

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

Spring/Summer 2021

## IN THIS ISSUE

- 1 Meet DMRF Canada Clinical and Research Fellow, Dr. JiaRen Chai
- 2 NEW Dystonia Journal Announced
- 3 Join Us for Freedom to Move: Run, Walk and Wheel for Dystonia – June 2021



*Introducing DMRF Canada Clinical and Research Fellow 2021-2023, Dr. JiaRen Chai.*

## PLEASE RENEW YOUR MEMBERSHIP FOR 2021

*Support the dystonia community with a donation to DMRF Canada.*

**visit: [www.dystoniacanada.org/donate](http://www.dystoniacanada.org/donate)**

*Thank you for your support.*

# Foundation Update

Dear Friends,

This year marks 45 years of the Dystonia Medical Research Foundation's service to the community. We remain committed to our mission to find a cure and we want to thank you for your continued support over these years.

It is a pleasure to share some exciting updates on behalf of DMRF Canada. Amidst an uncertain year, we've made some adjustments to the structure of our leadership team to ensure our continued success, and support of the dystonia community in Canada.

We're pleased to announce that Connie Zalmanowitz was recently elected to the position of Chair of the DMRF Canada Board of Directors. 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 – the year her son Laurie began showing symptoms. Like many of you, Connie's family navigated the challenges that came with the unfamiliar diagnosis at a time when dystonia was not known or understood. Connie's leadership over the past two decades has been critical to our progress, and we are certain that her dedication to the cause will ensure our continued success, helping to fill the void left by our former devoted and passionate Chair of the Board, Bill Saundercook.

We are also delighted to announce the promotion of Archana Castelino to the position of National Director. Since joining DMRF Canada in 2017, Archana has been committed to serving the community - from managing the needs of patients and families, to ensuring an efficient, sustainable, and evolving organization. In her new role, Archana's responsibilities include developing our long-term strategy and managing the day-to-day operations of the organization.

This past year has been hard, but there have been many silver linings. In all this uncertainty, we are here for you, more than ever before. DMRF Canada remains committed to our mission, and excited to explore the new, exciting ways that we can come together to advance our offering while staying safe in the midst of the pandemic.

One of the many things that we can celebrate is our upcoming nationwide, virtual fundraising and awareness initiative taking place throughout the month of June; Freedom to Move for Dystonia, in Memory of Chuck Saundercook.

Read on for more information on our newly selected Clinical and Research Fellow, upcoming events and support programs, and more ways for you to stay connected with the community – even from a distance.

Now and always the DMRF Canada board remains thankful for your generous support. It is an honor to be a part of this organization, and we look forward to the important work ahead.

Sincerely,



Connie Zalmanowitz,  
Chair

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



Archana Castelino,  
National Director

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

## Dystonia Medical Research Foundation Canada

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

### Board of Directors

Samuel Belzberg

Co-Founder

1928 - 2018

Frances Belzberg

Co-Founder & Honorary Chair

Connie Zalmanowitz

Chair

Pearl E. Schusheim

Secretary/Treasurer

### Directors

Dennis Kessler

Casey Kidson

Rosalie Lewis

Catherine Mulkins

## Our Heartfelt Thanks



DMRF Canada wishes to thank our outgoing Chair, Bill Saundercook, for his dedicated service to our mission and our community. Bill served on the DMRF Canada Board for over seven years; and most recently, as Chair of the Board.

Bill has always been a generous and passionate advocate for the dystonia community, dedicating countless hours to support our many initiatives, including Chuck's Run, Walk and Wheel for Dystonia. Thanks to Bill's efforts, and the passion, dedication,

and force of the Saundercook family, Chuck's Run was able to raise over one million dollars for DMRF Canada's research and support programs over the past many years. We are proud of this partnership and excited to continue to pay tribute to Chuck in our upcoming Freedom to Move virtual fundraising event, taking place again in June.

Bill's leadership and generous spirit led to new partnerships, ideas, and initiatives benefitting our mission. On behalf of the thousands of patients and families who have benefitted from Bill's vision and dedication to the Foundation, we thank Bill for his generous support.

## In Tribute

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

Arden Blakely

Margie Chamberlin

Harold Cohen

Roy Gordon

Conacher

Stuart Hooper Hicks

Elmer Holmquist

Mary McKay

Marcus Jacob

Merovitch

Rolande Parel

Patricia Ann Pilon

Annette Rudy

Dorothy Shaw

Shun-Tse Hsu



## 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](http://www.dystoniacanada.org/donate)



# Dystonia Research Continues despite COVID-19 Pandemic

By Jan Teller, MA, PhD, Chief Scientific Advisor

The unexpected and sudden arrival of COVID-19 has disrupted the lives of everyone, including researchers. The death toll and infection rates continue to rise around the world. Societies look to health and medical scientists to conquer the virus. The pandemic also impacts scientific research itself in an unprecedented way.

Laboratory work was put on pause. Only some researchers can continue operating their labs and projects. The financial ramifications have been severe. Academic and scientific institutions have lost revenue normally used to fund research; some people lost their jobs or simply cannot continue their regular duties. Many long-term experiments will need to re-start later. Doctoral students and postdoctoral fellows have been most severely affected. Social distancing prevented not only normal work but also scientific meetings, established collaborations, or other interactions that are typically necessary for conducting clinical trials or research involving patients. Recruitment of new study participants has slowed or stopped. Relatedly, the impact on

## AT A GLANCE

- COVID-19 has impacted scientific research
- Dystonia research has not been dramatically affected
- Movement disorder clinicians are recognizing the need for novel approaches to patient care

patient care has been profound. Many clinicians—including movement disorder specialists—were assigned to other, COVID-19-related emergency duties. Dystonia patients have experienced widespread and prolonged appointment cancellations, in many cases disrupting botulinum neurotoxin injection schedules or deep brain stimulation procedures.

At the same time, unforeseen opportunities have been revealed. Investigators who were forced to stay home had to come up with creative solutions to maintain research productivity. Paradoxically, the pace of publishing has not dropped. Unable to access their labs and places of work, scientists have used this time to analyze the data they already had, devoting

more time to thinking about new ideas or future projects. Interestingly, the number of grant applications to the National Institutes of Health has not dropped significantly.

Crisis drives change, shifting focus to finding new, unexpected opportunities. Collaborations within research institutions may strengthen, many internal policies and procedures will evolve, long-term support within organizations may stabilize institutional research by reducing reliance on external income sources.

Fortunately, dystonia research has not been dramatically affected. More papers are being published, grants submitted. Research that relies more on theoretical and conceptual approaches is flourishing. Some labs have begun to re-open. Although many meetings have been postponed, dystonia scientists are in constant touch by video conference and other communication means. The virtual annual meeting of the Dystonia Coalition in June attracted an unprecedented number of first-time attendees due in part to ease of participation without travel.

Movement disorder clinicians are calling attention to the urgent need for novel approaches to patient care, recognizing that the pandemic has had a distressing impact on many individuals and families impacted by





chronic diseases and disorders, including dystonia. Many movement disorder clinics have begun using telehealth and telemedicine technologies. Ironically this shift begins to finally address challenges many in the dystonia community have faced for decades, in terms of the frequent travel and mobility obstacles to visiting movement disorder clinics for treatment. Many health care providers across disciplines are mobilizing online platforms to help patients access not only important medical services but also supportive therapies such as physical and occupational therapy, and mental health services. While telemedicine consultations and assessments have their limitations, the pandemic may permanently and positively change the care of dystonia patients by making it easier to have access to doctors and health care providers outside in-clinic visits.

It will take time before we can fully comprehend the impact of COVID-19 on science and research. It has been, and will remain, profound—and hopefully, in numerous ways, for the better.

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## Dystonia Medical Research Foundation and Frontiers launch new Open Access Journal

We are thrilled to share that DMRF, with publishing partner Frontiers, has launched a new Gold Open Access journal, *Dystonia*. The journal will shine a spotlight on the global research effort for a greater understanding of dystonia, as well as breakthroughs in basic, clinical, and translational research in the field. This new, open-access journal will provide a platform to exchange scientific information about dystonia for a growing number of clinical and basic researchers studying dystonia.

The DMRF's chief scientific advisor Dr. Jan Teller said, "I am sure that the entire dystonia community, which includes patients, clinicians, and researchers will be absolutely thrilled to learn that, finally, we have a place to publish results of important studies on the dystonias. Recent explosive increases in the number of scientific publications devoted to dystonia fully justifies establishment of this open access journal."

Stay tuned for more information about the *Dystonia* journal in the coming months.

## Introducing Dystonia Information Sessions

We've been busy! Over the past 14 months of lockdown due to the COVID-19 pandemic, DMRF Canada has worked hard to deliver customized information and educational sessions to empower and support the community. Check out the new **Dystonia Information Session** listing, which includes a variety of informational webinar topics, formats and expert speakers, available at: [dystoniacanada.org/dystonia-information-sessions](https://dystoniacanada.org/dystonia-information-sessions).



# RESEARCH BITS

New dystonia studies are published daily.

Below are a tiny sample of recent data and discoveries.

## PLAN B.

TorsinA is a protein found in neurons (brain cells) that causes dystonia when it becomes abnormal due to small genetic changes. When TorsinA is abnormal, it cannot function properly in the cell. This loss of function ultimately leads to the development of dystonia symptoms. A related protein, called TorsinB, performs similar roles in neurons as TorsinA. A team of investigators recently demonstrated in mice that dystonia symptoms and related neuron dysfunction resulting from a loss of function of TorsinA can be corrected by increasing levels of TorsinB. These findings suggest that TorsinB may be mobilized to slow or prevent development of dystonia symptoms.

Li J, Liang CC, Pappas SS, Dauer WT. TorsinB overexpression prevents abnormal twisting in DYT1 dystonia mouse models. *Elife*. 2020;9:e54285. Published 2020 Mar 23.

Republished, with permission from DMRF Dystonia Dialogue, Winter 2020 Vol 43, No 3.

## DRIVER'S ED.

A research team in the Netherlands set out to explore driving performance and driving safety in individuals with cervical dystonia compared to individuals without cervical dystonia. All participants in the cervical dystonia group participated in the study 4-8 weeks after botulinum neurotoxin treatment, which tends to be the time of maximum benefit. Volunteers completed a simulated driving assessment that included lane tracking, intersections, and highway merging. In the individuals with cervical dystonia, there was no indications that driving performance or safety were significantly different than the group without cervical dystonia. However, cervical dystonia patients notably reported higher levels of fatigue before and after driving.

Van den Dool J, Visser B, Huitema RB, Caljouw SR, Tijssen MAJ. Driving Performance in Patients With Idiopathic Cervical Dystonia; A Driving Simulator Pilot Study. *Front Neurol*. 2020;11:229.

To read more Research Bits, please visit: <https://dystoniacanada.org/latest-dystonia-research-news>

## Supporting the Dystonia Community During the COVID-19 Pandemic

DMRF Canada was proud to develop a two-part webinar series in partnership with Allergan: an AbbVie company. The *Supporting Dystonia Patients During the COVID-19 Pandemic - Webinar Series*, aimed to provide the dystonia community with tools and resources that would empower, inspire, and educate, taking into consideration the many changes and difficulties that have resulted from physical and social distancing requirements.

The cornerstone of this series was a survey that DMRF Canada released in September 2020, to get a better sense of how the community was managing during the pandemic. The survey results helped to highlight the need for tools to help with self-management of dystonia symptoms, and resources to improve mental health during this time.

Through these webinars, individuals were able to access important information, including gaining a better understanding of pain mechanisms to manage dystonia pain; as well as helpful resources for making the most of conversations with their primary healthcare provider.

Thanks to the support of Allergan: an AbbVie Company and the Movement Disorder Specialists Dr. David Grimes, and Dr. Dung Nguyen who generously volunteered their time and expertise to the series.

To review the webinars, and access the tools, visit: [www.dystoniacanada.org/covid19impact](http://www.dystoniacanada.org/covid19impact)



# Introducing the DMRF Canada Clinical and Research Fellow: Dr. JiaRen Chai

## Supporting Dystonia Research in Canada

DMRF Canada, in partnership with Merz Therapeutics is pleased to introduce the recipient of the 2021 – 2023 DMRF Canada Clinical and Research Fellowship: Dr. JiaRen Chai, MD, who will be supported under the mentorship of Dr. Mandar Jog, MD, London Movement Disorders Centre and The University of Western Ontario.

This Fellowship is a testament of our continued support of the advancement of dystonia research and patient care in Canada, through the training and support of an exceptionally qualified individual in preparation for a clinical career in movement disorders, with a focus dystonia. “We are very fortunate to have had strong applications to this program. We need more experts in dystonia - for better diagnosis, better treatments, and to advance research to find a cure. Dr. Chai will be a great asset to the dystonia community in Canada with the experienced mentorship of Dr. Jog in London, Ontario” said DMRF Canada Chair, Connie Zalmanowitz.

Dr. Chai came highly recommended by his mentor, Dr. Jog, who commented: “Dr. Chai spent an elective month with us, and during that time, it was clear that he was interested in science and especially novel therapies for conditions such as dystonia. He will spend a minimum of two years learning about dystonia, its treatments including toxin injections, dystonia with other movement disorders and then expand the potential therapeutics using a novel non-invasive treatment paradigm developed in our laboratory.”

DMRF Canada’s Fellowship Committee was impressed by Dr. Chai’s dedication to improving treatments

available for persons with dystonia through research. Dr. Chai was inspired to pursue a specialization in movement disorders, specifically dystonia, through his experiences in medical school and while training at a movement disorder clinic in Newfoundland and Labrador. His research aims to better understand and improve the effectiveness of clinical treatments available for dystonia patients, “what drew me to movement disorders is the challenges and variety. Before, dystonia was not entirely recognized as something organic, and we’ve come a long way. Current treatments are focused on symptoms - and there’s a lot of potential for enhancements to this in the future. Hopefully, we can also get to the bottom of what causes dystonia.” said Dr. Chai.

“We are thrilled to partner with DMRF Canada to fund this fellowship which aligns with our commitment to expand education and training opportunities for the next generation of movement disorder specialists for the treatment of dystonia.” said Yannick Grosskreutz, Country Manager, Canada for Merz Therapeutics. “At Merz Therapeutics, we are focused on bringing better outcomes for more patients and this fellowship does exactly that.”

On behalf of DMRF Canada Board of directors, staff, and volunteers, we congratulate Dr. Chai and wish him the best of luck.

**Our thanks to Merz Therapeutics for their support.**



## THERAPEUTICS

Better outcomes for more patients.



## Mark Your Calendars;

### Freedom to Move: Run, Walk and Wheel for Dystonia

*In Memory of Chuck Saundercook*

DMRF Canada is pleased to present **Freedom to Move: Run, Walk and Wheel for Dystonia**, a national, month-long awareness and fundraising event that aims to raise funds for dystonia research and support programs in June 2021. This inspiring and dynamic event will bring together hundreds of individuals, families, teams and communities in cities and provinces across the country - all in the name of dystonia awareness, research funding and support.

Last year, due to our need for physical distancing, DMRF Canada's one-day Toronto based event; Chuck's Run, Walk and Wheel for Dystonia, was transformed into a month-long, national event. Local Freedom to Move community events from Vancouver, Hamilton, Sudbury, and Montreal, generously joined

our national effort, resulting in one of the most successful campaigns in our history!

***We want to do it again.***

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

**When:** June 1 – 30, 2021

**Where:** Anywhere in Canada!

**Why?** To raise, funds, awareness, and support for dystonia

*To register,  
scan with your  
camera app*



*Thank You to Our Generous Sponsor*





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

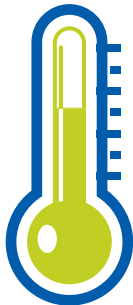
This year's event gives YOU the freedom to raise funds and awareness for dystonia your way:

1. Visit: [www.dystoniacanada.org/freedomtomove](http://www.dystoniacanada.org/freedomtomove) to register today. Participants can register as an individual, or as part of a team.

Your Registration Includes: DMRF Canada Freedom to Move swag, mailed directly to you after registration, a participation recognition certificate available for download after June 30th – and the knowledge that you are helping to support vital dystonia research and support programs.

**Register by May 18 to Save over 20%**

2. Set a goal – whether it be the number of kilometers you will run, walk or wheel – the number of times you share the event with friends or family - or the number of times you will get out and move in the name of dystonia, you have the freedom to move in any way you want!
3. Once you've registered, remember to share your news 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 to raise **\$75,000** for dystonia research and support programs. This critical funding could support one year of the Clinical and Research Fellowship award, as well as funding early investigators through the Banting Foundation Discovery Grant. We can't do this without you. Every step, every share, every dollar counts! Join Shelby, and hundreds of others at this year's event

Visit: [dystoniacanada.org/freedomtomove](http://dystoniacanada.org/freedomtomove) to learn more and register.

## Meet This Year's Freedom to Move Ambassador: Shelby Newkirk



Shelby Newkirk is hardly a new face to the dystonia community. At 24 years old, Shelby Newkirk is a force to be reckoned with. Shelby has spent the last ten years dedicating her free time to swimming.

And she's just getting started. Besides qualifying for the opportunity to swim for the Canadian Paralympic Team in the upcoming Tokyo Paralympics later this year, Shelby is also this year's Freedom to Move: Run, Walk and Wheel for Dystonia Ambassador.

"I am so honoured to be named the Ambassador for this year's Freedom to Move event. DMRF Canada has helped me so much over the years, and now I'm excited to give back. One thing that I've come to realize over the past year is the value and importance of community. This event is a great way to raise money - and awareness, but to also show people that they are not alone and that we are all in this together. I'm excited to work with the dystonia community from across Canada as we work together to reach our goal."

Learn more about Shelby, and her inspiring story at: [www.dystoniacanada.org/shelby](http://www.dystoniacanada.org/shelby)

# You Can “Do It” for Dystonia

Our inaugural *Do-It-For-Dystonia* was an astounding success, and we're already off to a great start in 2021! New DMRF Canada Board Member and Dyfying Dystonia Founder, Casey Kidson has launched her **Dyfying Dystonia's Spin for Dystonia** initiative as a way to “do-it” in 2021. As a certified spin instructor, Casey hosted free virtual spin classes twice a week throughout February and March 2021 and encouraging attendees to “pay it forward” by donating to DMRF Canada.

Start your own Do It for Dystonia campaign today by visiting: [www.dystoniacanada.org/doit](http://www.dystoniacanada.org/doit)

## Congratulations to our Top 2020 Fundraisers



**Dwayne Backer Sudbury, ON** has been a tremendous force in the dystonia community and a long-time supporter of DMRF Canada through various fundraising initiatives, including the Freedom to Move Sudbury event. Over the last 20 years, Dwayne has raised over **\$117,000.00** for dystonia research and support programs. Because Dwayne was unable to collect funds in-person due to COVID-19, he pivoted his fundraising efforts online through Facebook\* and was able to raise **\$2,095** in honour of his 81st Birthday.



**Brian Dickey Collingwood, ON** joined Do-It-For-Dystonia by penning “Tale of The Wednesday Niters”, a story reflecting on his fond memories of growing up playing hockey in Stayner, ON with profits benefitting DMRF Canada.

In total, Brian was able to raise **\$2,000** for DMRF Canada. Brian was inspired to fundraise in honour of his wife's daughter, Anna McNabb. Anna was misdiagnosed with cerebral palsy at six and didn't receive her correct diagnosis of dopa-responsive dystonia until eighteen years later.

To read more about Anna McNabb, please visit page 11.



**Chantale Boivin – Montreal Support Group Leader:** During Dystonia Awareness Month in September 2020, Chantale took on a 30-day posting challenge on her Facebook page to help raise awareness about the disorder online. Every day, Chantale would share her experience of living with dystonia, encouraging her followers to change the lives of people with dystonia by supporting DMRF Canada. Through her Do it Campaign, she was able to fundraise an incredible **\$1,310**.

A special thank you to the Kelowna-Okanagan British Columbia Support Group and Laurie Bell from Hamilton, ON for placing fourth and fifth respectively.

*On behalf of DMRF Canada, thank you to everyone that participated in the 2020 Campaign!*

\* Fundraising through Facebook is simple. If you'd like to learn more and start your online campaign today, visit: [www.dystoniacanada.org/facebookfundraising](http://www.dystoniacanada.org/facebookfundraising)

# Inspiration and Celebrations:

## Dystonia Thrivers Mapping their Own Course in Life



*Anna McNabb (left) and her mother, Maria Dickey (right).*

Growing up in the small cottage town of Collingwood, Ontario, Anna McNabb, noticed early on that she wasn't like other children. At three, "I was beginning to walk with a limp, more prominent on my left side. Stumbling and falling became a way of life for me, and shortly thereafter, I required assistance doing many everyday activities." Anna's mother, Maria Dickey, was puzzled by her symptoms. Anna's family thought they had found their answer when she was diagnosed with cerebral palsy at age six. For the next eighteen years, Anna and her family lived her with her misdiagnosis.

Due to her deteriorating mobility, Anna was told by doctors to live life while she still could - as eventually she would be wheelchair bound. "I endured pain to be able to participate in equal experiences to my friends. I denied that my life had to slow down, I did everything I could to prolong my independence. Sadly, at 18, I required assistive devices and spent much of my college freshmen year in a hospital instead of a dorm room" Anna shared.

Despite her challenges, Anna forged ahead. She met her future husband, a military man, and was touched that he never asked her what was "wrong" with her. They soon married, and her husband took over the role of caregiver from her family. She needed

assistance with everyday tasks including getting into bed, bathing, and even blow drying her hair. Despite reassurances from her loved ones, Anna felt like a burden.

After 18 years of living with cerebral palsy, Anna's diagnosis didn't seem the correct fit, according to her mother, Maria. Determined to find a more accurate diagnosis, Maria pressed for doctors to re-examine Anna, looking for new opinions on her symptoms, and new available treatments. Maria proposed that Anna could be suffering from a rare movement disorder that she had read about - dystonia. After booking an appointment, Anna vowed not to seek another diagnosis, "if [the results are] inconclusive, I will live as I can and deal with the pain caused by my limited mobility." The doctor ordered a blood test and results confirmed Anna and Maria's suspicions; Anna had dopa-responsive dystonia. To read the rest of Anna's story, please visit:

[www.dystoniacanada.org/annamcnabb](http://www.dystoniacanada.org/annamcnabb)

Our thanks to Anna McNabb and Maria and Brian Dickey for sharing their journey with dystonia.

Our website now features support persons to contact for different forms of dystonia, and other useful resources to help you live a better life with dystonia. To access more information please visit:

[www.dystoniacanada.org/resources](http://www.dystoniacanada.org/resources)

## The Jackson Mooney Patient Grant 2021 is Now Accepting Applications

Has your dystonia diagnosis changed or derailed your career? Are you looking for a way to get back on track?

The Jackson Mooney Dystonia Patient Grant was established to provide financial assistance of up to \$5,000.00 for individuals who are living with dystonia, in financial need and committed to furthering their education. If interested, candidates should submit a one-page letter of intent by May 15, 2021. Shortlisted candidates would then be invited to submit a full application in June 2021, with decisions to be made by the end of August 2021.

To learn more about eligibility criteria and timelines, visit: [dystoniacanada.org/dystoniapatientgrant](https://dystoniacanada.org/dystoniapatientgrant)

## Upcoming Virtual Community Events:

Stay tuned for upcoming educational and community events supporting the dystonia community via webinar.

Visit [www.dystoniacanada.org](https://www.dystoniacanada.org) to be kept up to date on the latest support group meetings and community events taking place virtually.

## Change the Lives of Those Living with Dystonia Through Legacy Giving

Did you know you can leave a gift to DMRF Canada in your Will - or set up a trust to be disbursed over a number of years? To learn more about how you can include DMRF Canada in your estate planning, visit: <https://dystoniacanada.org/legacy>

A special thank you to long-time DMRF Canada supporters and former Winnipeg Support Group Leaders, Barbara and Brian Crow for establishing a Trust to support DMRF Canada. Through the Trust, an annual gift will be made to assist with our dystonia support programming, and as an investment towards DMRF Canada's future service to the dystonia community.

## 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](https://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.