

# Dystonia Medical Research Foundation

## Calgary Chapter

ISSUE # 78

April 2009

### CHAIRPERSON'S CORNER

Hello everyone. As most of you know I have been away for several months enjoying the balmy climate of southern California. We had an easy and wonderful winter, but I know you cannot say the same. It was really amazing to see just how brutal the season was for you and all of Canada. Thankfully we came back to a wonderful break in the weather and know as you do that whatever comes in this next month or two, at least can't last for long. Hope you have all had an enjoyable Easter or Passover with friends and loved-ones.

I see you had a great presentation from Donna Piercy on coping skills in the face of chronic illness, depression, self-acceptance issues or other complications that life throws us. Later in the Newsletter, you will see Heather's excellent write-up. It appears that Donna Piercy has also offered to donate a personal counseling session to our members who might like to benefit from her individual support. Anyone who is interested in this wonderful offer should please advise myself or Heather. If we have a number of people wishing to take advantage of this bonus, we will draw names from a hat and let you know the results personally.

The DMRFC had their first Webinar Session in late March and I believe it was such a success that there will be future efforts using this media. This Webinar enabled many group leaders to hear first hand of the latest information and research going on in our community. Dr Jan Teller who is our Science Officer, spoke for forty-five minutes giving us a good overview and then we were able to submit questions to him. All this over our computers and the internet. Marvelous what technology can do these days. We now have 20 genes identified that are associated with Dystonia. Researchers are continuing this search, but also working to find the specific proteins that are affected by these genes and just how they work. The idea is that a means of turning them on or off as needed will soon be understood. There were questions about the emphasis on the original DYT1 gene, and its protein Torson A that were first discovered ten years ago. There is much work, time and energy being expended on studying this gene as it would appear that there is much common ground among the various genes discovered later and the way the body is affected. This is of course the gene that is best understood and has been replicated in mice, flies and roundworms. Existing

drugs are being researched to find something that would work as it exists, or could be modified, negating the frightfully expensive process in time and money of designing a new drug strictly for us. Someone else wondered if the new release in the USA for work with embryonic stem cell research would make a difference to us. Amazing as the information being learned about the body's ability to rejuvenate itself using stem cells is, it would not mean much to us as Dystonia is not degenerative. For people suffering with Parkinson or MS and such, whose nervous systems are constantly degenerating, this could be huge. All in all, it was very interesting and I look forward to more of these.

Laura McDougall and Wes Teskey had their specialized studies on Dystonia and movement disorders going on over the winter and we will look forward to hearing some of their results or new questions in future meetings. Hopefully many of you were able to volunteer to help in these studies.

There is a Deep Brain Stimulation Symposium in Nashville Tennessee mid April. Anyone who has had DBS, is involved with someone who has had, is seriously considering this surgery or just wants to know the exact state of this procedure and its results were invited. The information presented will be amazing, I'm sure. It is estimated that 1000 people worldwide have now experienced DBS surgery. Our own Libby Graham is making the trip to learn the latest information and meet some of the people who have opted for this major surgery. We know from some of our own people just what a difference it can make in their lives and we look forward to hearing what Libby learns from the larger cross-section of patients and medical personnel at this Symposium.

Time to mark your calendars for our 13<sup>th</sup> annual Walk and Wheel. Again this year it will be centred from my home, in Parkland, SE Calgary. This is planned for the morning of June 13<sup>th</sup>, Saturday. You will see a page of times and driving details further into the newsletter. For anyone who has not experienced this Walk before, we gather for an informal walk around the neighbourhood followed by a pot-luck picnic in our yard. Each of us ask family or friends to sponsor us for a set dollar figure like \$10, \$20 etc. We ask for a set amount rather than a per km as most of us are not in a position to commit to a long, predetermined distance. You can adjust your walk to suit your own health and fitness. Many people do not feel comfortable asking others for a pledge and instead make this the time for their own annual donation to Dystonia research. At any rate, this is an important social gathering for us, as well as our fundraiser. Come out and join us, bring a dish to share, and enjoy the morning. If you are unable to join us but wish to offer a pledge, please do so through one of us who will be taking part, but we would really like to see you if at all possible. It is not necessary that you walk if that is a problem for you, but be sure to come and enjoy the picnic which is always a fun and delicious lunch.

Our next meeting will be Saturday morning, May 2, 10 am to noon at our usual spot. Come and catch up with each other, and provide the support and understanding that each of us rely on in our daily battles with dystonia. We will talk about the two counselling sessions that are being so generously offered to us by Donna Piercy. If you cannot join us, please let us know how you are doing. You will be in our thoughts as always.

Marg Roy

## ITEMS OF INTEREST

### ITEM 1

*Another gene has been discovered! Research goes on, and we help to support it with all our fund-raising efforts. The following is part of an article posted on the DMRF Canada website.*

#### **Genetic Research Leads to New Discovery in Understanding Rare Neurological Disorder**

February 1, 2009 A study led by Laurie Ozelius, PhD at Mount Sinai School of Medicine has identified a gene associated with the development of primary torsion dystonia, also known as DYT6 dystonia. With funding provided by the Dystonia Medical Research Foundation (DMRF), Dr. Ozelius and her colleagues have found that mutations in the THAP1 gene cause DYT6 dystonia in Amish-Mennonite families, as well as in other ethnic groups.

“We are greatly excited about Dr. Ozelius’s findings, as they will help us to better understand the many different factors responsible for this puzzling and disabling disorder,” says Dr. Mahlon DeLong Scientific Director of the Foundation. “Dr. Ozelius has been a pioneer in genetic research on dystonia and we are grateful for her unwavering commitment to this and the broader dystonia community.”

‘I am grateful to the Foundation for their support in this research,’ adds Dr. Ozelius. “The DMRF has supported gene identification studies throughout its history and has been a leader in recognizing that these studies represent an important first step leading to molecular insights into the disease.”

### ITEM 2

At our February meeting, we had an excellent speaker, Donna Piercy. She has 25 years experience in health and wellness, is a Master of Counseling and has studied physical education, educational psychology, exercise physiology, and specialized in disability and rehabilitation. She is a warm, happy and friendly person, and shared with us that she has faced many health-related and emotional issues of her own.

Donna talked about keeping a positive frame of mind; watching for early signs of depression and how to recognize them; self acceptance; controlling the ways we deal with and think about our adversities even if we can’t cure them; and finding our own realities. She said that even though we have dystonia our own true

selves are not broken unless we allow them to be. She reminded us that we should always be kind to ourselves.

I know that some of us sometimes have feelings of isolation, depression and hopelessness. If any of you are feeling like that I would have no hesitation recommending a visit and a chat with Donna. She will understand, and will help you to see your challenges more clearly, and advise on coping techniques. One of her own is petting her pet pig Oscar!

You can contact Donna: Phone: 403-620-1847  
Email: [donnapiercy@efirehise.net](mailto:donnapiercy@efirehise.net)  
Website: [www.backontrak.ca](http://www.backontrak.ca)

As Marg mentioned in her letter, Donna is generously offering our group members some pro bono counseling sessions, this offer will be on-going and there will be a couple of appointments available every month. Let Marg or me know if you are interested. Donna is part of the Back on Trak team in Calgary. They deal with problems of stress, depression, and generally helping people to achieve health balance. Donna told me that if three or four of us want to see her as a group that would work well too. We will talk about all this at the meeting.

*HM*

### ITEM 3

I heard a piece on CBC Radio recently about a new kind of federally sponsored savings plan some of our banks are offering. Its called a **Registered Disability Savings Plan**. The cut-off date for last year was March 2<sup>nd</sup> (just like the RRSP deadline) but you can make contributions any time for this year. You must set up a plan at the bank and complete forms. The **Registered Disability Savings Plan** is dependant on income levels but the government also makes contributions. If your income is below \$21,287, and you have a **Registered Disability Savings Plan** set up, the government will contribute to it even if you do not. For incomes equal to or below \$75,769, you can receive \$3 for every \$1 you put into the plan for the first \$500. For the next \$1000 you put into the plan you will receive \$2 for every \$1. For those with incomes over \$75,769 the government will put in \$1 for every \$1 you put in, up to \$1000 annually. It all sounds a bit complicated, and seems to vary province to province, but might be worth looking into. I think this was initially set up for parents to provide for disabled children, but it is open to anyone, although there is an upper age limit of 59 (that rules me out)!!! Not all banks are offering this yet. As far as I can make out only Bank of Montreal, Royal Bank and CIBC, and I read on another website that you should be wary of setting up with a bank not already in the plan who may promise to get you in "when they join the scheme."

There is a website giving lots more information, it is [rdsp.com](http://rdsp.com) or ask at a bank.

*HM*

## INTRODUCING - Cheri Tannebaum

*This name may be unfamiliar to many of you, but you will all know her aunt, Lily Faider. Cheri has generalized dystonia. I've taken most of the following from Cheri's own writings for the Jewish Press, and part of it from an article in the Chicago News of January 22<sup>nd</sup> 2009 by Karen Meyer .* HM

During the second half of a year at Stern College in New York, Cheri began to see changes in her health. At first she didn't pay too much attention, not realizing that the changes were signs of the serious disease that was starting to take hold of her muscular system: it was called Dystonia.

While walking one day her right foot began to kick her left foot. Then Cheri found that she suddenly couldn't answer a question her mother had asked because her upper lip felt so tight and stiff it wouldn't move. The family doctor sent her to a neurologist who gave her a whole gamut of tests available at that time. The tests were all negative. As Cheri was in perfect health physically, the doctor recommended a visit to a psychiatrist to explore what was wrong mentally.

By this time Cheri had met and married Harvey Tannebaum. As Cheri writes, "Harvey and I had gotten married, hoping that our love for each other, moving to a new city and building a new home would snap me out of my health problems, but we were wrong. I continued to seek medical help while we were living in Los Angeles and finally a doctor identified my condition. I wasn't crazy after all! I was suffering from a rare neurological condition called *Dystonia Musculorum Deformance*, which unfortunately has no cure; the cause is unknown. I was comforted by the findings because now, those who didn't believe me would have to change their views, though I also felt overwhelmed with the knowledge that my symptoms would never leave me. I would be handicapped for life unless a cure would be discovered."

Cheri took a myriad of medications for thirteen years which produced almost no effect. Thirty years ago, Cheri's parents founded Dystonia Medical Research Foundation, gathering doctors and researchers from all over the world to try to find a cure for her. The Foundation has helped many, many people but ironically not Cheri.

Cheri continued to study at various universities. She found that children under five could understand her poor speech, and wanted to become a special education teacher, but discovered that she needed a regular education credential first and there was no way she could handle a group of 30 rowdy youngsters with her speech problem. So, she studied jewelry-making, it let her creativity flow, and she loved it!

Cheri realized that she wanted to have a child. Her daughter, Orit, now in her twenties is perfectly healthy, and is married with a daughter of her own. When Orit was small, the family moved to *Eretz Yisrael* and had two more healthy children. Cheri says, "My children are the joy of my life."

In Israel, Cheri saw a most beautiful skirt. It was made out of men's neck ties. She is now making neck tie skirts, under her label *Designs by Cheri*, and recently traveled to Chicago to showcase her unique designs in an emerging artist program. People donate ties, or she finds them at thrift stores.

Some people think Cheri must be deaf or mentally retarded and they shout. She has taken upon herself a special mission to sensitize others to the differences between us, and she uses a Palm Pilot or a Blackberry to communicate.

"Dystonia is not something I can ever get used to or forget about *for even one second*. No, anytime I need to make a move or say a word, there it is again. Mobilization and communication are the way of the world, and when you are limited in both these areas of life, living is a constant struggle. But, with my armor of faith, my fighting spirit, my courage, creativity and sense of humor and especially with the support of my husband and children, I keep on going, *one second at a time!*"

You can contact Cheri to discuss her article, or to purchase jewelry or tie skirts at: [cherbelz@yahoo.com](mailto:cherbelz@yahoo.com)



## ON THE LIGHTER SIDE

*These are from Teresa. I just love them!*

## CREATIVE PUNS

1. The roundest knight at King Arthur's round table was Sir Cumference. He acquired his size from too much pi.
2. I thought I saw an eye doctor on an Alaskan island, but it turned out to be an optical Aleutian.
3. She was only a whisky maker, but he loved her still.

4. A rubber band pistol was confiscated from an algebra class because it was a weapon of math disruption.
5. The butcher backed into the meat grinder and got a little behind in his orders.
6. No matter how much you push the envelope, it'll still be stationary.
7. A dog gave birth to puppies near the road and was cited for littering.
8. A grenade thrown into a kitchen in France would result in Linoleum Blownapart.
9. Two silk worms had a race. They ended up in a tie.
10. Time flies like an arrow. Fruit flies like a banana.
11. A hole has been found in the nudist camp wall. The police are looking into it.
12. Atheism is a non-prophet organization.
13. Two hats were hanging on a hat rack in the hallway. One hat said to the other, "You stay here; I'll go on a head."
14. I wondered why the basketball kept getting bigger, then it hit me.
15. A sign on the lawn at a drug rehab center said: "Keep Off the Grass."
16. A small boy swallowed some coins and was taken to a hospital. When his grandmother telephoned to ask how he was, a nurse said, "No change yet."
17. A chicken crossing the road is poultry in motion.
18. The man who survived mustard gas and pepper spray is now a seasoned veteran.
19. When cannibals ate a missionary, they got a taste of religion.
20. Don't join dangerous cults. Practice safe sects!



*Memberships for 2009 are due. Please bring to a meeting or send to Brian, see form below. Thanks!*

DYSTONIA MEDICAL RESEARCH FOUNDATION, CALGARY CHAPTER

CONTACTS

Chairperson: Margaret Roy - 403-271-4438

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Heather MacLellan - 403-289-0736 e-mail: hethmac@telus.net

NEXT MEETING

TIME 10 am to 12 noon

DATE Saturday, May 2<sup>nd</sup>, 2009

LOCATION DEVELOPMENTAL DISABILITIES RESOURCE CENTRE,  
4631, RICHARDSON WAY, SW, CALGARY.

GUEST SPEAKER. None

MEMBERSHIP FORM - 2009

NAME:

ADDRESS + POSTAL CODE:

PHONE: \_\_\_\_\_

TYPE OF  
DYSTONIA: \_\_\_\_\_

Please check off one of the following: New \_\_\_\_\_ Renewal: \_\_\_\_\_

MEMBERSHIP FEE: \$20.00

Please mail cheque payable to: DMRF Calgary Chapter

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