

## Dystonia Medical Research Foundation Canada



## TABLE OF CONTENTS

*Enclosed please find an overview of the various tools DMRF Canada has collected to help you in your mission to spread the word about dystonia to your local community.*

<b>TOOL</b>	<b>TOPIC</b>	<b>PAGES</b>
Fact Sheet	About Dystonia	Page 2 – 4
Fact Sheet	About DMRF Canada	Page 5 & 6
Matte Story <i>(to be placed in community paper)</i>	Dystonia Story to be provided to Media (Sarah's Story)	Page 7 & 8
Support Group Promotion	Promotion of DMRF Local Support Group	Page 9
Promotional Blurb	Radio announcement	Page 10
Online Promotional Materials		Page 11 & 12
Sample	Appendix A: Sizing for Advertisements	Page 13
Sample	Appendix B: Sample Advertisements used in the past	Page 14

## ABOUT DYSTONIA

### WHAT IS DYSTONIA?

- Dystonia is a neurological movement disorder that is characterised by involuntary muscle contractions, which force parts of the body into abnormal as well as painful movements or positions.
- It is a condition that knows no age, ethnic or racial boundaries – it can affect young children to older adults of all races and ethnicities.
- We estimate that 50,000 people in Canada have dystonia. Dystonia is the third most common movement disorder following essential tremor and Parkinson’s disease.
- Patients with dystonia may experience uncontrollable twisting, repetitive movements or abnormal postures and positions. These can affect any part of the body, including the arms, legs, trunk, face and vocal cords.

### WHAT ARE THE FORMS OF DYSTONIA?

- There are many different forms of dystonia. And dozens of diseases and conditions also include dystonia as a major symptom.
- Some dystonias impact one body part (for example the face, neck, hands or feet), while other dystonia’s impact may be generalized throughout multiple muscle groups.
- Dystonia may be genetic or result from other health conditions such as stroke, physical trauma, other diseases, or as a side effect of certain medications.

### WHAT ARE THE SYMPTOMS OF DYSTONIA?

- Those with dystonia will experience muscle contractions, muscle twisting and uncontrollable, involuntary spasms that can be very painful.
- Symptoms of dystonia are usually chronic but may also appear only during “attacks” or episodes.

*(Continued)*

## WHAT ARE THE BIGGEST CHALLENGES FOR DYSTONIA PATIENTS?

- The Dystonia Medical Research Foundation Canada conducted a survey last year to answer this very question (*see Real Patients, Real Answers, published in 2017*). We analysed the results and found:
- One of the biggest challenges for a person who has dystonia includes the time it takes to get a proper diagnosis, due to low awareness in general and even within the medical community. In many cases it takes years for someone who is suffering from dystonia to be properly diagnosed.
  - This is due to low awareness as well as the fact that there are a limited number of physicians who are familiar and well versed with dystonia.
  - Another challenge is that individuals who dystonia continue report difficulty finding physicians trained in movement disorders. Or they may have to wait months, or even years before an appointment to get treated.
  - Early this year (February 2018), DMRF Canada announced the first ever Fellow for a Clinical Fellowship in Movement Disorders with a Specialty in Dystonia. The goal of this program is to encourage growth and support of the field of movement disorders in Canada, with a focus on dystonia to support dystonia patients
- In the survey, we specifically asked the question, what is the biggest challenge you experience with your dystonia? The answers were very similar: depression, social anxiety, dealing with pain, having to give up their old life, having to quit work because of their dystonia, mobility.
- There is no known cure for dystonia and both treatment methods and specialists operating in the space are quite limited.

## WHAT ARE THE DIFFERENT TYPES OF DYSTONIA

- Physicians have developed a system to classify dystonia to help guide the treatment process:
  - The term primary dystonia is used to describe a case in which the dystonia is the predominant symptom, and the person is not affected by other neurological conditions.

- Secondary dystonia refers to dystonia that is associated with a known outside factor or condition (such as trauma, drug exposure, stroke, cerebral palsy, and others).

## WHAT ARE THE TREATMENTS?

- There is no cure for dystonia, but treatments are available. Most therapies are symptomatic, attempting to cover up or release the dystonia spasms; therefore, there is no single treatment program appropriate for every case.
- Treatments available include: drug therapy, botulinum toxin injections, surgery and complementary therapies.
- Botulinum Neurotoxin Therapy can be a very good therapy for focal dystonia, but it is masking the symptoms rather than curing the dystonia. Patients would have to continue to go into see a specialist for injections.
- In most cases, the type of doctor who is typically trained to diagnose and treat dystonia is a movement disorder neurologist. The most important step in treating dystonia is working with a doctor who is trained to treat dystonia.

For more information about the Dystonia Medical Research Foundation Canada, please visit: [www.dystoniacanada.org](http://www.dystoniacanada.org)

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EMAIL [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

## ABOUT THE DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

- The Dystonia Medical Research Foundation Canada is the only organization that is dedicated to supporting the 50,000 patients in Canada that are suffering from dystonia.
- We are a registered Canadian charity that was founded in 1976 by Sam and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia.
- The mission of the Dystonia Medical Research Foundation (DMRF) Canada is threefold:
  - To advance research for more treatments and ultimately a cure for dystonia;
  - to promote awareness and education;
  - to support the needs and well-being of affected individuals and families.

## OUR WORK

### **RESEARCH INTO BETTER TREATMENTS AND A CURE FOR DYSTONIA:**

- The Dystonia Medical Research Foundation Canada works in partnership with the Dystonia Medical Research Foundation based in the United States to ensure funding of the best and most relevant dystonia medical research worldwide, as well as with other like-minded organizations based in Canada.
- This year we awarded the first ever Clinical Fellowship for Movement Disorders with a speciality in Dystonia to Dr. Karlo Lizarraga from Toronto Western Hospital. Read the press release (Feb 2018) here:  
<http://www.dystoniacanada.org/clinicalfellowshipannouncement>
- We've also invested in a two-year Research Grant taking place at Toronto Western Hospital.
  - Dr. William Hutchison is investigating why deep brain stimulation works for dystonia treatment. The goal is to gain insight into the mechanisms of tremor and dystonia. The researchers hope to possibly translate this knowledge to develop new targets for pharmacological intervention. The goal is to gain insight into the mechanisms of tremor and dystonia. The researchers hope to possibly translate this knowledge to develop new targets for pharmacological intervention.
  - Read more about this study at: <http://www.dystoniacanada.org/dmrf-canada-fund-research-here-canada-tremor-ocillations-synaptic-plasticity-and-dbs-for-dystonia>

**EDUCATION AND AWARENESS:**

- DMRF Canada works with volunteers, medical professionals (neurologists, movement disorder clinics), and the media to raise awareness of dystonia in a variety of ways: through two printed newsletters, online updates, social media, media relations activities, events and activities at local community meetings, hospitals throughout the country.

**SUPPORT THE NEEDS AND WELL-BEING OF AFFECTED INDIVIDUALS AND FAMILIES:**

- There are approximately 40 Group Leaders and Area Contacts representing 33 areas across the country. The purpose of these groups is to provide support, guidance and options to those individuals (and their families) who suffer from dystonia.
- If you or someone you know is struggling with dystonia – or if you are looking for more information, contact the Dystonia Medical Research Foundation Canada at: [www.dystoniacanada.org](http://www.dystoniacanada.org) or 1-800-361-8061.

## DYSTONIA MATTE STORY: FOR PLACEMENT IN COMMUNITY PAPERS

### My Life with Dystonia: Sarah Anderson, Dystonia Medical Research Foundation Canada Ambassador

***50,000 patients in Canada suffer from dystonia, a neurological movement disorder that affects the nervous system. Abnormal signalling from the brain causes muscles to tighten and twist involuntarily. There are several forms of dystonia, and dystonia may be a symptom of many diseases and conditions.***

My journey with dystonia, though unknown at the time, began the very day I entered the world. As part of a complicated birth, I was born not breathing and for the first several minutes of my life doctors worked hard to clear my lungs. After an extended period, they were finally successful. However, it was a happy moment that would soon be accompanied by some life-changing news. Just days after my birth, doctors informed my parents that I had suffered brain damage due to a lack of oxygen. My official diagnosis was cerebral palsy (CP), a non-progressive condition characterized by impaired muscle coordination and potential cognitive challenges. The only symptom that initially led doctors to believe I had CP was the fact that my left hand was clenched tightly to my chest. As an infant, some of my milestones were either delayed or never met, which seemed to prove the accuracy of my diagnosis.

It was not until my pre-teen years that I, along with my family, noticed significant changes in my symptoms and abilities. I could no longer use a walker, something that I had been capable of since I was a toddler. In addition, my tremors progressed throughout my body and my legs started twisting to the left. These worsening symptoms convinced doctors to change my diagnosis to generalized dystonia. With this new discovery, I embarked on a medical journey exploring a variety of medications in hopes to reduce and control the associated symptoms and pain. This was all new to me, as for the first 12 years of my life I had never taken medication in relation to my disability.

Being a pre-teen at the time, I must admit that I was more concerned about the future than I was about the present. One of the first questions I asked my doctor was, "How fast are my symptoms going to progress?" He responded that every case is different so there is really no way of predicting the future. Though I deeply craved a more promising response, I knew that I had to accept that some answers are only revealed with the passing of time.



At that point, I also couldn't help but wonder if my dreams for the future were realistic. Despite living with a disability, I was always that typical child who wanted to grow up and attend university, pursue a career, and one day have a family. With that in mind, my first major goal was to graduate high school at age 18. However, the pain associated with my dystonia hampered my ability to attend school full-time. Suddenly, it seemed like the task that I once saw as achievable was now slipping from my reach. Knowing my desire to succeed academically, in my seventh year some adaptations were set in place with the help of my family and my school. Through working on assignments at school as well as at home, I was able to keep up with the course material.

Although I still cannot attend school full-time, I am currently a grade 12 honour roll student on track to graduate at the end of the school year. In an effort to further my passion for academics, I plan to attend university and pursue a career in education. As a small step toward this goal, I enjoy volunteering at the Manitoba Children's Museum. Through my dystonia diagnosis, I have also realized the importance of advocacy. We all have a voice, and we have the power to change lives.

If there was one thing I could say to other teens living with dystonia or any other rare disease, it would be to never give up on your goals. We may not always have control over our symptoms, but how we choose to live with them will forever remain in our hands. Always remember that whether positive or negative, every aspect of our lives helps to guide us on a journey to become who we are truly meant to be.

The Dystonia Medical Research Foundation (DMRF) Canada is the only organization that is dedicated to supporting the dystonia community in Canada. If you or someone you know is struggling with dystonia, you're not alone. Please visit [www.dystoniacanada.org](http://www.dystoniacanada.org) to find out about resources, research, and support.



***More Photos of Sarah Available upon Request.***

## **PROMOTIONAL BLURB**

### **FOR DYSTONIA MEDICAL RESEARCH FOUNDATION LOCAL SUPPORT GROUP**

Dystonia is a neurological movement disorder characterized by involuntary muscle contractions, which force certain parts of the body into abnormal, sometimes painful movements or postures.

Dystonia can affect any part of the body including the arms and legs, trunk, neck, eyelids, face or vocal cords.

It is the third most common movement disorder after Parkinson's disease and Tremor, affecting more than 300,000 people in North America.

Dystonia does not discriminate – affecting all races and ethnic groups.

#### **IF YOU HAVE DYSTONIA YOU ARE NOT ALONE**

**Join Us!**

**The (name of) Dystonia Support Group Is Here To Help You**

**Email: @ or Call**

## PROMOTIONAL BLURB

### 30 Second Radio Spot

Dystonia is a neurological movement disorder impacting over 50,000 people in Canada.

The Dystonia Medical Research Foundation was created over 40 years ago to fund better treatments, and ultimately a cure, and to provide education and support to dystonia patients and their families across Canada.

If you think you have dystonia or you're looking to support, visit [dystoniacanada.org](http://dystoniacanada.org) to learn about the treatments and supports available to you.

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## ONLINE PROMOTIONAL MATERIALS:

### ALL AVAILABLE UPON REQUEST

1. Here is what your gift will do:

#### 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.

2. Join Our Movement to Change the World for Dystonia Patients  
(with link to donate page)

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.

### 3. About Us – larger advertisement that talks about the work we do:



**The Dystonia Medical Research Foundation was founded by a family blindsided by Dystonia and eager for answers. 40+ year later, The DMRF Canada represents a community of families bonded by Dystonia and working together for the greater good.**



**Research:** We support research projects while acting as a catalyst to grow the field of dystonia research. We aim to address the most pressing unresolved questions in dystonia by working with researches and collaborators from all over the world.



**Community and Support:** We reduce social isolation of patients and families by offering peer-to-peer support programs that help patients and families connect with one another.



**Awareness and Education:** We offer awareness and education programs to improve timely diagnosis, improve societal understanding of dystonia, and further the Foundation's mission.



**Advocacy:** We work to improve quality of life for those affected by dystonia by educating elected officials on dystonia and the needs of the dystonia community. Working with Neurological Health Charities Canada, the DMRF Canada is one of over 15 neurological charities working to advocate the Canadian Government to support an action plan for the brain.



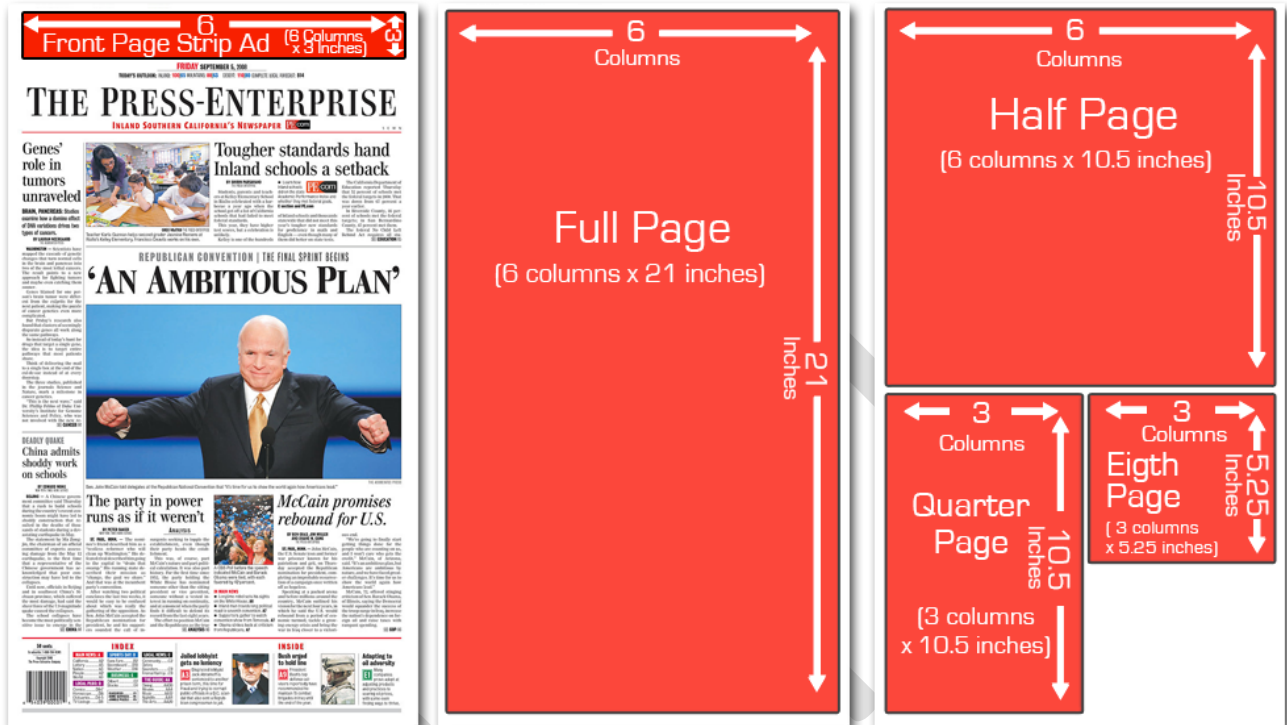
**Partnerships:** We partner with pharmaceutical companies, local healthcare providers, and government agencies to support the dystonia community.



**VISIT**  
**WWW.DYSTONIANCANADA.ORG**  
**FOR MORE INFORMATION.**

**CHARITABLE REGISTRATION #:**  
**12661 6598 RR0001**

## Appendix A: Advertisements



**Front Page Strip Ad**  
 (6 Columns x 3 inches)

**THE PRESS-ENTERPRISE**  
 INLAND SOUTHERN CALIFORNIA'S NEWSPAPER

**Genes' role in tumors unraveled**

**Tougher standards hand Inland schools a setback**

**REPUBLICAN CONVENTION: THE FINAL SPRINT BEGINS**

**'AN AMBITIOUS PLAN'**

**McCain promises rebound for U.S.**

**China admits shoddy work on schools**

**The party in power runs as if it weren't**

**INDEX**

**INSIDE**

**Back-splung to hold line**

**Adapting to all adversity**

**Full Page**  
 (6 columns x 21 inches)

**Half Page**  
 (6 columns x 10.5 inches)

**Quarter Page**  
 (3 columns x 10.5 inches)

**Eighth Page**  
 (3 columns x 5.25 inches)




## APPENDIX B: Quarter page Newspaper/Magazine Advertisement used in the past:

*What is Dystonia?*

Dystonia is a neurological movement disorder characterized by involuntary muscle contractions, which force certain parts of the body into abnormal, sometimes painful, movements or postures. Dystonia can affect any part of the body including the arms and legs, trunk, neck, eyelids, face, or vocal cords.

**Call 749-7401**  
<http://www.dystonia-foundation.org>



**DYSTONIA**

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OTTAWA CITIZEN   Habitat for Humanity   SAAB SALON SPA   ARC THE HOTEL

Buy online and save \$2 [ottawahomeshow.com](http://ottawahomeshow.com)

*What is Dystonia?*

“Dystonia is a neurological disease that results in uncontrolled muscle spasms”.

**Call 613-749-7401**  
<http://www.dystonia-foundation.org>



**DYSTONIA**

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