating cervical dystonia," she says. "The combination of botulinum toxin injections and physiotherapy had better outcomes than either alone." Dr. Liao notes that adding physiotherapy to a treatment plan can be especially helpful in decreasing pain.

Finding the Right Therapist

If physiotherapy sounds like it might be worth exploring, the next step is finding a therapist with the right expertise. "Ideally, you want to find somebody with at least a neurological rehab background," Bhatt says.

He also advises that it's okay to ask someone before working with them if they have ever worked with dystonia patients before. "I can technically treat a soccer player who gets injured at the World Cup, but that's not my expertise," he says. If someone is not a good fit, Bhatt also suggests asking if they have any recommendations since they may know where to find someone.

How Does the Process Begin?

Bhatt treats therapy as a collaborative effort between himself and the patient. In order to understand a person's needs, he first completes an assessment. He looks at how dystonia presents in terms of movement patterns, tension, range of motion and posture. A thorough assessment, he emphasizes, also looks at the person as a whole. This includes getting an idea of how nonmotor symptoms like pain, anxiety and stress are impacting movement, as well as gaining an understanding of what the person does in their daily life and how dystonia affects these activities.

The assessment is also an opportunity for the person with dystonia to decide if they will move forward with physiotherapy. "By the end of the assessment session, you should know if this is a path or approach that would be helpful for you," Bhatt advises.

How Treatment Works

Once the assessment is complete, treatment is tailored to the individual's symptoms, goals, and daily activities.

One of the first skills many dystonia patients gain in physiotherapy is awareness of movement. Bhatt notes that once certain postures and movements get patterned into the brain, many of his patients overestimate how pronounced they are. This in turn can exacerbate non-motor symptoms like anxiety, in a vicious cycle, leading to an increase in motor symptoms like tension. Bhatt often uses video feedback to help patients notice and track their movement, giving them a more accurate baseline.

Once a patient has a better sense of what is happening in their body, Bhatt strives to explore different ways of moving that increase function and alleviate discomfort.

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This involves strengthening and stretching certain muscles and using that increased body awareness to selectively activate muscles, achieving movement more efficiently.

He lists tools like vibration stimulation, breathing and relaxation, as well as sensorimotor exercises to achieve these different ways of moving. Bhatt will also explore sensory tricks that may alleviate symptoms.

There is no simple answer when it comes to timelines for treatment. This can vary based on a person's type of dystonia, previous experience, personal goals and resources. Bhatt's approach is focused on creating an exercise plan patients can do every day at home to build and maintain gains. Bhatt suggests being up front with your physiotherapist about limitations in the time or resources you have for physiotherapy and you can work towards a realistic plan together.

What Kinds of Improvements are Possible?

For Bhatt, physiotherapy isn't about perfect movement. It's about helping people do the things that matter most to them. He has many examples of functional goals his patients have been able to achieve through physiotherapy programs.

There was the teacher who wanted the ability to turn her head to address a group of students without a pronounced tremor interfering.

Bhatt recalls another person with dystonia who wanted to improve their balance to the point where they could navigate going to see a movie in a theatre. They worked together to build stamina and started with a short walk to the corner store. They introduced carrying, picking up a carton of milk to bring home. Eventually they worked their way up to carrying their popcorn up the steps to their seat in the movie theatre.

He recalls a woman who wanted to be able to write notes for her husband and continue signing her own cheques. They worked on modifying arm posture and relaxing the shoulder, giving her hand more freedom to hold a pen and write.

Recently, he had a patient remark that a year ago she could not have imagined being able to walk with her dog without pain. After working together on exercises to increase strength and strategies to manage pain, she was able to walk for longer distances and without pain.

It's these functional gains that make therapy motivating and effective. "People can go to physiotherapy for as long as they want," Bhatt explains, "But if there's no goal at the end of it, oftentimes they won't do the exercises and they don't understand how those exercises are going to help."

Dr. Jane Liao, MD, MSc, FRCPC
Movement Disorders Neurologist

Barriers to Access and How to Address Them

Access is a key barrier for many complementary treatments for dystonia. When it comes to physiotherapy, specialized knowledge in movement disorders can be hard to find. Bhatt provides services in person and online for those who are too far geographically. Telehealth has increased within provinces, however there are regulations requiring physiotherapists to be licensed in the province where they provide care. Increasing flexibility in licensing could mean that more people can access professionals with specialized knowledge across provinces. Contacting your provincial physiotherapy regulator or professional association can help in terms of making the demand for these changes to licensing known.

There is also the issue of cost. While publicly funded, multidisciplinary programs for disorders like Parkinson's disease exist, there isn't the same access for those with dystonia. Dr. Liao acknowledges this is an issue. "I hope we will see an increase in subsidized specialized physiotherapy and dystonia-specific group exercise programs in the future that can fill the unmet needs," she says.

Raising awareness and advocating for these services where you live, can be the first step in making physiotherapy a standard part of provincially funded movement disorders clinics.

While physiotherapy isn't a cure for dystonia, it can help many people move more comfortably, build confidence, and work toward meaningful everyday goals. Dr. Liao stresses that because dystonia can present differently in different people, specialists are learning more about it every day. "For many patients, the medications we currently have often only work partially or carry too many side effects. Complementary therapies such as physiotherapy are beneficial and carry no side effects." As Bhatt puts it, "It's about learning, experimenting and trying new approaches to movement."

DMRF Canada maintains a list of professionals who are knowledgeable about dystonia. To find a physiotherapist in your area, you can visit: www.dystoniacanada.org/physiotherapy-and-dystonia

We gratefully acknowledge AbbVie Canada's support of our work for the dystonia community.

abbvie

Community Education and Impact

DMRF Canada Is Built and Sustained by Volunteers: Read on to learn about our recent successes, current opportunities, and ways you can get involved.

Calling All Event & Fundraising Volunteers!

Do you enjoy planning events, bringing people together, or raising awareness for a cause you care about? DMRF Canada is looking for volunteers to help organize local fundraising initiatives and community events that support dystonia research, education, and support programs across the country.

Whether you have experience or are just looking to get involved, we'd love to hear from you. As a small national charity, our impact is made possible by the dedication and passion of volunteers from across Canada!

Seeking Support Leaders and Contacts

Give back in your local community and join our support group network! We are looking for volunteers in the following locations:

- Victoria BC (Co-leader)
- Greater Vancouver Area (Co-leader)
- Edmonton AB (Casino Chairperson, Co-leaders)
- Fredericton NB (New leader)
- Saskatoon SK (New Leader)
- Hamilton ON (New Leader)
- Peer Support for Youth (Canada)

To learn more or get involved, please contact us at info@dystoniacanada.org.

New Support Group in Victoria BC

We are pleased to welcome Susan Rivet of Victoria, British Columbia, as DMRF Canada's newest **Support Group Leader**. To connect with Susan and learn about support opportunities in the Victoria area, visit: www.dystoniacanada.org/victoria

Dystonia Education Materials and Resources

Updated Educational Resource: Functional Dystonia

Providing our community with trusted information to better understand dystonia and advocate for appropriate care is a key part of our mission. We have updated our **Functional Dystonia** brochure to help individuals, families, and healthcare professionals better understand this form of dystonia. Adapted from expert-reviewed information from DMRF USA and reviewed by specialist Dr. Sean Udow, we are grateful for their expertise and support.

The brochure, along with our full collection of educational resources, is available on our website: www.dystoniacanada.org/dystonia-information-materials

Status Dystonicus Educational Resource - Coming Soon!

Status dystonicus is a rare but one of the most severe and potentially life-threatening complications of dystonia. DMRF Canada's 2025–2027 Clinical and Research Fellow, **Dr. Lindsey Vogt** of SickKids Hospital, **Dr. Monica Ferrer Socorro** of Boston Children's Hospital - Harvard Medical School, and **Dr. Jonathan Mink**, DMRF, Chief Scientific Officer, are developing a family-centred educational resource to help caregivers recognize warning signs, and communicate effectively with healthcare teams.

Special thanks to the Rexall Care Network and Bingo World & Gaming Richmond Hill through the Ontario Charitable Gaming Association's Charitable Gaming Community Good program. Their generous support has helped make this Status Dystonicus resource possible.

Volunteer Spotlight: Helen Dyks

Meet Helen Dyks, of Kingston, Ontario. She's relatively new as a volunteer Support Group Leader, but her experience with dystonia started six years ago. Her symptoms began as uncontrollable blinking and for two years were wrongly attributed to causes like allergies, tics and depression, until a neurologist diagnosed her with Meige Syndrome (orofacial dystonia).

Helen started botulinum toxin treatments and achieved short-term management of some symptoms but there was something missing for her. "I kept looking at the foundation website," she says. "I started researching a little bit more and decided I should get involved because I didn't have anybody to talk to." If she was feeling lost, perhaps there were others as well.

She attended one of the National Virtual Support Meetings and started to find that understanding she was looking for. "Hearing others' stories offered valuable perspective on my own journey."

Connecting with people in other parts of the country was helpful, but Helen wanted to take it a step further and see if she could find a community closer to home. Since then, she has become a local source of knowledge for patients and medical practitioners, hosted a Freedom to Move walk in her area and hosts virtual support meetings for Meige Syndrome/Blepharospasm.

"I really find that it helps to talk to people who have dystonia because they understand what I am going through. And if I can help one person maybe make their journey not as hard as it was for me in the beginning, I want to keep doing that."

Thank you to volunteers like Helen who put their skills and compassion to use as our Support Group Leaders across the country. Your work keeps our community strong, hopeful and learning from each other.

Helen has also recently joined DMRF Canada's Support Advisory Group (SAG). The SAG was formed to provide enhancements to the support group structure and advise staff on support programs and strategies to address unmet needs within the dystonia community. To learn more about the Support Advisory Group and its members, visit: www.dystoniacanada.org/dmrf-canada-support-advisory-group

Helen joined by supportive friends in the rain at the 2026 Freedom to Move Run Walk and Wheel.

For more information on becoming involved with a support group in your area, visit www.dystoniacanada.org/support

Community Education and Impact (Continued)

September is Dystonia Awareness Month: Amplify Our Collective Voice

As DMRF Canada marks 50 years of supporting Canadians affected by dystonia, we invite you to help raise awareness this September. As the only national charity in Canada dedicated exclusively to the dystonia community, we know that greater awareness leads to earlier recognition, increased understanding, stronger support, and continued progress in research.

Here are a few ways you can get involved in person and online:

- **Wear Blue for Change:** Wear blue throughout September, share your photos on social media, and tag **@DMRFCanada using #DystoniaAwareness**.
- **Celebrate Blue Landmarks:** If you see a landmark illuminated in Dystonia Blue, take a photo, tag DMRF Canada, and share it online.
- **Spread the Word:** Share educational resources, facts about dystonia, or your personal story using **#DystoniaAwareness #DystoniaStrong**
- **Become a Dystonia Awareness Ambassador:** Help raise awareness in your community by sharing educational materials and connecting with others.

Together, we can continue building a future where everyone affected by dystonia is seen, supported, and understood.

Learn more at www.dystoniacanada.org/dystoniaawarenessmonth

Join Us This Fall: Free Educational Symposia

This fall, join us for two free educational events designed to bring the dystonia community together. Hear from leading experts, learn about the latest developments in care and research, and connect with others affected by dystonia.

Montréal Symposium
September 12, 2026 | 12:00 PM to 4:00 PM
Hosted by the Montréal French-Speaking Support Group (Dystonie-partage)

www.dystoniacanada.org/2026MontrealSymposium

Greater Toronto Area Symposium
October 25, 2026 | 9:00 AM to 4:30 PM
Hosted by the Greater Toronto Area Dystonia Support Group

www.dystoniacanada.org/2026GTHASymposium

Visit our Upcoming Events Page learn more about these symposia and other upcoming initiatives near you: www.dystoniacanada.org/upcoming-event

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Dystonia Medical Research Foundation Announces 2026 Grant and Fellowship Recipients to Advance Dystonia Research

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 possible.

GRANTS

Research grants are available in support of hypothesis-driven research at the genetic, molecular, cellular, systems, or behavioral levels that may lead to a better understanding of how dystonia changes the normal way the body works (pathophysiology) or new therapies for any or all forms of dystonia.

Darius Ebrahimi-Fakhari, MD, PhD & Katerina Bernardi, MD
Creating Clinical Trial Readiness for cAMP-Related Dystonias through Natural History Characterization and Therapeutic Discovery
Boston Children's Hospital

QUICK SUMMARY: Dr. Ebrahimi-Fakhari's research will study cAMP-related dystonias and how rare and severe childhood movement disorders are caused by genetic changes that disrupt communication between brain cells. Affected children experience uncontrolled movements, painful muscle contractions, and severe dystonic episodes, yet there are currently no disease-modifying treatments and few therapeutic options. This project will follow 100 children over two years to better understand how these conditions progress and to identify meaningful measures needed for future clinical trials. In parallel, researchers will create patient-derived brain cell models to study disease mechanisms and screen thousands of existing FDA-approved drugs to identify potential treatment candidates. The central hypothesis for this project is that systematic longitudinal characterization of cAMP-related dystonias will establish clinical trial readiness by defining standardized outcome measures and disease trajectories. While in the second part, patient-derived neuronal models will enable repurposable small molecule discovery that targets cAMP signaling. So that is our goal.

RESEARCHER'S PERSPECTIVE: What this DMRF award means to us, honestly, is hope—hope that we can bring back to he families in our clinic. Every week, I sit with patients who have watched their child develop one of these disorders, and the hardest part of my job is telling them there is no disease modifying treatment yet. This grant changes that conversation. That means we can now confidently say we're actively working on it, and here's exactly how. So, to the DMRF community, the families, the advocates, the scientists who build this foundation, thank you. Your support makes this work possible, and I'm honored to be part of it.

Ignacio Keller Sarmiento, MD
Integrative Transcriptomic and Machine Learning Framework for Novel Dystonia Gene Identification
Northwestern University

QUICK SUMMARY: The goal of Dr. Sarmiento's research is to improve genetic diagnosis, better understand disease mechanisms, and support the development of targeted therapies for affected children. This project will use advanced computational and machine learning approaches to analyze brain gene-expression data and identify new genes that may contribute to dystonia.

Article continues on page 20

Researchers will then examine large whole-genome datasets from children with dystonia to find rare, potentially harmful genetic variants in these candidate genes.

RESEARCHER'S PERSPECTIVE: Over the years, we have discovered several genes linked to dystonia. However, despite this progress, most people with dystonia still do not receive a clear genetic answer. This lack of answers can be incredibly frustrating for patients and families and limits the development of new treatments. The goal of my research is to help close this diagnostic gap. Being funded by the Dystonia Medical Research Foundation is incredibly meaningful to me. It represents the trust and support of a community that understands how urgent this work is. The DMRF plays a vital role in turning scientific discovery into progress for people living with dystonia. I am deeply grateful to the Foundation and to everyone who supports its mission.

RESEARCH FELLOWSHIPS

Postdoctoral fellowship awards recognize and support outstanding young scientists who have earned a doctoral degree and have embarked on a period of mentored research. The DMRF is supporting postdoctoral fellows who are working to fundamentally improve our understanding of brain dysfunction and molecular mechanisms underlying dystonia.

Viviana Hernández Castañón, PhD

Predictive Modeling of Dystonic Biomarkers Using Minimally Invasive EEG Recordings

Virginia Tech University

QUICK SUMMARY: Dystonia is a common movement disorder characterized by involuntary muscle contractions and abnormal postures, but its causes and early detection remain poorly understood. This project studies early brain changes using a mouse model in which some animals develop dystonia while others with the same mutation remain symptom-free. Researchers will record brain activity using electroencephalography (EEG) and track movement over time to identify patterns that predict when dystonia symptoms will appear. The goal is to discover early brain markers that could help doctors detect dystonia sooner and guide more effective treatments.

RESEARCHER'S PERSPECTIVE: One of the challenges with dystonia is that we still don't fully understand what is happening in the brain when dystonia develops, and that makes early diagnosis and the advancement of treatments more difficult. So in this project, we study how brain activity changes over time in dystonia. I am really grateful for the support that we receive from the Dystonia Medical Research Foundation. Thanks to this support, we are conducting this study with the ultimate goal of contributing to the lives of patients and families affected by dystonia.

Nguyen Minh Thu Pham, PhD

Autophagic Targeting of Nuclear Condensates to Restore Protein Homeostasis in Dystonia

Yale University

QUICK SUMMARY: DYT1 dystonia is a childhood-onset movement disorder caused by mutations in the torsin protein, which disrupts how cells maintain healthy proteins. This research found that cells lacking torsin form harmful protein clusters, called condensates, that trap important quality-control factors and lead to cellular stress. Building on previous discoveries, this project will test how activating autophagy—the cell's natural cleanup system—can remove these toxic condensates and restore normal protein balance. The goal of my research is to identify new therapeutic targets and potential treatment strategies for dystonia.

RESEARCHER'S PERSPECTIVE: My work is dedicated to identifying the molecular glitch in dystonia and finding ways to help cells repair themselves. With support from Dystonia Medical Research Foundation, we converted our research from theory to action. The postdoctoral fellowship from the DMRF allows me to conduct the next phase of our study. Thank you for making this work possible.

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Amplify Your Impact

Your story has the power to inspire generosity. Honour a loved one through fundraising and explore how Benevity can help multiply your impact.

Rob Bell, son of former Toronto Support Group Leader, Jacqueline Bell, continues to raise funds for dystonia with his family and the support of his workplace.

In our community, giving is not just a one-time act. At DMRF Canada, we have seen donors make an impact that ripples far beyond themselves. An example of this is former Toronto Support Group Leader, Jacqueline Bell, who passed away in July 2025. Jacqueline is described by her family as someone who "Passionately lived the identity of being a helper, at home and around her community." Inspired by her commitment, Jacqueline's family carry on her legacy of helping and giving, participating yearly in the Freedom to Move campaign as Team Bell.

To make an even greater impact in honour of Jacqueline's memory, her family members have been able to multiply the donations they receive by getting their workplaces involved. A key to this has been making contributions easy, through a Canadian-based platform called Benevity. Many workplaces engage in team building activities, allocating time and funds towards causes that are important to them and their employees. Benevity streamlines this process for workplaces even providing tools to match donations made by their employees. As a result of their commitment and giving through Benevity, Team Bell has raised thousands towards dystonia research and has no plans to stop.

Rob Bell is Jacqueline's son and a committed fundraiser. "Supporting the Freedom to Move Run for Dystonia became more than just attending the annual event," he emphasizes. "It was about sharing a cause that is deeply personal to me. By working with my employer's fundraising committee, sending an organization-wide email with event details and a Benevity donation link, and reaching out to colleagues one-on-one, I learned that genuine, heartfelt conversations are often what inspire people to get involved and make a lasting impact."

Team Bell is a prime example of how people and their stories inspire giving. If dystonia has had an impact on your life or a loved one's life, consider whether you have a workplace who could support your fundraising efforts through involvement and fund matching programs. We're thankful for the leadership of volunteers like Rob and his family, as well as tools like Benevity that make this possible. You could make a similar impact to Team Bell. Amplify your fundraising efforts today!

Leave a Legacy of Hope

Some gifts create an impact that lasts for generations. Over the past few years, DMRF Canada has been deeply honoured to receive several bequests and estate gifts from compassionate supporters who chose to include our organization in their wills.

These gifts are more than financial contributions. They help advance groundbreaking research, strengthen support programs for those living with dystonia, and bring us closer to a cure. They provide hope for the future. To the individuals and their families who have chosen to leave this remarkable legacy, thank you. Your generosity will continue to make a difference for years to come.

If you are considering how you would like to leave your own legacy, we invite you to learn more about including DMRF Canada in your estate plans and becoming a member of our Legacy Society.

Visit www.dystoniacanada.org/legacy to explore how your future gift can help create a world without dystonia.

Take the Challenge. *Do It* for Dystonia.

Support the dystonia community as DMRF Canada marks its 50th anniversary. Whether you have a hobby you love, a special talent to share, or have been looking for the motivation to try something new, this is your chance to make a difference while raising funds and awareness for dystonia.

There are no limits. Whatever you choose, *Do It for Dystonia*—and do it for yourself. To learn more and start your campaign today, please visit: www.dystoniacanada.org/doit

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.

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:**

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