



## Meet Dwayne Backer, DYSTONIA ADVOCATE AND INSPIRATION

This year's Dystonia Support Group of Sudbury and District Walk-and-Wheel 2018 event welcomed 28 walkers, supporters and volunteers - and raised close to \$20,000 for research and support programs for individuals living with dystonia in Canada. It also marked the 18th year of walking for dystonia for Sudbury resident, Dwayne Backer.

For years Dwayne has been walking, supporting the cause and spreading awareness for dystonia. But this year he reached an incredible milestone: With the help of 286 sponsors who supported his efforts this year, Dwayne raised over \$11,000, **bringing his cumulative fundraising total for the past 18 years to over \$100,000.00.**

"I believe very strongly in raising money to find a cure for dystonia, which I have had for my entire adult life" said Dwayne.

For Dwayne, dystonia has been a reality for as long as he can remember. In 1967, Backer was working in North Bay for the Canadian Air Force when he first started noticing the symptoms of what was later diagnosed as dystonia. He had a stiff neck which became progressively worse until his neck was bent down onto his shoulder. His condition became worse and worse until he was unable to move at all.

After years and many examinations by different doctors, Dwayne was finally diagnosed with dystonia, and underwent experimental brain surgery which, to some extent, finally succeeded in loosening his muscles.

It was during Dwayne's recovery from surgery in his hometown of Mattawa where he met his future wife, Pauline. The couple eventually moved to Sudbury,

where Dwayne attended Laurentian University, graduating with a sociology degree in 1972. Because he was unable to control a pen enough to write, he taped his professors' lectures and took his exams orally.

In 1974, Dwayne opened his own Smoke Shop on Durham Street, which he owned until 1998. Originally Dwayne thought this was a sign for him to retire, but he found that "there wasn't enough to do, and I wasn't ready to just stop working, so I applied to Wal-Mart in April 1999. Dwayne worked for Wal-Mart for many years, and for years, his colleagues at Wal-Mart were supporters of his fundraising goals at the annual Walk.

As for coping with the pain from his dystonia, Backer said the neurotoxin treatments he receives in every four months to relax his muscles have helped somewhat. He said he also appreciates the support he receives through the dystonia support group and believes in continuing to focus his efforts on fundraising to fund research for a cure.

Of his life with dystonia, Dwayne says: "When we were born we don't come with a warranty or instruction sheet. The stages of life have to be experienced. Some people glide through all these stages, others hit brick walls. We with Dystonia are examples of the obstacles we have to overcome. We lose a lot of our self-confidence and we need encouragement to carry on. Courage and hope are what we must not lose. Belief in something stronger than my flawed self has certainly helped me.... **'What I can, I must do'** Is my favourite quote."

On behalf of those of us in the dystonia community, we thank Dwayne for his bravery and for not giving up hope.

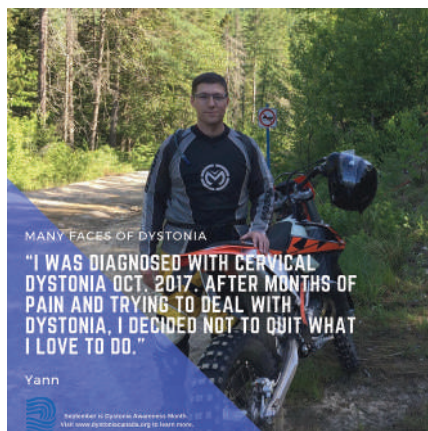
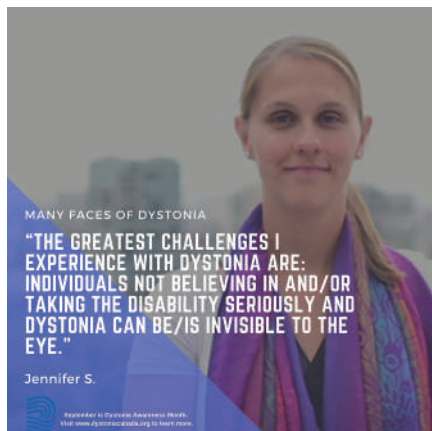
# Working Together to Move Canada for Dystonia



Once again, DMRF Canada is leading dystonia awareness efforts throughout the month of September and beyond. There are several ways for you to get involved. Here's How:

## Share the Faces of Dystonia Campaign.

Everyone experiences dystonia differently. Our thanks to our volunteers who helped put the **#facesofdystoniacampaign** together. For a complete list of faces, please visit: [www.dystoniacanada.org/faces](http://www.dystoniacanada.org/faces). If you want to submit your 'face' for next year, email a photo and a quote to: [info@dystoniacanada.org](mailto:info@dystoniacanada.org)



## Promote Dystonia Awareness Through Social Media.

Throughout the month of September, post, tweet, message, and promote dystonia awareness using **#dystoniamovescanada**  
**#dystoniamovesme**  
**#dystoniaawareness**

Make sure you are following us on Facebook and Instagram for a chance to win one of two Google Home Mini prizes.

## Check Out Local Landmarks.

This September, we're lighting up Canada in Blue and White! Visit: [dystoniacanada.org/dystoniaawarenessmonth](http://dystoniacanada.org/dystoniaawarenessmonth) for a complete listing of landmarks.

## Raise awareness in your Community

Encourage local healthcare professionals to display dystonia awareness materials in their waiting rooms. DMRF Canada will provide all the materials required to get the word out. Please contact [info@dystoniacanada.org](mailto:info@dystoniacanada.org) to request your materials today.



## Help Shape Dystonia Research

DMRF Canada is a proud partner of the Global Dystonia Registry. 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.





## WELCOME TO DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

THANK YOU FOR BECOMING A  
SUPPORTER OF THE DYSTONIA  
COMMUNITY IN CANADA.

DMRF Canada is the only organization that is dedicated to supporting the 50,000 patients in Canada that suffer from dystonia, a neurological movement disorder that affects the nervous system. For over 40 years, DMRF Canada has fought for those impacted by dystonia, working toward better treatments and a cure, funding research, providing advocacy and support and raising awareness of this devastating disorder.

THANK YOU FOR JOINING OUR MOVEMENT TO  
CHANGE THE WORLD FOR DYSTONIA PATIENTS.

YOUR SUPPORT IS VITAL TO OUR ABILITY TO FIND  
BETTER TREATMENTS AND A CURE, EDUCATE KEY  
STAKEHOLDERS AND SUPPORT AND EMPOWER  
THE DYSTONIA COMMUNITY.

The Dystonia Medical Research Foundation was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter Cheri was diagnosed with generalized dystonia.

Our mission is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well-being of affected individuals and families.

Since our inception, DMRF has contributed over \$10 million into dystonia related research projects. Because of these investments, our understanding of dystonia has changed dramatically. Today we know that complex communication between several different areas of the brain is responsible for controlling movement. To date, 23 dystonia (DYT) genes and gene markers have been identified. DMRF's work has inspired investigators around the world to collaboratively explore opportunities for new treatments and to find a cure.

DMRF is a registered non-profit Canadian charity governed by a volunteer Board of Directors.



“Investing in dystonia research is so important because it can lead to an earlier diagnosis and better treatment for others facing similar challenges. It would allow teens, and people of all ages who live with this condition, to look forward to the future with certainty instead of hope”

– Sarah A. Dystonia Patient

## HERE IS WHAT YOUR GIFT WILL DO

- ▶ **Fund Research:** Our globally-focused “Science Portfolio”, the single largest dystonia research program in North America, led by a committee of movement disorder specialists, is focused on contracting with researchers on specific projects, engaging the biotech industry and providing opportunities for the next generation of experts.
- ▶ **Provide Support:** The ongoing development of over 30 local support groups and contacts across Canada who are on hand to provide guidance to dystonia patients in their community.
- ▶ **Patient Care:** Support awareness and education programs to improve timely diagnosis, improve societal understanding of dystonia and empower patients to advocate for themselves.
- ▶ **Advance Advocacy Efforts:** Improve the quality of life for those affected by dystonia by educating elected officials on the needs of the dystonia community, as well as the need for additional research.



**Angie from Edmonton, AB**

*“I am so grateful to donate a small monthly fee to support dystonia, a word that many people have never heard of. It all starts with me, giving what I can, doing what I can so that someday dystonia will be a word everyone knows and researchers get the much needed funding to find a cure.”*

### KEEP IN TOUCH

DO YOU HAVE QUESTIONS? CONCERNS?  
DO YOU WANT TO GET MORE INVOLVED?  
HERE'S HOW TO REACH US.

Visit our website at [www.dystoniacanada.org](http://www.dystoniacanada.org).  
To get support or to make a donation by phone  
call: 1-800-361-8061.

DYSTONIA  
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FONDATION DE  
RECHERCHE  
MÉDICALE SUR LA  
DYSTONIE  
CANADA

*serving all dystonia-affected persons  
déservant toutes personnes atteintes de dystonie*

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