



Dystonia Medical Research Foundation Canada
Calgary Symposium
September 16, 2018

THANK YOU TO OUR GENEROUS SPONSORS!



ABOUT THE DMRF CANADA

- The DMRF Canada is a national charitable organization that was established in 1976.
- We are a volunteer led organization (with over 30 Group Leaders or Area Contacts), two full time staff, and a variety of interns, and dedicated volunteers.
- We are accountable to a ten-person Board of Directors.



ABOUT THE DMRF CANADA



- 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.



2018 VISION AND BEYOND: EMPOWER DYSTONIA PATIENTS IN CANADA



We have a vision – to strengthen the voice of dystonia patients in Canada. Give patients and their caregivers the support, education, and confidence to act as advocates for themselves and the disorder.

- **Build awareness of dystonia** to the general population and to the front line health care population,
- **Build confidence in DMRF Canada** within the dystonia community in Canada so that patients know that they have a relevant, credible organization who has their best interests at heart;
- **Give patients the education, tools and information** they need to be aware of all of their health care options
- Provide ways for **patients to act as advocates for the DMRF Canada and dystonia** in general.

RESEARCH: 2018 AND BEYOND

- **88% of Patients confirmed they would be interested in learning more about changes in research and available treatments.**
- DMRF's globally-focused "Science Portfolio", is 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.
- This proven formula for research progress includes a \$10 Million investment in science over the last decade alone.

RESEARCH: 2018 AND BEYOND



- **DMRF Research Program** – General Research Fund or Specific Projects. Currently Funding Year Two of Dr. Hutchison DBS Research Project.
- **Partnership with Banting Research Foundation:** Co-Funding of Dystonia Project with Dr. . Nomazulu Dlamini, MD PhD. Neurology, from the Hospital for Sick Children.
- **NEW: First Clinical Fellowship in Dystonia:** Launched in 2017, and continued in 2018 with addition of Research Component (to launch again in September 2018);
- **NEW: Launch of new Research Pilot Project in Fall 2018**

PATIENT SUPPORT



- Dystonia Patient Survey (and Survey Report) – Patients are Not Getting the Help They Need
- Increased focus on a variety of treatment methods – dystonia patient protocols based on patient needs.
 - Investment in research in this area
- Priorities:
 - Articles and Presentations Focused on Pain and Pain Management;
 - Focus on Anxiety and Depression, Focus on Financial Stress, Sleeping (Future – 2019)

PATIENT SUPPORT

PATIENTS ARE NOT GETTING THE HELP THEY NEED

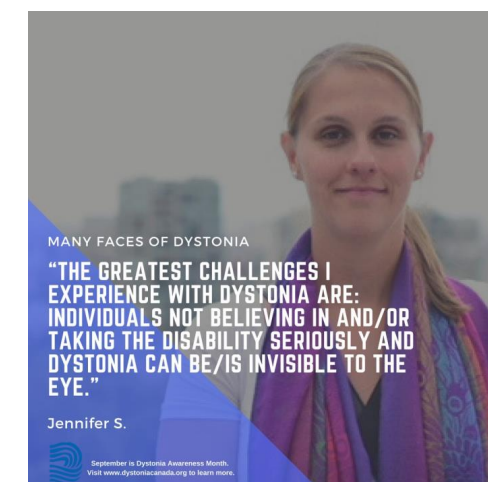


Programs to Bring the Community Together, to Educate and Empower – Encourage them to Advocate for Themselves

- **Support of over 30 Local Support Groups Across the Country:**
 - This could be local contacts getting together once a year, or groups that meet regularly.
 - Online support via DMRF Canada operated channels (Facebook, Twitter, Instagram)
 - IF YOU WANT TO START A GROUP LET US KNOW!
- **Opportunities for Education and Learning to Empower Patients:**
 - Calgary Symposium (Sept 15/16) – will be videotaped and shared with the broader audience
 - Montreal Symposium (French, September 8)

AWARENESS AND EDUCATION PROGRAMS

- Informational Literature (brochures, patient support materials, website, social)
- Dystonia Awareness Month (September 2018)
 - Social Media Campaigns
 - The Many Faces of Dystonia Campaign
 - Grassroots, Social Media
 - Lighting Up Landmarks Blue and White





MANY FACES OF DYSTONIA

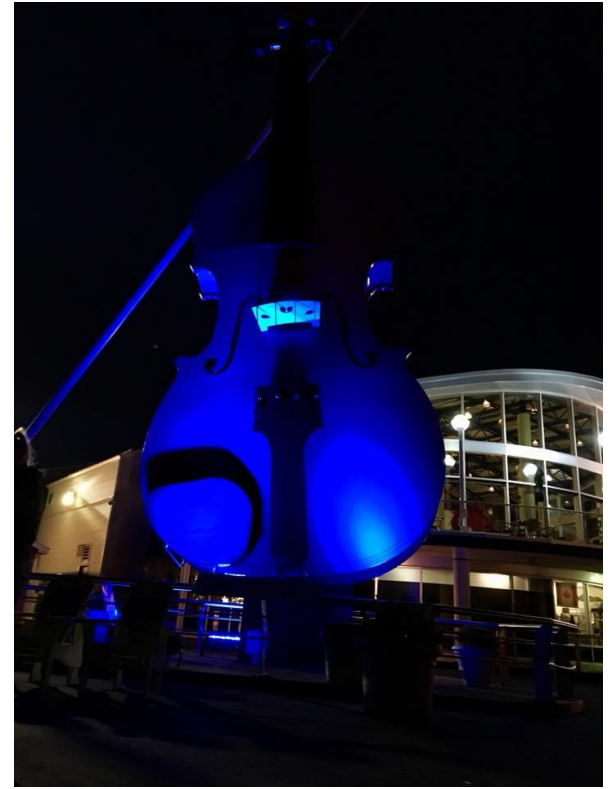
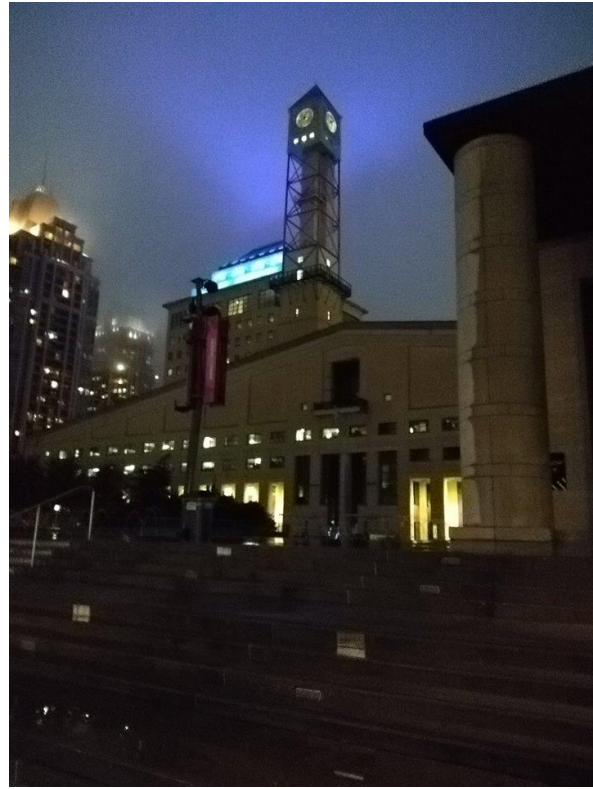
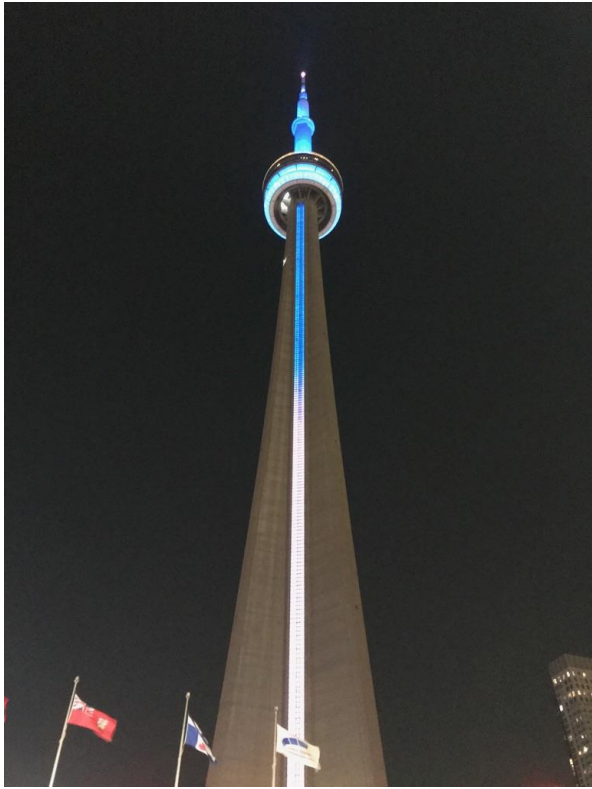
**“OVER THE LAST 8 AND A HALF YEARS I
HAVE LEARNT NOT TO FIGHT MY
DYSTONIA BUT INSTEAD ACCEPT THE
CHALLENGE THAT I FACE EVERY DAY”**

Shelby



September is Dystonia Awareness Month.
Visit www.dystoniacanada.org to learn more.

**SEPTEMBER IS
DYSTONIA
AWARENESS
MONTH!**



LANDMARKS LIT UP IN BLUE
#DYSTONIAAWARENESS

MANY FACES OF DYSTONIA

“OVER THE LAST 8 AND A HALF YEARS I HAVE LEARNT NOT TO FIGHT MY DYSTONIA BUT INSTEAD ACCEPT THE CHALLENGE THAT I FACE EVERY DAY”

Shelby Newkirk
Canadian Para Swimmer
Paralympic hopeful for Tokyo 2020
Two time World Record Holder

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MANY FACES OF DYSTONIA

“I TRY MY BEST NOT TO LET DYSTONIA DEFINE WHO I AM. IT WAS A LONG ROAD TO A DIAGNOSIS OF BLEPHAROSPASMS. STAY STRONG FELLOW SUFFERERS. EDUCATION IS OUR BEST WEAPON.”

Harriet B.

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MANY FACES OF DYSTONIA

“THE GREATEST CHALLENGES I EXPERIENCE WITH DYSTONIA ARE: INDIVIDUALS NOT BELIEVING IN AND/OR TAKING THE DISABILITY SERIOUSLY AND DYSTONIA CAN BE/IS INVISIBLE TO THE EYE.”

Jennifer S.

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MANY FACES OF DYSTONIA

“DYSTONIA ONCE CONVINCED ME I COULD NOT DEFEY THE STORM, WELL TODAY I RESPOND WITH I AM THE STORM AND I WILL CONTINUE TO DIFY DYSTONIA.”

Casey K.

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FACES OF DYSTONIA CAMPAIGN #FACESOFDYSTONIA

THANK YOU FOR BEING SUCH A STRONG, VIBRANT,
PASSIONATE COMMUNITY
WE ARE STRONGER TOGETHER

*"With research and time we will
beat this crippling disease"*

"I will overcome this disorder somehow..."

*"Thank-you for showing interest in a
condition that I often say I would not
wish on my worst enemy."*