

DYSTONIA  
MEDICAL  
RESEARCH  
FOUNDATION  
CANADA



FONDATION DE  
RECHERCHE  
MÉDICALE SUR LA  
DYSTONIE  
CANADA

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



# Dystonia Canada Report

A Newsletter from the  
Dystonia Medical Research  
Foundation Canada

## *Research and Clinical Fellow is Announced:*

### Encouraging Dystonia Patient Support and Clinical Research Here in Canada



*Turn to page 2 to learn more.*

DMRF Canada is pleased to announce our continued commitment to patient care in Canada – through the DMRF Canada Clinical and Research Fellowship, intended to support the training of exceptionally qualified individuals in preparation for their clinical career in movement disorders, with a focus on clinical research in dystonia.

After a competitive application process, DMRF Canada is pleased to announce our 2019 Clinical and Research Fellow: Dr. Mario Sousa, who will study under the expertise of Dr. Susan Fox, MD, Toronto Western Hospital.

Spring/Summer  
2019

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## PLEASE RENEW YOUR MEMBERSHIP FOR 2019

*Please consider supporting the dystonia community with a donation to DMRF Canada.*

*See the back cover for details on how you can make a difference or*

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

Thank you for your support of our community. Because of you, 2018 brought major discoveries in the dystonia field, spanning a broad spectrum of basic and clinical investigations.

Research funded by your support has dramatically advanced our understanding of the complex interactions of genes and proteins associated with dystonia, brain structures implicated in dystonia and the underlying neurological problems that ultimately lead to symptoms. These advancements would not have been possible without direct support from the DMRF and the research environment that we have assembled. We are already well into 2019 and we have new events, research findings, and opportunities for you to engage with us and others from the dystonia community.

We're pleased to be able to share with you just a few of the exciting research projects we are currently funding, along with news about upcoming awareness events, patient support resources, and ways for you to help the dystonia community.

We simply can't do any of this without you. Thank you.

Sincerely,



Stefanie Ince,

Executive Director

[stefanieince@dystoniacanada.org](mailto:stefanieince@dystoniacanada.org)



It is the editorial policy to report on developments regarding all types of dystonia but not to endorse any of the drugs or treatments discussed. DMRF Canada encourages you to consult with your physician about procedures mentioned herein.

# Bill Saundercook

*Elected to Chair,  
DMRF Canada Board of Directors*

The DMRF Canada Board has unanimously voted to elect Bill Saundercook to the role of Chair, DMRF Canada. This is an exciting development for DMRF Canada. In the words of DMRF's Honorary Chair and Co-Founder Fran Belzberg; "Under Bill's leadership, I am sure that we will continue to make strides toward finding treatment and THE CURE for Dystonia."

Bill was elected to the DMRF Canada Board of Directors in 2014, and since that time he has been a dedicated and passionate member of the dystonia community, working with the Board, Staff, and volunteers to continue to enhance DMRF's patient programs and events, including Chuck's Run, Walk and Wheel for Dystonia which takes place each year in June. Chuck's Run is in honor of Bill's brother Chuck, who was diagnosed with generalized dystonia at the age of 12. "I am delighted and honoured to be the family sibling representing my brother Chuck, on the DMRF Canada Board of Directors. I am also honoured and humbled to receive the support and confidence of the Board of Directors, to take on the role of Chair of the Board." On behalf of all of us at DMRF Canada, welcome to your new role Bill!



## You Can Help Shape Dystonia Research

The goal of the Global Dystonia Registry is to support future dystonia studies, including clinical and research trials, through the collection of data on persons affected by dystonia. Although the focal dystonias have many different manifestations, most experts believe they share a common pathogenesis or mechanism that causes the disorder. The common causes may be a similar gene defect, similar lifetime experiences, or both. Collecting information from different

patient populations may help us identify the common features that they may share.

Join Us Today - and help to guide future dystonia research. and help guide future directions in research. your responses will remain confidential. To learn more please visit: [www.dystoniacanada.org/research](http://www.dystoniacanada.org/research)

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



## In Tribute

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

Gary Armstrong  
Leonard Fisher  
Ted Keep

Lucy Beecraft  
Margaret Graham  
Janet (Jeannette) Julie Parent

## We've Moved!

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)

# Encouraging Dystonia Patient Support and Clinical Research Here in Canada

## ANNOUNCING: Mario Sousa, Clinical and Research Fellowship Awarded

*“DMRF Canada is proud to once again to be able offer this opportunity to a worthy candidate who has already demonstrated dedication and passion for the movement disorders field,”* said Bill Saundercook, Chair, DMRF Canada. “We know that proper evaluation by a movement disorder neurologist can make a significant difference in terms of the treatment options available to dystonia patients and the corresponding benefit from treatment. Providing the opportunity to encourage and support research in a clinical setting is critically important for the understanding and care for patients in the community.” said Saundercook.

Dr. Mario Sousa was very highly recommended by his Mentor, Dr. Fox, Director of the Movement Disorders Fellowships at the University of Toronto, Toronto Western Hospital, who said; “Dr. Sousa demonstrates excellent research potential. He is receiving additional training in Clinical Research from Harvard Medical School. He has shown an interest in dystonia during his Neurology residency and is particularly interested in the neuropsychiatric aspects of dystonia.”

This is a positive step for the movement disorder community, and dystonia patients. DMRF added the research component, and a second year of funding for this fellowship to allow Fellows the opportunity to learn from patients in the clinical setting. DMRF Canada is delighted that Dr. Sousa will be using his expertise and skills to further his clinical understanding – and his research capacity - at Toronto Western Hospital.

“My interest in movement disorders started very early when I was in the first weeks of my residency of neurology. The more patients with movement disorders I interacted with, the more I wanted to work to help them. I’m really excited to be given the opportunity to learn with the world class team of physicians at Toronto Western Hospital. I hope to become proficient in the management of dystonia and look forward to learning about the various treatments and methods for improving patient care and quality of life.” Said Dr. Sousa.

On behalf of the DMRF Canada Board of directors, our staff and volunteers, we congratulate Dr. Sousa on this Fellowship and wish him the best of luck.

## New Project Combines Artificial Intelligence & Deep Brain Stimulation to Treat Dystonia

**The DMRF is partnering with Jesse H. Goldberg, MD, PhD of Cornell University on a project to engineer a revolutionary new generation of deep brain stimulation (DBS) devices to treat dystonia and other neurological diseases.**

Dystonia results from abnormal brain activity that can be corrected by direct electrical stimulation of dysfunctional brain pathways. In current DBS systems, an implanted medical device delivers continuous stimulation to the brain and adjustments to the stimulation must be made using a remote control device in the hands of a highly trained clinician. A major obstacle to providing patients with maximum benefit from this therapy is

knowing where in the brain to stimulate and tailoring stimulation parameters to the unique needs of each patient. Dr. Goldberg proposes a radically new approach to DBS. He is using artificial intelligence to develop a system in which a computer, interconnected with the brain, figures out exactly how and where to stimulate to restore normal movement.

In this three-year project, Dr. Goldberg will establish the feasibility of this concept in mice. He is collaborating with Mert Sabuncu, PhD in the School of Electrical and Computer Engineering and School of Biomedical Engineering at Cornell University.

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**YOU CAN SUPPORT CRITICAL RESEARCH PROGRAMS TODAY.  
PLEASE MAKE YOUR DONATION TODAY.**

**REFER TO THE BACK OF THIS NEWSLETTER OR VISIT: [www.dystoniacanada.org/donate](http://www.dystoniacanada.org/donate)**

# Treatment with Cannabinoids Improves Dystonia in Huntington's Disease

Dystonia is a common motor symptom in Huntington's disease, a progressive brain disorder characterized by uncontrolled movements, loss of cognitive abilities, and emotional disturbances. A team of clinicians from Germany and Austria reported striking results after treating individuals with early onset Huntington's disease with cannabinoids, synthetic drugs that are derivatives of natural compounds found in cannabis (marijuana).

In all seven patients who participated in the study, the Huntington's disease was advanced and dystonia symptoms were severe. Cannabinoid treatment reduced dystonia symptoms in every participant. In some cases, the positive impact on quality of life was profound. One patient regained the ability to lift his head, which allowed him to engage socially and improved dental hygiene; he also regained use of a clenched hand. Another patient who was wheelchair bound regained the ability to walk without assistance. Several participants showed improvements in mood and behavior.

The investigators acknowledge the limitations of the study due to a small sample size, limited follow-up, and lack of randomization of the trial. However, the results are so encouraging that a double-blind, placebo controlled trial is highly warranted to

study in more depth the effects of cannabinoids on dystonia in Huntington's disease.

Reports on the use of cannabinoids in dystonia are very limited, but new data, often coming from studies like the one described here, increasingly suggest the need for more clinical trials.

*Saft C, von Hein SM, Lücke T, Thiels C, Peball M, Djamshidian A, Heim B, Seppi K. Cannabinoids for Treatment of Dystonia in Huntington's Disease. J Huntingtons Dis. 2018;7(2):167-173.*

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## Sharing Our Stories

One of the ways for us to combat anxiety and isolation is to come together as a community. We are proud to partner with dystonia bloggers that are living with dystonia and are a voice for the community. For a list of some of the dystonia bloggers we love, please visit: [www.dystoniacanada.org/bloggers](http://www.dystoniacanada.org/bloggers). If you have recommendations or read about other dystonia patients working hard to 'defy' their own dystonia., please let us know! Email [info@dystoniacanada.org](mailto:info@dystoniacanada.org). Read our dystonia patient stories at: [www.dystoniacanada.org/patient-stories](http://www.dystoniacanada.org/patient-stories)





# Dystonia Warriors Meet Jade

Meet Yann and Jade, Co-Group Leaders of English-Speaking Dystonia Support Group in Montreal - "Twisted Talk"

**“We have been able to connect with many people in the dystonia community. Each individual with their own story; just diagnosed, mis-diagnosed, and others who have had dystonia for a long time, happy to find out there was a dystonia English support group. We have been able to help many people connect to various specialists, but above all have been able to support and empathize with their dystonia journeys.”**

The dystonia community is extremely lucky to have Jade and Yann; co-leaders of the DMRF Canada Support Group, Twisted Talk. Read on to learn more about Jade and Yann, and how Twisted Talk was created.

**DMRF: Hi Jade! Thanks for sitting down with us to tell us a little bit about your dystonia story. First off - how long did it take you to get your dystonia diagnosis?**

JW: It took several years before I knew what dystonia was. Because I have secondary dystonia from a stroke that happened early on in my life, the dystonic symptoms were an unknown movement disorder.

**DMRF: What was your first thought after you were diagnosed?**

JW: It was interesting to finally define and name my spasticity as dystonia. I thought, what is this dystonia? How many other people does it affect.

**DMRF: What has made you decide to get involved with DMRF Canada as a volunteer Support Group Leader?**

JW: I have always been an advocate for helping others and wanted to be involved in the dystonia community. I wanted to connect others together so they could share a mutual conversation about living with dystonia. Since there was a lack of support for English speaking patients in the Montreal community, I decided to take on the role of Co-Leader, along with Yann and together we created "Twisted Talk". Yann and I are working on creating a cohesive group that instills comradery, acceptance, and support. It is still in the early stages, but we have high hopes for hosting guest speakers to talk on managing and living well with dystonia in the near future.

**DMRF: If you could describe dystonia in one word, what would it be?**

JW: Resilience. Dystonia is a daily challenge and brings an awareness to the perspective of life's true significance.

**DMRF: What has your dystonia taught you?**

JW: Patience, acceptance, and empathy. I am patient with my self and respect my own limits, especially in the fast paced world we live in. I find myself 'dancing to my own tune'.

**DMRF: If you could give others out there one piece of advice, what would it be?**

JW: Have patience with yourself and respect your body. Accept and love your dystonia. It does not define who you are, but it is non the less a part of you.

# Meet Yann

I was diagnosed with dystonia in October 2017. I had started to experience my symptoms a few months earlier, and at that time no one was able to confirm what my strange painful condition was.

After I finally heard the word dystonia my head was spinning, I wasn't too sure what to think about my diagnosis. It was a combination of a relief, knowing that I knew what I had - and also sadness, knowing that from now on everything would be different. Soon after, I went to a francophone group meeting in Quebec. It was nice to see other people with my condition and it was a nice opportunity to get to know more about dystonia. Soon after the Leader of the French group mentioned that they were looking for someone to start an English support group in Montreal.

I got in touch with DMRF and I found out that there was another person (Jade) who wanted to start a group as well. Together Jade and I came up with the idea of Twisted Talk. We started to work together to reach out to Anglophone people in Montreal who have dystonia.

At first it was a challenge to reach the Anglophone population in Montreal with dystonia. But soon I started to hear from patients with dystonia. All people with different stories, some who had just recently been diagnosed, some who had never been diagnosed and didn't know what to do, and some who had been living with dystonia for years.

As of today we are a small group, but I am glad that Jade and I worked with DMRF to make Twisted Talk happen. I have met extraordinary people and we have helped some to see the right specialist in Montreal. Its really rewarding to give back in that way.

“ *My advice for others who have dystonia? It takes bad days to have good days, don't be ashamed of what you have and do everything you can do to get better. Every day we fight, and this is what makes us dystonia warriors.* ”

To learn more about Twisted Talk and upcoming events, email: [twistedtalkmontreal@gmail.com](mailto:twistedtalkmontreal@gmail.com)





# Focus on Childhood Dystonias.

Dystonia in childhood is a movement disorder that causes uncontrollable muscle contractions. These muscle contractions result in twisting, repetitive movements and abnormal postures. The movements and postures may be chronic or occur in episodes. Symptoms can vary with body position, specific tasks, emotions, and state of consciousness.

Diagnosing dystonia in children is complex and requires careful evaluation by experts in pediatric movement disorders. Childhood dystonia often occurs as a symptom of an underlying brain disorder.

Dystonia can be the only movement symptom a child has or occur along with other movement symptoms—for example, myoclonus (jerking movements).

## Signs of Dystonia:

- » *A body part is flexed or twisted into an abnormal position.*
- » *Repetitive and patterned body movements, which may resemble tremor.*
- » *Movement symptoms worsen with voluntary action. This can cause the incorrect perception that the child is 'faking' the symptoms.*
- » *Symptoms may be present while walking but not running or swimming.*
- » *Symptoms diminish or disappear during sleep.*
- » *Attempting a movement task on one side of the body may activate dystonia symptoms on the opposite side.*
- » *Dystonic movements and postures may be temporarily relieved by a gentle touch or specific action called a sensory trick.*

Dystonia in children is diagnosed primarily by expert observation of the physical symptoms. The diagnostic work up may include blood tests, genetic testing, testing for metabolic disorders (lumbar puncture), magnetic resonance imaging (MRI), and electroencephalography (EEG).

Cerebral palsy is among the most common causes of dystonia in children. Additional causes can include hypoxic brain injury, infections, autoimmune disorders, metabolic disorders, stroke, toxins, and certain medications.

There are a number of inherited dystonias that affect children, many of which are attributed to a single gene variant.



Treatment may include physical therapy, occupational therapy, adaptive equipment and devices, speech therapy, behavioral strategies such as relaxation techniques, oral medications, botulinum neurotoxin injections, and/or deep brain stimulation surgery.

Treatment for dystonia in children tends to focus on reducing the movement symptoms, but there are non-movement aspects of dystonia can have a significant impact on overall quality of life and should be considered as part of a comprehensive treatment plan. These may include pain management, difficulties with daily tasks, trouble using the hands, difficulty with seating, mobility challenges, sleep difficulties, and sometimes communication issues. Children with dystonia, especially inherited dystonias, may have higher rates of anxiety and depression than children overall.

## Resources for Parents

Visit: <https://www.dystoniacanada.org/parentsupport> for a full list of resources available for parents, including:

- » Facebook group for Parents of Canadian Children with Dystonia (A closed peer support group on Facebook for parents);
- » Dystonia in Children & Adolescents - A webinar recording with pediatric neurologist and movement disorder expert Dr. Inge Meijer (recorded in November 2018);
- » Never Look Down by Zachary Weinstein & Alyssa Dver (An illustrated book for children with dystonia);
- » Teen Guide for adolescents with Dystonia, with thanks to the George Lunan Foundation;
- » A list of pediatric treaters in Canada



# CHUCK'S RUN

FOR DYSTONIA

## JOIN US!

Chuck's Run, Walk and Wheel is June 2, 2019:

Registration Is Easy! *Sign Up Today.* 

Register online at:

[dystoniacanada.org/chucksrn](http://dystoniacanada.org/chucksrn)

or call the DMRF:

416-488-6974 or 1-800-361-8061



## Meet This Year's Ambassador: Sarah-Anne and her daughter, Brelynn

“ Like many of you, I've been through the judgment, the stares, the looks, the curious faces, the skeptical friends. And like you, I've learned to be strong, to rise above and to want more for myself and for my family”

Meet our 2019 Chuck's Run Ambassador, Sarah-Anne. Last year, Sarah-Anne and her family participated in Chuck's Run, and it was a pivotal point in Sarah's journey with dystonia. “I was thrilled to be there and to walk the full 5 KM. To be there with everyone and to know that so many people there—strangers who I didn't know—had once been alone like me—was a feeling like no other” This year, we're happy to celebrate the dystonia community and encourage all of you to rise up in the face of your fears, to come out and meet others just like you.

Visit [www.dystoniacanada.org/chucksrn](http://www.dystoniacanada.org/chucksrn) to sign up today.

*Our thanks to **Merz Pharma Canada Ltd.** our Platinum Sponsor, and **Ipsen Biopharmaceuticals Canada Inc.**, our Gold Sponsor for their very generous support*





## Dystonia Strong: Walking, Running, Rolling and Sharing Our Way to a Cure

The dystonia community is coming together for a number of events over the next few months. **Join us!**

Visit: [www.dystoniacanada.org](http://www.dystoniacanada.org) to learn about the upcoming events in your community and how you can get involved.

EVENT	LOCATION	DATE
Scotiabank Montreal Charity Challenge	Montreal, QC	April 27, 2019
Yogatonina Session	Edmonton, AB	May 27, 2019
Chuck's Run, Walk and Wheel for Dystonia	Toronto, ON	June 2, 2019
Hamilton Freedom to Move Walk	Hamilton, ON	June 8, 2019
Sudbury Freedom to Move Walk	Sudbury, ON	June 9, 2019
Scotiabank Vancouver Charity Challenge	Vancouver, BC	June 23, 2019
Vancouver Dystonia One Day Symposium – FREE for patients	Vancouver, BC	November 1 - 3, 2019

### Working Together to Raise Awareness for Dystonia

DMRF Canada will be leading the 'Dystonia Moves Canada' campaign for Dystonia Awareness month in Canada for September 2019 and beyond!

### We're Looking for Volunteers!

Please email us if you're interested in getting involved.

Visit: [dystoniacanada.org/awareness](http://dystoniacanada.org/awareness) or email [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

to learn how you can get involved this year.

**Dystonia**  
**MOVES ME**



## DMRF Canada Encourages Living Well with Dystonia

Earlier this year, DMRF Canada hosted a special webinar presentation with Mike Stroh, Founder of 'Starts with Me'. Mike provided the group with tips, tools, and practices to cultivate a sense of agency to work with - rather than against - the challenges associated with Dystonia and that often arise in negative thoughts, feelings, behaviours, and body sensations.

*To listen in on the webinar, access the Starts with Me Self Care and Self Awareness Guide and to access a list of mental health resources in Canada, visit: <https://www.dystoniacanada.org/navigatingmentalhealthwebinar>*

## Are Your Dystonia Symptoms Under Control? See the Dystonia Wellness Checklist

DMRF Canada is committed to helping you live your best life with dystonia. The next time you are visiting your movement disorder specialist, keep your eye out for the Dystonia Wellness Checklist. This is a short test that asks questions about your well being to identify areas where you may need additional support. A number of movement disorder specialist have provided feedback into this tool, including Dr. Davide Martino, Director, Movement Disorders Program, University of Calgary.

"I personally think that patients would welcome a different model of clinic, with more time for follow-up and discussion on non-motor features, but probably also simply being examined more often to discuss some details of the motor symptoms and the impact these have on their functioning and quality of life. A tool like the Dystonia Wellness Checklist will help to generate discussion and increase awareness of the various aspects of a dystonia patients wellbeing."

*This Checklist will be in clinics and doctors offices later this spring. To learn more online visit: [www.dystoniacanada.org/dystoniawellness](http://www.dystoniacanada.org/dystoniawellness)*

## Dystonia Strong: The Edmonton Community Comes Together

The DMRF Edmonton Support Group has been supporting 'Yogatonia' for nine years. This wonderful two hour monthly yoga class is offered free of charge to participants, thanks to the support of the Alberta Gaming Commission (proceeds from the Edmonton Charity Casino). "We're thrilled to be able to offer this type of program for dystonia patients in Edmonton", said Connie Zalmanowitz, a long-time leader of the Edmonton Support Group. "Its great to get people out to meet others, and to come together as a community in such a positive way. We have been fortunate to have had two wonderful yoga instructors in all this time. They have been great listeners and tailor the classes to the needs of participants. Our present instructor Jaya, works hard to keep classes safe for all, regardless of disability level."



*The DMRF Edmonton Support Group is grateful to the Prana Yoga studio for their support of this important program. If you'd like to learn more about an upcoming class, please email: [yogatonia@gmail.com](mailto:yogatonia@gmail.com)*



## DMRF Canada

550 St. Clair Ave West, Suite 209

Toronto, ON M6C 1A5

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

Your gift can help boost our momentum toward the next great discovery. **Please Give Generously**

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 long-term improvements in the lives of individuals suffering from dystonia.

Yes, I want to support DMRF Canada. Please add your selection below.

☐ Yes, I want to invest in critical dystonia research. Here is my gift of:

☐ \$250 ☐ \$100 ☐ \$50 ☐ \$25 ☐ \$ \_\_\_\_\_

**Option 1:** ☐ I am sending my cheque made payable to the Dystonia Medical Research Foundation Canada.

**Option 2:** ☐ Please charge my credit card: ☐  ☐  ☐ 

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☐ Yes, I want to join the DMRF Canada Monthly Giving Team.

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**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.

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