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

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

Dystonia Canada Report

A Newsletter from
Dystonia Medical Research
Foundation Canada

Fall/Winter 2023

Tips for Supporting a Loved One with Dystonia -
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Foundation Update

This June, DMRF Canada National Director Archana Castelino, and a few members of the Board of Directors were pleased to attend the 6th **Samuel Belzberg International Dystonia Symposium,** which was held after nearly a decade. We were delighted to witness the discussions which took place between medical professionals from various disciplines who came together in Ireland for one common cause – to improve the lives of the families affected by dystonia. We are excited and eager for the advancements these conversations - and synergies - will bring.

These changes are not possible without a dedicated driving force. At DMRF Canada, we work closely with affected individuals and families, and other dedicated supporters. Through this newsletter, we'd like you to meet these individuals who have led us here and continue to lead us in the right direction, as well as those who make an impact within their communities, and beyond.

As DMRF Chief Scientific Advisor, Jan Teller, acknowledged at the symposium – we thank the many families for their blood, sweat, and tears. Thank you to all of you for your commitment to dystonia and for all you do each and everyday to support and promote our cause.

Connie Zalmanowitz,
Chair, DMRF Canada
Board of Directors

Connie

Archana Castelino,
National Director

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.

In Tribute

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

John Burgis
Paul Garramone
Barbara Hartford
Jill Mulkins

DMRF Canada National Office Update

To streamline our administrative processes, DMRF Canada has obtained a secure mailbox for all incoming donations and inquiries by mail. Please direct all mailings to:

PO BOX 1009 STN Toronto DOM
Toronto, ON M5K 1P2

Dystonia Medical Research Foundation Canada

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

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

Meet the DMRF Canada Board of Directors

Our Board of Directors is comprised of key dystonia community stakeholders – those impacted by dystonia, along with their loved ones. The Board provides direction and financial oversight of all operating programs and initiatives of the Foundation, including research.

Frances Belzberg, Co-Founder, Honorary Chair

Frances Belzberg Co-founded the DMRF with her late husband Samuel Belzberg after their daughter's dystonia diagnosis. Finding very little in the way of information on the condition and support for the community, Fran and Sam established DMRF so that other families impacted by dystonia would have a network of support and hope for a future without dystonia. Now, more than 45 years later, Fran continues to be an active board member, engaged in planning and setting strategic direction. In 2021, Fran was appointed to the Order of British Columbia, the province's highest recognition. In 1996, She was appointed to the Order of Canada, the nation's second highest honor of merit. The dystonia community is honored and grateful to Fran for her incredible ongoing contributions to our mission.

Connie Zalmanowitz, Chair, DMRF Canada

Connie has been proudly serving as a Director on the Board – as well as a Co-Leader of the Edmonton Support Group - for close to twenty years. Dystonia has been a part of Connie's life since 1995 when her son was diagnosed with generalized dystonia. A former speech-language pathologist for 40 years at the Glenrose Hospital in Edmonton, Alberta, Connie committed much of her career, to those with voice disorders, including patients with spasmodic dysphonia. Connie possesses the unique perspective of both a parent of a child with dystonia, as well as a medical professional who understands the challenges that exist in the field of medical research. With her appointment as the Chair of the DMRF Canada Board in 2020, Connie's solid leadership over the past three years has sustained progress during a particularly challenging time. Connie believes strongly in the value of advocacy for people living with dystonia and believes the key to helping is continued investment in high quality scientific research. She has put this belief into action for many years raising funds in Canada for education, support and research initiatives.

Pearl E. Schusheim, Secretary/Treasurer

Pearl became involved with DMRF Canada in a professional capacity more than 20 years ago as a Tax Partner at Ernst & Young. She now serves as Secretary/Treasurer on the DMRF Canada's Board of Directors. As the founder of P. Schusheim Advisory, Pearl is a strategic advisor to multi-generation high net worth families, entrepreneurs, foundations, and not-for-profit institutions. She works with complex wealth structures to ensure realization of succession and estate planning objectives, tax minimization, family governance development, philanthropic strategy, intergenerational wealth transfer and education. Pearl lives in Toronto with her husband.

Dennis Kessler, Director

Dennis Kessler and his wife Barbara got involved with DMRF US in 1982 when their son Art was diagnosed with dystonia. Dennis was invited to join the DMRF US and Canada Board of Directors shortly after that time and has been proudly serving both organizations ever since. Throughout Dennis's time with DMRF, the organization has witnessed many advancements for the community, including the identification of numerous dystonia genes, the discovery of neurotoxin treatment, the discovery of DBS and its use for dystonia, and the use of PGD to help families eliminate dystonia in future generations. Dennis is the President and Founder of Midwest Family Business Advisors, a consultancy that provides strategic guidance for family businesses. He currently serves on the Board of three family-owned businesses and provides invaluable governance expertise to DMRF. Dennis lives with his wife Barbara in Chicago.

Rosalie Lewis, Director

Rosalie joined the DMRF in the mid 1980's, shortly after her sons were diagnosed with generalized dystonia (DYT1). At that time the DMRF Board of Directors was small but very determined to develop a cadre of researchers and clinicians who could help find the answers to this rare disorder. As the mother of young sons challenged by generalized dystonia, Rosalie became focused on raising funds and awareness. Rosalie has proudly served in many positions on the DMRF US Board, including President. The DMRF US and Canada have made a profound impact in the world of dystonia research - we have succeeded in many efforts but many more remain. Although Rosalie's sons have benefitted tremendously by DBS surgery and are now married and have dystonia-free families of their own, Rosalie and her husband Richard remain absolutely committed to helping the dystonia community find cures.

Casey Kidson-Reid, Director

Casey Kidson-Reid is a dystonia thriver who joined the DMRF Canada Board in 2020. Casey first got involved with DMRF Canada as a Dystonia Ambassador and launched her campaign; Dyfying Dystonia to raise funds and awareness for dystonia. An avid cyclist, runner, and swimmer, Casey continues to 'dyfy' dystonia and serves as an inspiration to so many. She hosts the 'Dyfy the Storm' podcast, facilitates the DMRF Canada Kingston Support Group, has developed exercise videos, and was featured in DMRF Canada Dystonia Awareness video, which has now has more than 50,000 views. In her spare time Casey enjoys travelling with her husband and spending time with her two new rescue dogs Kleo and Luna, who is training to be a Therapy Dog.

Catherine Mulkins, Director

Catherine has been living well with dystonia for more than 20 years and has been active in the DMRF Canada community for 10+ years, having participated in DMRF Canada's Freedom to Move event in Toronto as an attendee, Team Leader, and a dedicated fundraiser. A human resource professional, Catherine has been recognized for her exceptional skills in employee relations, talent management, and project planning, and brings these skills to her role as a Director on the DMRF Canada Board. Recently retired, Catherine enjoys spending time with her family in Toronto.

6th Samuel Belzberg International Dystonia Symposium (SBIDS6)

On June 1, Frances Belzberg, co-founder of the DMRF and DMRF Canada, formally inaugurated the first day of the Symposium in Dublin, Ireland. The Symposium brought together more than 340 experts, researchers, and healthcare professionals to share knowledge, foster collaboration, and advance our understanding of dystonia. Groundbreaking research was presented on 107 scientific posters. Key topics covered include the latest advancements in dystonia research and emerging treatment strategies.

DMRF Canada is grateful to the DMRF US, who organized the event, along with the attendees, the Belzberg family, and the many donors who support research programs. Stay tuned for the lay summary, which will be available later this year.

Resources for Healthcare Professionals

Positioning Dystonia Research Highlights in Canadian Practice

Following this year's Dystonia Symposium, on June 29, a small panel of attendees and speakers shared key results, discussions, and takeaways with Canadian healthcare professionals through a webinar organized by the AbbVie Institute of Health Education. **A recording is available on our website** **www.dystoniacanada.org/healthprofessionals**

Some of the Canadian attendees and speakers at the SBIDS6 in Dublin, Ireland. (L-R) Dwight Stewart, Earl Consky, Robert Chen and John Adams

New Updates to the Resource Bank

Last year we launched a new online resource for professionals treating the dystonia community, with a goal to provide new opportunities for healthcare professionals to learn more about the disorder. We are pleased to share that the following updates have been added to the website as requested by the medical community:

- Details on upcoming educational events
- A comprehensive updated listing of healthcare professionals
- Resources for physiotherapists, such as the *Dystonia Physio Hub*, developed by Swedish physiotherapist Johanna Blom in close collaboration with Dystonia Europe. It is a platform that helps professionals design suitable personalized exercise programs for patients, as well as some educational videos.

Connecting Researchers with those Living with Dystonia

DMRF Canada is proud to be part of the first-ever patient registry devoted to focal dystonias. The Global Dystonia Registry is designed to collect data on persons affected by a focal dystonia(s), to assist in future research efforts and clinical trials.

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. This Registry compliments the current scope of research for the Dystonia Coalition, a National Institutes of Health (NIH USA) supported clinical research effort.

To date, over 6,500 people have registered from over 60 countries. This is a collaboration between dystonia patient organizations, including DMRF Canada, and the research leaders of the Dystonia Coalition.

> ***Your responses will help us better understand the dystonia experience and help guide future directions in research. We hope you will register today.***

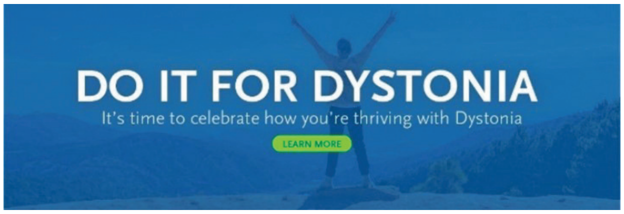
By completing your profile, your information will be utilized for research and clinical trials that could lead to future treatments and cures for dystonia! Please know your responses will remain confidential. Your participation is completely voluntary, and the parameters of each study will be defined for you should you decide to be involved.

Visit www.globaldystoniaregistry.org to learn more.

Shared with permission from the Global Dystonia Registry and Dysphonia International.

Join *Do it for Dystonia* Today for Tomorrow's Cure

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. Our Top Fundraiser will be featured in the Spring 2024 Newsletter. **Start your campaign today: www.dystoniacanada.org/doit**



Leave a Legacy of Research - Sign Up for the Legacy Society

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

Options Include:

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

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

Supporting the Dystonia Community in Canada: Introducing Our Newest Clinical and Research Fellow

DMRF Canada, in partnership with Merz Therapeutics, is pleased to introduce the recipient of the 2023 – 2025 DMRF Canada Clinical and Research Fellowship: Dr. Talyta Grippe. Dr. Grippe will hone her clinical and research skills under the mentorship of Dr. Robert Chen, Senior Scientist, Krembil Research Institute, Toronto.

The objective of this important investment is to improve and enhance skills contributing to the diagnosis and treatment of patients and to further develop skills for clinical research in dystonia. According to a 2022 study conducted by Parkinson Canada, while there are around 770 community neurologists in Canada, there are less than 80 neurologists – movement disorder specialists – specialized in treating neurological movement disorders like dystonia. To ensure the long-term sustainability of the dystonia community, DMRF Canada developed the Clinical and Research Fellowship program.

"We know that it is critical for patients to receive an accurate and timely dystonia diagnosis, and to receive the proper treatment in order to live their best lives with dystonia. We are confident that investing in excellent, consistent medical care is an important way for DMRF Canada to meet our mission – to enhance the experience of people living with dystonia in Canada", said DMRF Canada Chair, Connie Zalmanowitz.

As a Clinical Fellow at the esteemed Toronto Western Hospital Movement Disorders Centre, Dr. Grippe will gain invaluable experience in dystonia through exposure to a diverse range of expertise and a substantial number of patients. *"I am excited to embark on this new journey and look forward to the opportunities and avenues that this fellowship will unlock. I am grateful for the support of DMRF Canada and Merz Therapeutics and look forward to contributing to the important task of advancing research and innovation in dystonia."* Said Dr. Grippe.

Dr. Talyta Grippe and Dr. Robert Chen at the 6th Samuel Belzberg International Dystonia Symposium – June 2023

Dr. Grippe is developing her expertise in the electrophysiological assessment of movement disorders which is a unique training not available in other centers in Canada. She expects to become proficient in many advanced neurophysiology techniques and will also be trained in dedicated botulinum toxin injection clinics with several EMG machines and an ultrasound machine for muscle localization.

"We are honored to once again support the DMRF Canada Clinical and Research Fellowship Training Program, which reflects our commitment to providing medical education and training to early career specialists," said Yannick Grosskreutz, Canada Country Manager, Merz Therapeutics. "By investing in excellence in training and education today, we help pave the way for better outcomes for more patients living with dystonia and other movement disorders."

As an important component of this Fellowship is research, Dr. Grippe will work on a study with assessments that may have the potential to be used as diagnostic tools. She hopes the results will enable the design of novel non-invasive neuromodulation treatment protocols tailored to different types of dystonia.

On behalf of DMRF Canada and the 50,000 people living with dystonia in Canada today, we congratulate Dr. Grippe on this tremendous accomplishment. We look forward to receiving updates in the months and years to come!

With thanks to Merz Therapeutics for their support

MERZ THERAPEUTICS

Freedom to Move 2023: Running, Walking, and Wheeling Our Way Towards a Cure for Dystonia

Throughout June and July, the dystonia community across Canada united once again for our largest fundraising event of the year, *Freedom to Move: Run, Walk and Wheel for Dystonia.* This year's event drew in over 130 participants virtually and across our 5 in-person event sites. Thanks to the efforts of all participants, donors, and sponsors, the event raised over $50,000 for critical dystonia research and essential support programs.
Visit: www.dystoniacanada.org/freedomtomove to watch our event wrap up video.


Montreal

Our Montreal Group kicked off Freedom to Move with our first event on a sunny Saturday morning on June 3rd in Michel-Chartrand Park. Thank you to all that attended and supported the event through generous donations. Special thanks to our support leader, Chantale Boivin, for organizing the Walk.

Our Greater Vancouver Support Group hosted their first ever Walk on June 24th at North Delta Secondary Track. Thank you to all that attended including community members, support leaders, our 2023 ambassador Jirome and DMRF Co-founder Fran Belzberg. We are grateful to our support co-leaders Luisa Hudniuk and Robin Krantz, and all volunteers for their help in organizing the walk.


Greater Vancouver


Winnipeg

On June 25th, members of the Winnipeg dystonia community gathered at St. Vital Park for their Walk. Thank you to everyone that attended the event and made it such a success! We are grateful to our co-leader, Jennifer Lovell and all volunteers for helping to organize the event.

After a break due to the pandemic, the Toronto dystonia community finally connected in-person again on June 25th at Downsview Park. We are incredibly grateful to everyone who attended the event, including our Toronto Support Group members, DMRF Canada Board Member Catherine Mulkins, supporters from Toronto Western Hospital, and our wonderful volunteers. Special thanks to Debbie and Helene Bauer for their incredible efforts in securing prizing and food partners.


Toronto


Kingston

Thank you to the incredible dystonia community in Kingston for braving the stormy weather and completing their Freedom to Move on July 16th at CaraCo Track. We thank our co-leader and Board member, Casey Kidson-Reid, and the amazing volunteers who helped us organize this memorable day.


Jirome with DMRF Co-Founder, Fran Belzberg at the Greater Vancouver Walk on June 24th.

A Heartfelt Thanks to Our 2023 Ambassador, Jirome De Castro.

Thank you to our wonderful Ambassador, Jirome for his outstanding efforts throughout this year's event. From his inspiring training videos to proudly sharing his dystonia journey with his network, Jirome's united us all in our race against dystonia. Keep up with Jirome on his Instagram @tri_dystonia to see how he continues to raise awareness for dystonia through completing marathons and triathlons.

Thanks to Our Top Fundraisers

1. Mary Guy of Team Sudbury;
2. Franco Mazzella of Team Franco's Dystonia Busters;
3. Oliver Jaakola of Team Jaakola.

Congratulations to Mary Guy for receiving the inaugural *Dwayne Backer Memorial Award for Excellence in Fundraising*. This award is particularly important to Mary as Dwayne was a co-member of the Greater Sudbury and District Support Group and a dedicated long-time participant of the Sudbury Freedom to Move Event.

Special Thanks to Our Prizing Partners

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From the DMRF Journal

Observing the Diversity of Alleviating Maneuvers in Cervical Dystonia

Dystonia, the third most common movement disorder, is characterized by involuntary muscle contractions that produce abnormal postures of varying severity, intensity, and duration. Alleviating maneuvers (AMs), often referred to as "sensory tricks", have been defined as "voluntary actions that specifically correct the abnormal posture or alleviate the dystonic movements" (Albanese et al., 2013). For this study, the researchers extensively reviewed the existing clinical literature to select 15 commonly described AMs and then included any others described during patient interviews. These AMs were then divided into five groups based on their similarities. (See accompanying chart.) This study used a detailed patient interview to explore any patterns between different clinical features of cervical dystonia (CD) and the benefit of five different categories of AMs.

Study participants were selected if they had adult-onset focal CD and were excluded if they had cognitive impairment, movement disorders other than CD, other neurological conditions, and any prior neurosurgeries, including deep brain stimulation. All participants were undergoing treatment with botulinum neurotoxin injections. To avoid treatment influencing the data, data was collected from each patient 3+ months after their most recent injections.

This resulted in 100 participants, 71 of whom were female, with an average age of 62 years old, and an average time since symptom onset (disease duration) of 14 years. Of these 100 participants, 47 experienced head tremors, and 27 experienced tremors in a non-dystonic body area. In addition to basic patient demographics, the severity of their CD was assessed, and they were asked to describe their experience with AMs, the frequency with which they use them, and to rate their symptom "alleviating power" on a visual 10-point scale.

Frequency and therapeutic effect of the different categories of AMs

First and foremost, 75% of study participants reported using at least one AM, with the most commonly used being the passive category, reported by 58%. 62% of the study participants reported using more than one category and almost all (34/37) of the patients that reported using two or more categories use the passive AMs. Interestingly, the amount of symptom relief reported for these different categories of AMs was comparable, with the averages falling between 6 and 7 on a 10-point scale, 10 being the most effective. The only exception was the most commonly used category, the passive, which had a significantly greater alleviating impact than the least common group, the pure sensory.

> **Alleviating maneuvers (AMs), often referred to as "sensory tricks", have been defined as "voluntary actions that specifically correct the abnormal posture or alleviate the dystonic movements."**
>
> *Albanese et al., 2013*

Patterns between patient demographics and the success of different types of AMs

Correlation analyses are used to show whether there are associations between two features in a research study. Here the different features are the frequency of use and amount of symptom relief of the different AM categories and the patient demographics. The researchers found that the frequency of use of pure sensory AMs positively correlated with age, meaning the older participants used this category more frequently. They also found that patients who experience more severe CD symptoms or associated disability use the passive AM category more, and those with greater CD severity reported more symptom relief from this method. Furthermore, patients with greater dystonia-related disability, severity, and frequency of CD-related pain more commonly used a combination of the passive and active non-oppositional AMs than just passive alone. These findings suggest that not only do AMs continue to work for those with greater CD severity, disability, or pain, but many patients benefit from using a diverse set of AMs.

5 TYPES OF ALLEVIATING MANEUVERS FOR CERVICAL DYSTONIA

PURE SENSORY

The sensory effect that results from wearing a variety of head or neckware.

Examples: Wearing a scarf or neck collar, glasses, a hat, or a helmet.

COMPLEX MOTOR

Complex motor movements that are not directly related to the CD, such as walking, talking, yawning, chewing, or closing the eyes.

SENSORIMOTOR: PASSIVE

Intentional positioning that relaxes the muscles suporting the upright position of the cervical spine that are often engaged by CD.

Examples: Resting the back of your head on your hand, the car headrest, a pillow, the couch, or laying on a side.

SENSORIMOTOR: ACTIVE + NON-OPPOSITIONAL

Gently touching parts of your face (chin, nose, or cheek), neck, or the back of your head with your hands

SENSORIMOTOR: ACTIVE + OPPOSITIONAL

Using your hands to push against your chin, forehead, cheek, neck, or upper back, or pushing you head against vertical surfaces (ie: car headrest)

Interestingly, the active oppositional AMs were less effective and used less often by those with longer disease duration. The higher frequency of use and greater effect of active oppositional AMs earlier in the disease progression can be explained by a few possibilities. Early on in disease progression (1) the milder strength or severity of dystonic postures can make them easier to overcome by an applied, counteracting force; (2) patients may be more likely to instinctively counteract their dystonic postures using force; (3) perhaps due to the first two explanations, patients may be unaware that comparable relief can be attained through light touch (active non-oppositional), and that upon learning of these more easily applied AMs they discontinue the with the active oppositional AMs.

Notably, participants who used more than one type of AM used them with similar frequency and therapeutic effect.

Why are passive AMs so effective?

At first glance, passive AMs alleviate symptoms by a simple change in posture and possible added benefit from the sensory input provided by an object being used. However, the success and frequency of use of this method across the study participants also suggest that this method may temporarily correct one of the suggested causes of dystonia: an error in the proprioceptive feedback loop, the feedback loop that describes one of the communication systems between the body and the brain that is negatively impacted by dystonia.

Proprioceptors are specialized cells or neurons that communicate sensory information about movement, action, and your location in space from your body to your brain. The brain uses this information to deliver movement-related instructions back to the muscles. The cells that deliver these instructions from the brain back to the muscles, triggering muscle contractions, are another type of specialized neuron

Continued on page 12

called motor neurons. Together these cells make up a communication loop between the body and the brain and are responsible for maintaining stable body posture and coordinated movement as we navigate through varied environments. For example, allowing us to walk without having to actively think about each step.

In patients with CD, the information being sent from the muscles in the neck to the brain is misinterpreted. Botulinum neurotoxin, a primary treatment for CD, works by blocking the motor neurons that initiate a muscle contraction, blocking both the muscle contraction and the resulting information being sent to the brain that is then misinterpreted in CD patients. Reducing the information being sent to the brain decreases the wrong signals getting sent back to the muscles producing dystonia. It is thought that the passive AMs work through a similar mechanism. Repositioning the neck passively removes the need for muscle contraction (to support the head) reducing the signals being misinterpreted at the level of the brain in this feedback loop—functionally turning the volume down on the ongoing signals being sent between the muscles and the brain and back.

Study by *Drs. Laura Avanzino, Francesca Di Biasio, Gaia Bonassi, Elisa Pelosin, Nicholas Cothros, Roberta Marchese, and Davide Martino.*

Study brief originally published in the journal, *Dystonia,* May 17, 2022. Summary by *Kylie McPherson, PhD.*

STUDY OFFERS ADVICE FOR KEY FINDINGS

1. There are five categories of alleviating maneuvers (AMs) that produce the same degree of symptom relief for the cervical dystonia (CD) patients that use them.

Of the five types, one provides pure sensory input (ie: wearing a hat or scarf) and another is complex motor movement (ie: walking or talking). The other three are a combination of sensory and motor (termed "sensorimotor"), the first being sensorimotor passive (ie: natural positions that allow your dystonic muscles to rest like laying on a pillow), then sensorimotor active non- oppositional (ie: gently touching parts of your face, neck, upper back), and sensorimotor active oppositional (ie: pushing on your chin, forehead, etc.).

Advice: There are many AMs that work for CD patients, so explore these different possibilities and find what individual methods or types of AMs help best manage your symptoms.

2. The majority of patients find symptom relief from more than one category of alleviating maneuvers (AMs).

Advice: It is worth trying a variety of different AMs, even if you have found success with one category already, to increase the number of tools at your disposal. For example, if you currently exclusively use passive AMs (ie: laying down with a pillow), try active non-oppositional AMs (ie: light touch to your face, neck, or back) that would be more feasible in other situations like while driving.

3. Active oppositional AMs (ie: using your hands to apply force to your chin or head) are used less often and provide decreased symptom relief in patients with longer disease duration.

Advice: If you use active oppositional AMs, consider trying active non-oppositional AMs to determine if there are less-taxing methods that produce the same relief for you.

4. Patients who experience more severe CD symptoms or associated disability use the passive AM category more and report more symptom relief from this method.

Advice: If you have been reluctant to try sensory tricks because your symptoms are severe or have progressed recently, this could actually be an indication that you will receive greater symptom relief from passive AMs (ie: laying down).

Reprinted with permission from DMRF Dystonia Dialogue, Spring 2023 Vol 44, No 1.

Research Update: 2023 Grants

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 various research projects.

Please find below the latest research projects that have been funded by the DMRF. The DMRF supports research aimed at expanding the knowledge of the genetic, molecular, physiologic and pathologic basis of dystonia. The new 2023 grants are:

Neuroanatomical isolation of networks in dystonia through analysis of causal brain lesions
VDaniel Corp, PhD, Deakin University, Victoria, Australia
The goal of this study is to reveal the anatomy of dystonia by analyzing causal links between symptoms and brain structures affected by lesions. This will ultimately identify targets for new brain stimulation methods.

Theta burst transcranial focused ultrasound as a novel treatment for cervical dystonia
Jean-Francois Nankoo, PhD, University Health Network, Toronto, Canada
This project aims to explore the effects of a novel non-invasive brain stimulation technique that has the potential to be a safer, less costly, and more accessible alternative to deep brain stimulation.

Developing high-throughput assays to enable drug development for DYT1 dystonia
Christian Schlieker, PhD, Yale University, New Haven, CT
This project will use advanced molecular methods to develop new pharmacological approaches that disrupt the cellular cascade leading to neuronal dysfunction with the aim to select specific compounds with drug-like properties that may potentially be developed into dystonia drugs.

The DMRF is particularly committed to supporting young investigators pursuing dystonia-focused projects through research fellowships and to supporting the training of clinicians to improve treatment experience through the clinical fellowship program. The new 2023 research fellowships are:

Spike-triggered adaptive closed-loop cerebellar deep brain stimulation for dystonia
Linda Kim, PhD, Baylor College of Medicine, Houston, TX
Mahlon DeLong Young Investigator Award
This award, named for DMRF's Scientific Director emeritus, honoring his legacy of leadership and discovery, is awarded for outstanding scientific projects submitted by young investigators. Dr. Kim is the third individual to receive this honor. She will test the hypothesis that the unique pathophysiological cerebellar neural signals in dystonia can serve as robust biomarkers for triggering an adaptable closed-loop DBS response to restore movement with high precision.

The role of basal ganglia pathways engaged in skilled forelimb movement in a mouse model of DYT1 dystonia *Filipa França de Barros, PhD, Champalimaud Foundation, Lisbon, Portugal*
The aim of the project is to quantify and manipulate the brain activity underlying a dystonic forelimb movement in mice. The results should facilitate targeting specific neuronal populations of the direct basal ganglia to produce more efficient therapies.

Our sincere thanks to Dystonia Medical Research Foundation (USA) for allowing us to share this update.

Community Education and Impact

Meet the DMRF Canada Support Advisory Group

DMRF Canada's Support Advisory Group (SAG) was formed to provide enhancements to the support group structure and advise staff on support programs and strategies to address unmet needs of the community. These members bring not only their individual perspectives but also those of their respective groups – across different regions, age, gender and the challenges posed by their types of dystonia.

Robin Krantz, Greater Vancouver, BC

Receiving a cranial dystonia diagnosis (also known as Meige syndrome) in 2003, Robin knows all too well what the unique challenges a dystonia diagnosis can bring. Co-leading her Group from 2015-2023, Robin is an excellent leader as she carefully considers the needs of the community to ensure those with dystonia are living their best lives possible with the diagnosis.

Jennifer Lovell, Winnipeg, MB

Like many others with dystonia, Jennifer spent years undiagnosed and looking for answers. She spent 35 years searching and was relieved when she learned that she had dystonia. With her personal experience and having worked at the Faculty of Medicine at the University of Manitoba, Jennifer strives to build connections with the medical community and provide the support needed for affected individuals and families.

Yann Rondeau, Montreal, QC

Yann co-founded 'Twisted Talk'; a support group for anglophone people in 2018. Yann was diagnosed with dystonia in October 2017, a few months after experiencing symptoms. At that time no one was able to confirm what his condition was, and this experience inspired Yann to help others in a similar position. Yann understands the physical and emotional challenges that come with a dystonia diagnosis and understands how powerful connecting with others and building community can be.

Joanne Alford, North Edmonton, AB

Since her diagnosis, Joanne has been involved in dystonia support. She has been the leader of her group for more than two decades. Her objectives have been to build the network of persons affected by dystonia and those who treat it, so as to visibly enrich and enlarge the knowledge of dystonia through awareness, education, advocacy, and research; thereby, improving the well being of persons living with dystonia.

Casey Kidson-Reid, Kingston ON

Casey first got involved with DMRF Canada as an Ambassador and launched her campaign; Dyfying Dystonia. Since that time, Casey joined the DMRF Canada Board of Directors in 2020 and has taken on several responsibilities that advance DMRF Canada's mission, including supporting others with dystonia. Casey facilitates the DMRF Kingston Support Group, has developed exercise videos, and was featured in our Dystonia Awareness video.

Jason Young, Cape Breton, NS

Jason's journey with dystonia began when he was 25. Eventually he received a diagnosis of Paroxysmal Non-Kinesiogenic Dyskinesia (PNKD), though his dystonia has evolved over the years. After many late-night visits to the ER and challenges with medical professionals who were not familiar with dystonia, Jason is passionate about raising awareness for the condition as an advocate and Support Group Leader.

Building a Better Life with Dystonia – Enhanced Resources and Support

DMRF Canada has a vast variety of resources available to aid you in your journey with dystonia. From caregiving resources, tips for living well with dystonia, to a guide for the newly diagnosed and many more, we are here for you every step of the way.

Please visit: www.dystoniacanada.org/resources to see our list of resources available.

Information Sessions

Earlier this year, DMRF Canada was pleased to host a virtual informational session with Swimming Canada on the benefits of swimming for people with dystonia. This session provided information to individuals of all swimming backgrounds, whether recreational or competitive, and offered the opportunity to learn from the experiences of elite athletes - from adapting to swimming to getting started with competitive swimming.

We thank Swimming Canada and the panel for providing the dystonia community this important resource.

Please visit: www.dystoniacanada.org/swimmingwithdystonia for more information, resources, and to watch the recording.

For a list of all past dystonia symposia, information sessions, seminars and webinars, visit www.dystoniacanada.org/dystonia-information-sessions

Connecting a Global Community of Dystonia Thrivers

DMRF Canada is proud to partner with like-minded foundations and organizations around the world to ensure the best possible support is available for the dystonia community. To provide enhanced peer support for individuals living with blepharospasm and spasmodic dysphonia, we are honoured to collaborate with the Benign Essential Blepharospasm Research Foundation (BEBRF) and Dysphonia International to offer form-specific support meetings for individuals living with those types of dystonia.

To learn more about the BEBRF and Dysphonia International and to view a list of their upcoming virtual meetings, please visit: https://blepharospasm.org/events/ and https://dysphonia.org/calendar/

Benign Essential
Blepharospasm
Research Foundation

DYSPHONIA
INTERNATIONAL
FORMERLY NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

Looking for Support in Your Community? Dystonia Support Groups are here for You

To connect with a volunteer in your area, please visit: **www.dystoniacanada.org/support**

Throughout 2022-2023, we were honoured to welcome nine new support co-leaders across the country:

- Soreyea – Thompson/Okanagan, BC;
- Michael – Greater Vancouver Area, BC;
- Mehrafarin and Shari – Calgary, AB;
- JF, Safa, Sumayya, Justine, and Nasem –Toronto, ON

A heartfelt thank you to our two retiring leaders, Laraine (Calgary, AB) and Robin (Greater Vancouver, BC). Both Laraine and Robin dedicated themselves to building supportive communities through their outstanding years of service.

DMRF Canada Staff had the pleasure of meeting with our leaders at our Annual Leaders Conference on July 19, 2023. Thank you to all that attended.

Upcoming Meetings – Save the Date

Calgary, AB – September 23rd, 2023

Our Calgary Dystonia Group will be hosting on Fall picnic at 'Song Sparrow' in North Glenmore Park. from 12 to 2 PM MT. All are welcome! **For further details and to confirm your attendance, please visit:** **www.dystoniacanada.org/events/calgary-support-group-picnic**

Virtual Meeting for Young Adults and Family Caregivers of Children – October 14th 2023

On October 14th, meet with our wonderful volunteer, Neil, as he hosts a meeting for Young Adults (18-30 years of age) and Family Caregivers of Children from 1:00 PM to 3:00 PM ET. **To register, please visit:** **www.dystoniacanada.org/events/national-virtual-support-meeting**

Vancouver, BC – September 30th, 2023

The Greater Vancouver Group will be hosting a free half-day education and support session at the North Delta Recreation Centre from 10 am to 3 pm PT. Featured speakers include Dr. Kanungo, a neurologist and Sally Stelling from the BC Brain Wellness Centre. Make sure to secure your spot by September 15. **Register now at:** **www.dystoniacanada.org/events/2023vancouver**

Montreal, QC – October 29th, 2023

Our French-speaking support group in Montreal, Dystonie-Partage, will be hosting a session with featured speaker Dr. Emmanuel Flamand-Roze, a neurologist from France. **To register, please visit:** **www.dystoniacanada.org/events/2023montreal**

National, Virtual Meeting – November 2023

Join dystonia support meetings from the comfort of your own home through our virtual sessions. Stay tuned for details on the November National Virtual Support Meeting. These meetings provide an opportunity to connect with dystonia thrivers across Canada.

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

2023 Jackson Mooney Patient Grant Winner Announced

On behalf of the DMRF Canada Board of Directors, and grant sponsor, Jackson Mooney, we are pleased to announce that this year the Grant Committee opted to provide funding for education to Amanda Loewen of Windsor, ON. Our heartfelt thanks to Jackson Mooney and we wish Amanda the very best with the next step in her career path.

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**

Stayed tuned for our Spring 2024 Newsletter for an update from our 2022 Grant Recipients, Astrid Frauscher and Julie Emied.

Elevate, Educate, and Empower: Celebrating Our Self-Advocacy Contacts, Neil and Sarah

Congratulations to Sarah Anderson of Winnipeg, MB, on her incredible achievement of being named the 2022 Neurological Health Charities Canada (NHCC) Changemaker Award! Sarah's advocacy has shed light on the challenges faced by individuals living with dystonia and disabilities. In addition to being a NHCC Changemaker Awardee, Sarah is also the 2018 Jackson Mooney Patient Grant recipient as well as one of our self-advocacy peer contacts and our teen/young adult contact. **Checkout Sarah's story, the NHCC award announcement, and her inspiring acceptance speech on www.dystoniacanada.org/sarahanderson.**

DMRF Canada wishes Neil Merovitch our sincerest congratulations for graduating this spring with his Ph.D. in Physiology from the Temerty Faculty of Medicine at the University of Toronto. Like Sarah, Neil is also a past recipient of the Jackson Mooney Patient Grant having been our inaugural winner in 2017 and he is a support leader and our other self-advocacy peer contact. Neil recently was interviewed by writer, Julie Soudat, about his experiences as an advocate, doctoral student, and living with a disability. **To read more about Neil's story and his interview, please visit: www.dystoniacanada.org/NeilMerovitch.**

To get in touch with Neil or Sarah about your self-advocacy needs, please visit: www.dystoniacaada.org/disability-advocacy

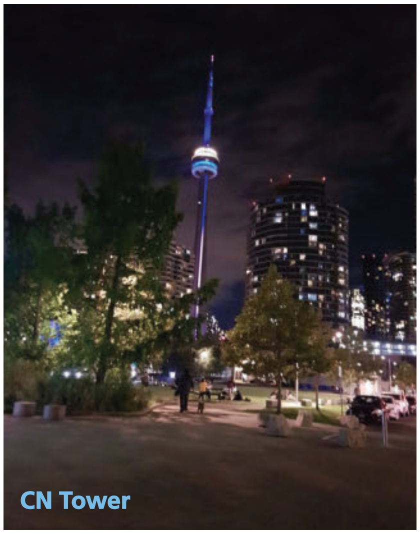
Our sincere thanks to the George Lunan Foundation for their support of Community Education and Impact section.

Increased Awareness of Dystonia Can Start with You – September is Awareness Month

As the only Canadian charity dedicated to serving the dystonia community, raising awareness about dystonia is an integral part of DMRF Canada's mission. In addition to improving society's recognition and understanding of dystonia, increased awareness directly impacts our ability to fundraise for research and identify people and families who need our help.

Throughout the month of September, unite with other dystonia thrivers across the country and help raise awareness about dystonia. Here are a few ways you can make an impact:

- ☑ **Wear Blue:** Show solidarity by wearing blue throughout September. Spark conversations and make a bold statement.
- ☑ **Become a Dystonia Awareness Ambassador**: Help increase awareness of dystonia in your local community and distribute dystonia informational materials. **Visit:** www.dystoniacanada.org/become-dystonia-awareness-ambassador
- ☑ **Look out for Landmarks in Blue:** If you see one, please take a picture and tag DMRF Canada on social media. Make sure to tag your local politicians as well to help spread the message. Exciting news! In partnership with the DMRF USA, the Peace Bridge connecting Buffalo, New York and Fort Erie, Ontario will be lit up. **Visit:** www.dystoniacanada.org/september-dystonia-awareness-month-o
- ☑ **Spread Awareness Online:** Harness the power of the global community through social media and post important facts about dystonia on your accounts. Remember to use #dystoniastrong and #dystoniaawareness when sharing.
- ☑ **Connect with Local Media:** Reach out to your local media using our Press Kit and request a feature about Dystonia Awareness Month or share your journey with dystonia. No one can tell your story better than yourself and awareness month is an apt time to share.



For further details and a complete list of activities, please visit: www.dystoniacanada.org/dystoniaawarenessmonth

September is Dystonia Awareness Month

DYSTONIA STRONG

Navigating Common Oral Medications Used for Dystonia

Dystonia patients perform a balancing act between medication benefits and side effects.

While no magic pill for dystonia exists, oral medications are one piece of the treatment puzzle to help manage the disease. Oral meds can provide relief from some dystonia symptoms, but they're imperfect. Dystonia patients and their doctors need to find the right balance between benefit and potential side effects for any treatment option.

Oral medications used to treat dystonia vary greatly for each individual and should be managed with your doctor. While other medications may be prescribed to address symptoms unique to individuals, this article focuses on the more common oral medications used to treat dystonia.

About 70% of dystonia patients take some type of medication either injectable or oral. Of patients taking medications, more than half either use oral medications alone or in combination with botulinum neurotoxin (BNT).

"All the drugs we use for dystonia are off label. There is no oral medication approved by the Food and Drug Administration specifically for use with dystonia," said Dr. Cynthia Comella, a movement disorder neurologist at Rush Medical Center, Chicago.

The most common oral medications used to treat dystonia fall into five categories: anticholinergics, benzodiazapines, baclofen, dopaminergic agents, and tetrabenazine. (See accompanying article.) All oral medications prescribed for dystonia are systemic, meaning they affect the entire body. Side effects are common and need to be managed under a doctor's supervision.

Relying On Experience

Patients should ask their doctors which medications seem to work best for their dystonia types, as well as possible side effects and how often they occur. "Patients need to be aware of side effects. If they occur, they should contact their physician so the medications can be altered," Comella said.

Unfortunately, there has not been a lot of research conducted on oral medications for dystonia, so little scientific data exists to point physicians to one medication over another. With no clear data, physicians and their patients rely on the experience of others with the medication. Physicians recommend what's worked with other patients who have similar dystonia types, and dystonia patients rely on their own experience by giving the drug a test run.

Neurologists typically start patients on small doses of medication and ramp the dosage up slowly to find the right balance between benefit and potential side effects. Introduction of an oral medication typically takes about three months, depending on the medication. "With dystonia you don't get an instant benefit. You want to give it some time to see whether it's beneficial and to see if there are adverse effects at that dose," Comella said.

Continued on page 20

Understanding Side Effects

Side effects and their severity vary by medication and individual, but nausea is common with many oral meds taken for dystonia. Anticholinergics can affect the memory, urinary retention and cause dry mouth. "I hear things like, 'I can't think. I can't remember things. I feel sedated,'" Comella said.

Benzodiazepines, which are typically used as antianxiety agents, are most frequently used by botulinum neurotoxin (BNT) patients who take the medications during the wearing off period before their next BNT injection. Common side effects include drowsiness, light-headedness, confusion and dizziness.

Baclofen can be effective particularly in children with dystonia because their brains can tolerate the side effects better, Comella says. Interestingly, children take higher doses of baclofen and reduce dosage or eliminate the drug as they age. Common side effects are sedation and nausea.

Some patients with specific types of dystonia respond very well to dopaminergic agents, which increase the neurotransmitter dopamine. While dopa-responsive dystonia is rare, Comella says it is worth exploring especially with newly diagnosed patients. "It responds almost in a curative fashion to low doses of carbidopa levodopa. You don't want to miss it, particularly in children," she said. Short term side effects are minimal.

Dopamine depleters, tetrabenazine being the oldest and most commonly used for dystonia, reduces the activity of dopamine. The main side effects are depression, sedation and possible drug-induced parkinsonism. Several newer modifications, deutetrabenazine and valbenazine, have demonstrated less severe side effects but remain largely untested for dystonia.

Evaluating Medications

Communicating with your doctor is critical when evaluating medication effectiveness, side effects, dosage and even termination. Just as you ramp up oral medication dosages under the supervision of a physician, dystonia patients need to ease off the medications with incrementally smaller doses as well.

"You don't want to start something, get a brain used to it and take it away cold turkey," Comella said.

CATEGORIES OF MEDICATIONS COMMONLY USED TO TREAT DYSTONIA

- **Anticholinergics**
  Anticholinergic drugs include Artane® (trihexyphenidyl), Cogentin® (benztropine), and Parsitan® (ethopropazine). These medications act by blocking a neurotransmitter chemical called acetylcholine, which plays an important role in muscle activation.

- **Benzodiazepines**
  Benzodiazepines include Valium® (diazepam), Klonopin (clonazepam), and Ativan® (lorazepam). These drugs act on the neurotransmitter chemical GABA-A among other neurotransmitter systems.

- **Baclofen**
  Baclofen (Lioresal®) stimulates the body's ability to process a neurotransmitter called GABA-B. Baclofen can be taken orally, or the medication can be continuously fed into the nervous system by a surgically implanted device, often called a baclofen pump.

- **Dopaminergic Agents**
  Some patients with specific types of dystonia respond to drugs that increase the neurotransmitter dopamine. The one used for dopa responsive dystonia is levodopa. Drugs that block or deplete dopamine are generally discouraged from use in treating dystonia because of the risk of tardive syndromes, which may worsen movement symptoms.

- **Tetrabenazine**
  Tetrabenazine (Xenazine®) is a drug that depletes dopamine. It can be effective but has many side effects. Deutetrabenazine and valbenazine are also dopamine depletors but have not been studied well for dystonia.

She also recommends patients talk with their pharmacists about possible interactions with other drugs they may be taking, such as anticoagulants, antiarrhythmics or antihypertensives.

Herbal medications are not recommended for treating dystonia, and patients need to inform their doctors of anything they're taking in that realm as well. "People think if it's an herb, it's natural, it's safe," Comella said. "Not true. You just don't know what you're taking when you take an herbal medication, and they all have pharmacological activity."

Managing oral medications for dystonia is a process that requires open communication and trust between doctor and patient. Doctors may even need to help patients "clean house" by getting rid of medications that aren't effective and are burdening them with side effects.

"Managing patient expectations is one of the most important things a doctor needs to do, educating them about what to expect and when to call us," Comella said. "We don't dictate treatments; we discuss treatments because every patient's situation can be different. If you don't focus on the patient, you're missing the boat."

STRATEGIES FOR MANAGING ORAL MEDICATION

- **Bring a list of all prescription medications to your doctor.** Before beginning oral medications for dystonia, bring a list of all current medications to your doctor to check for potential drug combination interactions and initiate open, honest communication about compliance.
- **Talk to your doctor about side effects before starting medications for dystonia.** Understand the common and more extreme side effects for oral medications, so you know what to expect and when to call your doctor should they occur.
- **Ramp up dosages slowly under your doctor's supervision.** It may take two to three months to increase dosage to achieve the right balance of benefit and side effects. Ramping up the amount slowly allows the body to get used to the medication, reducing the potential for more severe side effects.
- **Call your doctor if you're experiencing unusual or extreme side effects.** Side effects are common with all medications taken for dystonia. However, call your doctor immediately with any questions, concerns, or if you're experiencing something you've never had before.
- **Do not abruptly quit oral medications taken for dystonia.** If you decide the medication isn't right for you, call your doctor to help you ease off the medication with incrementally smaller doses.
- **Reevaluate oral medications periodically.** Sometimes the combination of oral medications taken for dystonia and other health problems can become unmanageable both in terms of side effects and daily maintenance. It may be time to "clean house" and reevaluate which medications are helpful and which ones are not.
- **Communicate with your doctor about any herbal medications.** Tell your doctor about any herbal remedies you take regularly because they have pharmacological effects as well. Just because it's "natural" doesn't necessarily mean it's good for you.

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Supporting a Loved One with Dystonia

Tips from Someone Living with Dystonia

Tim Williston lives in New Brunswick with his wife, Nancy. He is a traveller and a sports enthusiast, who loves a good action movie (although he'll concede the occasional compromise and watch a rom-com). He is a self-described positive person, and the effects of his positivity are apparent in his close relationships with family and friends. Tim has also been living with dystonia for the last 17 years and has weathered many of the challenges and permanent changes this has brought with it. Tim has worked and continues to work very hard at keeping his positivity shining through, while he acknowledges many of the challenges he faces internally.

We had the chance to find out how dystonia has changed Tim's life, how he manages to continue doing what he enjoys and how his family and friends support him. Tim shared his story in hopes that it will let others with dystonia know they are not alone and can help their loved ones further understand what it is like to live with this disorder.

The Ongoing Journey with Dystonia

Tim was diagnosed with torticollis and blepharospasm in 2004. His symptoms were severe and very apparent. "My head would move back and to the side very violently. It was apparent if you were in the room with me," he describes. Following unsuccessful treatments, he underwent Deep Brain Stimulation (DBS) surgery in 2006 and after a couple years of programming, found settings that were optimized for him. During that time, Tim became involved in DMRF Canada, first as a local contact, then a support group leader and finally a board member (from 2018-2020). The effectiveness of the DBS began to wane and in 2018, Tim underwent a second DBS. He has gone through a long process with the help of his family, friends and medical team to begin the road to "getting back into the groove" and prioritizing the things that are important to him.

Knowing Yourself

Tim says that he was previously known as a "social butterfly." He describes how his wife Nancy says, "everybody wants to talk to you!". While Tim describes that before dystonia, he was very outgoing, he now says, "I'm outgoing, to a point. I find it difficult and extremely tiring to socialize. I have to prepare by resting in advance and then suffer the fatigue after a social event." Tim has become attuned to listening to his body and acknowledging when he needs a rest. "I know what the signals are when I pass my expiry date," he explains. Noticing and accepting his limitations has been a big learning curve for Tim, but an extremely important factor in continuing to do some of the things he enjoys. Some things have had to take a backseat and while it is difficult, knowing his limitations allows Tim to participate in some of the things he enjoys.

Becoming an Advocate, and Recruiting Advocates

One thing that has come from Tim knowing himself so well, is that he is able to advocate for what he needs. He has communicated to his family and friends that he is sometimes up for socializing and sometimes isn't, depending on the day. He also finds that by 2-3 hours, he needs a break so will go to another room, often relaxing with a good TV show or movie. He describes that his close circle knows this and lets him do what he needs, no questions asked. He is thankful that Nancy is good about "doing her own thing" as Tim acknowledges he doesn't want to hold her back from doing things when he cannot. While he feels everyone is accepting, Tim wishes he still had the stamina he used to for socializing. "My wife tells me that she understands my physical and social limitations, but she does not truly understand what lies beneath the surface in my mind. Only we who have Dystonia understand this aspect."

Prioritizing his social connections has been beneficial for Tim, in that he now also has a circle of advocates. He admiringly describes that his wife "just won't stop till she gets what she wants" and that this has been instrumental for him when navigating the medical aspects of dystonia. He also says that all their friends know about dystonia, show their support by donating and by educating new people as well. For example, his good friends will let newcomers know before a bike ride that Tim may have to cut the ride short because of his dystonia and that's okay. He also says that if he is going to a party, everyone knows in advance that he has dystonia, and he doesn't have to go in and educate.

Staying Active

Tim prioritizes the things in his life that bring him the most enjoyment. He values physical and social activity and says this is key. He works hard at maintaining his positive attitude in public, admitting that this is sometimes hard. In response to "How are you doing?" he answers, "I'm good. Any day that I am above ground and vertical is a good day!" and will often deflect the question by asking others about themselves. Tim says this comes naturally, since before dystonia, "I never dwelled on myself anyway." He does want people to know though, that this positivity comes with hard work and very deliberate management of his energy so he can maintain enjoyment and social connections.

Acknowledging and Accepting Change

Dystonia has not been an easy road for Tim. He discusses how it has changed his personality, taken enjoyment out of things he used to enjoy and how he sometimes feels like he is on an emotional rollercoaster depending on his physical abilities. He also talks with appreciation for his wife of 45 years and the time they take to connect every day. He savours the time he gets to spend in nature from the vantage of a kayak, and the city streets he navigates from his bicycle. He surrounds himself with the ongoing support of extended family and friends. He recognizes that his abilities with dystonia fluctuate and says he is getting back to where he wants to be. While his life may not be the same as it used to be, there are things he can enjoy and he will continue to do so with his understanding of himself, compassion for himself and the support of those around him.

We thank Tim for sharing his story and giving insight into what it is like to live with dystonia. Do you have a story to share?
Get in touch at info@dystoniacanada.org

Live Your Best Life with Dystonia

We want to acknowledge that everyone's experiences are unique, please consult your doctor before making changes that could affect your health. Here is what Tim suggests to live your best life with dystonia:

- Take time to understand what you need and set limits.
- Advocate for yourself and enlist the help of those around you to become your advocates.
- Stay active both physically and socially.
- Acknowledge change and work towards acceptance.

You may find these tools helpful in navigating your own experiences with dystonia:

- Wellness checklist – **www.dystoniacanada.org/livingwell**
- Mental health resources – **www.dystoniacanada.org/nonmotor**
- Tools to educate healthcare providers – **www.dystoniacanada.org/healthprofessionals**

*We are grateful to volunteer **Jana Zalmanowitz** for writing this article for the dystonia community. Jana is a Speech-Language Pathologist and Content Writer. She hopes to help build a more inclusive and supportive world, one story at a time.*

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.*

Become a Member of the Monthly Giving Team

"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*

For a charity like DMRF Canada, revenues often fluctuate dramatically from month to month, and year to year making it challenging to plan multi-year research projects. A monthly donation of just $5/month will ensure a steady source of funding while reducing administrative costs.

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

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