



DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA
servicing all dystonia-affected persons

Dystonia Canada Report

A Newsletter of the Dystonia Medical Research Foundation Canada

Spring 2009



Lil Faider, DMRFC Board Member, and DMRFC Calgary Chapter member receiving \$10,000 donation from Beta Sigma Phi's first vice president, city council, Cecilia Merryweather

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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, British Columbia. DMRFC funds medical research toward 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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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 National Director



A full year has passed since I joined DMRF Canada. And it has been a year full of opportunities for dystonia awareness and research.

Our new website www.dystoniacanada.org has become a top “dystonia” choice on the Google search engine with 2,000 visits per month along with 6,000 page views and growing daily.

Dystonia has entered into its own in the mainstream media in the last few months, with television shows like Oprah Winfrey, The Today Show, Dateline and, The Doctors, featuring dystonia as a major topic.

We now have a French version of our *What is Dystonia? “Qu’est-ce que la dystonie?”* brochure. In this issue, we feature our new Quebec Regional Representative Steven Tremblay and our French TOLL free line support volunteer Chloe Belisle.

On the research front, DMRF Canada is entering into its second funded fellowship grant in partnership with Canadian Institutes for Health Research, SHOPP program.

We proudly partner with DMRF research program in the United States. In this issue, we have provided an outline of recent research discoveries. The last 12 months have been a remarkable period in dystonia genetics. Scientists identified or clarified seven genes, loci, and designations for genetic dystonias.

We are reaching out to governments through our participation with the Neurological Health Charities Coalition and the Ontario Neuromodulation Coalition. It is a busy time, with more initiatives planned in the coming months.

Sincerely,

A handwritten signature in blue ink that reads "Diane Gillespie".

Diane Gillespie
National Director

Each spring issue we plan to highlight a region of Canada – this issue Alberta

Alberta Highlights

In 2008, Alberta volunteers and donors raised a whopping \$114,000 in support of dystonia research. DMRF Canada board member Lil Faider assisted through the Alberta Provincial Gaming Casino with proceeds of over \$80,000 and through personal support and contacts. Connie Zalmanowitz of Edmonton contributed \$17,000 through her annual letter-writing campaign. The Calgary Chapter lead by Margaret Roy also raised \$17,000 dollars through their Walk and Wheel and other endeavours.

Lil Faider, DMRF Canada Board Member, Calgary Chapter Member

Lil Faider is a founding member of the Calgary Chapter. Lil dedicates her dystonia charity efforts to her niece Cheri Tannenbaum (nee: Belzberg) who was diagnosed with generalized dystonia when she was a young adult. Lil's brother Sam Belzberg and his wife Frances Belzberg, parents of Cheri founded the Dystonia Medical Research Foundation in 1976 as a result.

Since 1978, Lil has lead the way for dystonia research support in Alberta. Her efforts in organizing the Calgary Chapter Dystonia Casino Days over the years have raised close to \$400,000 for dystonia research. Before that, Lil volunteered with the Cancer Society for more than 30 years. The Cancer Society made her an honorary member, an honour bestowed on just five people per year.



“A group is only as strong as its leader. We are very lucky to have such a warm, wonderful and knowledgeable leader in Marg Roy” says Mrs. Faider. Lil also shares how proud she is of the medical research advancements in dystonia, and that she hopes that dystonia can

achieve the awareness level that it deserves.

Connie Zalmanowitz, DMRF Canada Board Member

My son Laurie was diagnosed with dystonia in 1995. I became active with the Edmonton Dystonia Support Group in 1999. Brenda Lewis was the President. Both Brenda and her mom Sharon Currey were very helpful and supportive, and along with them and two other active members Donna Bedard and Brenda Hirsekorn, we planned our first Run, Walk and Wheel. We advertised far and wide, received a lot of media support and sent out donor sheets to all our friends, friends of friends and families. That first year we had 300 walkers and collected \$15,000. We kept up the energy for another 2 years, with even better results and lots of community donations. Over the 3 years we made \$50,000 in the Run, Walk and Wheels.



Our energy for organizing the walks dwindled in 2002, but not our resolve to raise funds. At a DMRF meeting in Chicago I learned of other groups that had had success with letter writing campaigns; writing to others touched by dystonia, their friends and families. We had a list of over 900 people that had donated to our cause as sponsors of our walk. Brenda and I wrote personal letters to those we knew and with the help of the group we stuffed 800 envelopes. Our mailing list has gotten smaller over the years but Brenda and I continue to send our letter, updating our supporters on the successes of research and the need for continued funding. Since 2002, the letter campaign has raised over \$120,000, which we have passed to the DMRF-C to fund research and awareness programs to educate healthcare professionals and the public about dystonia.

This past year thanks to the generosity of the Alberta government we were given the opportunity to have our first casino in Oct 2008. In Alberta these are regulated through the Alberta Gaming commission. We enlisted the help of 40 volunteers (family and friends) to help us over the 2 day/night casino. We earned a whopping \$80,000! We plan to use it to fund research and to assist those in our local community who live with dystonia each day through some innovative programming as well as community/medical awareness and education. We will be eligible for another casino in about 2 years.

I never imagined myself to be a fundraiser and never liked asking people for money. But when I see what advances there have been in dystonia research in past 10 years and how it has improved the lives of those living with dystonia, I am so encouraged and cannot help but remain committed.

Marg Roy, DMRFC Calgary Chapter President



My own version of Dystonia is Writer's. It certainly impacted my sales work that required writing quotes, enquiries and orders all day long. Like many people, I had wrestled with this for years before writing became impossible and I was finally referred to a neurologist who recognized the problem immediately. Once I discovered I could still type, my wonderfully supportive employer ended up dragging the whole company into the computer age years before they might otherwise have done.

I was fortunate to discover our local support group through an amazing coincidence. Almost immediately after being diagnosed, my boss's wife mentioned this strange word "dystonia" and my problems at work to her friend Lil Faider. Lil of course knew exactly what this was and contacted me. I met a great assortment of people who had different symptoms than me but the same disorder. In no time, I was encouraged to take over the leadership of our group as then leader Donna Caldwell was working on her Masters Degree in Sociology and all of her time and energy was needed there. Lil and I have worked together since the early 1990's, along with some amazing members of our group who donated their time and energy towards our Newsletter, accounting functions, phone committee and all the other things necessary to keep Calgary Chapter going strong.

We tried different events over the years to raise funds to support our beloved researchers, but our Walk and Wheel of the last thirteen years has been our main annual fundraiser. We have always kept it amongst our own people, their family and friends. For many years we walked and picnicked in a provincial park, but the last few years we have based it from my house and walked the neighbourhood. We follow our walk with a potluck picnic in the yard and this simple version works nicely for us. Of course, we are forever grateful to our Alberta Gaming Commission for the way they disperse the proceeds of the various Calgary Casinos to non-profit groups. Our group with their friends provides the lay staff for two days and nights at a provincially controlled casino and for that effort we receive a portion of the casino profits. Our share has been a staggering amount each 18 months for several years now.

We have a great bunch of people supporting each other and our research efforts. I have learned so much from them and enjoy being a part of our Calgary Chapter. I attended several symposia over the years organized by Foundation and have met some wonderful patients and doctors all dedicated to helping each other and finding our cure. It is truly heartwarming to be part of this movement.

DYSTONIA RESEARCH UPDATE

The Twists and Turns of Dystonia Genes

How Genes Help Us Understand Dystonia

By Christine Klein, MD, Department of Clinical and Molecular Neurogenetics at the Department of Neurology, University of Lübeck, Germany & Member of the DMRF Medical & Scientific Advisory Council

The last 12 months have been a remarkable period in dystonia genetics. Scientists identified or clarified seven genes, loci, and designations for genetic dystonias. Below is a brief update on this expansive topic.

The Known and the New: Dystonia Genes and Gene Loci

There is a growing list of ‘DYT’ genes and gene loci. These genes and loci for familial forms of dystonia represent a ‘mixed bag’ of 20 different dystonia syndromes. All of these dystonia disorders share the characteristic features of involuntary twisting and repetitive movements resulting in abnormal postures. However, the DYT’s vary widely with respect to age of onset, distribution of symptoms, course of the disease, response to treatment, and mode of inheritance.

The year 2008 has seen a particularly large number of changes to the list of DYT’s including:

- Detection of a new dystonia gene (DYT16)
- Identification of new dystonia gene (DYT6) THAP1 gene

- Association of a dystonic syndrome with a gene previously linked to a complex metabolic disorder (DYT18)
- Identification of a new dystonia gene locus (DYT17)
- Designation of paroxysmal kinesigenic and nonkinesigenic dyskinesia as DYT19 and DYT20, respectively
- Re-definition of a suspected new form of dopa-responsive dystonia (DYT14) as the previously known form of dopa-responsive dystonia (DYT5)

Admittedly, it is difficult even for the dystonia specialist to keep up with these rapid changes in gene identification and locus assignment (i.e. mapping of a dystonia gene to a certain part of a particular chromosome). An overview of all currently known DYT’s is given in the table. Select forms will be presented in more detail below:

DYT1 Dystonia Also known as *Primary Torsion Dystonia* or *Early-Onset Generalized Dystonia*. DYT1 dystonia usually begins in

childhood, starts in a limb, and tends to generalize to other body parts as the disorder progresses. The pattern of inheritance is autosomal dominant which means that only one parent needs to have the mutation for a child to inherit that mutation.

Penetrance is reduced to about 30-40%. This means that more than half of gene carriers will remain unaffected throughout their lives despite carrying the mutation. However, they may still pass the mutation on to their children who may develop dystonia.

Unfortunately, it is currently impossible to predict who of the mutation carriers will remain healthy and who will get dystonia. Important recent data indicate, however, that the additional presence of a specific change in the gene sequence of the DYT1 gene (called a polymorphism), that is present in a fraction of both DYT1 mutation carriers as well as of the healthy population, may reduce the risk of developing the disorder.

DYT5 Dystonia *Also known as Dopa-Responsive Dystonia, Segawa Syndrome.* Dopa-responsive dystonia is characterized by childhood onset of dystonia, often in the legs, fluctuation of symptoms throughout the day, and a dramatic response to levodopa drug therapy. The dominantly inherited form of dopa-responsive dystonia is often caused by mutations in the GTP cyclohydrolase I gene (DYT5a). Mutations lead to a decreased production of levodopa and this explains the remarkable therapeutic effect of levodopa substitution.

DYT11 Dystonia

Also known as Myoclonus-Dystonia. In myoclonus-dystonia, a predominantly myoclonic (jerky) syndrome is combined with dystonic features. The symptoms are usually highly responsive to alcohol, and individuals are often affected by psychiatric disorder. Age of onset is usually in the first or second decade of life. The inheritance pattern is autosomal dominant, again with incomplete penetrance.

Myoclonus-dystonia is unique because it is currently the only DYT form where reduced penetrance can be explained and predicted in about 90% of the mutation carriers: If the mutation is passed on from the mother, it will be 'silent' in her children and the mutation

carrier(s) will not develop symptoms. Conversely, if transmission occurs through the father, the mutated gene will not be silenced and manifest as myoclonus-dystonia. As in all other cases of reduced penetrance, the mutation may be transmitted to the next generation through both affected and unaffected mutation carriers.

DYT12 Dystonia

Also known as Rapid-Onset Dystonia-Parkinsonism. Rapid-onset dystonia-parkinsonism is characterized by sudden onset of dystonia, particularly involving the face and throat with problems speaking and swallowing. In addition, the arms are predominantly affected, and signs of parkinsonism are often present such as slowness of movement and muscle stiffness. Symptoms usually manifest over hours to weeks and may be followed by moderate or no progression. Onset of symptoms is in adolescence or young adulthood, and mode of inheritance is autosomal dominant with reduced penetrance due to mutations in the Na⁺/K⁺-ATPase alpha 3 gene.

DYT16 Dystonia

Also known as Generalized Early-Onset Dystonia-Parkinsonism. DYT16 dystonia is a recessively inherited form of early-onset

Definitions and Concepts

Gene – A specific sequence of DNA located on a chromosome that codes for a certain protein

Gene loci – The location of a gene on a chromosome

Genetic - Caused by specific mutations in a person's DNA

Familial - A disorder that is inherited and occurs in multiple members of an extended family

Autosomal dominant - A pattern of inheritance in which only one parent needs to have the mutated gene for a child to inherit the disorder

Autosomal recessive – A pattern of inheritance in which both parents must have the mutated gene for a child to inherit the disorder

Penetrance - The percentage of people who inherit a dystonia gene mutation and actually develop symptoms. For example, only 30-40% of people who inherit the DYT1 mutation will develop dystonia. This phenomenon is called reduced penetrance

Torsion – Usually used in reference to generalized or segmental dystonia. Torsion refers to the twisting element of dystonia. It describes muscles contracting against each other

generalized dystonia associated with mutations in the PRKRA gene. Affected members from three Brazilian families shared the same mutation, inherited from a common founder. This mutation is associated with prominent face and throat involvement, similar to the acute phase of rapid-onset dystonia-parkinsonism.

Genetic Testing: Clinical Application of Dystonia Research

To date, a total of 10 different genes are known among the DYT1s (see table), and commercial testing is available for all of them. Depending on the size of the gene and the test involved, the costs vary per gene, and turn-around times for the results vary between laboratories from a couple of weeks to several months. Genetic testing should always be done in the context of careful genetic counseling both prior and following the testing. While a positive test result may establish a long-sought diagnosis, inform family planning, and even influence treatment choices, it may on the other hand cause uncertainty

and have unwanted implications on family relations. Of important note, although many test results come back negative, this does not necessarily exclude a familial form of dystonia. There are familial forms of dystonia that have yet to be associated with a specific gene and therefore testing is not possible.

The Future of Dystonia Research: Identify New Genes, Understand Dystonia Gene Function, and Find the Cure!



New dystonia genes will continue to be discovered. The identification of new genes and the study of known genes will improve our understanding of the familial forms of dystonia and of dystonia in general. Although genetics are likely to play an important role in the

much more common forms of focal dystonia such as writer's cramp, cervical dystonia, blepharospasm, and musician's dystonia no such factor has yet been unequivocally confirmed. New approaches (such as an approach called genome-wide association studies) have emerged as promising tools to discover dystonia genes. Because these kinds of studies require several hundreds or even thousands of patients, large-scale international research collaborations are necessary to achieve this important aim. The ultimate goal of genetic dystonia research, however, remains the

development of effective drugs for dystonia. It has been shown, for example, that the mutated form of the DYT1 gene can selectively be repressed using a technique called RNAi. While such approaches are unfortunately still limited to cell or

animal models, dystonia researchers are highly committed to translating their findings into better treatment options and a cure for individuals with dystonia.

Table: Forms of Dystonia with a DYT Designation

Designation	Dystonia Type	Inheritance	Gene Locus	Gene
DYT1	Early-onset generalized torsion dystonia	Autosomal dominant	9q	<i>DYT1</i>
DYT2	Autosomal recessive torsion dystonia	Autosomal recessive	Unknown	Unknown
DYT3	X-linked dystonia parkinsonism; “lubag”	X-chromo-somal recessive	Xq	<i>TAF1/DYT3</i>
DYT4	“Non-DYT1” torsion dystonia; whispering dysphonia	Autosomal dominant	Unknown	Unknown
DYT5/ DYT14	Dopa-responsive dystonia; Segawa syndrome	Autosomal dominant Autosomal recessive	14q 11p	<i>GTP-cyclohydrolase</i> <i>Tyrosine hydroxylase</i>
DYT6	Adolescent-onset torsion dystonia of mixed type	Autosomal dominant	8p	THAP1 gene
DYT7	Adult-onset focal torsion dystonia	Autosomal dominant	18p	Unknown
DYT8	Paroxysmal nonkinesigenic dyskinesia	Autosomal dominant	2q	<i>Myofibrillo-genesis regulator 1</i>
DYT9	Paroxysmal choreoathetosis with episodic ataxia and spasticity	Autosomal dominant	1p	Unknown
DYT10	Paroxysmal kinesigenic choreoathetosis	Autosomal dominant	16p-q	Unknown
DYT11	Myoclonus-dystonia	Autosomal dominant	7q	<i>epsilon-sarcoglycan</i>
DYT12	Rapid-onset dystonia-parkinsonism	Autosomal dominant	19q	<i>Na/K ATPase alpha 3</i>
DYT13	Multifocal/segmental dystonia	Autosomal dominant	1p	unknown
DYT14/ DYT5	Dopa-responsive dystonia	Autosomal dominant	14q	<i>GTP-cyclohydrolase</i>
DYT15	Myoclonus-dystonia	Autosomal dominant	18p	unknown
DYT16	Young-onset dystonia-parkinsonism	Autosomal recessive	2p	<i>PRKRA</i>
DYT17	Autosomal recessive primary torsion dystonia	Autosomal recessive	20pq	unknown
DYT18	Paroxysmal exertion-induced dyskinesia 2	Autosomal dominant	1p	<i>SLC2A1</i>
DYT19	Episodic kinesigenic dyskinesia 2	Autosomal dominant	16q	unknown
DYT20	Paroxysmal nonkinesigenic dyskinesia 2	Autosomal dominant	2q	unknown

Adapted from www.ncbi.nlm.nih.gov/omim/. New designations/loci/genes from 2008 are highlighted.

DMRF Canada Welcomes Steve Tremblay as the Province of Quebec Volunteer Representative

Here is my story...by Steve Tremblay

I am originally from Quebec City but was raised mostly in military environments, (PMQ), my father being in the Canadian Armed forces, Quebec, Labrador, France, Germany, Ontario and finally back to the Montreal area where my father retired . Later we left Montreal. and moved to the Saguenay region. This is where I met my lovely wife to be. It turned out we were a perfect fit. We were happily married in 1977. Soon after, we were raising two children – life was great!



Everything changed the 23rd of October 1992, the date of our automobile accident that would forever more govern our lives.

Only after many misdiagnoses, my wife, Ginette was diagnosed with secondary right hemi-dystonia. Now the problem with secondary dystonia caused by trauma is that doctors have a tendency to treat what is apparent and urgent to their eyes. Ginette had a concussion (without loss of conscience) in the accident and was for an hour or so highly confused... absent. She was transported by ambulance to the local hospital but with no apparent trauma other than being bruised and badly shaken. Five or six hours later, was sent home. That same night, Ginette had some sort of seizure, *“like being electrocuted”*, she said. *“I had lost control of my body and couldn’t move, or stop my body from contracting”*.

During the following weeks, Ginette underwent physiotherapy for her stiff neck (double whiplash), her lower back pain and her limping. As the therapy went on, I noticed and even pointed out to the psychotherapist... *“why was her right foot gradually turning inwards when she was pedaling on the stationary bicycle?”* No answers. After the prescribed physiotherapy, Ginette’s limping became worse and her neck didn’t get any better.

During the next months, she began having more and more of these mysterious *“attacks”*... excruciating pain, contractions beginning from the toe, moving up to the ankle, gradually to her whole right leg and finally up to neck and head. These *“attacks”* would last anywhere from thirty minutes to one or two hours leaving her in bed, twisted and weak. I compared these *“attacks”* to the exorcist movie. When the girl would start shaking and her body bent out of shape is taken over by some sort of demon! You can’t start imagining how you feel when you see all this suffering from pain. You can’t help much because doctors don’t know what’s happening.

The years went by, then in 1995, a neurologist by the name of Dr M. Panisset finally diagnosed Ginette with dystonia and put her on the appropriate medication. Many years later, she underwent Botox® treatments for certain *“trigger points”* that still caused unwanted painful muscle spasms.

Before this car accident, Ginette was a very active person and a very skilled medical secretary in the local hospital but unfortunately, even the present therapy did not permit her to get back what she lost. Losing a career you have worked hard to develop and perfect is a tragedy. No human being should have to face the harm dystonia does physically and emotionally.

But Ginette needed to do something. Meet and see people with the same condition as hers. More easily said than done, living six hours away (500km) from big cities like Montreal. Unsuccessful in her quest to meet in person such people, she decided to do something about this situation, on the web. She founded the first online MSN French Canadian forum for people afflicted with dystonia... **Dystonie-Qc** was born.

The goals of **Dystonie-Qc** were to eventually fund research, to spread awareness and education, and to assist (in French) people whose lives and careers have been changed. Within a five year period Ginette associated her website to **DMRF-Canada** in a partnership relation, offering information and support to all French speaking people suffering from dystonia (Quebecers, Canadians or Americans alike). We both yearn for the public to understand the need to find a cure for dystonia but this website is her baby, her creation, and a symbol of her perseverance.

For the past 16 years I had time to live, discover and find out certain essentials about dystonia. For sure, I did a lot of research on the subject and tried to assimilate the most useful information. Lately, working on Ginette's web site gave me an opportunity to be of assistance to whoever is affected by dystonia. To conclude I am very proud to be part of the [*Dystonia Medical Research Foundation – Canada as Provincial Representative, Province of Quebec/Province du Québec.*](#)

Saluting Suzanne Hébert



Suzanne Hébert has served DMRF Canada for over 10 years in many capacities as leader of the Eastern Townships Support Group, the National Leadership Coordinator and Quebec Representative all while managing the French Language TOLL Free help line, and translating, printing and mailing out the DMRF Canadian newsletter French version. Suzanne has travelled to a number of dystonia symposiums and was the DMRF Canada representative at an Allergan symposium in 2004.

Her dedication and enthusiasm to help people with dystonia has been outstanding. Tracy Henry, Tri-County Support Group Leader in Ontario says "Suzanne is very hard working, generous and thoughtful and always has a smile on her face."

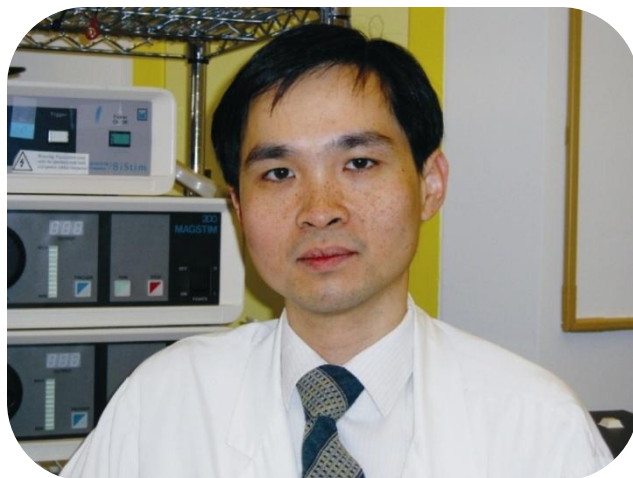
Suzanne is stepping down from her involvement with DMRF Canada. Her participation will be very much missed. We all wish her the very best in life and health.

DMRF Awards Research Grant to Dr. Robert Chen

Robert Chen, MA, MBBChir, MSc, FRCPC, Toronto Western Hospital has been awarded a two year research grant through the DMRF research program.

Title: Effects of internal globus pallidus deep brain stimulation for dystonia on cortical circuits and plasticity.

Dr. Chen is the Catherine Manson Chair in Movement Disorders Professor, Division of Neurology, Department of Medicine, University of Toronto Senior Scientist, Toronto Western Research Institute, Toronto Western Hospital,



Research Description

Deep brain stimulation (DBS) is an effective treatment for dystonia. Although it is still not known how it works, brain reorganization or plasticity likely plays an important role. Brain plasticity is known to be disturbed in dystonia. The proposed study will be performed in people with dystonia who had been treated with DBS of the internal globus pallidus (GPI), the usual brain target for treatment of dystonia. The first project will use recording of electrical brain waves to determine precisely when and which area of the cortex (superficial part of the brain) is activated by GPI DBS. The second project will examine the brain waves produced by GPI DBS is associated with part of the brain known as the motor cortex being more or less excitable. A method known as transcranial magnetic stimulation (TMS) will be used to stimulate the brain as various times after GPI DBS is delivered. The third project will determine whether pairing stimulation of the cortex by TMS and deep brain stimulation of the GPI at critical time intervals will induce brain plasticity or changes how excitable the brain is. The findings will make DBS programming easier and improve the outcome of this treatment. It will also improve our understanding of how DBS works and may lead to novel therapies for dystonia.

Farewell to Barbara Crow as Manitoba Support Group Leader

After 12 years as the Support Group Leader in Manitoba, Barbara Crow is taking a much deserved retirement. Barbara says she has seen a lot of advancements in dystonia research over the years. She enjoys working with people on the DMRFC help support line in Manitoba and will be staying on as an Area Contact so that she can continue reaching out to Manitobans with dystonia. Thank you so much to Barbara and to her husband Brian who have and continue to do so much to help others.



Pictured: Brian and Barbara Crow

Chloe Belisle Managing the French Toll Free Information Line and Start up of Montreal Area Support Group

Chloe Belisle, Area Contact for Montreal West Island, is now managing the TOLL free French help line. Chloe has wanted to play a larger role in helping people with dystonia for some time. Chloe will be starting up our new Montreal Support Group, as well.

"I have learned that dystonia is a part of me, but does not define me."
Chloe Belisle

Chloe has had dystonia since she was a young teenager. For years Chloe did not share that her head was uncontrollably shaking. When she was 17 years old her family doctor noted her shaking and followed up with tests that revealed spasmodic torticollis (cervical dystonia). Treatment with Botox® was recommended and really helped.

Today, Chloe's hands shake and she has trouble writing and has myoclonic jerks in her body. Thanks to medical research and a wonderful neurologist she says she really understands what she is dealing with.

"I have come a long way. And I know that others can too. That is why it is so important to me to help others by working with DMRF Canada managing the support line and starting up the Montreal Support Group."

Toronto Chapter Holds Awareness Day at Yorkdale Mall in Toronto

The Toronto Chapter had a very successful awareness day at Yorkdale Mall on April 16, 2009. The booth attracted the attention of a group who pledged to attend the Toronto Run/Walk on June 7th as a result.

Pictured: Cheryl Cook, Wendy Paul and Cathy Grandison



5th Children & Family Dystonia Symposium

The John H. Menkes 5th Children & Family Dystonia Symposium will take place August 15-16, 2009 at the Holiday Inn Mart Plaza in Chicago.

This is a special meeting for affected children, teens, and their families. The purpose of the symposium is to bring families together to learn about dystonia and the DMRF, interact with experts, and find support among one another. The event is named in memory and honor of John H. Menkes, MD, an iconic pediatric neurologist and founding Scientific Director of the DMRF.

DMRF Canada Joins Neurological Health Charities Canada

NHCC is a collective of sixteen organizations that represent people with chronic, often progressive, brain diseases, disorders and injuries in Canada. NHCC's role is to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health.

The mission of NHCC is to improve the quality of life for all persons with chronic brain disease, disorders and injuries, and their caregivers, by elevating brain health to the top of government agendas; increasing awareness and influencing government decision makers regarding brain health; and, ensuring that research, prevention, treatments and supports for those living with chronic brain conditions are universally accessible and fully funded. For more information visit: <http://www.neurohealthcharities.ca>

Tri-County Support Group on the Move

The Tri-County support group under the leadership of Tracy Henry has been busy raising awareness and fundraising. Beverly Benson (pictured in white) with the Nu Zeta Beta Sigma Phi Sorority raised \$1,150.00 through their "Pasta Dinner" event in January.



In February seven members of the support group went down to Wayne State University Hospital and spoke to nearly 400 medical students about dystonia. They broke up into small groups and met with twenty to twenty five students at a time for twenty minute sessions from 1:00 p.m. till 5:00 p.m. One of the spouses taped the session. Dr. George, head of the movement disorder clinic was so impressed he asked for a copy.

Tracy Henry made two presentations in March and April to different church groups.

June Awareness is Fast Approaching. Here is the most recent calendar of events.

Ottawa/Gatineau Support Group – May 30, Walk & Wheel
Kelowna Support Group – June Awareness, Kelowna General Hospital
Tri-County Support Group – June 7, Freedom to Move Walk
Toronto Chapter – June 7, Freedom to Move 5 km Run/Walk
Calgary Chapter – June 8, Walk and Wheel
Hamilton Area Support Group – June 13, Walk N Wheel
Sudbury Support Group – June 14, Freedom to Move Walk & Wheel
Golden Triangle Support Group – June 27, Walk & Wheel

Please visit our website www.dystoniacanada.org for information on these and other awareness and fundraising events in your area.

The Registered Disability Savings Plan

is a savings plan designed specifically for people with disabilities in Canada. The first of its kind in the world, this new tax-deferred savings vehicle assists families in planning for the long - term financial security of their relatives with disabilities. For more information on the RDSP please visit the Canadian Government Disabilities Webpage: <http://www.servicecanada.gc.ca/eng/goc/rdsp.shtml>

Dystonia Medical Research Foundation Canada Volunteer Leaders and Area Contacts

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