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

Spring/Summer 2022

Join us for Freedom to Move:
Run,Walk and Wheel For Dystonia - June 2022

IN THIS ISSUE:

PLEASE RENEW YOUR MEMBERSHIP FOR 2022

Support the dystonia community with a donation to DMRF Canada.

visit: www.dystoniacanada.org/donate

Thank you for your support.

Foundation Update

Our mission to fund research that will lead to better treatments and a cure for dystonia has always been central to what we do. For more than 45 years we have been committed to supporting scientific investigations that generate discoveries while building a research environment in which discovery is possible. In this issue you can read about the latest discoveries in the field of dystonia, including details on new dystonia drug possibilities, and the latest news from our Research and Clinical Fellow, Dr. Mario Sousa.

While the science is constantly evolving, the beating heart of DMRF Canada's mission is our overwhelming commitment to the community we serve; the 50,000 Canadians and their families impacted by all types of dystonia; the research community in Canada - and globally - who have dedicated their lives to understanding what causes dystonia with a vision to one day find a cure; the clinicians who work every day to produce the best treatments to improve the lives and well-being of their patients. With more than 30 Dystonia Support Groups operating across the country, driven by volunteers who believe in our mission and the power of community, we continue to inspire, educate, and encourage.

Ultimately, DMRF Canada is about YOU, and the incredible power of the community that we built together. This latest issue celebrates this community and provides options to connect:

- Through our largest annual fundraising event – Freedom to Move Run, Walk and Wheel, taking place virtually throughout the month throughout the month of June 2022, and open to everyone;

- Participating in our Do-It for Dystonia campaign – a completely customizable way for you to connect your community to our cause anytime throughout the year;

- Celebrating Dystonia Advocate Sarah Anderson, and others whose commitment to awareness and support continues to build up our network;

- Details on how you can take charge of your care and feel empowered to have conversations with others in your community – including your family, members of your support group, and your doctor.

As we continue to navigate through the third year of the Pandemic, it has become clear that what matters most – is people. Thank you for being a part of the DMRF Canada family, and for continuing to support our important cause.

Sincerely,

Connie Zalmanowitz,
Chair, DMRF Canada,
Board of Directors

Connie Zalf.

Archana Castelino,
National Director,
DMRF Canada

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.

Tribute to Lily Faider

DMRF Canada was saddened to learn of the passing of Lil Faider; sister of late DMRF Co-Founder Samuel Belzberg, and passionate dystonia advocate and life-long supporter of our mission.

Lil was responsible for one of the first Support Groups in Calgary, and she was actively involved in the that chapter.“My sister-in-law Lil Faider died a short while ago and with her passing went a staunch supporter of the DMRF Canada.” said DMRF Co-Founder, Frances Belzberg. “Lil will be greatly missed by our family, but she will also be missed by the DMRF Canada family.”Lil had a particularly close relationship with Cheri Belzberg, Sam and Fran’s daughter, and inspiration for the establishment of the DMRF. “My Aunty Lil didn’t have an easy life, but she chose to turn her pain and suffering into empathy and serving others through her volunteer work for DMRF, and the many boards she sat on.”

On behalf of the Belzberg family, we thank you for condolences and generous tribute donations.

In Tribute

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

Marie-Laure Dubé
Robin Foley
Lynne Gervais
Dorothy Hymes
Jacques Leclerc
Paul Mullen
Trina Myers
Hazel Waines

The Jackson Mooney Dystonia Patient Grant 2022 is Accepting Applications

Has dystonia altered or derailed your career path?
Are you looking for a way to take the next step?

The Jackson Mooney Dystonia Patient Grant provides financial assistance of up to $5,000 for individuals living with dystonia, in financial need and committed to refine their futures. This funding could be used for further education or skills to accommodate a change in career.

All interested applicants are asked to submit a one-page letter of intent by April 29, 2022. To learn more about eligibility and next steps, visit: **www.dystoniacanada.org/dystoniapatientgrant**

FREEDOM TO MOVE FOR DYSTONIA RUN WALK & WHEEL

June 2022

DMRF Canada is thrilled to once again host Freedom to Move: Run, Walk, and Wheel for Dystonia, a virtual, national month-long awareness and fundraising event that aims to raise funds for dystonia research and support programs.

Taking place during the entire month of June, Freedom to Move will allow individuals to get up and move, anytime, anywhere, and any way they want throughout the month to support the dystonia community.

Join hundreds from the dystonia community coast-to-coast uniting for one common purpose: a future without dystonia. The research breakthroughs of tomorrow count on the investments we make today.

Don't Wait, Register Today!

When: June 1 – 30, 2022

Where: Anywhere in Canada

Why? To raise funds and awareness for dystonia research and support programs

Scan and Register Now

Meet This Year's Freedom to Move Ambassador: Ellis Siliker

For long-time dystonia advocate and Freedom to Move participant, Ellis Siliker, this event represents more than an opportunity to complete a race. It's a chance to fundraise for critical dystonia research while raising the public profile of dystonia.

Having first developed symptoms at age 8, Ellis has lived most of his life with dystonia and is often questioned about it; "when people talk to me, they ask, 'were you hit by a car?'" Ellis explains. And I have to say "No. I have dystonia. People have heard of MS (Multiple Sclerosis) and cerebral palsy. They don't know about dystonia mainly because it's quite rare."

In 2021, Ellis and his team "Conquering Dystonia" amassed the largest team in Freedom to Move history with over 50 participants! And this year, they want to do it again. "I am honoured to be this year's Ambassador. Freedom to Move is a chance for the dystonia community to unite across Canada and amplify our voices for more research, more awareness, and more understanding and support. Every step, every share, every dollar makes a difference. Together, I know we can conquer dystonia." - Ellis Siliker

You Have the Freedom to Choose - Get Started With 3 Steps Today:

Step 1 - Register

www.freedomtomove.org. Participants can sign up as an individual, or as part of a team.
New this year: Children 13 and under can register for ***FREE!***

Your Registration Includes: DMRF Canada Freedom to Move swag, mailed directly to you after registration, a chance to connect with others in the dystonia community across Canada, and the knowledge that you are helping to support vital dystonia research and support programs.

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

Step 2 - Set a goal

This can be a fundraising amount that challenges you - 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.

Our Fundraising Goal:

Help us raise $75,000 this year. 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. Join Ellis, and hundreds of others at this year's event.

Visit: www.dystoniacanada.org/freedomtomove to learn more and register.

Thank You to Our Generous Sponsors and Partners

IPSEN
Innovation for patient care

Boston Scientific
Advancing science for life™

CUSTOM LABS

An Update from Dr. Mario Sousa -

2019-2021 DMRF Canada Clinical and Research Fellow

Dr. Sousa recently completed his DMRF Clinical and Research Fellowship at Toronto Western Hospital (TWH). “It was a truly enriching experience – I got a chance to work in different areas with leading experts in movement disorders and great teachers. In TWH there is a particular educational vocation and each faculty member has a special set of skills related to different areas of the movement disorders field, including phenomenology, pharmacology, basic research, DBS, epidemiology, imaging, neurophysiology, neuropathology, ataxia, functional disorders, etc. Besides being exceptional clinicians, the faculty at TWH are also very active researchers and leaders in their respective fields.”

Dr. Sousa shared that the most valuable part of this Fellowship opportunity was the exposure to a variety of patients and treatment methods: “Seeing from inside how highly skilled clinicians would approach diagnosis, differential diagnosis, and treatment of movement disorders was one of the main learning points. The holistic approach to treatment practiced in TWH was also a very positive highlight in my opinion, as well as the opportunity to acquire new skills such as EMG guided Botulinum toxin injections for dystonia, learning how to perform and interpret neurophysiologic studies, or better handle DBS programming in different movement disorders.”

DMRF Canada is proud to have awarded this Fellowship, and grateful to see how impactful it can be. Supporting the training of physicians in the field of dystonia is critical to improve diagnostic accuracy. The more specialised training, the easier and faster they can diagnose, and manage symptoms. Dr. Sousa is grateful to the community for the opportunity that was given to him, and excited about the trajectory of dystonia research. “Dystonia research is definitely moving forward – there have been several new discoveries both in terms of diagnostic tools and treatment options, which I believe will start to have a positive impact on the community in the next few years. That’s really good to see”.

Dr. Sousa is finalizing his research on the Psycho-Social Aspects of Dystonia, and it will be shared later this year.

Dystonia Research Progress Presentation

Dr. Scott Norris MD, Associate Professor, Neurology, Washington University, USA delivered an outstanding presentation on the many exciting advances in dystonia related research at the DMRF Virtual Dystonia Educational Symposium in November 2021. In his talk, Dr. Norris conveyed excitement and optimism regarding future efforts to better understand and treat those affected by dystonia. You can watch this informative presentation and more from the DMRF virtual symposium at: **www.dystoniacanada.org/latest-dystonia-research-news**

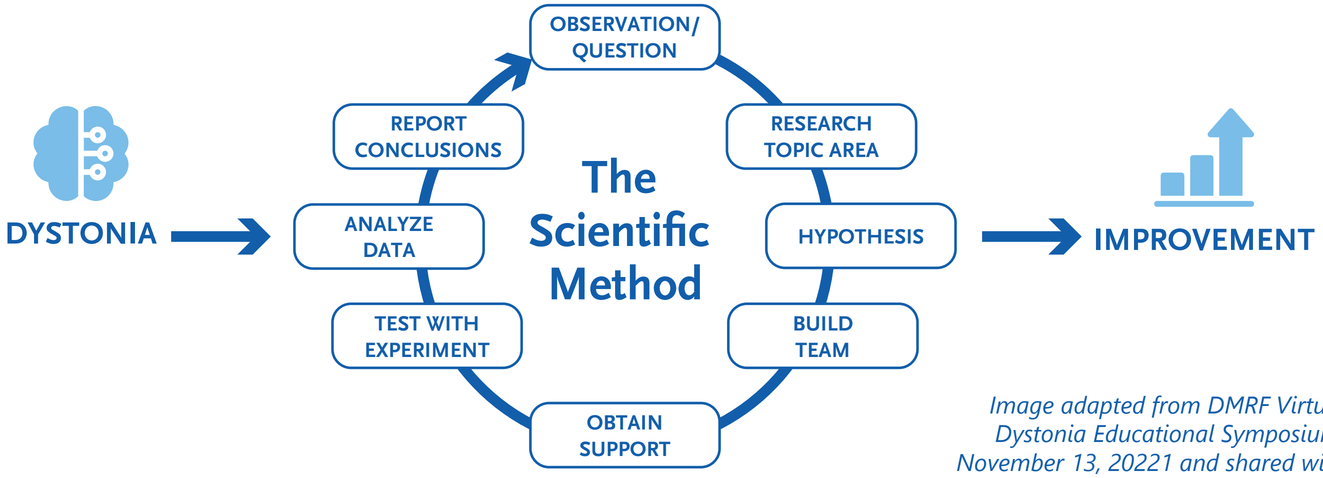


Image adapted from DMRF Virtual Dystonia Educational Symposium, November 13, 20221 and shared with permission from DMRF.

Dystonia Ambassador's Journey from Teenager to Adult

Sarah Anderson: Inspiring Us and Advocating for Accessibility

In 2017, as a grade twelve high school student, Sarah Anderson brought a new perspective to DMRF Canada's Support Network. As our first Teen Ambassador, Sarah became a point of contact for dystonia youth to reach out to and connect with. That same year, Sarah was featured in our Newsletter and shared her diagnosis journey. To read more about Sarah's dystonia journey, please visit: **www.dystoniacanada.org/sarahanderson**

Today, Sarah is in her fourth year at the University of Winnipeg. Through her time at the University, Sarah discovered a passion for advocating for increased accessibility for people with disabilities. She has been the Accessibility Director on the University of Winnipeg Students' Association Board of Directors for the past three consecutive terms.

As Accessibility Director, Sarah helped spearhead the University's *More Than a Door* Campaign, focused on increasing the number of automatic doors on campus. So far, the Campaign has successfully installed ten automatic doors. Sarah shared, "barriers exist in a way you might not see. Something as simple as a door can be challenge for a person with a disability as it can hinder their independence."

For Sarah, the necessity to self-advocate for her needs became crucial once she entered the post-secondary environment. She noticed that

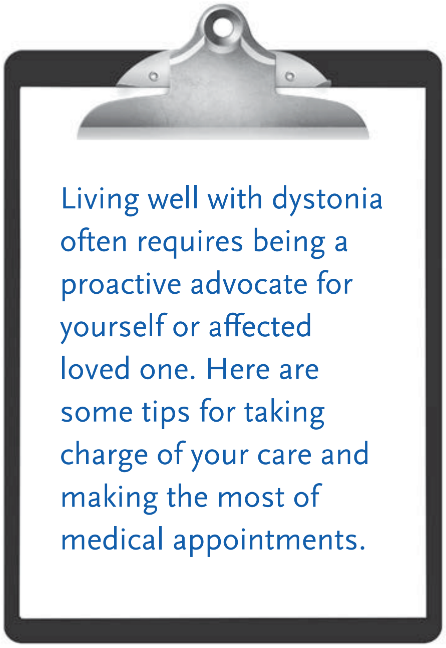
> ***"through kindergarten to grade twelve, I had so many supports in school made available to me. But once I entered university, it was up to me to tell the university or my professor what I needed. The essential skill of self-advocacy was something I had to learn through experience."***

Sarah's passion for disability advocacy and increased accessibility won't end once she leaves university. After graduation, she plans to become a middle school or a high school teacher. For her and thousands of other Canadians living with disabilities, it is vital that they see people like them in leadership positions as it helps dispel the incorrect notion that they are not qualified to do the same tasks as able-bodied people. "When you have a disorder like dystonia, your freedom depends on you finding your independence differently. You must be creative and think outside the box. People with disabilities are just people that do things differently."

No matter at what stage in life you are at, Sarah stresses, "you can't face dystonia alone and you shouldn't have to. A support system is crucial and if you don't yet have one, reach out and find one. Much like how it takes a village to raise a child, it takes a community to support each other for dystonia", said this 2018 Jackson Mooney Dystonia Patient Grant awardee.

If you are looking for peer-support in the dystonia community, please visit: **www.dystoniacanada.org/support** *to find a local support contact near you.*

Taking Charge of Your Care



Living well with dystonia often requires being a proactive advocate for yourself or affected loved one. Here are some tips for taking charge of your care and making the most of medical appointments.

☑ Make Yourself a Priority.

Even under the best of circumstances, dystonia is a life-changing disorder that requires management over time. Treatment can be time-consuming and inconvenient. When life gets busy or stressful, it can be tempting to 'just deal with' pain, medication side effects, or changes in how you feel. It may be easy to rationalize or ignore new or changing symptoms, delaying evaluation and care. Listen to your body and reach out to your medical team when you need help. Remember that mental health is healthcare too.

☑ Be Prepared.

Read up on dystonia and treatments, or ask a loved one to help you. The more informed you are, the more meaningful questions you will be able to ask. Prepare a list of questions for your doctor or nurse prior to each appointment. It can be difficult to remember each question when a lot of information is being exchanged during an office visit. If possible, ask a loved one to attend appointments with you to take notes or help retain information.

☑ Establish Rapport.

It is important to establish a positive relationship with your physician and healthcare team. Consider your medical team as partners in your care. Clear communication is key. Your doctor will have questions for you and you will have questions for them too. Medical appointments may feel intimidating or uncomfortable at times. You may feel understandably concerned, anxious, or in pain. Do your best to listen carefully and express your questions and concerns.

☑ Focus Your Questions.

Ask in advance how much time you can expect to have with your doctor during an appointment. Your doctor wants to address your questions and concerns but may have time restraints due to many patients who require their time and attention. Take time to write or audio record your questions in advance and take them with you. Start with your most urgent questions and concerns. If you are left with unanswered questions following an appointment with your doctor, follow up with a nurse or the admin staff to get the information you need.

☑ Know Your Medical History.

You will often be asked to recount your medical history, which may be lengthy. Have the essentials in a concise written format and bring it with you to appointments. Information to include may be: illnesses, traumas, and injuries, history of medication use and allergic reactions, family and medical history including cases of dystonia or other movement disorders in family members, allergies, and other medical conditions.

☑ Investigate Telehealth.

Movement disorder clinics are increasingly using video conferencing, smartphone apps, and additional telehealth technology to care for and interact with patients. You may have the option to conduct appointments from the comfort of your home. Secure video conferencing can save you time, energy, and expense from traveling to your doctor's office.

☑ Build Your Own Record.

You are the center of your care team. It is helpful to have copies of your imaging scans, and test results at your fingertips when you need them. Your doctors may refer back to parts of your medical record or you may need them to seek a second opinion. As part of your personal record, consider keeping a health journal that includes regular observations about your symptoms and pain, documents the dates and duration of treatments, your response to treatments, and other information relevant to your dystonia and general health.

Maintain a record of your medications. Keep detailed records of supportive therapies and complementary/integrative therapies, including vitamins, supplements, and herbs.

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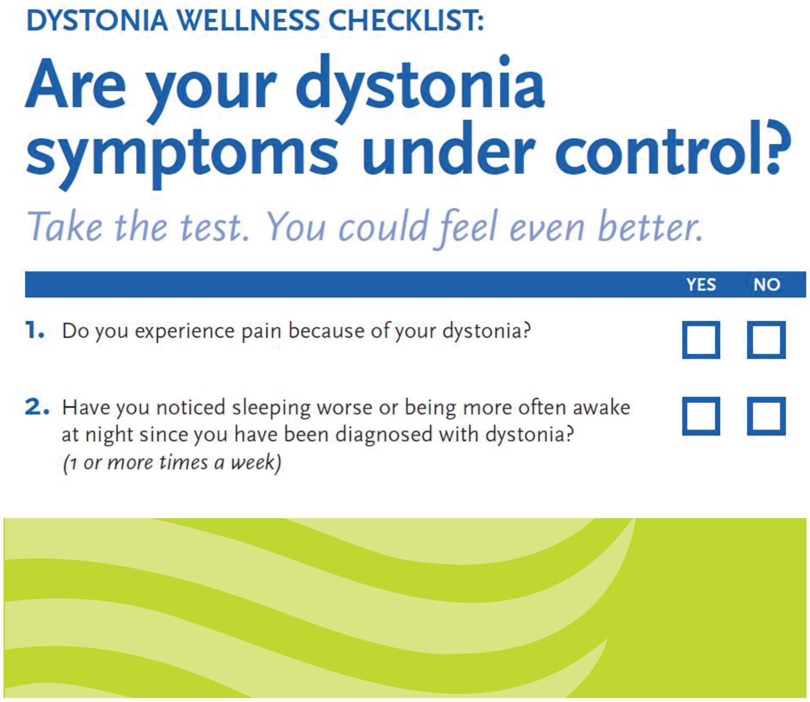
Are Your Dystonia Symptoms Under Control?

We want to help you live your best life with dystonia. Working with Ipsen Canada, we developed the Dystonia Wellness Checklist; a tool to help facilitate honest conversations with Doctors and about your well being. This checklist asks a few simple questions to identify areas where you could use additional support. **The Dystonia Wellness Checklist is available in clinics and doctors' offices or you can download it here: www.dystoniacanada.org/livingwell**



DYSTONIA WELLNESS CHECKLIST:

Are your dystonia symptoms under control?

Take the test. You could feel even better.

	YES	NO
1. Do you experience pain because of your dystonia?	☐	☐
2. Have you noticed sleeping worse or being more often awake at night since you have been diagnosed with dystonia? *(1 or more times a week)*	☐	☐

Updated Online Resources and Support for the Community

Living with Dystonia: Blepharospasm/Meige's Syndrome

In January 2022, DMRF Canada had the pleasure of presenting *Living with Dystonia: Blepharospasm/-Meige's Syndrome* webinar with Dr. Sylvain Chouinard and the support of the Benign Essential Blepharospasm Canadian Research Foundation. To watch this webinar and access other resources, visit: **www.dystoniacanada.org/blepharospasm**

Pain Management Resource Update

In order to provide the community with the tools and resources required to live well with dystonia, we have updated our chronic pain and pain management resources on our website. To find a province based listing across Canada, visit: **www.dystoniacanada.org/resources**

Common Misunderstandings in Dystonia

Incorrect information about dystonia is easy to find, - not only just on the internet, but in media stories and even from sources that claim to be authorities on the condition. Our thanks to the DMRF for a compiling a list of common misunderstandings and allowing us to share it here: **www.dystoniacanada.org/common-misunderstandings**

Not Born Yesterday: Dystonia & Aging

Whether someone has lived with dystonia for months or decades, the disorder often requires adjustments across many areas of daily life. The advantages of experience and aging can help ease certain aspects of the dystonia journey, while evolving realities may create new challenges.

Being aware of the natural aging process and how it may impact dystonia symptoms can help ensure optimal treatment outcomes and quality of life. If you are an adult over the age of 55 living with dystonia, you may wish to have a conversation with your movement disorder specialist about how the following issues may impact your individual treatment.

Changes in Response to Medications

As people age they may become less responsive to drugs or more likely to experience side effects. Changes in the body's physiology may reduce the benefits of some drugs but create a potential for benefit in another, even if that drug has been tried before. For example, an individual who could not tolerate a drug at an average dose in their 40s may experience a benefit from the same drug a decade later at a fraction of the dose. Some individuals find that after trying many prescription medications, adequate relief with the least side effects can be achieved through over-the-counter analgesics and practices to support overall wellness such as regular relaxation practices and gentle exercise.

Bone & Joint Conditions

Although bones and joints are not directly targeted by dystonia, the disorder may accelerate the onset of certain orthopedic or bone-related conditions. At the same time, the development of expected orthopedic conditions such as osteoporosis (a loss of bone mass resulting in fragile bones) and arthritis (inflammation of the joints—namely the cartilage and protective cushion structures of the joints) may aggravate dystonia symptoms. Both osteoporosis and arthritis can cause pain and restrict movement. Controlling the dystonia as much as possible may help delay the onset of these conditions, and addressing the bone and joint conditions will help avoid aggravating the dystonia.

Long-term Effects on Bones, Joints & Muscles

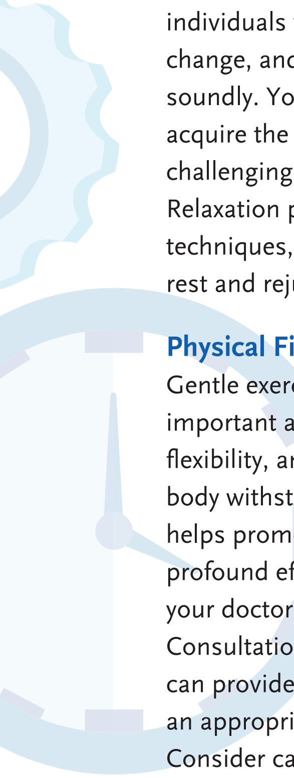
Dystonia may cause long-term effects in bones, joints, and muscles. Individuals with cervical dystonia may be at risk for chronic arthritis of the neck with compression of the spinal cord, inflammation or dislocation of discs in the upper spine, pain from pinched nerves, and chronic neck pain with secondary head pain and headache. Truncal dystonia symptoms (affecting the torso) may create inflammation or dislocation of discs in the spine and pain from pinched nerves. Arthritis of the spine may also be present. Individuals with dystonia in the legs may develop hip pain and arthritis. Severe dystonia in the legs may cause joint fusion in the ankle and/or muscle contracture. Focal hand dystonia may cause shoulder pain and arthritis in the shoulder, wrist, elbow, hand, and fingers.

Dystonia may cause painful muscle inflammation caused by excessive muscle contractions. This condition is called myofascial pain syndrome. The effects of degenerative bone and joint conditions and myofascial pain syndrome may be prevented and treated through medications, non-drug approaches to pain such as gentle massage and/or meditation, physical therapy to preserve range of motion and strengthen weakened muscles, and occupational therapy to address everyday challenges at home, in the workplace, and general mobility.

Mobility & Balance

A number of factors associated with natural aging—including conditions such as osteoporosis and arthritis mentioned above—can affect a person's mobility and balance. One of the most serious dangers that these factors create is risk of injury due to trips and falls. Developing lower body strength and engaging in exercises focused on balance and smooth movement can help prevent falls. The potential side effects of certain medications may also contribute to mobility and balance problems.

The same factors that increase the risk of falling may also diminish a person's ability to recuperate as quickly from falls or other injuries. You may need to give yourself added time to recover from demanding such as traveling or rigorous household projects. Taking care of your joints and maintaining physical flexibility may help your body withstand flexibility may help your body withstand such as traveling or rigorous household projects. Taking care of your joints and maintaining physical flexibility may help your body withstand these stresses. Small changes to your home may make the environment safer by addressing poor lighting or tripping hazards.



Fatigue & Rest

Adequate sleep is an important component of good health and daily coping. Sleep challenges are common among individuals with dystonia. As people age, sleep patterns change, and it may become more even difficult to sleep soundly. You may need to spend more time in bed to acquire the same amount of sleep. It may become more challenging to stay physically comfortable in bed. Relaxation practices like self-hypnosis, breathing techniques, and meditation can help the body achieve rest and rejuvenation if you have trouble sleeping.

Physical Fitness

Gentle exercise and maintaining physical fitness is important at every age to improve strength, balance, flexibility, and endurance. Each of these can help the body withstand the impact of dystonia. Exercise also helps promote a healthy emotional outlook, which has a profound effect on quality of life. Consider speaking with your doctor about the exercise options that are right for you. Consultation with a physical therapist or fitness trainer can provide direction regarding suitable types of exercise, an appropriate routine, and activities to modify or avoid. Consider cardiovascular exercise, strengthening techniques, flexibility exercises, water exercise, and inclusive fitness instruction classes and programs that prioritize accessibility for all body types and abilities.

Emotional Health

Living with dystonia often involves constant problem-solving and overcoming challenges. Alternating feelings of empowerment and frustration are common. Because dystonia can be exhausting both physically and emotionally, some individuals feel worn out by years of coping with a chronic illness. Changes in employment, activities, living arrangements, finances, and relationships may lead to feelings of sadness, regret, denial, and frustration. Depression and anxiety are common among individuals with dystonia of all ages. It is normal to react to loss. Negative feelings that persist for more than two weeks may signify a need for professional support. Left untreated, mood disorders and anxiety can have serious health consequences. Treatment is available and may involve counseling,medications, and/or self-help practices

Tips for Maintaining Emotional Health

- If you feel overwhelmed by sadness, anger, fatigue, or worry, reach out for help. Consider speaking to your doctor about being evaluated for depression and anxiety.
- Remain as socially active as possible. Accept invitations from friends and family, and cultivate new friendships with people of all ages.
- Find activities that are meaningful to you, particularly those that connect you to a greater community.
- Revisit activities that you enjoyed in the past.
- Develop and explore your spirituality.
- Physical exercise may help you feel better emotionally.
- Cultivate your curiosity and intellect. Learn about subjects that interest you.
- Participate in a dystonia support group, locally and/or online. Support groups provide the opportunity to simultaneously give and get support.

Vision

Normal age-related vision changes typically begin around age 40. Individuals may begin to notice slight changes in vision that tend to progress over time. Blepharospasm (dystonia of the eyelid muscles) is a focal dystonia that can affect eyesight directly by causing excessive blinking or involuntary, and typically begins late in life. Additional forms of dystonia may also affect vision. Involuntary postures of the neck may make it challenging to face forward while walking or doing other tasks. Tremors and movements may make it difficult to insert contact lenses or wear glasses. Executive or progressive lenses may be more practical than traditional bifocal lenses. You may need to help inform your eye doctor about dystonia and how this affects your vision needs.

Multiple Healthcare Providers

If you are consulting multiple doctors for various conditions, it is vital to keep each physician's office informed about the services and prescriptions provided by the others. Keeping all of your doctors informed of your total care will reduce the risk of undergoing procedures or receiving medications in combinations that are ineffective or unsafe.

Living Well with Dystonia

Being aware of the natural effects of aging may help you anticipate ways to better manage dystonia and maintain and improve the quality of your life. The experience and wisdom accumulated by dealing with dystonia overtime is an invaluable asset to your wellbeing.

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Our Community is "Doing it" for Dystonia

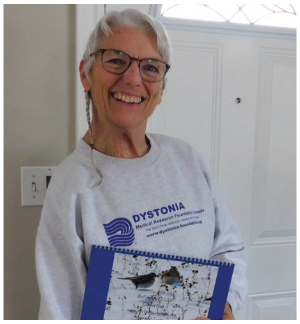
Once again, the dystonia community found creative and inspiring ways to raise awareness and funds through our *Do It for Dystonia 2021 campaign*. From hosting spin classes to birthday fundraisers, *Do It for Dystonia*, gives you the freedom to fundraise the way you want and when you want. Join Dystonia Thrivers across Canada raising funds for research and support programs.

Start your campaign today, visit: www.dystoniacanada.org/doit

Congratulations to our 2021 Fundraisers

Anna McNabb – Having lived with a misdiagnosis of cerebral palsy until she was 20, Anna never dreamed she could walk around a block - yet alone 25 KM at one time! That belief changed once she was diagnosed with dopa-responsive dystonia at 21. Anna's mobility improved greatly and in 2021, she and her mother, Maria, decided to challenge themselves. They set out to walk 25 KM (63 laps around a racetrack), launched their campaign 63 Laps to Give Back, and encouraged their networks to donate to DMRF Canada.

Sisters, Laurie Bell and Penny Patterson are no strangers to fundraising for DMRF Canada, having participated in our Freedom to Move Hamilton event for many years. With their fundraising events interrupted due to Covid-19, the sisters pivoted to virtual fundraising and launched their own campaigns.



Laurie outdid herself in 2021, hosting two campaigns. First, she designed and sold calendars with net proceeds benefitting DMRF Canada. She also set up a birthday fundraiser on Facebook.* In lieu of gifts, Laurie asked her friends and family to donate to DMRF Canada.

Penny hosted a virtual birthday fundraiser for DMRF Canada. Although fundraising can be intimidating, Penny's advice is to just "Do It". Start small and remember reach out to your networks beyond your close friends and family like your local shop owner or people in your gym/yoga class, you'll be surprised at the results.

*Facebook Fundraising

Starting your own fundraising campaign can be overwhelming. Thankfully, fundraising through Facebook is simple. For Laurie, it was the best platform to host her birthday fundraiser as it was easy to post messages to her friends encouraging donations and she had peace of mind knowing her donors received their tax receipts immediately.

To learn more and get started today, visit: ***www.dystoniacanada.org/facebookfundraising***

New Dystonia Drug Candidates Discovered

Several research teams reported major advances in the development of new drugs to treat movement disorders including dystonia. In one of these preclinical studies, investigators identified several compounds that retain the beneficial effects of anticholinergic drugs like Artane while eliminating side effects. Another research group successfully corrected dystonic brain abnormalities in mice with a Food & Drug Administration (FDA)-approved antiviral drug. These studies represent remarkable leaps forward in the effort to develop novel dystonia treatments.

P. Jeffrey Conn, PhD and colleagues have worked for years in pursuit of dystonia-specific drugs.

Next Generation Anticholinergics

A research team from Vanderbilt University School of Medicine led by past DMRF Medical & Scientific Advisory Council (MSAC) member Dr. P. Jeffrey Conn and colleagues Drs. Aaron Bender and Jerri Rook discovered and extensively characterized new compounds that reduce parkinsonism and dystonia in mice by targeting specific cholinergic receptors.

Many drugs work by acting on receptors, which are cellular proteins that receive information from outside the cell. Drugs binding to receptors may either activate or inhibit them, and this affects various cellular processes. Sometimes a drug acts to prevent other molecules, like neurotransmitters, from binding to that receptor.

Anticholinergic drugs, such as trihexyphenidyl (Artane), can be effective at controlling dystonia symptoms but are not a viable treatment for many patients because the side effects, including memory difficulties, sedation, or even hallucinations, can be unbearable. These unwanted effects occur because existing anticholinergic drugs act on many receptors in the brain, not only the receptors associated with dystonia symptoms one would want to target. If the drugs acted more precisely, and targeted only the receptors associated with dystonia, this would eliminate the side effects.

The Vanderbilt research team first identified such specific receptors and then synthesized novel compounds that specifically reduced dystonic symptoms in dystonia mouse models. Three of these compounds have been thoroughly tested and characterized, making them prime candidates for further drug development and clinical testing. (continued)

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New Dystonia Drug Candidates Discovered Continued

In a subsequent paper, the team described a discovery of another highly selective preclinical drug candidate for the treatment of dystonia and other movement disorders.

These discoveries represent many years of research and are major advances in the exploration of more potent and specific anticholinergic drugs that reduce motor symptoms in dystonia and other movement disorders.

"Most dystonia patients are familiar with often terrible side effects of anticholinergics Finding drug candidates that target specific cholinergic receptor subtypes without affecting others has been a true Holy Grail for pharmacologists. After many years of hard work, the Vanderbilt team led by Dr. Jeff Conn, finally delivered. We can only hope that these drug candidates will ultimately be as effective in the clinic as they are in the lab," said Dr. Teller.

Current MSAC member, Dr. Ellen Hess of Emory University School of Medicine and Dr. Mark Moehle, a past recipient of the DMRF's prestigious Mahlon DeLong Young Investigator Award, currently at the University of Florida, Gainesville, also participated in these studies.

> **"The dystonia community, patients and researchers, have been waiting for these kinds of studies for years. And it took years to get to this point! Enormous research and organizational efforts were required to achieve these scientific feats."**
>
> *~ Dr. Jan Teller, DMRF*
> *Chief Scientific Advisor*

Nicole Calakos, MD, PhD and her team identified a promising new drug for dystonia that is already FDA-approved.

Antiviral Drug Corrects Dystonic Brain Abnormalities

A team of researchers from Duke University led by past DMRF grant recipient and current member of the MSAC Dr. Nicole Calakos discovered that an existing FDA-approved drug corrects dystonia-specific brain changes in a mouse model of DYT1 dystonia.

DYT1 dystonia is a genetic dystonia that typically begins in childhood and progresses to generalized symptoms. Screening a library of drugs by using an assay they developed, the researchers found that the HIV antiviral drug ritonavir was among 18 compounds shown to have a specific and robust effect. Ritonavir belongs to a class of drugs called protease inhibitors and is used in combination with other drugs to treat HIV/AIDS (human immunodeficiency virus/ acquired immunodeficiency syndrome). Ritonavir corrected abnormal TorsinA migration in the dystonic mouse neurons. Critically, ritonavir corrected the striatal cholinergic physiology disrupted in dystonia through a unique mechanism that is different from the mechanism that slows HIV infection. In the dystonia models, ritonavir acts on pathways related to cell stress response, in which TorsinA appears to play a critical role.

The results of this study provide strong preclinical support to further explore ritonavir and other analogous protease inhibitors for dystonia.

Dr. Teller said, "The Duke team led by Dr. Nicole Calakos achieved something quite astonishing. Many groups try to 'repurpose' existing drugs, to see if already approved and safe medications can be used for different indications. This can be a very chaotic process. The Duke team used a beautiful, systematic approach. They not only identified a promising drug for dystonia but, equally importantly, showed that its beneficial effects are inherently linked to a biological process compromised in DYT1 and other dystonias."

Also from Calakos Lab, earlier this year DMRF grant recipient Dr. Ashley Helseth led a study with important implications for dystonia. The study characterized the influence of a specific cellular pathway engaged in cell stress response on dopamine signaling in part of the basal ganglia. This linked the pathway to processes in the brain related to learning and movement, suggesting it may be a potential target for novel treatments.

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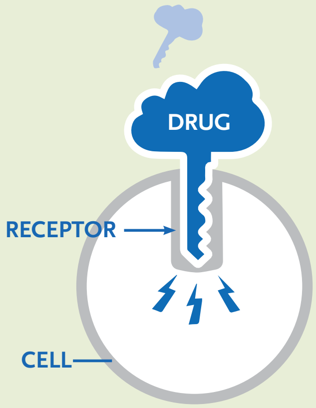
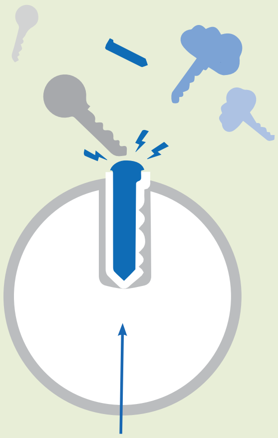
DRUGS & RECEPTORS: HOW DRUGS WORK



Drugs most often work by acting on receptors in the brain and body. Receptors are protein molecules in cells that can receive information from outside the cell.

Receptors are like locks that are activated by a matching key.

A drug activates the receptor by binding to it. The activated receptor then sends signals to the cell in response to the drug.



SOMETIME DRUGSS ACT BY BLOCKING A RECEPTOR.

Sometimes a drug fits into a receptor but only acts to block other molecules from binding to that receptor.

Neurotransmitters, hormones, and other molecules also work by binding to receptors.

DMRF-Funded Investigators Develop New Approach to Studying Motor Control

DMRF grantee Jesse Goldberg, MD, PhD, Associate Professor and Robert R. Capranica Fellow in the Department of Neurobiology and Behavior at Cornell University, has developed a groundbreaking new approach to studying dystonia and other movement disorders.

The study of dystonia has always required posing fundamental questions about how the human brain controls and coordinates movement. The act of reaching an arm to pick up an object is an incredibly complex neural task—and uncovering precisely what goes wrong in the brain when dystonia interferes with such a task is equally tricky. Much of what is known about human movement control and coordination has come from the study of reaching and grabbing in monkeys, because of the obvious similarities. Lab models such as mice, for example, do not have the anatomy or behavior to replicate human reaching with a limb.

However, Dr. Goldberg and his team discovered that the movements of a mouse's tongue when it licks water from a spout are neurologically comparable to a primate reaching an arm to grab an object. While a hand reach and a mouse lick may not initially appear to have much in common, in both cases the brain must coordinate fine motor adjustments in relation to a specific target. The investigators designed experiments using water spouts fitted with sensors, high-speed cameras, and artificial intelligence applications capable of sifting through millions of image frames to track the mouse tongue movements. Additional techniques allowed the researchers to observe that the licking mice activated the brain's motor cortex in remarkably similar ways to reaching primates. They demonstrated that a single mouse lick is controlled by the brain in a similar way to a human reach. This work opens up new opportunities to study the motor cortex function to understand normal movement as well as the neural basis of movement disorders like dystonia, Parkinson disease, and others. The hope is that this methodology will provide a best-in-class method for closely examining mouse motor control with the right level of precision to clarify behavioral abnormalities in dystonia mouse models, which are critical for strategizing and testing new treatment approaches.

DMRF is proud to have supported Dr. Goldberg's lab in partnership with the Dorothy Feiss Scientific and Medical Research Fund.

Bollu, T., Ito, B.S., Whitehead, S.C. et al. Cortex-dependent corrections as the tongue reaches for and misses targets. Nature (2021).

Reprinted with permission from DMRF Dystonia Dialogue, *Summer 2021 Vol 44, No 2.*

NHCC's National Neurological Strategy for Canada

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. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions.

As Canada emerges from the pandemic, NHCC and its members believe that now is the time for unprecedented collaboration within the brain health community, building on existing national strategies and global initiatives.

It is vital that a National Neurological Strategy for Canada be developed to tackle the knowledge gaps and needs of the millions of Canadians living with neurological disease, illness or injury. This national strategy will encourage the following:

- Strengthening Government of Canada leadership of neurological health
- Investing in and improving accessibility to early diagnosis, comprehensive treatment and care
- Investing in capacity building of neurological health care workforce
- Reducing stigmatization and discrimination of brain diseases, disorders and injuries
- Strengthening health information systems
- Fostering strategic approaches to research into neurological conditions

Stay tuned for more details in the months to come, and visit: **www.mybrainmatters.ca** to learn more.

NHCC
NEUROLOGICAL HEALTH CHARITIES CANADA

DMRF Canada Needs Your Help - Now More Than Ever

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

Become a Member of the Monthly Giving Team

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. Help us build a stronger Foundation by becoming a monthly donor. A monthly donation of just $5/month will ensure a steady source of funding while reducing administrative costs. *Become a member today, please visit:* **www.dystoniacanada.org/donateonline**

"My husband and I became 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, a Monthly Donor from Ontario*