Dr. Martin J. McKeown and Dr. Joseph K.C. Tsui at the Vancouver General Hospital presentation of the movie Twisted
DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA

The Dystonia Medical Research Foundation Canada (DMRFC) is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRFC funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families. DMRFC Canada works in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partners with the Canadian Institute of Health Research (CIHR) in funding excellent dystonia research in Canada.

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Canadian Donations should be sent to:
Dystonia Medical Research Foundation Canada
121 Richmond St. W. Suite 305
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It is the editorial policy to report on developments regarding all types of dystonia but not to endorse any of the drugs or treatments discussed. We urge you to consult with your own physician about procedures mentioned.

A Message from the Executive Director

More and more the Dystonia Medical Research Foundation Canada, looks to the community at large to help raise the funds so vitally necessary to our on-going funding of dystonia research.

Because of the generosity of our donors, we have been able to significantly improve the lives of individuals with dystonia and provide help to families at a time when they need it the most. We are reaching more people than ever before through support groups, online networks and education events. These programs successfully help the newly diagnosed and the physicians who treat them.

In 2012, DMRF Canada partnered with the DMRF’s aggressive million-dollar research project to identify drug targets related to a specific gene and protein implicated in dystonia. This is the first step in developing new treatments. The DMRF is on course to finding new medicines specifically designed to treat dystonia. And, right here at home in Canada, DMRF Canada works with the Canadian Institutes of Health Research in funding fellowships for the brightest new minds in dystonia research.

DMRF Canada is proud of the growth of its research funding program. But we need your help!

We are appealing to you to please make a gift to the Foundation and move us closer to our goal – a future free from dystonia. We invite you to contact us for information on how you can join a support group, fundraise in your community, learn more about dystonia, or to order awareness materials about dystonia.

As always, a very special thank you goes out to all our volunteers across the country who dedicate their time to help people with dystonia. To learn more about some of the activities of our support groups please refer to pages 13 & 14 in this newsletter.

Sincerely,

Diane Gillespie, Executive Director
The Medtronic Foundation has granted the funds to screen the movie Twisted in major centres across Canada. To date, DMRF Canada has held and supported screenings of the award winning documentary in Halifax, Ottawa/Gatineau, Toronto, Waterloo, Winnipeg, Edmonton, Calgary, and Vancouver.

**Vancouver General Hospital, Vancouver, BC**

On January 26, 2012, Martin J. McKeown, BEng, MD, FRCP(C), Professor of Medicine (Neurology) presented and moderated Twisted at the Gordon and Leslie Diamond Health Care Centre Lecture Theatre, Vancouver General Hospital. The panel consisted of Dr. McKeown, Silke Appel Cresswell, MD and Joseph K.C. Tsui, MBBS, MRCP, FRCP(C).

**Toronto Western Hospital, Toronto, Ontario**

On April 2, 2012 in partnership with Toronto Western Hospital and Medtronic, the move Twisted was screened at Toronto Western to an audience of close to 100 people. Dr. Richard Walsh MD, FRCSC, Wendy Paul, DMRF Canada Toronto Chapter President and Diane Gillespie, Executive Director, DMRF Canada participated in the panel discussions with the audience. Special thanks to Miu Lin Wong, MEd, RSSW, Community Health Educator/ Health Promoter Patient and Family Library, Women’s Health Initiative, and Family Health Team for organizing this screening.

**Dystonia in Children and Adolescents Information Forum**

On Saturday, May 5, DMRF Canada in partnership with Sick Kids Hospital and Medtronic Foundation hosted a very successful Children and Adolescents Dystonia Forum in Toronto with over 60 people in attendance. Dr. Teesta Soman, neurologist and Director of the pediatric Movement Disorders Clinic at Sick Kids was the moderator for the forum and provided the opening session topic What is Dystonia.

Joining Dr. Soman were Dr. William Logan, Senior Staff Neurologist, the Hospital for Sick Children, Medical Management of Dystonia; Dr. Robert Chen, Catherine Manson Chair in Movement Disorders, Transcranial Magnetic Stimulation as a Research tool and as a Potential Treatment for Dystonia; our own Connie Zalmanowitz, DMRF Canada Board Member, Speech Language Pathologist, Glenrose Rehabilitation Hospital, Connie’s son Laurie Zalmanowitz, Student, University of Western Ontario, M.ED Counselling Psychology, gave very moving and inspiring presentations on living with dystonia from both a parent perspective and patient perspective; Dr. Anne Kawamura, Director, Developmental Paediatrics, Holland Bloorview Kids Rehabilitation Hospital, Botulinum Toxin A for Dystonia in Children; and Dr. Scellig Stone, senior Neurosurgery Resident, University of Toronto, Functional neurosurgery for dystonia.

All of the presentations were highly informative and well received.
What’s Going On in Dystonia Research?
Progress Continues in Treatments, Gene Discovery & Advancing the Science

In the last quarter of each year, the DMRF in the United States invites investigators to submit applications for dystonia research funding. Recent grant cycles have generated more proposals than ever before, and the field of dystonia has never been more active. There are numerous reasons to feel inspired and hopeful about how research is progressing.

Greater Interest from Researchers
More investigators and clinicians are interested in dystonia, participating in the research, and joining the effort to find better treatments and a cure. Commenting on the 5th International Dystonia Symposium in late 2011, DMRF Science Officer Jan Teller, MA, PhD acknowledges some of the challenges of advancing research for a rare disorder like dystonia: “I would periodically get this uneasy feeling,” he explains, “that dystonia would be perpetually overshadowed by the ‘big’ neurological diseases—that research on dystonia was too scattered across the globe, across different institutions, that there was not enough momentum. But I was wrong.” The Symposium represented the latest in a series of international dystonia meetings organized by the DMRF since 1975. The meeting attracted 560 dystonia clinicians and researchers from 38 countries – unprecedented numbers. The interest is so great that the DMRF is considering organizing the next Symposium in 2015.

Pursuing Drug Targets
The DMRF is working with BioFocus, a biotechnology company, to identify new drug targets. These efforts may ultimately lead to a whole new generation of dystonia therapies that interrupt or alleviate dystonia at the cellular level. The project has successfully progressed through the first two stages, identifying several potential targets. While no one cannot predict where these results will lead, this development is very encouraging. The next step is to validate and confirm the preliminary data. The DMRF is partnering with Tyler’s Hope for a Dystonia Cure in this effort. (DMRF Canada partnered in this project in 2012.)

Every Dystonia Gene is a Potential Therapeutic Target
Over 20 genes or gene markers are associated with certain forms of dystonia, and advancing technology is leading to new genes being discovered at a rapid rate. Every time a gene is associated with dystonia (there are currently 12), this provides an important clue about how dystonia impacts the nervous system and may ultimately lead to symptoms. Each gene discovery provides a protein that is a potential new therapeutic target. Every therapeutic target is one step closer to a brand new approach to treatment.

New Stimulation Methods
In addition to deep brain stimulation, other therapeutic stimulation methods such as cerebellar and premotor cortical stimulation are under investigation. This is the direct result of a growing understanding of how specific brain areas are involved in dystonia. “None of us think of dystonia as just a basal ganglia disorder anymore,” explains Scientific Director Mahlon DeLong, MD of Emory University School of Medicine. “Dystonia is a network disorder – much more complex.” Research is demonstrating that in addition to the basal ganglia, other areas of the brain are implicated in many cases of dystonia including the cerebellum, motor cortex, thalamus, and corpus callosum. Each of these brain structures represents an area for investigating new therapeutic approaches, and simultaneous advances in neurostimulation are presenting opportunities for less invasive techniques.
Making Treatments Work for More People
Research is not solely focused on discovering new treatments. There is a widespread effort among clinicians to make existing treatments benefit greater numbers of patients. Meticulous attention is being paid to how patients respond—and why some respond better than others—to certain medications, botulinum neurotoxin injections, deep brain stimulation, and other methods. There are ongoing studies aimed at minimizing side effects of medications, and a greater selection of botulinum neurotoxin products available. Deep brain stimulation is gradually and conscientiously being applied to treat not only primary generalized dystonias but also secondary dystonias, certain focal dystonias, and others with positive results.

Next Generation of Dystonia Leaders
The DMRF is committed to helping young investigators establish and pursue careers in dystonia. Dr. Teller explains: “Young investigators are critical to the future of the field by providing fresh ideas and new initiatives that lead to important discoveries.” The DMRF creates numerous opportunities—through research funding and scientific meetings—for young investigators to interact with established dystonia experts who often become role models and source of continuous inspiration.

Few things are more important to living well with dystonia than a knowledgeable doctor who is trained in movement disorders.

The DMRF is fostering the next generation of dystonia clinicians by offering one-year fellowships to support clinical training of physicians in preparation for a career in movement disorders with special focus on dystonia. The training is patient-oriented and includes hands-on experience in clinics as well as participation in professional meetings and workshops. The inaugural year of the Clinical Fellowship Program was made possible by a grant from Merz Pharmaceuticals. In the second year of the program funding will be provided by both Ipsen Biopharmaceuticals and Merz Pharmaceuticals.

From Research to Real Life
Dystonia science efforts aim at improving people’s lives, both in terms of individual treatment and overall quality of life. Two projects that are part of the Dystonia Coalition involve establishing rating scales that measure dystonia symptoms, one scale for cervical dystonia and one for spasmodic dysphonia. Rating scales are particularly useful to the process of applying for Social Security disability benefits, because they measure the impact of the disorder on a person’s life in very specific terms such as driving, reading, and activities of daily living as well as the impact of pain, mobility, depression, and anxiety. An improved rating scale for cervical dystonia and the creation of a rating scale for spasmodic dysphonia will make it easier for people to demonstrate their eligibility for Social Security disability benefits, which is often the biggest hurdle for individuals during the application process. Rating scales are also essential to accurately and consistently measuring benefit to therapies, in both healthcare and research settings. The DMRF is playing a significant role in the development of the cervical dystonia rating scale by working closely with lead investigator Cynthia Comella, MD and subcontracting with the clinical sites.

For more information on the DMRF’s science activities, visit: http://www.dystonia-foundation.org/research
Article reproduced, with permission, from DMRF Dystonia Dialogue Winter 2012
From Here to There and Back Again
Shirley Sharkey, Moncton, New Brunswick

As far as I know no one in my family history had ever developed this condition, but in 2003 I was diagnosed with cervical dystonia. After a year of running from doctor to therapist to pain clinics to chiropractors, funnily enough, it was actually the chiropractor, who diagnosed it and told me I needed to see a neurologist.

In the ensuing years I learned a whole new language – most of which I didn’t want to know.

To anyone who has the condition, I don’t have to explain the pain, the losses, the frustration, the pills, the shots and the constant running to doctors – all the while, trying to live life in a worthwhile way.

My husband Jim and I went to London, Ontario twice to see doctors there, but I couldn’t tolerate the medication that one doctor gave me and another doctor was reluctant to enter me into a program that far from home, where I could not be adequately monitored,

Throughout all this, I did find that laughter helped immensely. Fortunately, all my friends and family have the same off-the-wall sense of humor as my own. Laughter could give me two or three hours, pain free.

In 2008, I was scheduled to have the Deep Brain Simulation (DBS) procedure but the results of a blood test indicated that I was not a good candidate for the surgery. That was hard. After I enjoyed a couple months of wallowing in self pity, I had to make up my mind to learn to live with my dystonia. So I began the routine of good days, bad days, better days, worse days. If you have dystonia then you know the drill.

Then, denervation surgery was suggested. We went to the McGill Neurological Institute in Montreal in 2011 for a consultation with the surgeon. After X-rays, EMGs and MRIs I was scheduled for the operation in July 2011. However, when I had a pre-surgery Echo gram and blood aggregation testing, the Echo gram showed I had a small hole in my heart and could not be a candidate for the surgery.

I had the hole in my heart repaired and was put on a 6 month regimen of blood thinners. No big deal. But, since I am accident prone, I was either getting a bruise, having a bruise, recovering from a bruise or preparing for the next bruise.

Finally, I received good news. The blood tests I had in Montreal showed that my blood was in fact normal. Fired up with this knowledge, I was determined to have the DBS surgery. I was referred to Halifax Movement Disorder neurosurgeon Dr. Rob Brownstone and in June of this year 2012 I had the DBS surgery, and as they say, the rest is history.

Dr. Brownstone and his team were fantastic. I can’t say enough about them. They were funny, helpful, kind and gentle. I was indeed blessed to have such wonderful people caring for me. I was awake during the initial procedure and had a halo attached to my head. Although while
having the halo on wasn’t much fun, I got to hear my brain. Later, I was put to sleep so the leads and extenders could be implanted under the skin down the back of my neck and down to my midriff. I went home the following afternoon.

Three weeks later the stimulator was programmed and turned on. At first, I didn’t feel anything, but the next day my head started to straighten, my arm relaxed and the pain was gone. I had been sitting in the garden and I realized when I looked up that I was straight! That sent me into paroxysms of crying and laughing. I still wake up in the middle of the night and find myself smiling.

There will be fine tuning done in the next few months, but it is again awesome what I can do now – things I have not been able to attempt in the past ten years. As with most life changing conditions, no one really understands unless they’ve been there.

### Laughter is strong medicine for mind and body

Laughter is a powerful antidote to stress, pain, and conflict. Nothing works faster or more dependably to bring your mind and body back into balance than a good laugh. Humor lightens your burdens, inspires hopes, connects you to others, and keeps you grounded, focused, and alert.

With so much power to heal and renew, the ability to laugh easily and frequently is a tremendous resource for surmounting problems, enhancing your relationships, and supporting both physical and emotional health.

### Laughter is good for your health

- **Laughter relaxes the whole body.** A good, hearty laugh relieves physical tension and stress, leaving your muscles relaxed for up to 45 minutes after.
- **Laughter boosts the immune system.** Laughter decreases stress hormones and increases immune cells and infection-fighting antibodies, thus improving your resistance to disease.
- **Laughter triggers the release of endorphins, the body’s natural feel-good chemicals.** Endorphins promote an overall sense of well-being and can even temporarily relieve pain.
- **Laughter protects the heart.** Laughter improves the function of blood vessels and increases blood flow, which can help protect you against a heart attack and other cardiovascular problems.
January 2012 was the most horrific time in my life. But, looking back I couldn't have asked for a better outcome than what my life has turned into now.

It was at the beginning of January 2012 that I was diagnosed with focal Cervical Dystonia after a year of agonizing pain, disability and misdiagnoses. There are so many horror stories surrounding dystonia. I hope to showcase a different point of view.

Up until 2011, I was leading an extremely active lifestyle which included working out with a trainer twice a week, running, biking, hiking...you name it...I was doing it. Around my 31st birthday (December 2010) I started to notice that I could not keep my neck straight, although I was in no pain. This progressed until February 2011 when I woke up and my neck was completely tilted to the left and I was in a ton of pain! I was able to work and go to school but that was about it. Then I began a year of seeing general practitioners, emergency room doctors, chiropractors, physiotherapists, and naturopaths etc. In the end, it was my aunt, a nurse in Ottawa, who was the first to tell me I needed to see a neurologist, and about two days later, my physiotherapist told me he thought I may have dystonia.

In December of 2011, the dystonia turned into a monster! The pain was excruciating and my head was being violently forced to the left and backwards. Unable to walk for long, I thought for sure that my life as I knew it must surely be over. I felt as if I had been given a life sentence.

Fortunately, I was able to see a neurologist in my home town in February 2012. She took one look at me and said I was the worst and youngest dystonia case she had ever come across...Nice!

Words one always wants to hear. The neurologist gave me Botox (botulinum injections) and told me to come back in four weeks to see how it worked. She was able to get me back to about 60% normal but I was still in a bit of pain and it was very difficult to turn my neck to the right, so she suggested I go and see Dr. Consky, a movement disorder neurologist, in Toronto.

He was amazing! Dr. Consky told me that with treatment my dystonia would hopefully become more like a minor nuisance rather than a central focus in my day-to-day activities. I couldn't believe it! A minor nuisance from a life sentence! I'll take it! He gave me botulinum injections and within two days I was driving again...within two weeks I travelled to Australia...within three weeks I took my maiden jogging voyage along Swan River in Perth, Western Australia! And, I was able to keep my title as Maid of Honour at my best friend’s wedding in October.

I still notice the dystonia in my neck. It doesn't go away, but Dr. Consky was right...it is only a minor annoyance. I am able to do everything I want (listening to my body of course) and I am pretty positive no one can tell that I have dystonia.

There are so many people, including my employer, I needed to thank for their help in getting me through the proper channels and ultimately leading me to treatment. These were normal every day people who went above and beyond to help someone they barely knew. Never will I forget their kindness. I know this has shaped the person I am today, as well as the one I will be in the future. It is so important to live a positive life, to be grateful for all of our experiences and to "Pay it Forward" every chance we get.
Volunteer Chapter/Support Group Leaders and Area Contact

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<thead>
<tr>
<th>Province</th>
<th>Name</th>
<th>Position</th>
<th>Phone</th>
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<tbody>
<tr>
<td>BC</td>
<td>Anne Skomedal</td>
<td>Kelowna Support Group Leader</td>
<td>250.763.7739</td>
<td><a href="mailto:rskomedal@shaw.ca">rskomedal@shaw.ca</a></td>
</tr>
<tr>
<td></td>
<td>Brian Hoar</td>
<td>Kelowna Area Contact</td>
<td>250.764.5005</td>
<td><a href="mailto:bbhoar2@gmail.com">bbhoar2@gmail.com</a></td>
</tr>
<tr>
<td></td>
<td>Cindy McKay</td>
<td>Kelowna Area Contact</td>
<td></td>
<td><a href="mailto:cansoda@shaw.ca">cansoda@shaw.ca</a></td>
</tr>
<tr>
<td></td>
<td>Arlene Czop</td>
<td>Chilliwack Area Contact</td>
<td>604.824.9849</td>
<td><a href="mailto:rczop@telus.net">rczop@telus.net</a></td>
</tr>
<tr>
<td></td>
<td>Grant Kaiser</td>
<td>Vernon/Salmon Arm Area Contact</td>
<td>250.542.8509</td>
<td><a href="mailto:cgkaiser@telus.net">cgkaiser@telus.net</a></td>
</tr>
<tr>
<td>AB</td>
<td>Margaret Roy</td>
<td>Calgary President/Support Group Leader</td>
<td>403.271.4438</td>
<td><a href="mailto:roymg@telusplanet.net">roymg@telusplanet.net</a></td>
</tr>
<tr>
<td></td>
<td>Brenda Lewis</td>
<td>Edmonton Support Group Leader</td>
<td>780.915.4294</td>
<td><a href="mailto:bklewis@telus.net">bklewis@telus.net</a></td>
</tr>
<tr>
<td></td>
<td>Joanne Alford</td>
<td>Edmonton Area Contact</td>
<td>780.752.8604</td>
<td><a href="mailto:jealford@shaw.ca">jealford@shaw.ca</a></td>
</tr>
<tr>
<td>SK</td>
<td>Diane Haugen</td>
<td>Saskatoon Support Group Leader</td>
<td>306.477.0577</td>
<td><a href="mailto:dystonia@sasktel.net">dystonia@sasktel.net</a></td>
</tr>
<tr>
<td>MB</td>
<td>Barbara Crow</td>
<td>Manitoba Area Contact</td>
<td>204.255.2633</td>
<td><a href="mailto:bcrow@mymts.net">bcrow@mymts.net</a></td>
</tr>
<tr>
<td>ON</td>
<td>Monica McCool</td>
<td>Cornwall Area Contact</td>
<td>613.936.1356</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Judy Horsch</td>
<td>Golden Triangle Support Group Leader</td>
<td>519.767.9721</td>
<td><a href="mailto:jjmarie@rogers.com">jjmarie@rogers.com</a></td>
</tr>
<tr>
<td></td>
<td>Laurie Bell</td>
<td>Hamilton Area Support Group Co-Leader</td>
<td>905.774.4111</td>
<td><a href="mailto:landbell@shaw.ca">landbell@shaw.ca</a></td>
</tr>
<tr>
<td></td>
<td>Rose Gionet</td>
<td>Hamilton Area Support Group Co-Leader</td>
<td>905.575.3534</td>
<td><a href="mailto:rgionet@shaw.ca">rgionet@shaw.ca</a></td>
</tr>
<tr>
<td></td>
<td>Margaret Ebdon</td>
<td>Kingston Area Contact</td>
<td>613.345.2115</td>
<td><a href="mailto:Marge1002@gmail.com">Marge1002@gmail.com</a></td>
</tr>
<tr>
<td></td>
<td>Jane Soules</td>
<td>Kingston Area Contact</td>
<td>613.498.1472</td>
<td><a href="mailto:soules1@sympatico.ca">soules1@sympatico.ca</a></td>
</tr>
<tr>
<td></td>
<td>Michelle Goodhue</td>
<td>London Area Contact</td>
<td>519.455.7457</td>
<td><a href="mailto:bgood137@sympatico.ca">bgood137@sympatico.ca</a></td>
</tr>
<tr>
<td></td>
<td>Bruce Goodhue</td>
<td>London Area Contact</td>
<td>519.455.7457</td>
<td><a href="mailto:bgood137@sympatico.ca">bgood137@sympatico.ca</a></td>
</tr>
<tr>
<td></td>
<td>John Heney</td>
<td>Ottawa Area Contact</td>
<td>613.224.6888</td>
<td><a href="mailto:jiheney@rogers.com">jiheney@rogers.com</a></td>
</tr>
<tr>
<td></td>
<td>Brian Hall</td>
<td>Peterborough Area Contact</td>
<td>705-931-8689</td>
<td><a href="mailto:bdh333@gmail.com">bdh333@gmail.com</a></td>
</tr>
<tr>
<td></td>
<td>Mary Guy</td>
<td>Sudbury Support Group Leader</td>
<td>705.524.0606</td>
<td><a href="mailto:mrguy@personainternet.com">mrguy@personainternet.com</a></td>
</tr>
<tr>
<td></td>
<td>Wendy Paul</td>
<td>Toronto Pres./Chapter Group Leader</td>
<td>416.789.0154</td>
<td><a href="mailto:drntoronto@rogers.com">drntoronto@rogers.com</a></td>
</tr>
<tr>
<td></td>
<td>Tracy Henry</td>
<td>Chatham-Kent, Sarnia-Lambton Support Group Leader</td>
<td>519.354.6833</td>
<td><a href="mailto:tracyhenry1224@yahoo.ca">tracyhenry1224@yahoo.ca</a></td>
</tr>
<tr>
<td></td>
<td>Chloe Belisle</td>
<td>Montreal Support Group Leader</td>
<td>514.696.0949</td>
<td><a href="mailto:honeylocas@sympatico.ca">honeylocas@sympatico.ca</a></td>
</tr>
<tr>
<td></td>
<td>Queenie Grosz</td>
<td>Montreal Area Contact</td>
<td>514.223.2394</td>
<td></td>
</tr>
<tr>
<td>NB</td>
<td>Edna Jordan</td>
<td>Fredericton Area Contact</td>
<td>506.453.0708</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tim Williston</td>
<td>Fredericton Area Contact</td>
<td>506.457.2388</td>
<td><a href="mailto:tim.williston@hotmail.com">tim.williston@hotmail.com</a></td>
</tr>
<tr>
<td></td>
<td>Shirley Sharkey</td>
<td>Moncton Support Group</td>
<td>506.204.2722</td>
<td><a href="mailto:j.s.sharkey@rogers.com">j.s.sharkey@rogers.com</a></td>
</tr>
<tr>
<td>NS</td>
<td>Marcellin Chiasson</td>
<td>Port Hawkesbury Area Contact</td>
<td>902.625.1811</td>
<td><a href="mailto:marcellin.chiasson@ns.sympatico.ca">marcellin.chiasson@ns.sympatico.ca</a></td>
</tr>
<tr>
<td></td>
<td>Marion Nauss</td>
<td>Queen's County Area Contact</td>
<td>902.677.2506</td>
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**In Memoriam — Jean Palmquist**

Sadly, Jean Palmquist, DMRFC Support Group Leader/Area Contact in Regina, Saskatchewan passed away in early January 2013. Jean was a long time supporter of the dystonia cause. When she could no longer speak, she wanted to keep communicating with people with dystonia through email from her nursing home. Jean is remembered by Diane Haugen, Support Group Leader, Saskatoon “Jean was so energetic and really took on the leadership in Regina. She wanted to do her very best with her support group, and do it right. Jean will be missed a lot.” Our most heartfelt sympathy goes out to Jean’s family and friends.
# Dystonia Medical Research Foundation Canada

## Statement of Financial Position

**Year ENED December 31, 2011 and 2010**

### Assets

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</tr>
<tr>
<td>Accounts payable &amp; accrued liabilities</td>
<td>35,141</td>
<td>3,460</td>
</tr>
<tr>
<td>Deferred Revenue</td>
<td>3,500</td>
<td>25,000</td>
</tr>
<tr>
<td><strong>Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unrestricted</td>
<td>422,654</td>
<td>503,665</td>
</tr>
<tr>
<td><strong>Total Liabilities &amp; Net Assets</strong></td>
<td><strong>461,295</strong></td>
<td><strong>532,125</strong></td>
</tr>
</tbody>
</table>

## Statement of Operations & Net Assets

### Revenue

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations/Grants/Fundraising</td>
<td>381,429</td>
<td>459,912</td>
</tr>
<tr>
<td>Interest</td>
<td>3,693</td>
<td>5,849</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>385,122</strong></td>
<td><strong>465,761</strong></td>
</tr>
</tbody>
</table>

### Expenses

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research grants &amp; activities</td>
<td>256,920</td>
<td>152,484</td>
</tr>
<tr>
<td>Awareness, Education &amp; Services</td>
<td>111,613</td>
<td>114,944</td>
</tr>
<tr>
<td>Fundraising</td>
<td>48,323</td>
<td>45,989</td>
</tr>
<tr>
<td>Administrative and professional costs</td>
<td>39,450</td>
<td>35,865</td>
</tr>
<tr>
<td>Advocacy</td>
<td>8,635</td>
<td>9,039</td>
</tr>
<tr>
<td>Governance</td>
<td>1,192</td>
<td>1,125</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>466,133</strong></td>
<td><strong>359,446</strong></td>
</tr>
</tbody>
</table>

### Excess of Revenues over Expenses

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Excess of revenues over expenses</strong></td>
<td>(81,011)</td>
<td>106,315</td>
</tr>
</tbody>
</table>

### Net Assets, Beginning of Year

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Assets, beginning of year</strong></td>
<td>503,665</td>
<td>397,350</td>
</tr>
</tbody>
</table>

### Net Assets, End of Year

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Assets, end of year</strong></td>
<td>422,654</td>
<td>503,665</td>
</tr>
</tbody>
</table>
In Recognition

The Dystonia Medical Research Foundation thanks its many supporters, donors, sponsors and benefactors in 2011. This support provides the funds needed to support our mission 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.

$50,000 and up
Calgary Chapter - DMRFC
Edmonton Dystonia Support Group

$25,000 to $49,999
DMRF Toronto Chapter (in participation with DMRFC Freedom to Move 5k Walk/Run)
Anonymous - Calgary Chapter

$10,000 to $24,999
Allergan Inc.
Merz Pharma Canada Ltd.
Sudbury and District Support Group.

$5,000 to $9,999
Great Canadian Gaming Corp.
Hamilton Support Group
W. Bernard Herman
Lutsky Families
The Alvin and Mona Libin Fnd
Camille Villeneuve

$2,500 to $4,999
Chatham/Kent, Sarnia/Lambton Support Group
CIBC Children’s Foundation
Deans Knight Capital Management
Deloitte and Touche Foundation
Diamond Foundation
Theresa Furey

$1,000 to $2,499
3M Canada Company
John David Anderson
Brian and Barbara Crow
Daylight Company
Lil Faider
Goldie Feldman
Golden Triangle Support Group

K.C. Whalen Memorial Fund
Heather MacLellan
Manitoba Support Group
Ian McPhee
Ottawa Gatineau Support Group
Ivan Papazov
PDA Architects
Evan Roberts
Olaf Schneider
Pearl Schusheim
Barry Slawsky
The Dianne and Irving Kipnes Fnd
The Prospero Group
United Way of The Lower Mainland
Wal-Mart Canada Corp.
Wedgewood Hotel and Spa
Witten LLP
Daniel and Connie Zalmanowitz

$500 to $999
Suzanne Bélair
Randy Blundon
Julius Gaudio
Doug and Carol Gordon
Murray and Tracy Henry
Harry Hole
Lila Lewis Irving
Gregory Kasparian
Kelowna Support Group
Kenneth Kirsch
Yolande Landry
James and Marilyn Luffman
Terry and Linda McBride
Kelly McNeil
Brian Mullen
Myguy Management Services Ltd.
National Council of Jewish Women
Julia Pietneva
Sgt. Rick McDonald Memorial Fund
Barbara Smeaton
Sonamguy Inc.
Carmen Talarico
TD Commercial Banking, Mississauga
Tim Wun
Hal Zalmanowitz

$250 to $499
Robert Abells
Grant Vogel and Lemoire Alima
Gary and Joanne Appelt
Janice Andrews
Jennifer Barnett
Fritz Becker
Dennis and Donna Bedard
David and Laurie Bell
Jack Brandreth
Paul Brown
Mary Burke
Lou and Nancy Canton
Cardinal Couriers Ltd.
Earl Consky
Richard and Sheron Currey
Sheila Davis
Doug Downey
Laura Fedynyszyn
Lloyd and Yvonne Frazer
Diane Gillespie
Mildred Good
Libby Graham
Adrian Greene
Greg Saari Merchandising Ltd
Richard and Mary Guy
Carol Hartman
Mark Hope
William Jago
Doug and Sherry Julien
Darlene King
Doris Littleton
John Lloyd
Jan Marlow
Eleanor McChesney  
McDonogh Family  
Regina Meints  
Mike Mitchell  
PAL Canada Foundation  
Polytec Quality Consulting  
Provincial Employees Community Services Fund, British Columbia  
Amir Roizman  
Royalty General Construction  
Bill Saundecook  
Paul Savard  
Thelia Shelton  
Claire Smith  
Courtney Stephenson  
Eileen Sweeney  
The Hydrecs Fund  
United Way of Elgin-St. Thomas  
United Way of Ottawa  
Evelyn Wigham  
Lorne Wisebrod  
Lauren Woods  
Colin Wymes  
YLT Consulting  
Jeffrey and Beryl Zeifman

$100 to $249
Bernice Alford  
Derek Allen  
Michael Ambrosio  
Keith Anderson  
Delores Andrello  
APS-Antian Professional Services  
Brenda Arseneau  
Shirley Avery  
Lynda Bain  
Elizabeth Baker  
Lance and Karen Balch  
Donna Ball  
George Ballos  
Gary E. Balmer  
BBT Machining Inc.  
Joan Black  
Brenda Blakey  
J. Leigh Blonde  
Erica Bochow  
David Bookhalter  
Wayne Brassem  
Anne Brown  
Michael Butler  
Centre of Excellence for Public Sector Marketing  
Fraser Chapman  
Hugh Chapman  
Michael and Bonnie Chetner  
Todd Christensen  
Tim Christmann  
Sharlene Claerhout  
Kyra Clarkson  
David and Floretta Clement  
Micheline Coderre  
Bob Cogle  
Laurence Cohen  
Alison Cook  
Andrew Cook  
Laurine Cowie  
Barry Cox  
Elizabeth Coyne-Dubeau  
Jaqueline Crawley  
Tom Cronin  
Arlene Czop  
Sami Dabliz  
Amanda Dano  
John Dathan  
Kathy David  
Jeremy Deacon  
Brian and Barb Death  
DeCaria Engineering Limited  
Andrew Dencs  
Mario Deschênes  
Diamond Corp  
Gisele Dillon  
Kelly Dip  
Len and Catherine Dolgoy  
David Douglas  
Daniel Dulfage  
Patricia Dunphy  
Betty Eade  
Teresa Ebbeling  
Don Eby  
Linda Elardo  
Encana Corporation  
Errol Raff Professional Corp.  
Josephine Evans  
Anne Fanning Binder  
Greg and Catherine Farnell  
Marie Faughnan  
Robert Steele and Marleen Ferguson  
Bunny Ferguson  
John Ferrante  
Flaherty, Dow, McCarthy & Elliot  
Doreen Ford  
Mike Fraser  
Irene Frolic  
Fulton United Church Women  
Fleurette Gallen  
Chantel Gaudet-Montsion  
Rosita Georgieva  
JM Ghent  
Mehdi Ghiyaei  
Roland and Rose Gionet  
Glover Customs Brokers Inc.  
Tim and Robin Gofine  
Aubrey Goldstein  
Mindy Goodman  
Myrtle Gowans  
Barry and Kathryn Gowling  
James and Marilyn Graham  
Sabrina Grando  
Maria Grando  
James and Marilyn Gray  
Jennifer Guy  
Rejeanne Guy  
Mark Hammerschlag  
Barbara Hampe  
Judy Harsch  
Nick Hertz  
Stu and Mary Higdon  
Brenda Hirsekorn  
Deborah E. Horowitz  
Donald J. Hudson  
Wendy Huseman  
Jean Hutton  
Christien Iafrate  
Adam and Ida Janvary  
Heather Jessiman  
Florence Johnson  
David Jonas  
Kyler Jones  
Zosia Judek  
Juniper Networks' Company Matching Gifts  
Henna Jutila  
Grant Kaiser  
Dan Kane  
Mariana Kant  
Dennis R. Kapp
**Toronto**

The Toronto Chapter’s Annual Dinner was held at Hazelton Place on Saturday November 24, 2012. Guests were treated to a fun filled evening. To begin there was a 50/50 raffle and a game "Draw a Number from the Hat." Guests visited the silent auction which featured over 70 items; including symphony tickets, restaurant gift certificates and a weekend at a Collingwood Resort. Highlighting the evening was a performance by the Hank Williams inspired band "Pull Me From The Wreckage.”

**Hamilton Area**

The Flyer’s Local Music Night for Dystonia $$$$ in Dunville raised over $450. Members of the Support Group came from Hamilton and all had a great time. In November the group welcomed Doris Keinitz, a registered yoga and meditation practitioner/instructor and author from Selkirk. She spoke about the importance of deep breathing and stretching.

**Edmonton**

Brenda Lewis and Connie Zalmanowitz have been busy raising funds through the Edmonton Casino initiative and the Support Group Letter Campaign resulting in a combined total of $87,000 raised in support of dystonia research.

The Edmonton “Yogatonia” Yoga for Dystonia program held 6 times each year has been running now for over 3 years and there is increasing interest each year. Many of the participants have taken the yoga lessons as a starting point for other forms of yoga using the knowledge gained to what their safe limitations are. The sessions have been attended by people with oromandibular dystonia, cervical dystonia, and generalized dystonia. This important program is promoted by the Edmonton Movement Disorders Program at the University of Alberta and includes physiotherapy expertise and assistance at the sessions. Many thanks to the volunteers that lend a helping hand in Edmonton.

**London, Ontario**

The London group had their yearly information booth at the St. Julien Park Festival in September. Pictured right is a group outing in November. Bruce and Michelle Goodhue the Support Group Co-Leaders welcome new members, and would like to send out an appeal for new leadership for the group. If you are interested in joining the London Support Group and/or are interested in a leadership support role, please contact Diane Gillespie, DMRFC Executive Director at 1-800-361-8061.

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**Recognizing Cathi Sweetnam**

Our most heartfelt gratitude to the late Cathi Sweetnam who most generously left a bequest to DMRF Canada in her will. Cathi was a long time supporter and friend to DMRF Canada and the Edmonton Dystonia Support Group. She had lived with cervical dystonia, and had denervation surgery some years ago that helped her greatly with her dystonia symptoms. Cathi died unexpectedly in 2011 of causes unrelated to her dystonia. Brenda Lewis, President Edmonton Support Group remembers Ms. Sweetnam “Cathi smiled and laughed all the time despite what she was going through with her neck and shoulder(s). She was always ready to volunteer when we would have tables set up at malls with information to give to the public. Cathi was a very kind woman and always supportive and it did not surprise me to learn that she had left a great donation to dystonia!” Our deepest condolences go out to Ms. Sweetnam’s family and friends.
Ottawa
Regularly-scheduled monthly morning coffee-shop gatherings are one way the Ottawa Group connects and discovers what’s brewing. It’s an inexpensive and flexible means to stay in touch, share strategies, provide support and build friendships, including with family. “Whether we’re few or we commandeer many tables, it’s relaxing, an event to look forward to, and a chance to appreciate each other beyond our challenges,” reports local contact John Heney. “Laughter, good stories and circulation that helps everyone!” Email and phone reminders also help gauge attendance in light of the weather and personal commitments.

Kelowna Awareness
Anne Skomedal Support Group Leader reports: “Our group continues to be focused on awareness of Dystonia. We have made presentations to the Parkinson’s Group and the Rehabilitation Department at Kelowna General Hospital. The Physiotherapy Department at KGH was able to say “it made a difference in our practice.” The UBCO Faculty of Medicine, Southern Medical Program, have again requested that individuals with Dystonia be part of their At Home Interview Program for first year medical students. Second year medical students will be starting their Neurology Block and they have requested that individuals with Dystonia participate. We are really excited about the Medical School being in Kelowna and the ongoing awareness that is happening.”

New Brunswick
Shirley Sharkey and Tim Williston Co-Leaders of the New Brunswick Support Group Network are busy recruiting members for the group. A message from Shirley and Tim:

“The two of us who are setting up the network, Tim Williston and Shirley Sharkey, have dystonia and have travelled long roads ourselves finding the answers and treatments for our dystonias. Both of us have had deep brain stimulation surgery for dystonia with good success. If you would like to learn more about dystonia, new treatments, and to meet others who share the same challenges, please contact either of us.”

Tim Williston/Fredericton:
email: tim.williston@hotmail.com
phone: 506-206-4444

Shirley Sharkey/Moncton
email: j.s.sharkey@rogers.com
phone: 506-204-2722 or TOLL FREE: 1800-361-8061

Calgary
In October, Dr Kraft of the Calgary Movement Disorder Centre spoke to the Calgary group. Dr Kraft works with many dystonia patients and is also the coordinator for patients considering and undergoing DBS surgery. In this special capacity he is working closely with Neurosurgeon Dr Kiss. The group found the presentation both excellent and informative.

Winnipeg
Barbara Crow plans on making presentations in Selkirk Apr 25, Apr 30, and May 15 at 2 p.m., through the Community Wellness Initiative, providing education to tenants of three buildings. Barbara will be showing TWISTED, preceded by an introduction to symptoms, types and treatments of dystonia.

Chatham
Each year Tracy Henry has a Union Gas awareness poster. Sharon from Dresden made dystonia presentations to two different groups. Thanks for 16 years of volunteerism for dystonia, Tracy!

Golden Triangle
In 2012 the group celebrated its 20th Anniversary. “This is a long time for a group to keep going” says Judy Harsh, Group Leader, “thank you everyone for their participation. Let’s keep up the good work”.
We Need Your Help!

Clip and return this form to: Dystonia Medical Research Foundation Canada, 305-121 Richmond St. West, Toronto, ON M5H 2K1

☐ I wish to renew/start my Dystonia Canada Report/Dialogue subscription ($40)

☐ I wish to make a donation in honour of ________________________________, ☐ Please send an acknowledgement letter/card to this person

☐ I would like information sent to me regarding DMRFC Planned Giving Program

☐ I wish to make a general donation ☐ $1,000 ☐ $500 ☐ $250 ☐ $100 ☐ $25 ☐ Other $_______

☐ I would like to make a monthly gift ☐ $75 ☐ $50 ☐ $25 ☐ $10 ☐ Other $________

PAYMENT OPTIONS

☐ Please charge my credit card: ☐ VISA ☐ MasterCard ☐ American Express

Name on Card: _____________________________ Card Number: _____________________________

Expiry Date: _______________________ Signature _____________________________

INFORMATION

Name _________________________________________

Address ______________________________________

City ______________________________________ Province ______________________________________ Postal Code ______________________________________

Phone ______________________________________ Email Address _____________________________

Charitable Registration Number 12661 6598 RR0001