

# Dystonia Medical Research Foundation

## Calgary Chapter

ISSUE # 82

May 2010

### CHAIRPERSON'S CORNER

Hello everyone. Hope you are all enjoying our spring and wonderful sunshine. Calgary usually a mixed bag of weather about now, but behaving very well overall. Lots of beautiful days for us to get outside and shake off the winter cobwebs. We are back from California and did have a very easy winter. Winter was cooler than normal there, but positively balmy as far as we were concerned. We had a hard snowy trip home, but great once we got to Calgary.

I did manage to attend a second support meeting in Palm Desert. This one was set up to have Dr Hermanowitz talk on the current status of Dystonia information and also that of Essential Tremor. Their group is made up of a combination of people affected by these two problems. This seems to work very well for them and Kim Hough is an excellent leader. Dr Hermanowitz's talk was very interesting and he then took many questions from the group, answering in his very relaxed and personable style. I said that we often hear Essential Tremor referred to as Benign Essential Tremor and he said that was an old name: there is nothing benign about it and the word has been dropped. I believe there were over 100 people at this presentation. They did this special evening event last year as well and it was very well accepted. Dr Hermanowitz is a local Neurologist who dedicates much time and energy to this support group and many of these people were his own patients.

Our Casino Days were accomplished with a little mad scrambling by Lil at the last moment to keep us organized. Life came along with illness and other complications affecting those who had planned to help us, but Lil managed to get

us a full working complement. Kudo's to her as always and thanks to all of you who helped with this major fundraiser for us. We will learn of our earnings later this quarter.

There has been some reorganization within the Dystonia Medical Research Foundation and Canada is now recognized as a separate entity. We of course still work just as closely with the Foundation in the USA, but are no longer considered simply a region. Diane Gillespie now holds the title of Executive Director of Dystonia Medical Research Foundation Canada. Congratulations to her for this recognition of all her hard work and the progress made with our Federal Government, the Department of Health in particular and the Neurological Health Charities Canada (NHCC). We now have a Canadian research grant where a Canadian Institute of Health Research program shares the funding with monies raised by ourselves. You will recall we met Diane last fall when she came out to visit us and told us about all the wonderful projects she has on the go for us.

It is time to mark your calendars for our annual Walk and Wheel scheduled this year for Saturday, June 12. This will again be centred from Gord's and my place in Parkland. Location details and pledge sheets are further into this newsletter. We meet here, walk the neighbourhood and then return to the house for a pot-luck picnic. This is the time of year, we all ask our family and/or friends to support us with a pledge for our walk. As we all have different distance abilities, we ask for a flat sum, nothing based on laps or specific distances. All donations are appreciated and all those of \$10 or higher will receive Income Tax receipts. If you do not feel you can ask others for financial support, then make this the time for your personal donation. This is our one personal fundraiser of the year and your help and support in this is very important to us all. This walk and the always delicious picnic based from our yard seem to work for us and we hope many of you will join us this year. We need help from each of you to keep our amazing researchers working for us. Research project results are what separate us from a full cure. Remember that when this cure is found, because Dystonia is not a degenerative disease, it will simply go away. Staggers the mind, doesn't it!

Our next meeting will be May 15, Saturday morning 10 to noon at our usual spot, the Calgary Developmental Disabilities Bldg. Do come out and lend your personal strengths, insights, and support so important to each of us. If you cannot join us, please let us know how you are doing as you will be in our thoughts.

Marg Roy

## ITEMS OF INTEREST

Greetings from DMRF's New President - Art Kessler





I essentially grew up with the **Dystonia Medical Research Foundation (DMRF)** and it is my great pleasure to now serve as President of the Board of Directors. My predecessor Claire Centrella led the DMRF through many important and exciting years, and her leadership was critical to our success. I join the dystonia community in thanking her for her committed and steadfast service.

A little about me: my parents, Dennis and Barbara Kessler, have been involved with the DMRF since the very beginning. Their commitment was fueled by the desire to make a significant difference in the quality of my life, for I had been diagnosed with early onset dystonia at the age of 12. This diagnosis came after years of unexplained symptoms, countless doctor visits, and many a sleepless night.

As a child, I was struck by their drive to make things better, not just for me, but for all families devastated by this disorder. They taught me to work hard for a cause bigger than myself and that is exactly what I plan to do. They didn't give up and they instilled in me that same unyielding desire to find the answers.

I support the work of the DMRF because it is making a difference. As an adult, I learned that I was positive for the DYT1 gene mutation, a gene found through funding by the DMRF. My two sons were conceived through a form of *in vitro* fertilization that ensured they would not inherit the mutated gene. They are dystonia free and, at 6 and 2 years old, are busy and energetic. Their childhood will be very different from mine, and that means the world to me.

In 2007, when it became too painful to walk to the park with my son, I decided to undergo deep brain stimulation surgery, the results have been life changing. My wife and sons now have a husband and father who, despite having dystonia, is physically able to be active and fully engaged. None of this would have been possible without the DMRF.

I know dystonia. I know the DMRF. Over the years, I have come to know many of you and I am optimistic about our future and our plans to wipe out dystonia. I look forward to working hard on your behalf and with your partnership. Thank you for your support.

Sincerely,

Art Kessler  
President



## ON THE LIGHTER SIDE

A mechanic was removing a cylinder-head from the motor of a Harley motorcycle when he spotted a well-known cardiologist in his shop. The cardiologist was there waiting for the service manager to come and take a look at his bike when the mechanic shouted across the Garage, 'Hey Doc, want to take a look at this?' The cardiologist, a bit surprised, walked over to where the mechanic was working on the motorcycle. The mechanic straightened up, wiped his hands on a rag and asked, 'So Doc, look at this engine. I open its heart, take the valves out, repair any damage, and then put them back in, and when I finish, it works just like new. So how come I make \$39,675 a year and you get the really big bucks when you and I are doing basically the same work?' The cardiologist paused, smiled and leaned over, then whispered to the mechanic...

'Try doing it with the engine running.'

*Teresa sent me this one in an email:*

### The Irish...

Six retired Irishmen were playing poker in O'Leary's apartment when Paddy Murphy loses \$500 on a single hand, clutches his chest, and drops dead at the table. Showing respect for their fallen brother, the other five continue playing standing up.

Michael O'Connor looks around and asks, 'Oh, me boys, someone's got to tell Paddy's wife. Who will it be?'

They draw straws. Paul Gallagher picks the short one. They tell him to be discreet, be gentle, don't make a bad situation any worse.

'Discreet??? I'm the most discreet Irishmen you'll ever meet. Discretion is my middle name. Leave it to me.'

Gallagher goes over to Murphy's house and knocks on the door. Mrs. Murphy answers, and asks what he wants.

Gallagher declares, 'Your husband just lost \$500, and is afraid to come home.'

'Tell him to drop dead!', says Murphy's wife..

'I'll go tell him.' says Gallagher.

*And this from a friend in the UK:*

## **WHY?**

Why does Safeway make the sick walk all the way to the back of the store to get their prescriptions while healthy people can buy cigarettes at the front?

Why do people order double cheeseburgers, large fries, and a diet coke?

Why do banks leave both doors open and then chain the pens to the counters?

Why do we leave cars worth thousands of dollars in the driveway and put our useless junk in the garage?

Why do they have drive-up ATM machines with Braille lettering?

EVER WONDER ....Why the sun lightens our hair, but darkens our skin ?

Why women can't put on mascara with their mouths closed?

Why don't you ever see the headline 'Psychic Wins Lottery'?

Why is 'abbreviated' such a long word?

Why is it that doctors call what they do 'practice'?

Why is the man who invests all your money called a broker?

If flying is so safe, why do they call the airport the terminal?

Why is the time of day with the slowest traffic called rush hour?

Why isn't there mouse-flavoured cat food?

Why didn't Noah swat those two mosquitoes?

Why do they sterilize the needle for lethal injections?

You know that indestructible black box that is used on planes? Why don't they make the whole plane out of that stuff?!

Why don't sheep shrink when it rains?

Why are they called apartments when they are all stuck together?

*A little philosophy I received in an email recently:*

## **TWO WOLVES**

One evening an old Cherokee told his grandson about a battle that goes on inside people.

He said, "My son, the battle is between two wolves inside us all. One is Evil - It is anger, envy, jealousy, sorrow, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority, and ego. The other is Good. It is joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, truth, compassion and faith."

The grandson thought about it for a minute and then asked his grandfather: "Which wolf wins?"

The old Cherokee simply replied, "The one you feed."



*Please remember to let me know if you change your address or email address, or if you no longer want to receive this newsletter.*

*Memberships now due for 2010!*

**DYSTONIA MEDICAL RESEARCH FOUNDATION, CALGARY CHAPTER  
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**NEXT MEETING**

<b>TIME</b>	10 am to 12 noon
<b>DATE</b>	Saturday, May 15th 2010
<b>LOCATION</b>	DEVELOPMENTAL DISABILITIES RESOURCE CENTRE 4631, RICHARDSON WAY, SW, CALGARY
<b>SPEAKER</b>	None

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**MEMBERSHIP FORM 2009**

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

PHONE: \_\_\_\_\_ EMAIL ADDRESS: \_\_\_\_\_

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

Please check one:            New \_\_\_\_\_            Renewal \_\_\_\_\_

MEMBERSHIP FEE \$20

Please mail cheque payable to:    DMRF Calgary Chapter

To:                    Brain Larke, Treasurer  
                          29, 275 Woodridge Dr. S. W.  
                          Calgary, Ab T2W 4S4