



Dystonia Medical Research Foundation Canada  
*2017 Highlights and Updates*

# ABOUT THE DMRF CANADA

- The DMRF Canada is a national charitable organization that was established in 1976 by Sam and Fran Belzberg, after their daughter was diagnosed with dystonia.
- The DMRF Canada is dedicated to supporting individuals (and their families) who suffer from dystonia, a neurological movement disorder.
- 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.
- We are a volunteer led organization, accountable to an nine-person Board of Directors.
- We are national in scope, but based in Toronto with two full-time staff.



## ABOUT THE DMRF CANADA

- The Dystonia Medical Research Foundation has existed in North America for over 40 years, with two offices – one in Toronto and one in Chicago;
- It is more than a non-profit organization intent on curing dystonia; the DMRF represents a community of people who understand and welcome each other.
- The strength of this organization is rooted in the volunteers who contribute their time and energy to building a brighter future for those touched by dystonia and creating opportunities to bring the community together (like this!);
- DMRF Canada is a small office of three staff based in Toronto. We work very closely with the DMRF who are based in Chicago – but we are dedicated to doing more for the dystonia population in Canada.

# VISION: 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, to reduce the length it takes for a dystonia patient to obtain a proper diagnosis;
- **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 and alternatives to their current treatment;
- **Provide ways for patients to act as advocates for the DMRF Canada and dystonia in general.** Encourage them to raise awareness of the disorder within their own lives and communities through educational events and community activities.

## WHAT WE HAVE ACCOMPLISHED

- In the past several years, 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.
- 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.

# WHAT WE HAVE ACCOMPLISHED

- This proven formula for research progress includes a \$10 Million investment in science over the last decade alone.
- Put simply, the most significant scientific advancements and discoveries in dystonia would not have been possible without the DMRF or without the research environment we built over the last four decades.
- Scientific advancement in dystonia is possible due to the tremendous support we have received and the research environment the Foundation has build over decades, with over \$10 million dollars invested in research to date.

# WHAT WE ARE DOING IN CANADA



- **Recently, we announced the launch of the first ever Clinical Fellowship for Movement Disorders with a Focus on Dystonia.**
  - Why Is This Program So Critical? Individuals with dystonia continue to report difficulty finding physicians trained in movement disorders. Or they may wait months (or even years) before an appointment opening.
  - DMRF Canada is responding to the urgent need for additional movement disorder specialists by offering this program.
  - There is an urgent need for training additional movement disorder experts in dystonia through clinical fellowships.
  - Evaluation by a movement disorder neurologist can make a significant difference in terms of the treatment options available to dystonia patients and benefit from the treatment.

# WHAT WE ARE DOING IN CANADA

- **This year, DMRF made a commitment to fund research taking place, right here in Canada (two-year funding commitment).**
  - Why Is This So Important? Our policy has always been to fund the best and brightest researchers – not just those researchers who are in Canada. The fact that this program happened to be run out of a Canadian hospital speaks to the level of expertise in movement disorders in Canada.
  - Dr. William Hutchison (Toronto Western Hospital) is investigating how Deep Brain Stimulation works and why it works.
  - We know that it is effective treatment, but we don't understand the mechanisms. This study seeks to better understand how and why DBS works by investigating cell activity in neurosurgical target sites in the brain.
  - The goal of this research is to gain insight into the mechanisms of tremor and dystonia, and possibly translate this knowledge to develop new targets for drug treatment.



# WHAT WE ARE DOING IN CANADA

- **New Support Programs Launched for Dystonia Patients**
- Jackson Mooney Patient Grant was established to provide financial assistance of up to \$5,000.00 for Canadian residents who are living with dystonia, in financial need and committed to enhancing their current situation through furthering their education.
  - Last month, DMRF awarded the first ever Dystonia Patient Grant to Neil Merovitch.
  - Neil was diagnosed with Cervical Dystonia at the age of 7, and later his diagnosis become generalized dystonia.
  - Neil completed his undergraduate degree at the University of Dalhousie and Neil is currently completing the first year of his PhD in molecular genetics at the University of Toronto.

# WHAT WE ARE DOING IN CANADA



- **New Support Programs Launched for Dystonia Patients**
- We recently launched the Dystonia Parent Support Group in Canada.
  - There will be many projects rolled out as part of this initiative, including the development of several research guides, for parents of children with dystonia, as well as for teens.
  - We have launched a Facebook Group for parents who have children with dystonia in Canada.