

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

*serving all dystonia-affected persons
d'asservant toutes personnes atteintes de dystonie*

Dystonia Canada Report

A Newsletter from
Dystonia Medical Research
Foundation Canada

Spring/Summer 2023

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Join us and our Ambassador, Jirome De Castro at this year's
Freedom to Move: Run, Walk and Wheel for Dystonia - June 2023
(Photo Credit: Brian Dee)

PLEASE RENEW YOUR MEMBERSHIP FOR 2023

Support the dystonia community with a donation to DMRF Canada.

visit: www.dystoniacanada.org/donate

Thank you for your support.

Foundation Update

As we hoped, 2022 saw the dawn of a new era where our community came together to support each other through the aftermath of the pandemic, to propel our mission forward.

Last year DMRF Canada supported five new research projects in Canada, addressing different needs across various disciplines. Multifaceted research continues to be our priority – to address the present care needs of the community, while simultaneously looking for a cure.

We continue to work with our partner in the USA, DMRF, to support the best research efforts worldwide, some of which the community has directly contributed through participation in clinical trials and research studies. You can read the results of these efforts in several articles throughout the Report.

As you know, the needs of our community vary across dystonia types, life stage, and locations. In recognition of this, we strive to develop better ways to reach those who need us with the help of our Support Group Leader network and our newly formed Support Advisory Group. Check out page 9 for updates on the impact of these initiatives.

We remain committed to addressing all new and ongoing challenges to help you and your loved ones by working with our dedicated staff, Board members, advisors, volunteers, partners, and the medical community. We also look forward to finally seeing our community come together once more in person at our annual Freedom to Move: Run, Walk, and Wheel for Dystonia, taking place in communities across the country this June.

Your continued support and participation is so important for the many people whose lives are impacted by dystonia, and we are always grateful for that.

Sincerely,



Connie Zalmanowitz,
Chair, DMRF Canada,
Board of Directors

A handwritten signature in black ink that reads "Connie Zalmanowitz".



Archana Castelino,
National Director,
DMRF Canada

A handwritten signature in black ink that reads "Archana Castelino".

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.

Board of Directors

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Co-Founder

1928 - 2018

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Dystonia Journal Update

The DMRF's official journal, aptly titled *Dystonia* has now published over 18 articles and provides open access to premier research on all basic, clinical, and translational aspects of the different forms of dystonia. To stay up to date on the latest developments, please visit:

www.frontierspartnerships.org/journals/dystonia

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.

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



DMRF Canada National Office Update

We've moved! Our new address is:
130 King Street West, Suite 1800
Toronto, ON M5X 1E3

In Tribute

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

Dwayne Backer

Victor Fineberg

Lloyd Frazer

Laura-Lynn Frost

Joel Jacobson

Gregory Kasparian

Dorothy Richards

Barbara Welch

Susan Yellin



This Dystonia Canada Report is supported by a grant from Ipsen Biopharmaceuticals Canada Inc.



We are thrilled to announce that we will once again be hosting our biggest event of the year: **Freedom to Move: Run, Walk, and Wheel for Dystonia in June 2023!**

After hosting virtual events exclusively for the last three years, we are excited that this year's event will be a mix of both in-person and virtual event opportunities. Participants will complete a walk, run, or wheel - either virtually in their own community or at one of five in-person sites taking place across Canada, including our Toronto event, which will be held on **June 11th at Downsview Park.**

Don't Wait, Register Today!

When: June 1 – 30, 2023

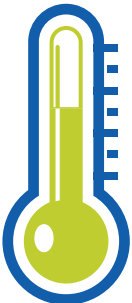
Virtually: Anywhere in Canada

In Person: Kingston, ON; Montreal, QC;
Toronto, ON; Winnipeg, MB and Vancouver, BC.

***Scan and
Register Now***



Early Bird Deadline - Register by May 3rd to Save 30%



Our Fundraising Goal:

Help us to raise **\$70,000** for dystonia research and support programs. These much-needed funds could support one year of the DMRF Canada Clinical and Research Fellowship, as well as other important dystonia research studies. We can't support these important projects without you.

Freedom to Move Ambassador 2023: Meet Jirome De Castro



For Jirome, the Freedom to Move event provides a special opportunity to connect with others in the dystonia community; something that has been deeply important to Jirome ever since his diagnosis of cervical dystonia in 2015. Inspired by stories from others with dystonia, he completes marathons and triathlons with a goal to direct all funds raised towards improving the lives of others with dystonia.

The power of community became even more relevant to Jirome after he and his family moved to Canada from the Philippines last year. He quickly became involved in the Greater Vancouver Area Dystonia Support Group and found great value in forming bonds with other group members over their shared experiences.

Join Jirome and the hundreds of others from the community across Canada at this year's Freedom to Move event, to support research, awareness and programming for the dystonia community. Together, we can make a difference in the lives of 50,000 Canadians living with dystonia.

Sign up, Warm up, Show Up– Start Your Race, Your Way Today:



Step 1 - Register

www.freedomtomove.org. Participants can sign up as an individual, or as part of a team.

Your Registration Includes:

- ✓ DMRF Canada Freedom to Move swag;
- ✓ A chance to connect with others in the dystonia community across Canada;
- ✓ The knowledge that you are helping to support vital dystonia research and support programs.



Step 2 - Set a goal

Whether you're joining us for an in-person event or completing your race virtually, set a goal that challenges you. From the amount you'd like to raise – the number of kilometers you will run, walk or wheel - or the number of times you share the event with friends or family – this event gives you the freedom to move the way you want!



Step 3 - Share!

Once you've registered, remember to share your fundraising page with your network. Encourage others to sign up or support you in your effort to raise funds for dystonia.

Remember to use the hashtag [#FreedomToMove](#) when you share online.

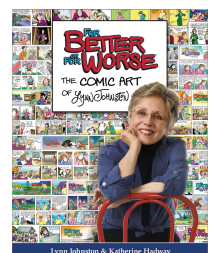
Dwayne Backer Memorial Award for Excellence in Fundraising



In 2022, the dystonia community lost a proud champion and advocate: Dwayne Backer. As a dedicated supporter of DMRF Canada and long-time participant of Freedom to Move, Dwayne raised close to \$120,000 for dystonia research and support programs over the last 20 years. He was incredibly passionate about supporting the dystonia community and was never afraid to ask his network of friends and colleagues for their support.

We are immensely grateful to Dwayne for his unwavering support and are proud to announce the launch of the *Dwayne Backer Memorial Award for Excellence in Fundraising* to honour his memory. The award will recognize the top individual fundraiser at this year's event and ensure that Dwayne's outstanding fundraising efforts will continue to inspire others.

Thank You to Our Generous Sponsors and Partners



Multi-Center Dystonia Research Project Launched

With the support of a very generous donor, DMRF Canada is facilitating a one-year, multi-center research project that will aim to validate a clinical and deep learning-based tool for recognition assessment and monitoring of complex movement disorders in dystonia patients.

"If successfully completed, this project will provide a dynamic system for unbiased diagnosis and clinical evaluation of dystonia and other movement disorders."

- DMRF Chief Scientific Advisor
Jan Teller

Led by Lead Principal Investigator, Dr. Laura Cif, MD, PhD, at the LRENC Montpellier, France, in partnership with Co-Principal Investigators Xavier Vasques, PhD (at LRENC CTO IBM Technology, France), Alexandre Legros PhD (Principal Investigator, Lawson Health Research Institute and Associate Professor, Western University, Canada), PhD (Western University, Canada) and Gabriella Horvath, MD, PhD (Associate Professor at the University of British Columbia), this project aims to improve and facilitate the assessment, monitoring and management of complex dystonia syndromes, with a particular focus on pediatric onset movement disorders.

This project deals with the development and validation of a complex 'scale' that can be used to identify and monitor dystonia and associated motor symptoms. The team will also attempt to develop a deep learning-based library to train models from clinical video recordings to ultimately perform video-based clinical classification and assessment to precisely diagnose movement disorders.

The Jackson Mooney Patient Grant:

Accepting 2023 Letters of Intent: Deadline - April 30, 2023

The Jackson Mooney Dystonia Patient Education Grant provides financial assistance of up to \$5,000 for individuals with dystonia, providing the opportunity to further education or upgrade skills to pursue new career goals. To learn more about application requirements and to submit a letter of intent, please visit: www.dystoniacanada.org/dystoniapatientgrant

Providing Hope & Help Towards a New Career Path: Updates From Our 2021 Grant Recipients

Emily

The Grant allowed me to study at my own pace and take on a workload I could manage. Because of this support, I was able to make it on the Dean's list this past year, and I found a work placement with a Canadian company online that allowed for flexible schedule and accommodations.

I have learned so much from this past year of school about the fashion industry, but also about myself and what is important to me. I have always seen volunteering with non-profits as important work and I got the chance to do more for my community, finding new ways to give back.

Perhaps one of the best parts of the past year was being surrounded by creative individuals who also care about the community. The Grant allowed me to gain an education and explore my interests, helping me gain not just opportunities now but in the future as well.

Laura

Receiving the Grant from DMRF Canada provided the funds to cover the majority of the tuition for my first three courses of my doctoral degree. This coursework is preparing me for research in rehabilitation science, working towards bringing experiential knowledge from patients into the academic discourse in order to improve accessibility and quality of rehab services for patients with long diagnostic delays and/or medically invisible symptoms.

In order to manage my dystonia I need to study part time as a visiting student, which is not open to other streams of funding for disabled students. Receiving this grant allowed me to start my studies slowly and set myself up for success!

Over the past 7 years, DMRF Canada has been pleased to be able to provide grants to a wide range of people from within the community, providing hope and enhanced professional development. This would not have been possible without the support of our community, including the Mooney family, who has been supporting this grant since the beginning.



From the DMRF Journal Investigators Create Pilot Tele-Yoga Program for Cervical Dystonia

Cervical dystonia (CD) is the most common type of adult-onset dystonia. It affects muscles that control the head and neck. Symptoms can include tremor and muscle spasms. Quality of life is influenced not only by the muscle-symptoms but also by frequent pain, anxiety, depression, and sleep difficulties.

Botulinum neurotoxin is currently the main treatment to improve the motor symptoms and pain associated with CD, however, individuals often experience symptoms in between injections. There is great need to identify safe supplementary treatments that can provide additional relief.

Yoga is a system of lifestyle practices with roots in ancient India. Some aspects of yoga have become popular in mainstream fitness and wellness communities. Low-impact yoga exercises and breathing techniques have been shown to be beneficial for individuals with chronic neck pain and other movement disorders such as Parkinson disease, however, the value of yoga for CD symptoms has not been evaluated. To increase access to this intervention, investigators at Rutgers University led by DMRF Medical & Scientific Advisory Council Member Jean-François Daneault, PhD set out to test whether remote yoga or “tele-yoga” could have a positive impact on CD.

Fifteen CD patients with little to no previous yoga experience enrolled in a six-week program of twice-weekly live one-on-one yoga sessions with a certified instructor. Each session included 30 minutes of breathing exercises, yoga postures, and relaxation. The study measured the patients’ ability to adhere to the program, technological challenges, any adverse events, enjoyment, whether the participants continued the yoga practice after the first six weeks, CD symptoms, overall physical abilities, and quality of life features.

AT A GLANCE

- Investigators offered live yoga instruction to individuals with dystonia via video conference.
- Study participants rated the experience a 9 out of 10 for enjoyment.
- Yoga exercises may need to be modified for individuals with dystonia for optimal benefit.

Of the 14 participants that completed the full study, tele-yoga attendance was high with 168/180 sessions completed and 11 participants attending 100% of their sessions. All participants reported CD-related pain and/or additional pain (hip, lower back, and ankle) prior to starting the tele-yoga program. Seven participants reported temporary increases in pain from specific postures. Mild adverse events such as brief dizziness, headache, or CD symptom increase related to posture changes

did occur and ended after the session. The tele-yoga also produced five incidences of new soreness. These instances prompted the instructor to modify the yoga treatment for those individuals, which resolved all reported issues prior to the end of the study. This suggests that individuals should be prepared to communicate with instructors about possible exercise modifications to increase benefit and avoid discomfort.

Importantly, participants ranked their overall enjoyment of the yoga intervention at 9+ on a 0-10 scale. More specifically the breathing exercises were ranked 8, 9+ for the postures, and 8+ for the relaxation portion.

Participants experienced three significant benefits from the program: a reduction in CD-related stigma, reduction in CD severity (but not pain), and improved emotional wellbeing. Overall, this study finds tele-yoga to be feasible, safe, and beneficial for individuals with CD. The findings support further research on tele-yoga as an addition to an individual’s treatment program.

Thank you to all members of the community who participated in this study.

James-Palmer Aurora M., Daneault Jean-François.
Tele-yoga for the management of cervical dystonia:
A safety and feasibility trial. *Dystonia*. 2022; 1.
doi:10.3389/dyst.2021.10015

Community Education and Impact

Enhanced Support Services and Resources



Look for me on the bottom left-hand side of the website for your accessibility needs.

A refreshed version of our website: www.dystoniacanada.org has officially launched! Complete with an improved user interface and an accessibility widget to help you customize screen viewing, it is now easier for users to find information on the resources they need to help live their best lives with dystonia.

DMRF Canada has also updated our Going Forward Dystonia Care Package for the newly diagnosed. New additions to the package include updated information on financial supports available, as well as a new fact sheet on the non-motor symptoms of dystonia.

Please visit: www.dystoniacanada.org/patient-care-package to download your copy today.

Our thanks to AbbVie Canada for their support of these initiatives.

Finding your Voice: Become a Self-Advocate



Self-Advocacy is a crucial skill that people with dystonia often need to develop to advocate for themselves to communities, organizations, and governments. It is an important part of making sure you have the resources available to have your needs met and are not discriminated against because of impairments or disability. There are many ways to become an effective self-advocate, and anyone can do it. To learn more, please visit our new resource page: www.dystoniacanada.org/disability-advocacy.

If you would like to speak to someone with dystonia who has experience in developing self-advocacy skills, please reach out to our wonderful volunteers Sarah and Neil. Their contact information can be found on our disability advocacy page linked in the paragraph above.

Advocacy Update

DMRF Canada is proud to be a member of Neurological Health Charities Canada (NHCC); a coalition of organizations that represent people with brain diseases, disorders, and injuries in Canada.

Over the last few months, NHCC met with Members of Parliament who are focused on health and disability, educating them about the needs of the community.



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

As part of this endeavour, NHCC participated in

Finance Canada's 2023 pre-budget online consultation pressing for the inclusion of the development of a National Neurological Strategy for Canada in the upcoming budget.

Together with the Canadian Brain Research Strategy, which involves charities and other organizations focused on brain research, DMRF Canada submitted a brief to the Standing Committee on Science and Research for its study on Moonshot Programs that aim to resolve difficult environmental and social problems, set ambitious research and development programs, and attract researchers from around the world.

Through our advocacy efforts, we continue to work towards developing relationships with key stakeholders who have a direct impact on the policy needs of the dystonia community.

Strengthening Support Services in a Post-Pandemic World

As we reintegrate in-person socializing into our routines, our Support Advisory Group (SAG) Committee and DMRF Canada Staff have been hard at work developing plans to revitalize our support network and improve support services for people with dystonia post-pandemic.

The SAG Committee is comprised of support leaders living with different forms of dystonia and representing geographically diverse regions across Canada. The Committee ensures that people living with dystonia have direct input in the development of the support they receive.

If you'd like to connect with a support volunteer in your area, please visit: www.dystoniacanada.org/support



Pictured: DMRF Canada Support Group Leaders at the 2018 Calgary Symposium

Connect with your Community – Join a Support Group Today



DMRF Canada Support Groups are here for you. See what our Support have been up to and stay tuned for what's next.

On January 28th, our French-speaking support group in Montreal; Dystonie-Partage, started the year off strong with a meeting providing members the opportunity to connect after the holidays and bond over their shared experiences with dystonia.

On March 4th, the Greater Vancouver Support Group held their first in-person support group meeting of the year, and welcomed some new members who benefitted from this important information sharing event.

On March 18th, the National Support Meeting welcomed members from all over the country. Recognizing that not all members of the community can attend in-person meetings, our wonderful volunteers, John and Neil, have been hosting quarterly virtual meetings open to all across Canada. Stay tuned for details on the next meeting.

Upcoming Meetings

Winnipeg Support Group Virtual Monthly Meetings – With their in-person meeting space currently unavailable, the Group pivoted their meeting format to virtual, allowing flexibility for members across Manitoba – and even beyond – to connect. The next Winnipeg Support Group meeting will be taking place on May 5th.

Dystonie-Partage Meeting on Dystonia Research Updates

On May 6, 2023, neurologist Dr. Sylvain Chouinard will present on this topic, for the French speaking community in Montreal. This meeting will have a live webcast for those who cannot attend. Thanks to Merz Therapeutics for their generous support of this meeting.

For a full listing of upcoming events, please visit: www.dystoniacanada.org/upcoming-events

Swimming with Dystonia

Join Swim Canada this spring for a virtual informational session on the benefits of swimming for people with dystonia. All skill levels are welcome!

Speakers: Swim Canada and a panel of dystonia swimmers.

Time: May 6, 2023 at 12:00 PM Eastern Time.

Register: Please visit www.dystoniacanada.org/swimmingwithdystonia



Celebrating our Community: Jenn Ashton

"I feel like winning the Jackson Mooney Dystonia Patient Grant opened so many doors for me, not only in terms of receiving further grants and scholarships, but it boosted my confidence to where I felt 'seen' and gave me the courage to keep moving ahead, saying 'yes' instead of 'no', to many opportunities."

– Jenn Ashton



Jennifer (Jenn) Ashton was introduced to the DMRF Canada community in 2020 as one of our Jackson Mooney Patient (JMP) Grant winners. With the funds provided by the grant, Jenn was able to successfully complete the Higher Education Teaching Certificate at Harvard and has gone on to do incredible things. An accomplished author and visual artist living in North Vancouver, B.C. Jenn continues to inspire with her boundless energy and creativity. Since winning the Grant, Jenn has been published a further 29 times, and has received the following writing accolades:

- Honourable Mention, Subterrain Magazine, Lush
- Triumphant Literary Award for Nonfiction (2022) For "Qualifying Hymns"
- Longlist: Susan Crean Award for Nonfiction(2022) For "100 Better Days"
- Shortlist: Indigenous Voices Award for Unpublished Prose in English (2022) For "Hail Mary, Mother of Pearl"
- 1st Place - Doula Support Foundation's Birth Story Contest (2021)

In addition to writing accolades, Jenn was successfully accepted into a national screen writing program; Tricksters and Writers, through Women in Film and Television Vancouver – and she has just received word that one of her short films was selected for the Vancouver Island Short Film Festival! Beyond her creative pursuits, Jenn has successfully received a number of other scholarships, and awards, including a scholarship to study at the University of Oxford. Most recently, she was accepted into the University of Edinburgh to begin her MSc in History this coming fall.

At times over the past few years, Jenn's dystonia has been challenging. "Higher stress levels, workloads and little time for regular exercise have set me down some painful roads, but it is also a great reminder that I must take care of myself first." Jenn continues to work to find balance in all things, including taking on a role as a volunteer for DMRF Canada, but says: I couldn't be

happier with my life and will always be grateful for my diagnosis and the support of DMRF Canada! I can't wait to see what happens next."

A friendly reminder that we all need to remember to take care of ourselves first! Please refer to www.dystoniacanada.org/living-with-dystonia for a collection of tips and tools.

To learn more about Jenn Ashton, visit her website at: <https://jenniferashton.ca/>

Our sincere thanks to the George Lunan Foundation for their support of the Community Education and Impact section of this Report.

Deep Brain Stimulation in Children: Questions for the Medical Team

Deep brain stimulation (DBS) is a surgically implanted medical device used to treat a variety of neurological disorders. The stimulation to the brain is adjusted by remote control.

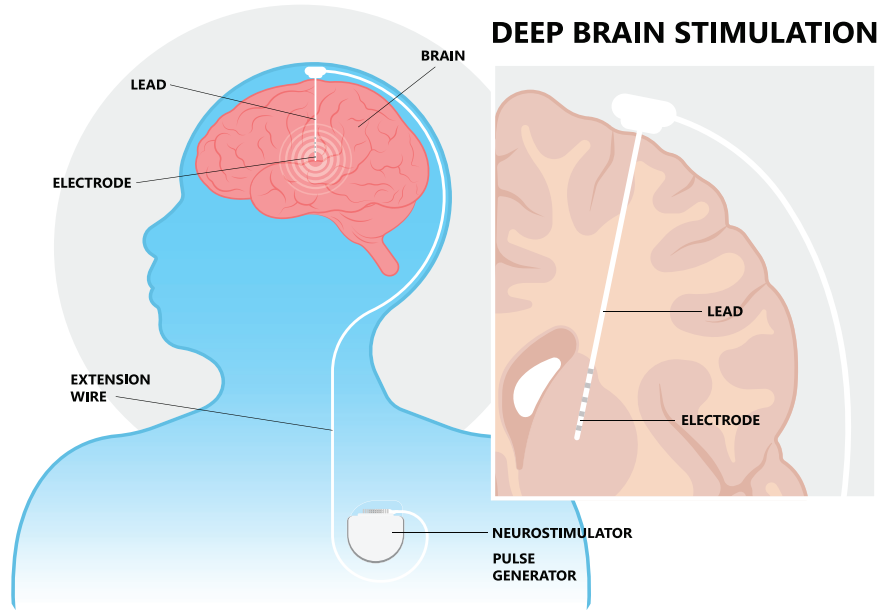
DBS may be an option for children with dystonia when it becomes clear that medical therapies are not successfully controlling symptoms.

Not all children with dystonia are candidates for DBS. It can be difficult to predict the amount of benefit to expect.

The following factors tend to influence outcomes from DBS in children:

- A short time between symptom onset and beginning DBS therapy tends to favor beneficial outcomes.
- Children with genetic dystonias, including DYT1/TOR1A, KMT2B, and DYT11/SCGE dystonia, tend to have favorable results from DBS.
- Children with dyskinetic cerebral palsy tend to have less response to DBS with only about 27% experiencing significant improvement in cases studied.
- Dystonic movements may respond more rapidly and better than fixed dystonic postures.
- Symptoms that tend to not improve with DBS include weakness, ataxia, and spasticity.

Contact DMRF Canada to connect with families who have been through the DBS process: www.dystoniacanada.org/contactus



12 QUESTIONS FOR CHILD'S MEDICAL TEAM

If you are considering deep brain stimulation for your child, the following questions may be helpful in conversations with your child's medical team.

1. Is my child a good candidate for DBS? Why or why not?
2. What are the steps and timeline of the DBS process, from beginning to end (including work-up, surgeries, device programming, stimulator upgrades, etc.)?
3. What are the advantages, and disadvantages, of having DBS?
4. What benefits can we expect for my child?
5. Is there a chance their symptoms will get worse? If so, which symptoms?
6. To what degree will DBS help [insert symptom/issue: pain, walking difficulties, trouble using hands, difficulty with seating, sleep difficulties, speech/communication challenges, etc.]?
7. What are the risks: during surgery, after surgery, and long-term?
8. What is the experience of the medical center and surgical team with DBS for dystonia in children?
9. What are the most common complications your young DBS patients have, how often do they occur, and how are they resolved?
10. How will the stimulator programming and adjustments take place? How many appointments, over what period of time, should we expect?
11. Is there anything about DBS for my child I should know that we have not yet discussed?
12. Plus questions the child may have.

For more information regarding deep brain stimulation surgery, please visit:
www.dystoniacanada.org/about-dystonia/treatments/deep-brain-stimulation

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DMRF-Funded Project Explores Non-Invasive Neuromodulation Therapy for Focal Dystonia

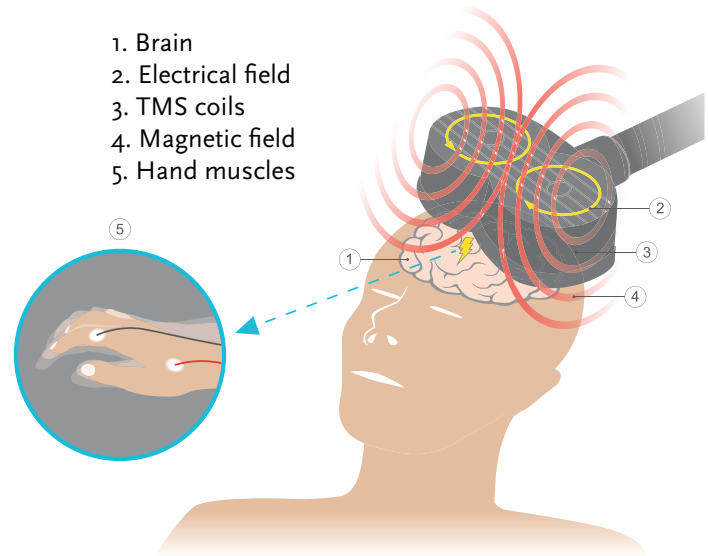
Last year, DMRF issued a call for research proposals focused on non-invasive brain stimulation therapies to treat dystonia. The following project was supported through DMRF's Cure Dystonia Now Fund.

Personalized Functional Neuromodulation of Common Deficits in Focal Dystonias
Leighton Hinkley, PhD
University of California, San Francisco

Non-invasive neuromodulation—where brain stimulation is delivered without surgery—is an exciting new method for treating movement disorders including focal dystonia. One particular technique, repetitive transcranial magnetic stimulation (rTMS), has provided clinical benefit for many neurological and psychiatric conditions and has been approved by the US Food & Drug Administration (FDA) to treat conditions such as major depressive disorder. While great effort has been made over the past two decades to develop rTMS as a treatment option for focal dystonia, studies have failed to deliver a consistent effective protocol to reduce the dystonia symptoms.

Although there are different ways to deliver rTMS, most studies using rTMS for dystonia stimulated the exact same region of the brain across all patients, assuming that this one location is the focus of the disorder. Focal dystonia can impact different structures of the body, for example, the vocal cords in laryngeal dystonia or the hand in task-specific focal hand dystonia. One reason why previous rTMS trials for dystonia have not had great success may be because the optimal rTMS stimulation target is not in the exact same location for each and every person.

In this study, investigators are adopting a personalized approach for identifying the correct place to stimulate using rTMS for focal dystonia. They hypothesize that the specific regions of the brain that act as dystonia “hotspots” for stimulation will vary across the frontal and parietal lobes of the brain in each patient, true to the nature of dystonia being different in every individual. To identify these specific hotspots, they take a next-generation approach using non-invasive neuroimaging including functional magnetic



Non-invasive neuromodulation like rTMS delivers stimulation to targets in the brain through the skin and skull.

resonance imaging (fMRI) and magnetoencephalography (MEG) to identify abnormally connected or abnormally active regions of the brain in patients. Resting-state fMRI maps are a powerful way to look at functional connections in the brain and differences in those connections. Guided by this brain imaging data, the investigators will generate personalized maps of optimal sites to stimulate with rTMS. Using these personalized maps as a guide, they will deliver a single session of rTMS to see if stimulating that patient-specific region has an effect on symptoms of laryngeal dystonia and task-specific focal hand dystonia as well as some of the cognitive and behavioral features seen in those movement disorders.

The goal of the project is to provide a framework and option for delivering neuromodulation in a better way than what is currently available. The investigators need to understand the best way to deliver neuromodulation for each patient before advancing to large scale treatment trials and ultimately the clinic. A more informed approach guided by neuroscience for the treatment of dystonia will ultimately help patients get the greatest benefit from neuromodulation.

Dystonia Coalition Engages Investigators Around the Globe

Update on Recent Projects & Programs

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 participating. New investigators and institutions may join the effort at any time. The Dystonia Coalition began in 2009 with a \$6 million, five-year grant from the Office of Rare Diseases Research (ORDR) and the National Institute of Neurological Disorders & Stroke (NINDS). The Coalition is currently funded through 2024 by the ORDR in the National Center for Advancing Translational Sciences (NCATS) and the NINDS. The Program Director is Dr. H. A. Jinnah of Emory University School of Medicine. DMRF Scientific Director Dr. Joel S. Perlmutter of Washington University in St Louis is Co-Director.

In Dr. Jinnah's most recent update webinar on the Dystonia Coalition for patients and families facilitated by DMRF, he explained: "What do we need to establish new treatments. We need cooperation among experts and engagement from people who have dystonia, we need a good understanding of dystonia, we need good tools to measure new treatments and know if they work or not, and we need new approaches—new ideas for treatment and new experts to help study dystonia. The Dystonia Coalition is filling gaps in all these areas."

The Dystonia Coalition's open invitation to new investigators and broad collaborations have led to the collection of unprecedented amounts of detailed clinical data, video recorded



10 ANNUAL MEETINGS

180

Scientific Papers
Published

56

Participating
Research Centers

4CONTINENTS

Research Center Locations
NORTH AMERICA | EUROPE | ASIA | AUSTRALIA

examinations, and DNA samples from thousands of individuals with dystonia across different projects. Additional accomplishments include developing and testing new rating scales for cervical dystonia, blepharospasm, and laryngeal dystonia. Dystonia Coalition investigators have published 180 research papers in the medical literature to share discoveries and advancements.

Goals

The Dystonia Coalition has focused its major projects on key unmet needs for translating scientific discoveries into potential new therapies. Studies that address clinical trial readiness have been a priority

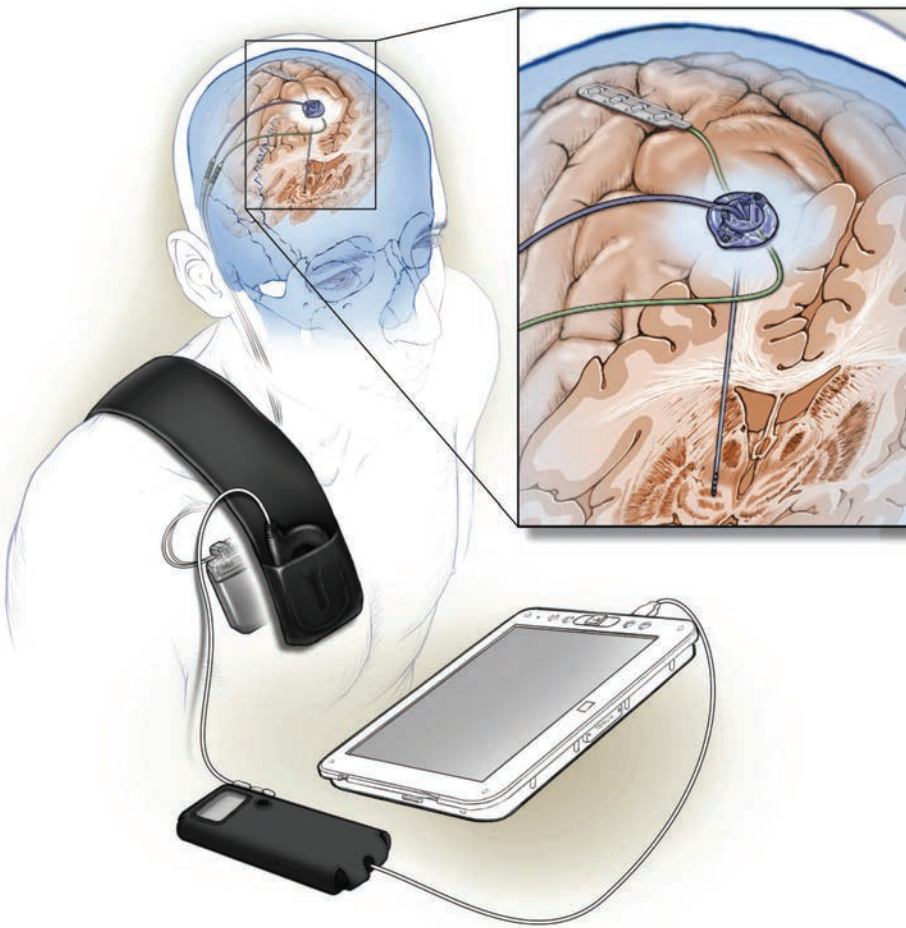
priority. The Dystonia Coalition focuses initially on the isolated focal dystonias including cervical dystonia, laryngeal dystonia, blepharospasm and craniofacial dystonia, and limb dystonias.

Additional Programs

The Dystonia Coalition encourages the development of new studies and investigations relevant to dystonia through funding efforts that include:

- **Pilot Projects Program.** The goal of this program is to foster the most promising clinical and translational studies relevant to isolated dystonia. DMRF is currently co-supporting two Pilot Projects.
- **Career Development Award.** The primary goal of this program is to facilitate career development for junior investigators interested in clinical and translational research relating to dystonia.

Case Study: “Smarter” Deep Brain Stimulation Increases Treatment Benefit



AT A GLANCE

- New DBS devices can adjust to individual brain activity.
- Adaptive DBS is beginning to be explored for dystonia.
- Adaptive DBS may improve response to DBS by reducing side effects and conserving energy.

Electrodes capable of stimulating and sensing electrical activity are implanted in the brain and connected to a small computer under the scalp. Data from the computer can be read by an external device. Image courtesy of Starr Lab/Ken Probst.

Deep brain stimulation (DBS) is a well-established treatment option for dystonia that applies constant stimulation to targeted brain regions. Regular stimulation at high frequencies can reduce the brain activity that produces dystonia but also reduces signaling within the same region, potentially affecting other brain functions. This can lead to side effects such as involuntary erratic movements, slowed movement, and impaired

speech, depending on the area of the brain treated.

A DBS method where the stimulation intensity adapts to fluctuating symptom severity, referred to as adaptive DBS (aDBS), has been used in people with Parkinson's disease to customize stimulation parameters according to an individual patient's needs. Adaptive DBS is a possible method to better treat dystonia symptoms by decreasing

side effects that can occur with the constant high stimulation used with current DBS treatment. A study published last year in *Experimental Neurology* led by DMRF grant recipient Simon Little, MBBS, MRCP, PhD of University of California, San Francisco, investigated the application of adaptive DBS for dystonia treatment.

The central goals of the study were to:

1. Identify patterns of brain activity in the absence of DBS stimulation that were altered by conventional DBS stimulation,
2. Use those patterns to trigger adaptive DBS stimulation, and
3. Compare the therapeutic success between the two types of stimulation.

A single patient with cervical dystonia had a neurostimulator implanted with sensing electrodes on the surface of the brain and stimulating leads targeting the pallidum deep in the brain. In addition to delivering the therapeutic brain stimulation, these leads were able to sense the electric signals of

the brain activity which could then be analyzed by the investigators.

The researchers successfully identified a specific pattern in brain activity that was present before the brain stimulation was applied and suppressed by the addition of conventional DBS. When using this pattern to trigger DBS stimulation they found a small improvement in the objective cervical dystonia measurements and a larger improvement in the patient's self-assessment, which included a subjective rating of tremor, neck stiffness, and pain. Overall, they found that adaptive DBS reduced the total electric energy delivered via stimulation by 71%, despite having a higher possible maximum level of stimulation compared to conventional DBS.

The researchers concluded that adaptive DBS improved patient benefit expanded therapeutic potential, and reduced the total electrical energy delivered. Future studies with larger numbers of study participants will be helpful to further confirm the therapeutic success.

Johnson V, Wilt R, Gilron R, Anso J, Perrone R, Beudel M, Piña-Fuentes D, Saal J, Ostrem JL, Bledsoe I, Starr P, Little S. Embedded adaptive deep brain stimulation for cervical dystonia controlled by motor cortex theta oscillations. *Experimental Neurology*. 2021 Nov;345:113825.

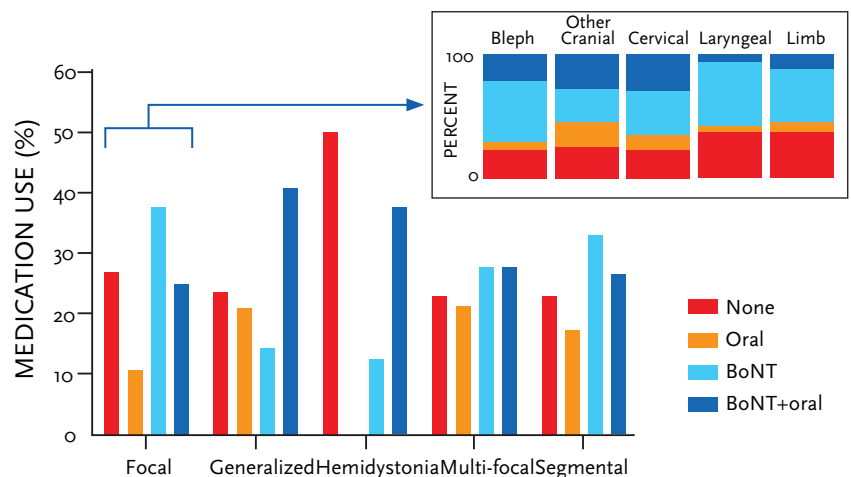
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Investigators Examine Medication Use Across Dystonia Types

Dystonia Coalition researchers set out to learn more about what medical therapies individuals with dystonia are using. They reviewed 2,100+ individuals across 37 movement disorder clinics in the United States, Canada, Europe, and Australia. The patients included individuals with focal, generalized, segmental, multi-focal, and hemi- dystonia.

They found 73% of individuals were using medications (oral or injected medications) and 27% using no dystonia medications. Furthermore, 61% of the total group used botulinum neurotoxin (BoNT) therapy alone or in combination with oral medications. Differences were found in medication use patterns by dystonia type, with the lowest oral medication use in focal dystonia and highest use in generalized dystonia.

The goal of this investigation was to better understand medication use in the dystonia community. This study provides an opportunity to explore possible strategies to customize dystonia treatment among the various dystonia types, always with the intention to improve results for patients.



Pirio Richardson S, Wegele AR, Skipper B, Deligtisch A, Jinnah HA; Dystonia Coalition Investigators. Dystonia treatment: Patterns of medication use in an international cohort. *Neurology*. 2017 Feb 7; 88(6):543-550.

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.

There are many ways to ensure a brighter tomorrow for the 50,000 Canadians living with dystonia. Your support matters. We exist, and our mission survives because of you.



Join our Monthly Giving Team and Provide Year-Round Support

"My husband and I become monthly donors for many reasons. I have had dystonia since 1993 and my daughter was diagnosed with dystonia about 10 years ago. At my age, I don't have to remember to donate (not that my spasms would ever let me forget) but hopefully by donating monthly, ongoing research will help future generations fight this disorder."

- Tracy, DMRF Canada Monthly Donor



Join the DMRF Canada Legacy Society

Did you know that May is Leave a Legacy Month in Canada? DMRF Canada established the Legacy Society to acknowledge those who have made a lasting commitment to supporting dystonia research by naming DMRF Canada their estate plans. Your legacy can be a future world free from dystonia. For more details on estate planning, please visit: www.dystoniacanada.org/legacy



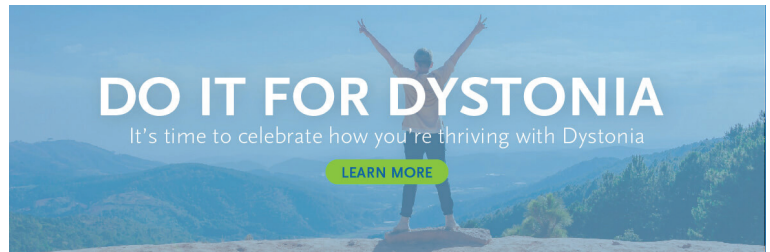
Start your Do It for Dystonia Campaign Today

Through Do It for Dystonia, you can raise funds for critical dystonia research and support programs when you want and the way you want. Join other dystonia thrivers across Canada by raising funds for a future without dystonia. Start your campaign today:

www.dystoniacanada.org/doit

Congratulations and thank you to Laurie Bell of Hamilton, ON for raising the most funds during our 2022 Do it for Dystonia Campaign. Laurie hosted a birthday fundraiser through Facebook for her 'Do It' campaign. In lieu of gifts, she asked her network to donate to DMRF Canada. For tips on you can fundraise through Facebook, please visit:

www.dystoniacanada.org/facebookfundraising



Please note: Starting Fall 2023, DMRF Canada will be removing mailed in credit card information as a payment method to help safeguard donor information. You can still make a credit card donation by visiting our website:

www.dystoniacanada.org/donateonline or scan the QR code below. You can also

call our office at 1.800.361.8061. **Charitable #12661 6598 RR0001**



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