

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 2020

## IN THIS ISSUE

- Learning More about Deep Brain Stimulation for Dystonia;
- Join Us! Upcoming Virtual Educational and Community Events;
- Celebrating our Dystonia Thrivers; and More!

## Meet Shelby Newkirk

Para swimmer

World Record Holder, 2x Americas record holder,  
12x Canadian record holder, Dystonia Thriver.

*"I recognize my limitations, but I don't focus on  
that. I focus on what I can do"*

*Full story on page 11*

## PLEASE RENEW YOUR MEMBERSHIP FOR 2020

*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.

## Board of Directors

### Co-Founder

Samuel Belzberg (1928 - 2018)

### Co-Founder & Honorary Chair

Frances Belzberg

### Chair

Bill Saundercook

### Secretary / Treasurer

Pearl E. Schusheim

## Directors

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Heather Connor

Dennis Kessler

Rosalie Lewis

Tim Williston

Connie Zalmanowitz

# Bill Saundercook

## *Chair, DMRF Canada Board of Directors*

Dear Friends from the Dystonia Community,

As I reflect on my first year as Chair, I would first like to speak to all of you, our Dystonia community, and say how privileged I am to have this responsibility. I think about all of you regularly, wondering what the future has in store for you.



Recently, I have been reading more Deep Brain Stimulation (DBS) surgery for Dystonia, given the Foundation's recent investment in two research studies (our Better Clinical Treatments Grant, which were awarded late last year). In the following pages, you will find an article on DBS. My late brother, Chuck, was a pioneer patient for DBS and Dystonia, and we are grateful to the many gains that have been made in this area since Chuck's diagnosis back in the late 1970s. I know that if he were still with us today, he would be pleased to learn how far we have come. It is with thanks to all of you in the patient community who continue to fight to live your best lives with Dystonia.

I want to assure you that the DMRF Canada Board of Directors are with you each step of the way. Enclosed you will find information on our Dystonia 'thrivers', new information on virtual information sessions, webinars and new ways to get involved while social distancing - including a virtual edition of Chuck's Run, Walk and Wheel for Dystonia. To learn more, please visit: [www.dystoniacanada.org/chucksrn](http://www.dystoniacanada.org/chucksrn).

Thank you for continuing to be the fuel that drives our organization forward. I want to assure you that we will do our best to deliver the quality programs and services you have come to depend on from the Foundation during this uncertain time. For now, our support will be delivered by phone, email, and webinar. Rest assured, DMRF Canada is always here for you.

Sincerely,  
Bill Saundercook,  
Chair of the Board

# Foundation Update

Dear Friends,

As you know, research is at the heart of what we do. Our organization began over 40 years ago, with a vision to find a cure, once and for all. We continue to remain dedicated to doing just that. Stay tuned for news and updates on some of our research projects in the months to come.

During these uncertain times, I want to assure you that DMRF Canada remains dedicated to supporting our community of clinicians, volunteers, patients and thrivers. We will be offering support group meetings and educational sessions by webinar in the months to come.

We are still available if you need us! Please feel free to email: [info@dystoniacanada.org](mailto:info@dystoniacanada.org) or call: 1-800-361-8061. Wishing you and your families good health and safety at this time.

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.

## 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)

## 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)



## In Tribute

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

**John "Scott" Gollan**  
**Rosalind (Roz) Krupka**  
**Muguette St-André**  
**Carol Vince**  
**Arlene Czop**  
(DMRF Canada Chilliwack Area Contact)



# Learning More About Deep Brain Stimulation for Dystonia

**Neuromodulation is the science of altering brain activity to treat disease, often by using electrical stimulation. Deep brain stimulation (DBS) is a neuromodulation technique that uses a surgically implanted medical device to treat dystonia and other disorders.**

DBS applies electrical stimulation to interrupt the abnormal brain activity that causes dystonia symptoms.

A DBS system includes an electrode placed deep in the brain, an implanted neurostimulator, and a wire that connects the electrode to the neurostimulator. The neurostimulator contains a battery and electronic circuitry that generates the signals delivered to the brain. Once the system is surgically implanted, the electrical stimulation is adjusted by remote control. The neurostimulator batteries must be periodically replaced. Rechargeable and non-rechargeable neurostimulators are available.

## Who is a Candidate?

***DBS treatment for dystonia is recommended on a case-by-case basis. DBS may be considered if:***

- ✓ Symptoms cannot be adequately treated with medications and other treatments.
- ✓ Surgical risks are justified against quality of life.

### ***Types of dystonia most often treated with DBS:***

- Genetic childhood onset dystonias, e.g. DYT1/TOR1A and DYT28/KMT2B
- Cervical dystonia
- Tardive dystonia/dyskinesias
- Myoclonus-dystonia
- X-linked dystonia-parkinsonism

There is encouraging early data about the use of DBS to treat cranial dystonias, including oromandibular dystonia and blepharospasm.

## What are the Benefits?

Benefits of DBS include reduced dystonic movements, postures, and pain. It is difficult to predict which patients will benefit and to what degree. Numerous studies have shown that the benefits of DBS are sustained long-term.

**50-60%**

***Average improvement in dystonia patients***

**90+%**

***Degree of improvement in some patients***

## Risks

The most common adverse effects from deep brain stimulation are infection (5%) and lead breakage (4%). There may also be stimulation-related side effects, which are typically temporary.

## DBS Medical Team

DBS is a highly specialized therapy that requires a team of medical professionals to evaluate and treat patients:

- ✓ Movement disorder neurologist
- ✓ Neurosurgeon
- ✓ Neuroimaging specialist
- ✓ Neuropsychologist
- ✓ Psychiatrist
- ✓ Nurses

Medical centers vary in their DBS procedures and practices. Individuals considering DBS may wish to consult more than one DBS team before making a selection.

## Beware

Certain medical MRI imaging, diathermy therapies, security metal detectors, and security wands may interfere with the DBS device. Individuals must clarify with their doctor and device manufacturer what restrictions apply to their implanted DBS system.

## Technology Advancements in Deep Brain Stimulation

The neuromodulation field combines biomedical research with cutting-edge engineering design, often inspiring collaboration among academic research programs and private companies.

Multiple efforts are underway to make DBS systems more personalized and more effective. DBS is evolving from a strategy to suppress dystonia symptoms toward the possibility of correcting the underlying brain circuit dysfunction that causes symptoms.

### ***Emerging DBS Advancements Include:***

- Creating DBS systems that automatically make stimulation adjustments by sensing and responding to brain activity. This involves improved sensors and increased device memory.
- Deciphering biomarkers in the brain that help predict a positive result from DBS.
- Rechargeable IPG batteries to increase the duration in between battery replacements.
- Smaller devices. Ultimately, IPGs may be small enough to implant under the scalp rather than the abdomen.
- Upgradeable devices. Patients may one day have the ability to upgrade their DBS systems as easily as upgrading apps on a smartphone.
- Improving electrode design for more selective targeting and reduction in unwanted stimulation side effects.
- Greater flexibility of stimulation options, including the ability to have different settings for specific brain targets.

Additional information about DBS for dystonia can be found at: <https://dystoniacanada.org/deep-brain-stimulation> DMRF Canada reminds all patients that every dystonia case is different. Please speak with your movement disorder specialist about any new course of treatment.

Reprinted with permission from DRMF Dystonia Dialogue Vol 42, Number 3.

## Better Clinical Treatment Grants for Dystonia

DMRF Canada, with the very generous support of Lance Howitt and his family, have invested in two research grants which both focus on DBS surgery of the treatment of dystonia and are currently in process. These studies are:

### ***Project One:***

“Mechanisms of Action of DBS for Dystonia: Cholinergic Contributions to Plasticity” by Drs. Zelma Kiss and Davide Martino at Department of Clinical Neurosciences, Hotchkiss Brain Institute, University of Calgary.

### ***Project Two:***

“Mapping Brain Response Patterns to Deep Brain Stimulation with fMRI” by Drs. Alfonso Fasano and Andres Lozano at Toronto Western Hospital.

Stay tuned for updates on these research projects in the coming months.

To learn more about these studies, and others, please visit: [www.dystoniacanada.org/latest-dystonia-research-news](http://www.dystoniacanada.org/latest-dystonia-research-news)

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

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

# Are Your Dystonia Symptoms Under Control?

## Dystonia Wellness Survey Results

DMRF Canada is dedicated to helping you live your best life with dystonia. Last year, we launched the Dystonia Wellness Checklist; a tool that would help to facilitate conversations with doctors about your well being. This short test asked questions to help identify areas where dystonia patients could need additional support.

We're pleased to announce the survey results are now available online at: [www.dystoniacanada.org/wellnesssurveyresults](http://www.dystoniacanada.org/wellnesssurveyresults).

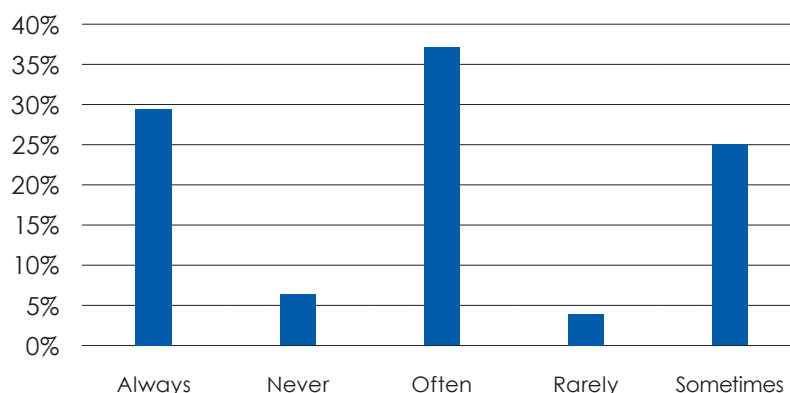
Dystonia has a profound impact on a patient's wellbeing. Every aspect of a patients life is impacted, including their social lives and spending time with friends and family, their ability to work well and without pain, quality of sleep, and more. Below are some of the key findings from the Dystonia Wellness Survey.

### Dystonia Patients Experience Pain

9 out of 10 Respondents Experience Pain.

6 out of 10 Respondents are Always or Often in Pain.

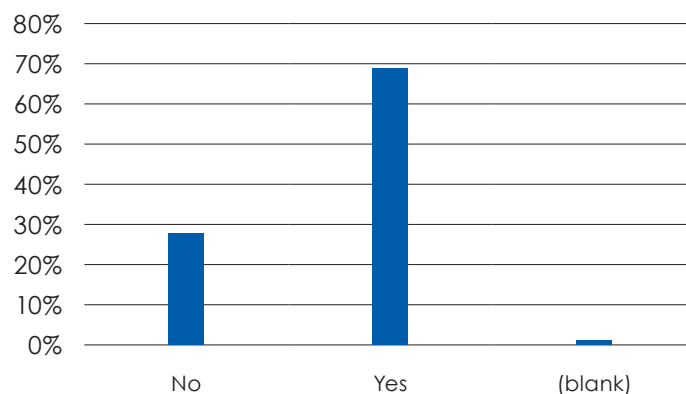
Do you experience pain because of your dystonia?



### Anxiety and/or Depression is a Real Part of Life for Many Patients:

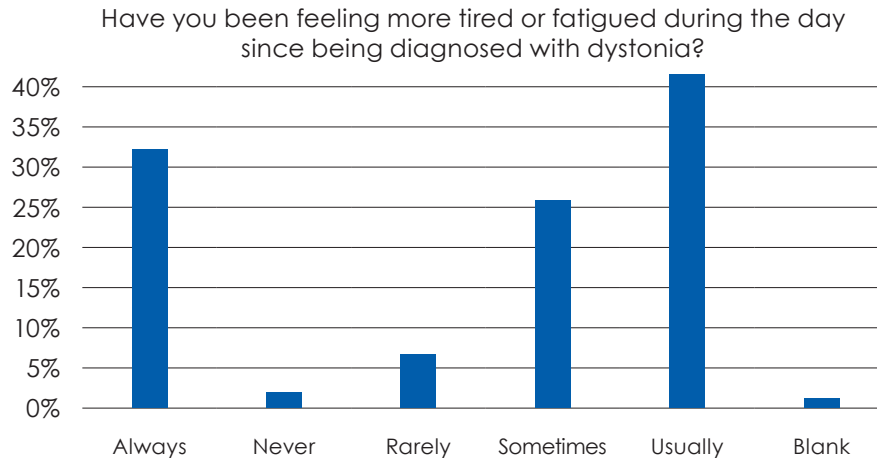
69% of Patients Suffer from Anxiety or Depression

Do you suffer from anxiety or depression since you have been diagnosed with dystonia?

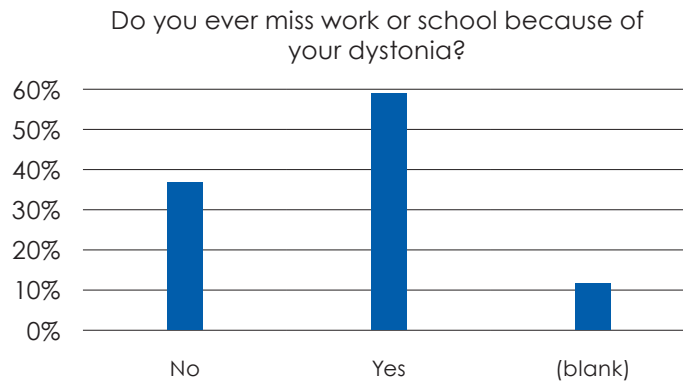




**Anxiety and/or Depression is a Real Part of Life for Many Patients:**  
**7 out of 10 Respondents Feel Fatigued or Tired During the Day.**



**More Than Half of Patients will miss Work or School Because of Their Dystonia**  
**More Than Half of the Respondents (55%) miss Work or School due to their Dystonia.**



**Our thanks to Ipsen Biopharmaceuticals for their support of the Dystonia Wellness Checklist.**



**Introducing the First Webinar in the Living Well Webinar Series, Designed to Help You Live Well with Dystonia**

## **Dystonia & Sleep**

**Presented by:** Davide Martino MD PhD, Director, Movement Disorders Program,  
Cumming School of Medicine, University of Calgary.

**When:** June 24, 2020 at 1:00 pm EST **To Register visit:** [www.dystoniacanada.org/livingwellseries](http://www.dystoniacanada.org/livingwellseries)

## **Announcing: Dystonia Wellness Survey Winners**

**Congratulations to prize winners Johanna from BC, and Florie and Beth from Ontario.**

# Dystonia: Frequently Asked Questions

## What is dystonia?

Dystonia is a neurological disorder that causes excessive, involuntary muscle contractions. These muscle contractions result in abnormal muscle movements and body postures, making it difficult for individuals to control their movements. The movements and postures may be painful. Dystonic movements are typically patterned and repetitive.

Dystonia can affect any region of the body including the eyelids, face, jaw, neck, vocal cords, torso, limbs, hands, and feet. Depending on the region of the body affected, dystonia may look quite different from person to person.

## What causes dystonia?

There are many known causes for dystonia. Dystonia may occur due to an inherited or new genetic mutation. Dystonia may also result from changes in brain activity caused by another health condition such as a traumatic brain injury. Certain drugs are known to cause dystonia. However, for many people who develop dystonia, there is no identifiable cause.

## Can dystonia affect the heart and other vital organs?

Dystonia affects muscles that can be controlled voluntarily, mostly the skeletal muscles. Dystonia does not affect smooth muscle, such as the heart.

## Is dystonia fatal?

In the overwhelming majority of people with dystonia, it does not shorten life expectancy or result in death. In extreme cases, the development of increasingly frequent or continuous episodes of severe generalized dystonia can cause a medical emergency called status dystonicus. If untreated, this rare condition can cause life-threatening

complications. Status dystonicus is a treatable condition and, with prompt medical attention, symptoms typically can be brought under control. Dystonia does occur as a symptom of several degenerative diseases, some of which do impact mortality, but the dystonia itself does not shorten life span.

## Dystonia is making it hard to function. Who can help me?

Living well with dystonia is possible. The early stages of symptom onset, diagnosis, and seeking effective treatment are often the most challenging. In some cases, treatment can dramatically reduce or suppress symptoms.

Individuals and families living with dystonia are strongly encouraged to:

- *Seek treatment from a neurologist who specializes in movement disorders.*
- *Learn about dystonia and treatment options.*
- *Develop a multi-layered support system of support groups, online resources, friends, and family.*
- *Seek expert mental health professionals to diagnose and treat possible co-existing depression and/or anxiety disorders.*
- *Investigate complementary therapies that support overall wellness.*
- *Get active within the dystonia community.*

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If you have a question you would like to see addressed, email us at [\*\*info@dystoniacanada.org\*\*](mailto:info@dystoniacanada.org)

Used with permission from Dystonia Dialogue, Winter 2019, Vol 43, No 3.





# Introducing Our Nationwide Chuck's Virtual Run, Walk and Wheel

May 31 - June 30, 2020

Due to the COVID-19 virus, and our need to adhere to physical distancing, this year's event has been transformed into a virtual event - but with the same great perks as our in person event.

Participants will receive a special participant package by mail, along with some great DMRF Canada and Chuck's Run swag that you can wear as you run, walk, or wheel for dystonia.

Participants have the entire month of June to participate - and you can do any combination of running, walking and wheeling to raise funds to help us to find a cure for dystonia once and for all.

Simply **visit:** [www.dystoniacanada.org/chucksrn](http://www.dystoniacanada.org/chucksrn) and select 'register'. We look forward to our support of this important event!



## The History of Chuck's Run, Walk and Wheel for Dystonia

The first Chuck Saundercook fundraiser for dystonia began over forty years ago after Charles (Chuck) Saundercook passed away due to pneumonia, following his Deep Brain Stimulation (DBS) surgery for dystonia at 16 years old. In 1977 this was one of the first times this procedure was performed in Canada, and Chuck was a pioneer. Chuck's unfortunate death occurred after contracting pneumonia during recovery from the second surgery. After Chuck's death, his family dedicated themselves to supporting DMRF Canada and finding a cure for dystonia.

The first Chuck Saundercook fundraising event, which took place in the summer of 1978, and was as a "Swim-a-thon" event hosted in Chuck's family's backyard pool (donated to Chuck for his therapy). Twenty-four of Chuck's friends began a 24-hour swimming competition where they took turns swimming five minutes each and raised pledges of \$200 and more.

The solidarity and the spirit of fundraising for Dystonia had been deeply embedded in the community Chuck had grown up in. Even before the swim competition, Chuck's friends had raised \$12,000 for DMRF, and were able to bring a dystonia specialist from San Francisco to Toronto Western Hospital, to pursue his research in dystonia.

The goal of the first swim competition event in honor of Chuck was to raise \$30,000. Over the years, the dystonia community has raised close to one million dollars for critical dystonia research through Chuck's Run, and other Chuck Saundercook inspired fundraisers.

Last year, Chuck's brother Bill Saundercook was elected as the Chair of the DMRF Canada Board by the Directors. Bill is more dedicated than ever before to drive more fundraising to support more research to find a cure for Dystonia. Bill joined the Board in 2015, as a Director.

Bill has shared the responsibility of heading up the Toronto based Chuck's Run, Walk and Wheel for Dystonia with his wife Anne, his mom, Betty and all of Chuck's siblings and friends and others including David Jaakkola who was instrumental in this event for many years. This year's event will be nationwide - and the first ever strictly virtual event, but with the same great benefits as our in-person event. Participants will receive some great swag from DMRF, with a great opportunity to interact with the dystonia community while raising funds for a great cause!

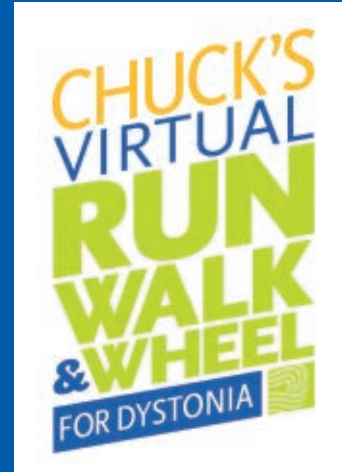
Learn more at: [www.dystoniacanada.org/chucksrn](http://www.dystoniacanada.org/chucksrn).

# We Are Dystonia Strong: Virtually Walking, Wheeling, Riding Towards a Cure

We are grateful to the dystonia community across Canada for their continued support of our research and support programs benefiting dystonia patients and families. Thanks to your generous support, DMRF Canada has raised close to \$1,000,000.00 through Chuck's Run, Walk and Wheel for Dystonia. Every dollar raised will benefit critical research and support programs. Thank you for your support.

This year's event is a little bit different, due to our need to keep a safe distance. This year, we're thrilled to announce that Chuck's Run, Walk and Wheel will be a virtual nation wide event, taking place over the month of June.

Simply visit: [www.dystoniacanada.org/chucksrn](http://www.dystoniacanada.org/chucksrn) to register as a virtual participant today.



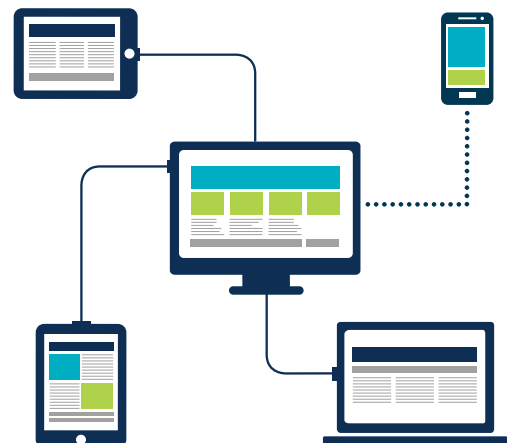
*Our thanks to **Ipsen Biopharmaceuticals Canada Inc.**,  
sponsor for their very generous support of  
Chuck's Virtual Run, Walk and Wheel for Dystonia*



## Upcoming Virtual Community Events:

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

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



# Our Heartfelt Thanks:

## Meet Barbara and Brian Crow, Winnipeg Support Group

Barbara and Brian Crow have been an inspiration and the heart of the Winnipeg Support Group for 25 years. With the recent appointment of Jennifer Lovell, as the new leader of the Dystonia Winnipeg, Support Group, DMRF Canada sat down with Barbara to thank her for their service, and to hear about what she's learned over the years.

### ***DMRFC: What year did you first get involved with the DMRF Canada?***

BC: 1994, just a year after I was first diagnosed with dystonia.

### ***DMRFC: What have you learned from your dystonia?***

BC: Patience, acceptance, compassion, tolerance, and methods to live with pain.

### ***DMRFC: How has your work with DMRF Canada and/or the Winnipeg Support Group helped you?***

BC: My work with DMRF has really helped me (and others from the support group) to find the resources that I needed for my dystonia. It helped me to understand my symptoms better. It showed me that I wasn't alone.

### ***DMRFC: What did you learn from your time leading the group?***

BC: I've seen firsthand how important public awareness of dystonia is. There are so many people suffering, but they don't know why, or where to turn for help.

I also learned that there are very good people out there. There are some very good doctors who have a lot of compassion, and I have been very fortunate to have a strong advocate to support me in difficult times.

### ***DMRFC: Do you have any advice for anyone who is interested in leading a support group?***

BC: Leading a Support Group is a very rewarding experience. It requires empathy, and patience. It's important to be able to listen and learn from others, and it provides many wonderful opportunities to support others, while also gaining support for yourself and your family.

It's important to work well with others and to promote awareness and community building. I would

encourage anyone who is interested in getting more involved with DMRF Canada to take the opportunity to learn about dystonia during DMRF organized conference calls and seminars, and to share that information back with your local community.

### ***DMRFC: Is there anything else you'd like us to know?***

BC: Awareness is happening, diagnosis times are becoming shorter as more doctors become aware, and medical/surgical help is getting closer as research levels increase.



Pictured above: Winnipeg Support Group Leader Barbara Crow, and Winnipeg Movement Disorder Specialist, Dr. Doug Hobson.

# Stories That Inspire: Meet Two Dystonia Thrivers



## Meet Shelby Newkirk

*“I recognize my limitations, but I don’t focus on that. I focus on what I can do.”*

Meet Shelby. Para swimmer. World Record Holder, 2x Americas record holder, 12x Canadian record holder. **Dystonia Thriver.**

At 23 years old, Shelby Newkirk is a force to be reckoned with. Shelby has spent the last nine years dedicating her free time to swimming. *“I train a lot. I’m in the water five days a week and in the gym two days a week. I work with a home coach and I also have a personal trainer. I regularly meet with a nutritionist, and a sports psychologist. I know how important mental training and preparation is. It’s really important to do that.”*

For Shelby, everything else takes a back seat to swimming: her friends work around her schedule; her family makes sacrifices to ensure she is doing everything she can to attain her dream. “I can’t take as many classes because of my training schedule, so I’m currently only taking two classes each semester. I am training all the time”.

Shelby has the dedication and passion of an Olympic athlete. And on top of all of that; Shelby is a dystonia thriver. She was diagnosed with dystonia ten years

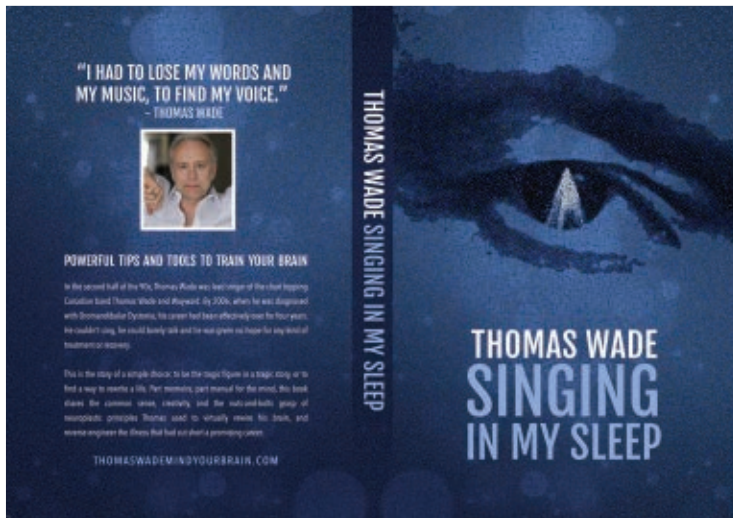
ago in 2010; “at first they thought it was just focal dystonia, but slowly things changed.” Shelby’s dystonia is progressive, which means that she has to deal with her abilities changing over time. “There are things that I used to be able to do that I am not able to do anymore, but I have a great team of medical people here who really help me.”

Being in the moment and having a clear focus – swimming – has been hugely helpful for Shelby and her family; “doing all that I can to succeed in swimming is where I’m focused and where I’m putting all my energy. After that’s finished, we’ll see what comes next!”

When asked what has helped Shelby to gain perspective, Shelby credits her first coach; “She tried to understand it and learned all that she could about how to train and coach someone in my position. She talked about my dystonia in terms of chapters - she said to think of each stage as a chapter of my life. It’s not the whole part of me, but it’s the reality of my life.”

When asked if she had any advice for others dealing with a dystonia diagnosis, Shelby shared: It’s important to know where you need help. And to realize what you can and cannot do. It’s okay to be sad about it - and then it’s okay to move ahead and live your life.





## Meet Thomas Wade

**DMRF Canada is pleased and proud to announce our 2020 Chuck's Virtual Run, Walk and Wheel Ambassador: Canadian country music artist, Mr. Thomas Wade.**

Thomas began his career as the lead singer of the group Thomas Wade & Wayward. Between 1997 and 1999, Thomas Wade and Wayward received seven CCMA awards, winning best group or duo three times, and both independent single and song awards for '97 and '98. The group was also nominated for three Juno Awards for Best Country Group or Duo in 1997, 1998 and 1999.

However - by 2001, Thomas could no longer sing, he could barely talk and he was given no hope for any kind of treatment or recovery. Finally, in 2006, Thomas was diagnosed with Oromandibular Dystonia, a form of dystonia that forces contractions of the face, jaw, and tongue causing difficulty in opening and closing the mouth, making speech very difficult and singing impossible.

In 2019, after more than 10 years after receiving his official diagnosis, Thomas published; "Singing in My

Sleep". This book chronicles his struggle his dystonia – but more importantly, relates the amazing details of how, against the odds, he overcame it all and has regained his voice.

Thomas is very committed to raising awareness of dystonia and wants to do all that he can to support those who are struggling with dystonia. Being this years Ambassador for Chuck's Virtual Run, Walk and Wheel for Dystonia in 2020, Thomas looks forward to seeing everyone Join him (virtually!) at Chuck's Run to raise awareness and funds for dystonia.

Learn more about Thomas Wade, and, and his book, at: [www.dystoniacanada.org/thomaswade](http://www.dystoniacanada.org/thomaswade).

**Do you Know a Dystonia Thriver?  
Someone Who Inspires You Daily?**

If so, we would love to hear from you. Send your story ideas to: [info@dystoniacanada.org](mailto:info@dystoniacanada.org)



# Do It For Dystonia

**Do you want to support the dystonia community? Do you have a hobby or special interest you love doing? Need that push to try something new? Here's an opportunity to let yourself shine while raising funds and awareness for dystonia:**

This year, DMRF Canada wants to see you 'Do It for Dystonia'! The perfect way to tackle a personal goal, while adhering to physical distancing due to COVID-19.

The spirit of this campaign is to **empower people to put their passions, skills, and talents on display in order to raise awareness and funds for dystonia**. We want to celebrate how individuals with dystonia succeed in all aspects of life. It can be either something you love to do or something you haven't tried yet. It can be anything you want it to be! All that matters is that you do it for dystonia – and for yourself.



## How To Participate

1. Set Your Goal
2. Design Your Online Page: Describe what you will do and why you are doing it
3. Tell them where the money will go and how they can make a difference
4. Tell your family and friends, as well as DMRF Canada of your plans, and share your journey using the hashtag **#doit4dystonia**
5. Say Thank You: Provide updates and let people know how close you are to reaching your goal

Join the Facebook Group **DoIt4Dystonia** so that you can draw inspiration from others and keep each other motivated!

To learn more, visit [www.dystoniacanada.org/doit](http://www.dystoniacanada.org/doit) or call us at **1-800-361-8061**

With this campaign, you'll be tackling your own individual challenges, inspiring others, raising much-needed awareness of dystonia – and inspiring others! Plus you can win great prizes!

DMRF Canada will feature the top five 'Do It for Dystonia' fundraisers in the Spring 2021 Newsletter. Please submit your story, along with campaign details by January, 2021. (All cheque donations can be sent to DMRF Canada, 209 - 550 St. Clair Ave. West, Toronto, Ontario, M6C 1A5 Canada.)

### Follow Us On Social!



One of the ways that you can help us to get the word out about dystonia, and DMRF Canada, is to follow us on Facebook, Twitter and Instagram.

Visit: <https://www.dystoniacanada.org/support-us-find-us-social>



Here are some great ideas from other dystonia advocates around the world who you can draw inspiration from:

### ***Facebook Birthday Fundraiser***



In 2019, Laurie from Hamilton, Ontario held a birthday fundraiser on Facebook, collecting funds for dystonia research. In total Laurie's birthday fundraiser raised \$400.

### ***Lemonade Stand for Dystonia***



A dystonia supporter in Toronto, Ontario ran a Lemonade Stand in September 2017 for Dystonia Awareness Month. Her lemonade stand helped to raise funds and awareness at the same time while also delivering a refreshing glass of lemonade to her visitors.

### ***24-hour Swim Marathon***



Though this fundraiser was in 1978, it can still be done today! In memory of Chuck Saundercook, this 24-hour marathon was organized by his 15-year-old sister Jane. She even got family and friends to join. Approximately 24 friends and family joined her too, logged 37 miles in a pool and raised \$12,000. In celebration, they all jumped into the pool with her after the achievement.

### ***Cycling for Dystonia***



A Dystonia warrior raised funds by cycling 25 miles around a lake in the UK. Cervical Dystonia had threatened to halt her efforts to lead a normal life. Her partner, and daughter, joined her in the challenge.

## DMRF Canada

550 St. Clair Ave West, Suite 209  
Toronto, ON M6C 1A5

# 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.

Your gift can help boost our momentum toward the next great discovery. **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 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: ☐  ☐  ☐ 

Card #:

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Expiry:

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☐ Yes, I want to learn more about how to include DMRF Canada in my Will.

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

☐ \$50 a month ☐ \$25 a month ☐ \$10 a month ☐ \$5 a month ☐ \$ \_\_\_\_\_ a month

☐ Please charge my credit card: ☐  ☐  ☐ 

Card #:

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Please provide an email address: \_\_\_\_\_

**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.

Charitable #12661 6598 RR0001

Cut along dotted line

