

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

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



Dystonia Research at Work

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.

Visit dystoniacanada.org/researchforcure to learn about the latest dystonia research and treatments.

In the summer of 1995, my nine-year old son Laurie was once again busy on the soccer field with the neighbourhood boys. One evening my friend Dan and I noticed that he was running differently...on his toes. Dan dubbed Laurie 'the antelope', for his high, graceful stride. His new running style was not however the result of Laurie's determination to be faster, but born out of an inability to lay his foot squarely on the ground. With each step, his toes curled, and his right foot turned in.

His symptoms were not the result of an athletic injury as we first suspected, but the beginnings of a neurological movement disorder named dystonia. Over the next two years, armed only with a diagnosis, we watched our perfect athlete lose muscle control rapidly in his right hand, right leg, and left leg.

By age 11, Laurie was using a wheelchair.

In two years, we learned all that we could about dystonia. We learned that it is a neurological movement disorder, affecting many or single muscle groups in the body. In its generalized and often severe form, it strikes in childhood, but can also affect grown men and women. We learned that there were treatments, but no cure and the course of the disease is unpredictable. We also learned, sadly, that Laurie's form of dystonia was genetic, though there are forms that are not.

Through this difficult period, we were given information, support and reassurance from the Dystonia Medical Research Foundation (DMRF), an organization that was founded by two Canadians - Frances and Samuel Belzberg of Vancouver started the Foundation after their daughter, Cheri, was diagnosed with dystonia. At the time of her diagnosis, there was no information available, so the DMRF was founded to assist their daughter, and many other families like them, to cope and to find a cure.

Now, 40 years after the Belzberg's launched the Foundation, there are two offices; one in Chicago and one in Toronto. Over \$10 million dollars have been invested into research to date, and many incredible discoveries have taken place along the way.

Sadly, we have not yet found a cure for this devastating disorder.

The DYT1 gene was discovered in 1997; two years after my son's onset of dystonia. We had Laurie tested and he did indeed have the gene. I started to query whether other family members had also suffered with dystonia, but were undiagnosed. I remembered my great aunt, who was very physically disabled, unable to control her limbs and speak clearly. We thought she had cerebral palsy, but it was dystonia. My uncle had developed a lifelong problem with his right hand at 12, which made it impossible for him to write or throw a ball. It too, was undiagnosed dystonia.

Knowing that this disorder can affect a family so unfairly makes me more determined than ever to bring people together to find a cure for DYT1 dystonia, and all dystonias. This genetic connection means that there are other young families out there who are also desperate for a cure.

Please consider supporting this important research by giving a gift to DMRF today.

My son Laurie, now 31 years old and just married, has a 50% chance of passing the gene onto his children. Because of the research programs supported and funded by DMRF, there are now ways to conduct tests and determine whether the gene is passed on. Dystonia will end in my family, because of these amazing advances.

Coping with a child's illness is a parent's worst nightmare. During those first few years, our lifeline was the DMRF. The Belzberg's, DMRF Canada Staff, and countless patients, Doctors, and volunteers work every day to support the dystonia community and to fund research with an objective to never give up until they find a cure. I am proud to be part of this wonderful team as a Director on the DMRF Canada Board of Directors and do all that I can to change the future for many young families in Canada struggling with this disorder.

Sincerely,

Laurie's Mother