

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

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

Dystonia Canada Report

A Newsletter from the
Dystonia Medical Research
Foundation Canada

Fall 2020

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Dystonia
is a
**movement
disorder**

DYSTONIANCANADA.ORG

PLEASE RENEW YOUR MEMBERSHIP FOR 2020

Support the dystonia community with a donation to DMRF Canada.

visit: www.dystoniacanada.org/donate

Thank you for your support.

Dystonia Medical Research Foundation Canada

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

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Foundation Update

Dear Friends,

We wish to thank our incredible Support Group Leaders and Area Contacts, who have continued to provide support to patients while maintaining social distancing. We now offer support group meetings via webinar, telephone, and email and have added virtual yoga, courtesy of the Edmonton Support Group.



This year's Chuck's Run, Walk and Wheel went virtual.

Chuck's family, the Saundercooks, and the DMRF staff, were "ahead of the curve" in planning this virtual event, ACROSS THE COUNTRY!

Our Co-Founder, Fran Belzberg, "raised the bar" in convincing James Pattison to donate the use of his 500 outdoor digital signs nationally, with an ad appearing every minute from May 31-June 30, producing more than 30,000,000 impressions! The excitement at the opportunity to raise awareness nationally had us all working around the clock, looking for the best slogan to attract many who would be seeing "Dystonia" for the first time. After a 30-day virtual campaign, we successfully connected our Dystonia family across Canada and raised almost \$70,000, exceeding our GOAL during this pandemic!

Thank you for all that you do to keep us focused on our end goal: a cure for Dystonia. Until then, we appreciate your dedication to doing all that we can to improve lives for Dystonia patients today.

A handwritten signature in black ink that reads "Bill Saundercook".

Bill Saundercook,
Chair, DMRF Canada Board of Directors

Thank You for Your Support

Canadian donations should be sent to:
Dystonia Medical Research Foundation Canada
550 St. Clair Ave West, Suite 209,
Toronto ON, M6C 1A5
www.dystoniacanada.org/donate

DMRF Founding Member Shares Philosophy for Living Well

Cheri Tannenbaum has long pushed back against society's tendency to applaud individuals with disabilities as inherently inspirational. She finds the "inspiration pedestal" strange and isolating.

"How would you like to be unable to speak intelligibly? How would you enjoy having an awkward gait that makes you prone to falling and causes people to stare as you shuffle by? Living with dystonia is not something I would have chosen for myself," Cheri explained. "To tell the truth, what I really long for is normalcy. Wherever I go, people are always telling me that I am an inspiration. This makes me feel like a total fraud, because to my mind I'm just doing what I have to do to drag myself out of bed every morning and face another day."

Cheri, daughter of DMRF Founders Samuel and Frances Belzberg, has published a memoir, *Woman of Few Words: My Creative Journey with Dystonia*. She is sharing her philosophy on how to be a functioning, fulfilled individual despite daunting challenges.

"If others are inspired by me, I consider it an honor," she said. "I do hope this book heartens all those who have been tested by God through a disability. I fervently believe that, with faith, courage, and fortitude, you can live a fulfilling life full of happiness, blessings, and contentment."

Cheri was born and raised in Canada. She spent her teen years during the 1960s as a fun-loving, free spirit. While attending college in the United States, she began experiencing unexplained, debilitating symptoms. She became unable to speak or walk normally. After two years, she was diagnosed with dystonia. Soon after her diagnosis, in 1976, her parents founded the DMRF.

Cheri pursued a career in education, married, and has three children. When dystonia made it too difficult to continue teaching, she established Designs By Cheri and built a successful career as a jewelry and garment designer. She lives in Efrat, Israel with her husband of 45 years, Harvey.

DMRF is grateful to Cheri for sharing her profound story to increase awareness of dystonia and offer validation and understanding to others in the dystonia community. *Woman of Few Words: My Creative Journey with Dystonia* is available for purchase through Amazon and Gefen Publishing (www.gefenpublishing.com).

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Cheri Tannenbaum is the daughter of DMRF Founders Samuel and Frances Belzberg.

You Can Help Shape Dystonia Research

Are You A Parent Of A Child With Dystonia? Have You Considered DBS Or Had DBS?

The Baylor College of Medicine is recruiting participants for a study to learn about the experiences and perspectives of children with dystonia and their caregivers, and to learn what you think about pediatric deep brain stimulation (DBS).

For more information, visit www.dystoniacanada.org/dbstudy

In Tribute

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

**Shirley Avery
Richard Wilfrid Currey
Patricia Ann Dingle
Claude Milette
Joe Timmers**



DMRF Canada Research and Clinical Fellow Explores the Psycho-Social Aspects of Dystonia.

Last year, DMRF Canada proudly announced our DMRF Canada Clinical and Research Fellow to the dystonia community. Mario Sousa, of Toronto Western Hospital was selected to be the DMRF Clinical and Research Fellowship winner in July 2019.

Now, in his second year, DMRF Canada had the chance to catch up with Dr. Sousa, to learn more about these learnings, his focus on research, and his experience of treating dystonia patients during the time of COVID-19.

DMRF Canada: Tell us, Dr. Sousa, how has COVID-19 impacted your year – and your ability to treat dystonia patients in the clinic at Toronto Western Hospital?

Dr. Sousa: To maintain social distancing, we had to change our scheduling to allow more time for each patient, and not to concentrate people in the waiting room. We also had to move patients to video and teleconferencing whenever possible. I believe that using these virtual formats we were able to maintain a good support to our patients.

DMRF Canada: How has that change in format been? Have you learned anything helpful because of the required social distancing measures?

Dr. Sousa: I think we did a good job of continuing to help patients at a very difficult time. It was a good experience to understand how helpful these virtual modalities can be. Telehealth and online patient meetings were not something we had used as much in the past, but maybe now we will be able to use it more regularly for follow up visits. We now have much more experience in conducting remote meetings and the feedback we have been receiving from our patients is very good. However, in some cases there is no

alternative to see the patient in person – especially for botulinum toxin injections for example. But for patients with mobility issues, we may look at offering virtual follow up visits at some point. It will be up to the patient, of course - and would not be the same for everyone. I think what we are learning is that we can be more flexible with patient care than we had thought.

DMRF Canada: Tell us about your research, Dr. Sousa. What are you currently focused on?

I remain dedicated to the psycho-social aspect – specifically anxiety – and its impact on dystonia. Our research, originally scheduled for earlier this year, was placed on pause due to COVID-19, and we have had to make some changes in the way that we are collecting data.

At Toronto Western Hospital, we have been studying anxiety in cervical dystonia patients. We know that botulinum toxin injections significantly improve motor symptoms of dystonia, but the literature suggests that other non-motor issues, like anxiety, might also be a source of disability and lack of quality of life. Our research aims to compare patients who use botulinum toxin injections vs. those who do not. We're actually recruiting patients with Cervical dystonia who are from the Greater Toronto Area that never received treatments with botulinum toxin injections or have not received treatment for > 1 year. If patients are interested in learning more, they can reach out to our clinic at: mario.sousa2@uhnresearch.ca.

DMRF Canada: Thank you for the update Dr. Sousa. We look forward to hearing the results of your research in 2021. Stay tuned for updates on these research projects.

TAKE THE COVID-19 IMPACT SURVEY TODAY

We want to hear from you! Let us know how COVID-19 has impacted your dystonia – and your overall wellbeing. We'll be analyzing these results and hosting a special webinar on COVID-19 and the Dystonia Community in November 2020.

Visit: www.dystoniacanada.org/COVID19impact
to take the survey and register for the upcoming webinar today.

Research Bits

Quick Questions with Dr. Jan Teller

The DMRF leads a global research effort, grounded in the belief that the best service the Foundation can provide the dystonia community is to work every day toward improved therapies and a cure. Jan Teller, MA, PhD, DMRF's Chief Scientific Advisor since 2006, recently commented on a handful of areas in which DMRF-funded investigators have made critical discoveries and progress.

DD: How would you summarize DMRF's contributions to dystonia research over 40+ years?

JT: Almost half a century ago, DMRF spearheaded dystonia research as we know it today. DMRF initiated, supported, stimulated, and catalyzed essential scientific and medical efforts that created the modern dystonia field and gradually engaged critical institutions and participants in the process. Passion and unwavering commitment on the part of the Board of Directors have driven the Foundation over the years to stay the course.

DD: How have DMRF's efforts clarified how dystonia affects the brain?

JT: Work by DMRF Scientific Director Emeritus Dr. Mahlon DeLong was ground-breaking and clearly pointed to the brain circuit abnormalities in dystonia. The basal ganglia, structures deep in the brain, have since been a focus of dystonia research for decades now. Scores of DMRF-funded investigators have collectively helped further clarify the underlying neurology of the dystonia brain. What is emerging is a very complex picture of dystonia as a disorder involving brain pathways where interactions among specific neurons impact movement. Central to these problems are neurotransmitters, chemicals that direct body movement. These neurotransmitters are produced and influenced by processes at the microscopic cell level.

DD: How did the DYT1/TOR1A gene discovery mark an important new era in dystonia research? Why are genetic studies important?

JT: One of the major goals of modern medicine is to identify molecular causes of diseases. Genes are the windows into these molecular causes. Once gained, this knowledge helps in designing therapeutic



Dr. Jan Teller summarizes DMRF research impact in key areas.

strategies based on biological mechanisms. This is in contrast to current therapies, which suppress symptoms without correcting the underlying problem. Identifying the DYT1/TOR1A mutation as the cause of early onset isolated dystonia played such a role. It showed that this form of dystonia is firmly linked to a gene defect and cellular consequences of it. This discovery opened a new chapter in dystonia research and prompted more, ultimately also successful, studies in dystonia genetics. DMRF-funded investigators have since identified numerous genes including DYT6/THAP1, DYT25/GNAL, DYT16/PRKRA, and others.

DD: Many investigations funded by DMRF have applied cutting edge techniques or technologies to learn about dystonia, often at critical times. How does the evolution of technology impact dystonia research progress?

JT: Technology drives medical and scientific progress. New tools extend our capability to explore biological mechanisms of disease. Undoubtedly, numerous new technologies, often enhanced by novel computational methods, tremendously help in basic and clinical dystonia research. Especially, modern engineering and material science dramatically improve medical diagnosis and treatment that is available to neurosurgeons and neurologists in the treatment of dystonia. Neuroimaging and deep brain stimulation come to mind as examples—the technologies are rapidly changing.

Visit: www.dystoniacanada.org/DystoniaResearchCanada for updates on dystonia research in Canada.

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Celebrating Dystonia Change Makers



Toronto Support Group Co-Leader Shirley Lee, with her NHCC Changemaker award.

Congratulations to Shirley Lee!

DMRF Canada was proud to announce that long-time Toronto Support Group Leader Shirley Lee was recently recognized by Neurological Health Charities Canada with the Change-Maker Award. This award is for individuals who are making a difference in the lives of people impacted by brain conditions.

On behalf of all of us at DMRF Canada, congratulations to Shirley Lee.

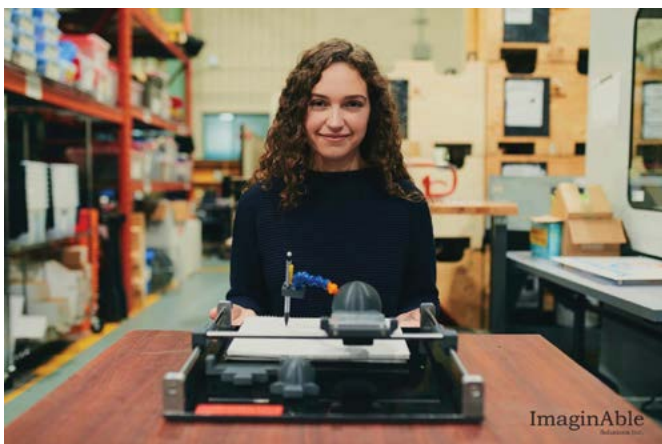
Shirley's new Co-Leader, Stephanie, has been busy compiling a list of resources for the Dystonia Community. Thank you, Stephanie! You can find the updated list of federal resources at:

www.dystoniacanada.org/financialsupport/federal

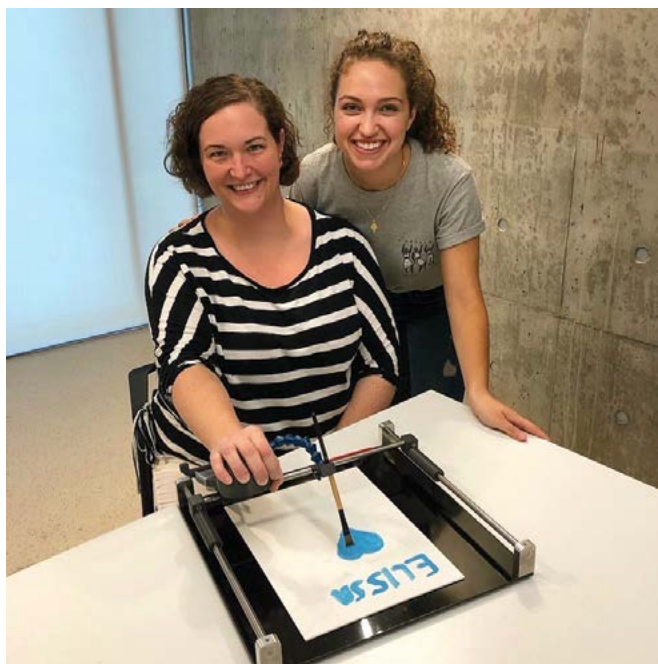
Introducing ImaginAble Solutions

Lianna Genovese is the CEO & founder of **ImaginAble Solutions** and the inventor of the international award-winning product **Guided Hands™**: an assistive device that enables people living with dystonia to write, paint, draw, and use a tablet or a computer.

Lianna's journey began in 2017 when she met Elissa, a woman living with primary generalized dystonia. Hearing Elissa's story inspired Lianna to invent the first prototype of Guided Hands™ as her final McMaster University project.



By June 2019, Lianna's biomedical and mechanical engineering background helped her transform the prototype into Guided Hands™. The device's unique sliding mechanism guides hand movements in all directions as the user grasps a handpiece customized to their level of hand impairment.



Today, ImaginAble Solutions and their passionate founder, Lianna, work alongside a team of professionals at McMaster Children's Hospital and McMaster University's Faculty of Engineering to enable people like Elissa to live the life they had always imagined!

To learn more, visit: www.dystoniacanada.org/guidedhands or visit www.imaginablesolutions.ca

A reminder that DMRF Canada does not endorse any specific product or service. Please speak with your Movement Disorder Specialist to discuss your unique needs.



Introducing **#mydystonia&I** Webinar Series

In celebration of Dystonia Awareness Month, and in an effort to continue to bring the dystonia community the education, tools, and resources we know you are looking for, we're pleased to launch the **#mydystonia&I** webinar series with thanks to Merz Therapeutics Canada.

During the month of September, DMRF Canada, in partnership with Merz Therapeutics, will be bringing you five separate webinar events – focusing on empowering patients and optimizing patient treatment outcomes.

Each of these Webinar events will be based on a specific topic and will bring you face to face (virtually) with Movement Disorder Specialists from all over the country!

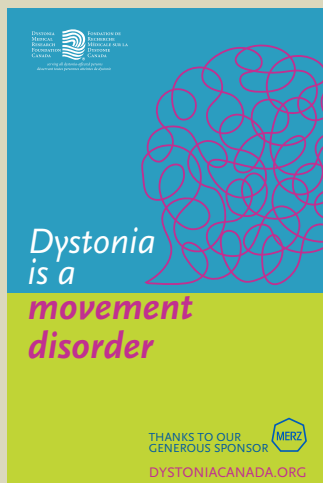
Topics will include:

- Understanding how to optimize treatment methods
- Dealing with anxiety and stress
- The latest in dystonia research and techniques
- **PLUS:** All sessions will provide an opportunity for specific questions that you would like to have answered by our specialists

Our hope is that although we are all home – we can use this time to learn more about what can be done to ensure the dystonia community is well supported and well versed about their options for living their best life with dystonia. Don't miss out on this special event – the webinar series will be taking place during the week of September 21st – with a different topic, and guest speaker presenting each day.

We know that everyone's journey with dystonia is personal and unique, but there is strength in numbers – and we are stronger together.

Visit www.dystoniacanada.org/mydystonia to register today.



Dystonia Lanyards are Here

Based on feedback from the patient community, we've created a special lanyard to raise awareness of dystonia, and to encourage honest discussion about what it means to have a movement disorder. These lanyards can be worn around your neck, used as a keychain, or attached to backpack/purse/luggage. Help us to raise awareness of dystonia and get your free lanyard today!

Email: info@dystoniacanada.org or call 1-800-361-8061 to request your dystonia awareness lanyard today.

You can also visit www.dystoniacanada.org/merchandise to download and print this from home!

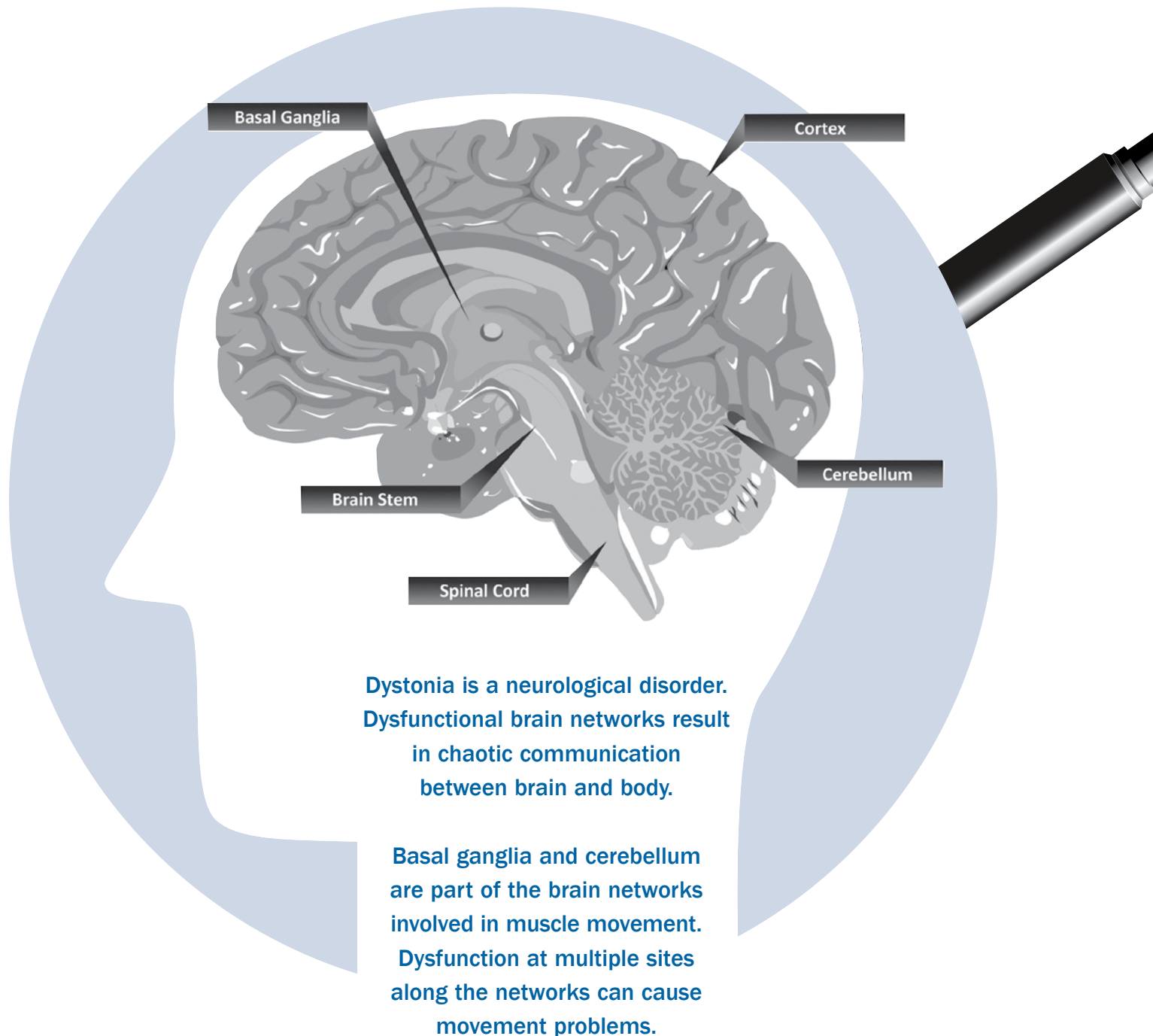


Thanks to Merz Therapeutics for their support

Body of Evidence Why Does Dystonia Happen?

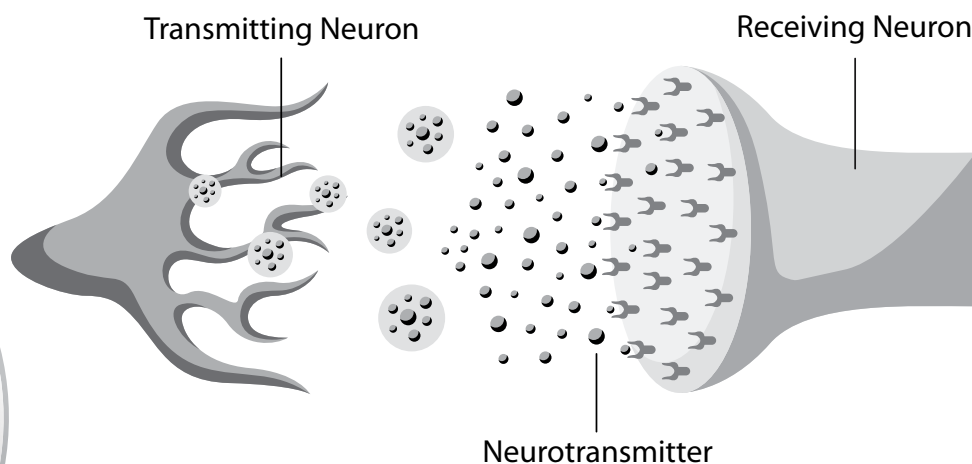
Dystonia is often described in relation to the part of the body affected by symptoms. For example, cervical dystonia affects muscles along the cervical spine in the neck. Blepharospasm causes excessive, involuntary blinking and closure of the eyes. But what's going on deep inside the body to cause these symptoms?

Here are a few examples of what investigators have identified as dystonia problem points.

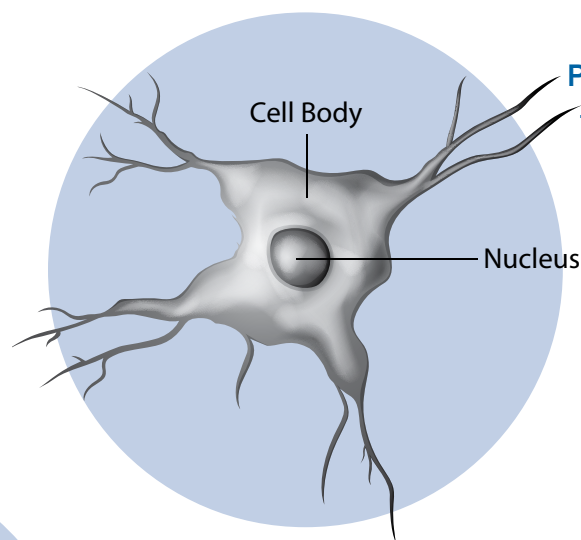




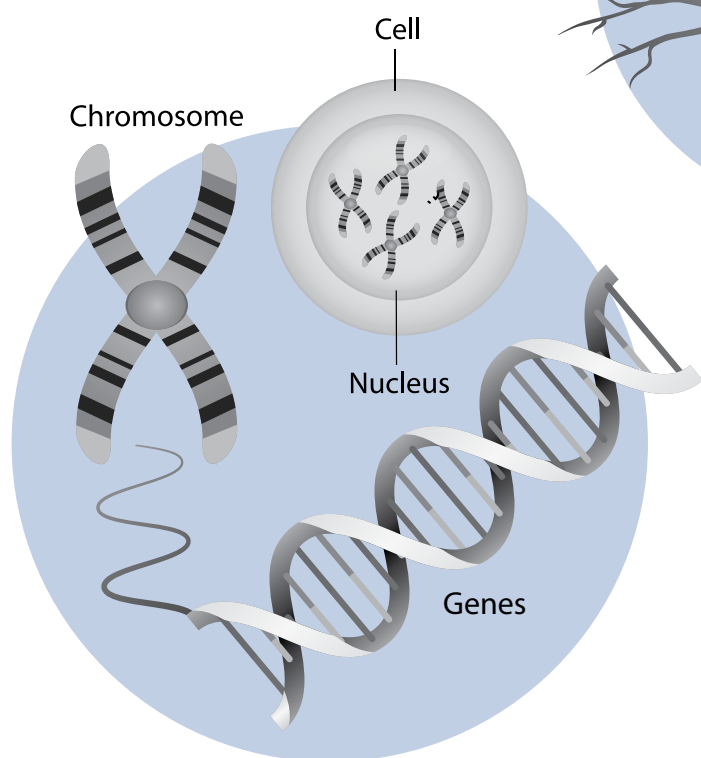
Neurons fire signals along brain pathways. Specific groups of neurons signal abnormally, which disrupts the pathways.



Neurotransmitters communicate instructions for movement control. Dystonia disrupts the normal balance of neurotransmitters necessary for smooth, controlled muscle movement.



Proteins are responsible for processes in cells. Mutated proteins cannot do their jobs properly. This causes neurons to malfunction.



Different dystonia-causing genes appear to be involved in some of the same biological processes. Finding a common mechanism underlying different types of dystonia would be a major advancement toward novel therapies.

Walking, Wheeling, Riding Towards a Cure – While Social Distancing

The dystonia community is a passionate, dedicated group of individuals who continue to fight for greater awareness and more funding for dystonia research and support programs – even in the time of COVID-19.

This year, DMRF Canada launched the first ever Chuck's Virtual Run, Walk and Wheel for Dystonia,

taking place over the entire month of June –, and for the first time ever was open to all Canadians – coast to coast.

The event drew in over 175 participants from 32 teams – participating across the country in 49 cities! Thousands of individuals engaged online, and thanks to the support of Pattison Outdoor advertising, over 30,000,000 impressions of the Chuck's Run digital advertisement were displayed over the month of June.

Thank you everyone who was involved in participating and supporting Chuck's Virtual Run Walk and Wheel. We greatly appreciate your contributions - either financially and/or by promoting it on social media – and letting everyone know how much their support means to the dystonia community.

Visit: www.dystoniacanada.org/chucksrn for highlights from this year's event.



Thank You to Our Generous Sponsors



With Thanks to the Benign Essential Blepharospasm Canadian Research Foundation

DMRF Canada wishes to extend a sincere thank you to the [Benign Essential Blepharospasm Canadian Research Foundation Inc. \(BEBCRF\)](http://www.dystoniacanada.org/bebcrf), for their very generous donation.

Founded in 1992 to raise awareness of blepharospasm, cranial dystonia, and hemifacial spasm, the BEBCRF ceased operation on June 30th, 2019, and is no longer active. BEBCRF has generously shared their valuable resources which can now be found on www.dystoniacanada.org/blepharospasm. Stay tuned for more programs and tools in the months to come.

2020 Jackson Mooney Patient Grant Winners Announced

On behalf of the DMRF Canada Board of Directors, and grant sponsors Jackson and Jefferson Mooney, we are pleased to announce the recipients of the 2020 Jackson Mooney Patient Grant for Dystonia.

The Jackson Mooney Dystonia Patient Grant is an annual grant that was established by Jackson and his brother Jefferson to provide financial assistance of up to \$5,000.00 for Canadian residents who are living with dystonia, in financial need, and committed to enhancing their current situation through furthering their education.

This year, the grant committee opted to provide funding for education to two very worthy candidates:

2020 Jackson Mooney Patient Grant Recipients:



Jennifer Ashton

"Thank you very much to the Committee, and to the Mooney family. I am so grateful that you felt that I was a good candidate for this competition."

Jennifer Ashton of British Columbia, was diagnosed with Cervical Dystonia this past February, after nearly 20 years of being misdiagnosed with MS. A writer, artist, and life-long learner, Jenn's goal is to take a Certificate in Advanced Education Leadership with the long term goal to go on to teach and/or help to write policy and procedure at the administrative level for First Nations programming, which is a particular passion, given that Jenn is of Squamish First Nations Ancestry.

The Jackson Mooney Patient Grant Review Committee was moved and inspired by Jenn's story, and felt that her courage to continue to learn and grow over the course of her life was an important lesson for those living with dystonia.



Shelby Newkirk

"I am so excited and feel so honoured! This grant will allow me to purchase assistive technology that will help me so much with my education."

Shelby Newkirk was originally diagnosed with focal dystonia in 2010 at the age of 13 as it seemed that only her right foot was affected. As time went on, her dystonia progressed, and her diagnosis was changed to generalized progressive dystonia. Now, because of the effects of her dystonia, she is no longer able to walk without mobility devices and use a wheelchair most of the time. Her dystonia affects her limbs, torso, face and throat.

Because of Shelby's progressive dystonia, and the fact that she now tires more quickly, she of had to alter her initial plan of working full time with young people who have a disability, and is now focusing on working as a consultant with schools to ensure they are more accessible for students. As someone who has had to experience the challenge of being a student, Shelby is well equipped and passionate about this career path.

On behalf of the dystonia community, DMRF Canada wishes to thank Jefferson and Jackson Mooney, and we wish Jenn and Shelby the very best with the next step in their career path. To learn more about Jenn and Shelby, and the Jackson Mooney Patient Grant, visit: www.dystoniacanada.org/thrivers

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

We hope we can count on your support during this very difficult time for fundraising. If you're interested in supporting the dystonia community, consider giving a small monthly gift! For as little as \$5.00 a month you can support DMRF Canada initiatives for the cost of just over a dollar a week!

Monthly giving offers you a way to support our programs and services throughout the year. Join a group of dedicated individuals who are committed to improving the lives of people living with dystonia.

Make online donations at: dystoniacanada.org/donate-now

* Each payment, including the first payment, will be made in the middle of the month.
You can stop your monthly gift at any time by contacting DMRF Canada.

Dystonia Moves Us All – Celebrating Dystonia Awareness Month

DMRF Canada will be leading dystonia awareness efforts throughout the month of September and beyond. Below, we have some great awareness activities and resources that can help you raise awareness about dystonia in your local community and on a national level!

This September, there are several ways for you to get involved. Here's How:

- **Promote Dystonia Awareness Through Social Media:** Post, tweet, message, and promote dystonia awareness using #dystoniainmovescanada #dystoniainmovesme #dystoniaawareness to your networks. You can also promote awareness in your community – just remember to practice social distancing. Please contact info@dystoniacanada.org to request your materials.
- **Check Out Local Landmarks:** We're lighting up Canada in Blue and White! Visit: www.dystoniacanada.org/dystoniaawarenessmonth for a complete listing of landmarks.
- **Support DMRF Canada and Stay Safe:** Consider purchasing a DMRF branded facemask or bracelet. Visit us online: www.dystoniacanada.org to purchase today. You can also consider hosting your own fundraiser event to raise funds for dystonia. Visit: www.dystoniacanada.org/doit.

Plus – We have some initiatives that are new for this year:

- **Awareness Bingo:** Now, you can check off your awareness activities for a way to win some great prizes. Visit: www.dystoniacanada.org/bingo for more details.
- **Dystonia Lanyards:** An easy and eye-catching way to raise awareness about dystonia is through our movement disorder sign. You can display this sign as a car hanger, wear it as a lanyard, or even use it as a luggage tag. Refer to page 6 for additional details on how to order.
- **Get Active for Dystonia:** Dystonia thriver and Kingston Support Group Co-leader, Casey, has created a useful stretching and work-out video for the dystonia community. You can see Casey's video at: www.dystoniacanada.org/dyfyng-dystonia-series. PLUS: Stay tuned – Dyfying Dystonia will be launching a patient focused podcast later this year!

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