

Dystonia Canada Report

The Newsletter of the Dystonia Medical Research Foundation Canada

Spring 2015



Dr. Barbara Connolly, MD, FRCPC
Neurology (Movement Disorders) Hamilton Health Sciences, Hamilton, ON
Assistant Professor, McMaster University

The Hamilton, ON Support Group was extremely pleased to present Dr. Barbara Connolly at their November 2014 Dystonia Information Session. See Page 7

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**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, BC. DMRFC funds medical research towards a cure, promotes awareness and education, and supports the well-being of affected individuals and families. DMRF 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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T: 416-488-6974 or TF: 800-361-8061

Email: info@dystoniacanada.org

Website: www.dystoniacanada.org

It is 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.

Farewell to Diane Gillespie

Goodbyes are always difficult, and especially so when someone has been with an organization for seven years. Diane Gillespie retired as the Executive Director of the DMRFC at the end of 2014, but continues



to offer support during the transition to a new Executive Director.

During Diane's service the foundation grew significantly in all three pillars of its mission – to advance dystonia research for more treatments and ultimately a cure, building dystonia awareness and support of affected individuals and families. Our Support Groups are extremely grateful for her tireless assistance, and for always being accessible when they had a question or required help with information meetings, fund raising and awareness events and dystonia related information.

In parting Diane said:

It is hard to believe that I have worked at DMRF Canada for almost seven years. I will miss working with all of you very much. From your warm welcome when I first started, your patience while I learned the ropes, your guidance and help with understanding dystonia and how it has impacted you and people with dystonia across Canada has been so much appreciated. The best part of this job has been working with you.

Thank you, Diane, for sharing the dystonia journey with us.

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In this issue we honour our Chair and Founder Samuel Belzberg's philanthropy; we announce the formation of a Vancouver Support Group with Jackson Mooney and Robin Krantz as Co-Leaders; we celebrate volunteer John Heney, Ottawa Area Contact & Government Relations Representative. Look for our latest articles on research, notably critical new information about the origins of dystonia and we announce the ground breaking National Population Study of Neurological Conditions.



## **DMRF Founder Sam Belzberg Honoured for Philanthropy**

DMRFC Co-Founder and Chairman of the Board, Sam Belzberg was honoured by Weizmann Canada at a national gala on November 16, 2014. Weizmann Canada was celebrating its 50th anniversary by recognizing outstanding Canadian men who exemplify philanthropy, success, and the desire to make a difference. The DMRFC congratulates Sam on being named a Weizmann Leading Man

Sam Belzberg is a highly successful real estate developer, noted philanthropist, and financier. He and wife Fran founded the DMRFC in 1976 shortly after their daughter was diagnosed. For nearly 40 years Sam has remained steadfastly dedicated to the Foundation and the dystonia community.

In addition to his trailblazing work with dystonia, Sam founded Action Canada in 2001 which is an institution that partners with the Government of Canada to endow 20 fellowships a year for individuals who are interested in making a positive difference in Canada. His many awards include the Order of Canada in 1988 from the Governor General. In 1989 Simon Fraser University officially opened the Samuel and Frances Belzberg Library.

In 1992 he received the Governor General of Canada Award, and in 2001 was promoted to Officer of the Order of Canada. The Order of BC was bestowed upon him in 2009. The Yeshiva University presented Sam with an Honorary Doctorate in 2010, and, in 2012, he was awarded the Queen Elizabeth II Diamond Jubilee 60th anniversary commemorative medal.

## **DMRF Announces Partnership to Explore New Dystonia Treatment**

The Dystonia Medical Research Foundation (DMRF) has entered a collaboration with Addex Therapeutics in Geneva, to explore the use of dipraglurant to treat dystonia. Dipraglurant has shown promise in the treatment of levodopa-induced dyskinesia and dystonia in Parkinson's disease, and has also been shown to normalize the effects of the TOR1A/DYT1 dystonia mutation in the brains of mice. The objective of the collaboration is to design a detailed development plan and regulatory path as well as identifying key option leaders and patients for a Phase 2 clinical trial. In addition, Addex recently reported plans to start clinical testing of the therapeutic effect of dipraglurant in patients with cervical dystonia in collaboration with Professor Dirk Dressler of The Hannover Medical School. This drug represents an important opportunity for the dystonia community to examine a potential new treatment option in collaboration with established experts in drug discovery and development.

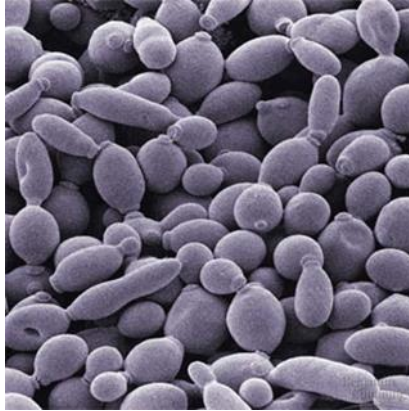
\* Article excerpted from DMRF Media Release – January 20, 2015

# DMRF-Funded Researchers Discover First Torsin A Chaperone Protein *BiP* Revealed as Potential Therapeutic Target

A study co-funded by the DMRF reveals a critical new information about the origins of dystonia. Since 1997, scientists have known that a mutated protein called torsinA causes one of the most severe primary torsion dystonias, but the function of the protein remains unknown. A team of researchers has made important headway by uncovering a close relationship between torsinA and BiP, a well-studied cellular protein that was not known to have an association with dystonia until now.

Dystonia is believed to result from improper signals in the nervous system that instructs muscles to contract involuntarily. Researchers do not yet fully understand the neurological mechanisms that cause the abnormal muscle contractions.

Jeffrey Brodsky, PhD, Professor and Avinoff Chair of Biological Sciences at the University of Pittsburgh, and Michal Zolkiewski, PhD, Associate Professor of Biochemistry and Molecular Biophysics at Kansas State University, co-lead a study that used a sophisticated yeast cell model to investigate several proteins that interact with normal torsinA and its dystonia-causing mutant. The cell proteins belong to a family of chaperones, which are molecules that help other proteins take shape and function properly or, in case of faulty proteins, disassemble and deactivate them. When torsinA is mutated, it cannot function properly and becomes a target for chaperones— and particularly for BiP, which appears necessary to degrade mutant torsinA. BiP stabilizes



both normal and mutated torsinA in mammalian cells; it is the first identified chaperone to act on torsinA.

Dr. Brodsky explains, “For the first time we identified a cellular protein—known as BiP that helps torsinA attain its proper shape in the cell. Because drugs that target cellular helpers such as BiP are in development, we hope that these might someday be used to treat primary torsion dystonia.”

The study also found that secondary mutations in torsinA amplify the effects of the defective protein when the dystonia-causing mutation is present. Brodsky laboratory is known for its expertise in studying cellular proteins in yeast. The yeast genome makes it possible to conveniently track genes and proteins, especially those that have human equivalents, making it a valuable model for research on human diseases. Although the discovery that the BiP protein modulates torsinA function was made in yeast, the researchers were able to validate the results in human cells.

“The next step is to identify other cellular helpers that impact torsinA,” says Dr. Brodsky. This work is now conducted by DMRF research fellow Lucia Zacchi, PhD, Research Associate at Fundacion Instituto Leloir in Argentina. Dr. Brodsky adds: “Additional proteins from her continued analysis might one day also be targets of newly developed drugs to treat primary torsion dystonia.”

*Citation: The BiP Molecular Chaperone Plays Multiple Roles during the Biogenesis of TorsinA, an AAA+ ATPase Associated with the Neurological Disease Early-onset Torsion Dystonia. Zacchi LF1, Wu HC, Bell SL, Millen L, Paton AW, Paton JC, Thomas PJ, Zolkiewski M, Brodsky JL. J Biol Chem. 2014 May 2;289(18):12727- 47. doi: 10.1074/jbc.M113.529123.[Epub ahead of print]*

\* Excerpted from DMRF Dystonia Dialogue



# Celebrating Our Volunteers - John Heney

## Ottawa Area Contact & Government Relations Representative

If one thing has kept John Heney going after the sudden onset of generalized dystonia felled him one morning in 1991, it has been his choice to, nonetheless, engage in a purposeful life.

Nothing prepared him for the shock through his nervous system in the shower that day that left him crumpled on the floor, unable to speak or use any fine motor skills. Given the times, and the lack of awareness of dystonia (and what dystonia is and is not), it took *years* for a proper diagnosis; that along with consequential economic and personal losses, jarring turns in his private and professional lives, and the conclusion by one specialist that he had been left with “a hideous and horrible way to have to live.”

“You have to ask what you can still do, and what you can accomplish with any such capacity,” John recalls of his slow but steady return to a contributing existence. Even as it took seven years to regain his ability to use a keyboard, he called upon his research, journalism and public policy background. First at the local level, and then in a national scope, he helped those afflicted, their families, and also social workers, medical staff and politicians to better recognize and understand the condition. Also how coping skills can develop, even as we raise funds, support research, and move toward solutions.



Working within the Ottawa dystonia support group founded by Stu Higdon, Kelda Whalen and Cameron MacLeod, John also helped the emerging and now well-established DMRFC office in Toronto, often called upon to help shape local and national awareness campaigns and initiatives. He has appeared in local and national newspaper coverage, and on Ottawa television and radio. Along the way, he has addressed a parliamentary press conference and met with MPs and senators toward wider awareness, financial support and research initiatives.

Every little bit helps. Collapsing one day into a major dystonic episode outside his home after being bitten by a dog, John lay on his back while neighbours watched him instructed paramedics what to do and not to do; this led to deeper dystonia awareness within the Ottawa paramedic and police services, including the potentially adverse effects tasers could have on those with neurological conditions.

“Assisting in how dystonia was included in a major set of studies on the state of Canadian neurological health care was a distinct privilege,” John recalls. A major player in this was Neurological Health Charities Canada (the NHCC), of which the DMRFC is a partner. Those findings were recently released.

Along the way, John has authored three books and helped several organizations. He has received the City of Ottawa Distinguished Service Award for his support of many aspects of local heritage – all part of his focus on service and engagement, so crucial in keeping one healthy. You can visit him at [www.johnheney.ca](http://www.johnheney.ca).

“Whether you are afflicted, or alongside, or caring for someone who is, we must all remember, that there are *many* aspects to any person. Crucial parts of who you are can wither if not also nurtured and exercised, just like our bodies. We more easily deal with challenges when our wider self stays purposeful and in circulation. Support something bigger than yourself. Something that gives you fulfillment – accomplished by what you can do, no matter how small. That’s the key!”

# National Population Study of Neurological Conditions

Members of the Neurological Health Charities Canada Coalition included John Heney, representing the Dystonia Medical Research Foundation Canada (back row centre), and representatives from Canadian Institutes of Health Research, Canadian Epilepsy Alliance, Canadian Neurological Sciences Federation, Alzheimer Society of Canada, the Honourable Rona Ambrose, Canada's Minister of Health, Neurological Health Charities Canada, Parkinson Society Canada, Neurological Health Charities Canada, Heart and Stroke Foundation, Public Health Agency of Canada, Public Health Agency of Canada, Brain Injury Canada, and the Canadian Neurological Sciences Federation, Ontario Neurotrauma Foundation.



**What?** The \$15 million, four-year National Population Health Study of Neurological Conditions (the Study) represents Canada's first-ever population health study of neurological conditions. Undertaken between 2009 and 2013, the extensive research program of the study included three national surveys, 13 pan-Canadian research projects, the expansion of ongoing surveillance to include certain neurological conditions, and the development of a micro-simulation model to estimate impacts of neurological conditions over the next 20 years. *Mapping Connections: An Understanding of Neurological Conditions in Canada* is the final report synthesizing key findings from the Study.

**Who?** The study was developed in partnership between the Government of Canada and NHCC a

collaborative of 24 health charity organizations representing the voice of individuals and families impacted by neurological conditions across Canada. Approximately 177,000 Canadians with neurological conditions and their caregivers offered insight and personal experience into key areas of the Study. In addition, the study successfully engaged 130 researchers.

**Why?** The study was designed to address the lack of information about neurological conditions in Canada. Findings are intended to inform Canadians and governing bodies about the impact neurological conditions have on affected individuals, families and the health care system, and inform future program and policy development.

**What does this mean for Canadians?** The study marks an unprecedented level of collaboration across fields, professions, jurisdictions, conditions, and interests. It provides information on neurological conditions within a Canadian context, including that neurological conditions, regardless of the specific diagnosis, present similar challenges for individuals, families, health care systems and the Canadian economy. Findings will help Canadians realize the scale, scope and financial burden of neurological conditions in Canada.

**For more information** on the National Population Health Study of Neurological Conditions or neurological conditions, visit the NHCC website ([www.mybrainmatters.ca](http://www.mybrainmatters.ca)) or the Public Health Agency of Canada website ([www.phac-aspc.gc.ca/cd-mc/nc-mn/ns-en-eng.php](http://www.phac-aspc.gc.ca/cd-mc/nc-mn/ns-en-eng.php)).

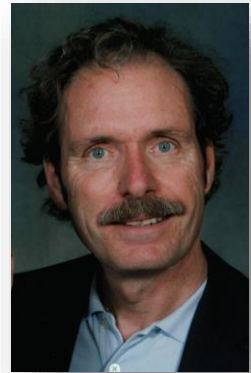
**To download a copy** of *Mapping Connections: An Understanding of Neurological Conditions in Canada*, visit <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php>

# Welcome Vancouver Support Group

DMRF Canada is very pleased to announce the formation of the Vancouver Support Group with Co-Leaders Jackson Mooney and Robin Krantz.

## Jackson Mooney

Jackson was diagnosed with cervical dystonia 10 years ago. He had DBS surgery in 2014. Jackson wants to reach out to people in the Vancouver Area to provide support. He strongly believes that people with dystonia should be given the opportunity to interact and learn from each other. You can reach Jackson at: 778 887-5054 and/or [jackson.mooney@gmail.com](mailto:jackson.mooney@gmail.com).



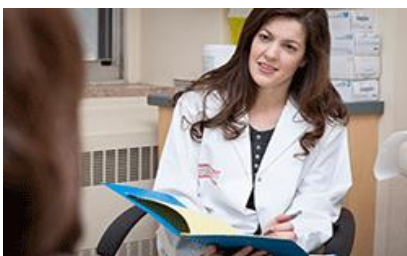
## Robin Krantz

Robin was diagnosed with cranial dystonia (Meige syndrome) in 2003. "The cranial dystonia involved my eyes, mouth, jaw, and neck and affected my eating, speaking and breathing as well as my vision. I have progressed favourably over the years and currently receive regular Botulinum injections for the Blepharospasm portion of my dystonia. I look forward to meeting, sharing and learning from those also affected by and living with dystonia. Even though dystonia is an individual condition it shouldn't have to be suffered alone". You can reach Robin at: 778-298-4113 and/or [rokrantz@hotmail.com](mailto:rokrantz@hotmail.com)

# Dystonia Information Sessions

## Calgary – Dr. Tamara Pringsheim

The Calgary Chapter headed by President Marg Roy hosted an awareness/information session on May 10, 2014 at the Carriage House Hotel in Calgary. Over 50 people were in attendance. The keynote Tamara Pringsheim, MD, Assistant Professor, Department of Clinical Neurosciences, Psychiatry, Pediatrics and Community Health Sciences, University of Calgary. Dr. Pringsheim presented a special paper on the prevalence of dystonia and a presentation of types of dystonia and treatments.



## Hamilton – Dr. Barbara Connolly

Rose Gionet and Laurie Bell, Co-Leaders for the Hamilton Area support group hosted a presentation by Dr. Connolly on November 7, 2014. Dr. Connolly, MD, FRCPC Neurology (Movement Disorders) Hamilton Health Sciences, Hamilton, ON, Assistant Professor, McMaster University presented the background, causes, and treatments of dystonia drew a large audience from the area.

**DYSTONIA MEDICAL RESEARCH FOUNDATION CANADA**  
**STATEMENT OF FINANCIAL POSTION**  
**YEAR ENDED DECEMBER 31, 2013 and 2012**

| <b>ASSETS</b>                      | <b>2013</b>    | <b>2012</b>    |
|------------------------------------|----------------|----------------|
| <b>Current Assets</b>              |                |                |
| Cash                               | 412,520        | 375,634        |
| Guaranteed investment certificates | 100,679        | 100,349        |
| Amounts receivable                 | 7080           | 7,376          |
| Prepaid expenses                   | 1858           | 1,858          |
|                                    | <b>522,137</b> | <b>485,217</b> |

| <b>LIABILITIES &amp; NET ASSETS</b>    |                |                |
|----------------------------------------|----------------|----------------|
| <b>Current Liabilities</b>             |                |                |
| Accounts payable & accrued liabilities | 4363           | 8,004          |
| Deferred Revenue                       |                | 1,620          |
| <b>Net Assets</b>                      |                |                |
| Unrestricted                           | 517,774        | 475,593        |
|                                        | <b>522,137</b> | <b>485,217</b> |

**STATEMENT OF OPERATIONS & NET ASSETS**

| <b>REVENUE</b>               |                |                |
|------------------------------|----------------|----------------|
| Donations/Grants/Fundraising | 406,921        | 544,811        |
| Interest                     | 1,265          | 1,607          |
|                              | <b>408,186</b> | <b>546,418</b> |

| <b>EXPENSES</b>                       |                |                |
|---------------------------------------|----------------|----------------|
| Research grants & activities          | 153,779        | 267,000        |
| Awareness, Education & Services       | 89,541         | 102,319        |
| Fundraising                           | 60,995         | 59,853         |
| Administrative and professional costs | 50,545         | 53,629         |
| Advocacy                              | 9,828          | 9,467          |
| Governance                            | 1,317          | 1,211          |
|                                       | <b>366,005</b> | <b>493,479</b> |

|                                         |                |                |
|-----------------------------------------|----------------|----------------|
| <b>EXCESS of revenues over expenses</b> | 42,181         | 52,939         |
| <b>NET ASSETS, beginning of year</b>    | 475,593        | 422,654        |
| <b>NET ASSETS, end of year</b>          | <b>517,774</b> | <b>475,593</b> |



# *In Recognition*

The Dystonia Medical Research Foundation thanks its many supporters, donors, sponsors and benefactors in 2013. 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.

## **\$100,000 and up**

Bel-Fran Charitable Foundation  
Calgary Chapter - DMRFC

## **\$25,000 to \$49,999**

DMRF Toronto Chapter (in participation with DMRFC Chuck's Run/Walk)  
Edmonton Dystonia Support Group

## **\$10,000 to \$24,999**

Canterbury Coffee Corporation  
Dystonia Support Group of Sudbury & District

## **\$5,000 to \$9,999**

Hamilton and Area Dystonia Support Group  
John W. S. Preston Charitable Foundation  
Lohn Foundation  
Merz Pharma Canada Ltd.  
The Alvin and Mona Libin Foundation

## **\$2,500 to \$4,999**

Diamond Foundation  
Karl Parnoja and Linda Hurlburt  
Wal-Mart Canada Corp.

## **\$1,000 to \$2,499**

Margaret Brick  
Brian and Barbara Crow  
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Dunpar Developments Inc.  
James T. Farrar

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The Joseph Segal Family Foundation  
Witten LLP  
Daniel and Connie Zalmanowitz  
Barry Zalmanowitz and June Ross  
ZLC Foundation

## **\$500 to \$999**

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Atlas Copco, Lively, ON  
Jennifer and Michael Barnett  
Canada Life Assurance  
Peter Ender  
Goldie Feldman  
Golden Triangle Support Group  
Chris Greco  
Sharon Herman  
John Lloyd  
Maryln and James Luffman  
Brian Mullen and Penny Patterson  
Steven Pataki  
Evan Roberts

Stephan and Denise Rogow  
Lee and Mary Sauer  
Lorraine Scott  
Sgt. Rick McDonald Memorial Fund  
Turco Persian Rug Company  
Hal Zalmanowitz  
Jeffrey and Beryl Zeifman

## **\$250 to \$499**

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Thomas Allen  
Fritz Becker  
Dennis and Donna Bedard  
Harriet Berkal  
Alyssa Boyd  
Mark and Mary Burke  
Joey Cecchini  
Earl Consky  
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Greg and Catherine Farnell  
Debbie Farquharson  
Brian Felesky  
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Sweeney  
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Barrie Thomson  
Jerry and Anne Tollinsky  
Grant Vogel and Lemore Alima  
Alanna Walters  
Marvin Waxman  
Lauren Woods

**\$100 to \$249**

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Phil Hauser  
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Joseph and Deby Wohlgernter  
Maureen Wolfenden  
Tony and Christine Wygergangs  
Mary Yannakis  
Leo and Diane Zalmanowitz  
Kitty Zanata  
Mike Zaranyik

## In Memoriam

Our deepest condolences to the family and friends of: *William Jackson Jr., Marika McCaffrey, Norman Levi Peirce, Peirre Marcil, Theresa Swartzenburg and Gary Muir.*

# Hold or Join an Event



## **Hold an Event or Participate in an Event to Help People Living With Dystonia**

**It's Fun and we can help you make it easy to do. There many types of events that you can hold.**  
Golf Tournament • Dinner Party • Car Wash • Musical Gathering • Group Walk • Bowling Tournament  
Fashion Show • Pledging for Personal Achievements such as Running or Swimming

**Contact us for information on event fundraising:**

**1.800.361.8061**

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

## **FREEDOM TO MOVE WALKS/RUNS**

**Chuck's Run/Walk, June 7, High Park, Toronto, ON**

**Hamilton Area Walk, June 13, Battlefield Park, Stoney Creek, ON**

**Sudbury Walk, June 14, Howard Armstrong Rec Centre, Hanmer, ON**

**Golden Triangle Walk, (Date TBD) Victoria Park, Kitchener, ON**

**For event details and for information on holding an event visit: [www.dystoniacanada.org](http://www.dystoniacanada.org)**

*Charitable Registration Number 12661 6598 RR0001*