

Dystonia Medical Research Foundation

Calgary Chapter

ISSUE # 81

February 2010

CHAIRPERSON'S CORNER

Hello everyone. Hope you have gotten the New Year off to a good start and didn't make too many resolutions to unfairly challenge yourselves. One about appreciating the many good things in our lives and another about being healthier are plenty for most of us.

Our last meeting we were happy to have Diane Gillespie, our National Director join us. It was most interesting to hear the various projects she has underway for Education and Fundraising. She has been working closely with the Federal Government re matching grants for some of our research programs. You will see further into this Newsletter an outline of her talk. This was an excellent presentation for those who could attend and I want the rest of you to be afforded the chance to learn some of what we did. It was great to meet Diane who is an energetic, committed and generous leader for us all.

As you know, I have escaped for a good part of the winter. We are in southern California and thoroughly enjoying ourselves. It has been raining here for the last week, just so you know it isn't perfect here: close though. Unusual for this area to get so much rain at one time, just about their year's worth, so causing real problems in some areas. The desert does not handle monsoons well. Know your winter was off to a tough start, but hope that eases off a little. Know how those Chinooks are cherished.

While here I have had the good fortune to attend a Support Group Meeting in the valley. Very interesting to see how this group is doing under the very capable and warm leadership of Kim Hough. Kim has S.T. and when finally diagnosed two years ago, she asked about a support group in the area. On hearing there

was nothing closer than San Diego or Los Angeles, she jumped right in and formed a group for the Coachella Valley. They meet at a local hospital about every six weeks and theirs is a combined group of Dystonia and Essential Tremor patients and their support people. There were twenty some people at this meeting and my timing to catch this was perfect in that we had a very special speaker. Fran Belzberg, co-founder with her husband, of our very Foundation was in town and gave us a great understanding of its beginnings and the tough reasons behind it. They started the Dystonia Medical Research Foundation and its Scientific Board with three Neurologists who between them had seen two or three people with dystonia in their careers. The Belzbergs as lay people sat right in with the doctors as the merits were discussed and decisions made about which research projects to support. To this day, the Board Members attend the Scientific Board Conferences hearing all the discussions and decisions reached about where our treasured funds are directed. Having the Board present and involved in the Grant process is apparently unique among research foundations. We heard how patients with dystonia started to appear once there was a group of doctors knowledgeable and dedicated to their needs and conditions. Even more so, once Alergan's Botox was approved and an available treatment seemed possible. As you know, there have been a number of drugs used over the years, but the side effects are generally very difficult to tolerate. Botox seemed the most effective and best tolerated solution. Of course, now we have another couple of versions of this botulinum toxin, including the new Xeomin by Merz, a pharmaceutical company in Germany. It is very helpful for doctors and patients to have choices. DBS surgery is now so successful for many of our people, but is not suitable for the Belzberg's daughter Sherri, who started all this help for us. She has a complicated life due to this disease, but has raised a loving family and adapted her life to accommodate her condition. She does all this with the love and support of her family, and much personal determination and great courage. Marvellous to hear of all this foundation history from the warm, caring and knowledgeable bundle of energy that is Mrs. Fran Belzberg.

Remember that our Casino Days are coming up beginning of March and Lil Faider has been working to get our team together to staff these two days. This time of year, many of our friends who normally work a shift for us are away. This organizing can be a challenge at the best of times, so please contact Lil and offer your services. I know she has been working diligently to settle all this, but there are always surprises and extra people needed when the actual dates come along. Do volunteer to help us in this major fund-raiser commitment.

Your next meeting is scheduled for Saturday, February 27th, our usual spot at the Developmental Disability Bldg, from 10 to noon. Aside from the normal generous support you exchange, you will see a video about Billy McLaughlin, a guitarist who has reclaimed his gift of music while battling with Dystonia. I will be thinking of you all and sending my best wishes along. If you cannot join us, please let us know how you are doing as you will certainly be in the hearts and minds of those gathering.

Marg Roy

Marg, we all extend a huge THANK YOU to you for your work on our behalf, which continues wherever you are. I know that you put in hours of effort that we don't see or hear about, and without you our support group would not be the steady success that it is.

HM



FOLLOWING IS AN OUTLINE OF THE INFORMATION DIANE GILLESPIE, OUR NATIONAL DIRECTOR, PRESENTED US WITH WHEN SHE ATTENDED OUR OCTOBER MEETING. IT WAS WONDERFUL TO HEAR FIRST HAND OF THE GROWING MOMENTUM IN RESEARCH, AWARENESS AND GOVERNMENT SUPPORT THAT IS UNDERWAY WITHIN CANADA.

Marg

DMRF Canada is part of the National Health Charities Canada who has successfully lobbied the Canadian Government to fund a \$15 million study of neurological conditions including Dystonia, over a five year period. There is a standing committee in Parliament dedicated to this. I am fully active and engaged in this initiative, attending meetings and on the membership committee.

In terms of research we contribute to the DMRF research program that funds the best world wide research in Dystonia, through this collaboration we are funding Dr. Robert Chen's research in Deep Brain Stimulation out of Toronto Western Hospital. We are also funding two Canadian fellowships in partnership with the Canadian Institutes of Health Research.

We are eager to promote Canadian research, and in doing so I attended the Canadian Neurological Health Sciences Federation Congress last June, and had an awareness booth, promoting Dystonia research. I also sent letters and emails to all the Canadian Dystonia researchers and neurologists encouraging their fellows to apply for our 2010 competition. I am pleased to say that as a result we have had an unprecedented number of qualified applicants this year.

Our strong network of Support Groups and Area Contacts continues to support awareness activities in June and throughout the year. We craft press releases for Support Group use for Dystonia Awareness week, and provided all of the groups with events with Freedom To Move baseball caps as fundraising bonuses. We also provided pledge sheets both printed and on-line available from the various Support Group websites.

The Dystonia Canada newsletter is published in the spring and the fall. The fall issue is combined as an annual report with our financial statements. This is no longer coming from the United States DMRFC.

All of our pamphlets and brochures have been changed to be of Canadian content only, and our Canadian website is now one year old and visited by 3,000 people each month.

Diane Gillespie, National Director, DMRFC

EDITOR'S ESSAY

When I was at school, many, many years ago, we had to write a lot of essays. We were told it meant "an attempt" or "a try" from the French *essayer*, to attempt or to try. I wonder if kids still have to write lots of essays? Everything is probably more high-tech by now!

In the most recent copy of Dystonia Canada Report (copies of which I have to hand out at the next meeting) there are several encouraging write-ups about current research into Dystonia. Dr Xiang is looking at drugs like Artane, which often produce intolerable side effects, and trying to find compounds that work on the same parts of the brain but cause fewer side effects. Anne Blood, PhD is using MRI images to track abnormal brain activity in Dystonia patients. Work is being done on genetic Dystonia and why some family members are protected while others are vulnerable to symptoms. These are just three avenues of research mentioned, but I know there are many other scientists all over the world working on our behalf to find better treatment, or a cure, for Dystonia. This is exciting and wonderful news, but it all takes money. Each June at our Walk and Wheel we raise money for research in Canada, which in due course will benefit all of us. If there are any of you who missed the Walk but would still like to make a donation its not too late! You can send a cheque to our treasurer, Brian Larke whose contact information is on the last page of this newsletter. Cheques should be made out to DMRF Calgary Chapter. It is time for the 2010 membership dues, so a research donation could be included with that. Receipts will be issued for amounts over \$10. The membership is for our support group expenses and postage for the newsletter, but anything extra will go straight to Toronto for research. Even small amounts add up, so if you could contribute now, or next June when we will be having our next Walk and Wheel, it would be much appreciated, and may speed us towards a cure. Who knows? All we can do as lay people is "to attempt" or "to try" to help the doctors and scientists working on our behalf to get closer to that goal by giving to Dystonia research.

HM

INTRODUCING: Brian Larke

Here is the next part of Brian's story:

Up to this point I have related some of my life experiences in the U.K and I am now progressing to life in Canada.

In the Fall of 1966 we contacted Canada House to see if we would be able to emigrate to Canada and filled out reams of forms with lots of questions to be answered. I was not familiar with the term "ethnic" origin and I had to look in a dictionary to find the meaning. We then had an interview with a representative from the Canadian Embassy who assured us that we could emigrate as soon as we were ready, pending satisfactory medicals.

The Canadian Government would give us a "no interest loan" to pay our air fare!

Decisions, decisions!!! Would it be fair to leave Sheila's father, who had lost his wife less than two years previously? We are both only children. Would it be fair to our parents to deprive them of seeing their grandchildren grow up? Were we being selfish and not thinking of other's feelings? What about health care? How much would we make? What if we don't like it when we get there?

At the time I was making about 20 pounds (\$60) a week plus expenses and Sheila was making 11 pounds (\$33) a week and we had a mortgage costing 13 pounds (\$39) a month. I had a company car and Sheila was driving a Renault Gordini (a piece of junk, but it was better than walking). We did not have any debts other than a mortgage at a fixed rate of 5%. Were we crazy thinking about leaving all this to move half way round the World, to what?

Meanwhile Lois had contacted her sister in Calgary who was prepared to meet us and give us a place to stay until we got settled in. It all seemed too easy, things were falling into place and we were destined to go to Canada.

Later in the Fall of 1966 I went to London on a sales training course with Oxo. While there I decided to go to see a technical placement agency based in London, the one that George had used to get a job in Canada. The results were amazing. A few minutes into the interview the agent picked up the 'phone and to my amazement called to their Toronto office and I was offered a job in Calgary with Dominion Bridge starting as soon as I could get there, with the princely sum of \$550/month (185 pounds/month) more than twice as much as I was making in UK.

So the die was cast, and we were Calgary bound. The next few months were spent in selling our house and the disposal of our furniture and arranging for the transport of the things we wanted to take with us. When we left UK we had about \$6500 in the bank to start our new life.

At the end of February 1967 we left UK bound for Canada,

Monday: Feb 26, We flew from Heathrow to Toronto.

Tuesday: Feb 27, We flew from Toronto to Calgary and were met by Ed & Dolores Madsen.

Wednesday: Feb 28. I checked in with Dominion Bridge and arranged to start the following Monday.

Thursday: March 1, I took my driving test in a British Morris Minor which belonged to the Madsen's and passed despite trying to change gear with the door handle.

Sheila went to Canada Manpower, was sent to Pacific Pete, and was hired on the spot after taking a typing test on an electric typewriter. It was the first time she had seen an electric machine and was timed at 120 wpm.

Friday: March 2, Moved into a furnished apartment costing \$135.00/ month.

Saturday: March 3, Bought an almost new 1966 Ford Mustang, white with red upholstery.

Sunday: March 4, Went to Banff with the Madsens, went in the hot springs.

Monday: March 5, We both started work!!!!!!!!!!.

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ON THE LIGHTER SIDE

Teresa sent me this, it sure has cleared up a lot of computer mysteries for me!!??!! If you don't have a computer, just enjoy the poetry.

Why Computers Sometimes Crash! By Dr. Seuss. Read this aloud to yourself - it's great!

If a packet hits a pocket on a socket on a port, And the bus is interrupted at a very last resort, And the access of the memory makes your floppy disk abort, Then the socket packet pocket has an error to report.

If your cursor finds a menu item followed by a dash, And the double-clicking icon puts your window in the trash, And your data is corrupted cause the index doesn't hash, Then your situation's hopeless and your system's gonna crash!

If the label on the cable on the table at your house, Says the network is connected to the button on your mouse, But your packets want to tunnel to another protocol, That's repeatedly rejected by the printer down the hall, And your screen is all distorted by the side effects of gauss, So your icons in the window are as wavy as a souse; Then you may as well reboot and go out with a bang, 'Cuz sure as I'm a poet, the sucker's gonna hang.

When the copy on your floppy's getting sloppy in the disk, And the macro code instructions are causing serious risk, Then you'll have to flash the memory and you'll want to RAM your ROM, And then quickly turn off the computer and be sure to tell your Mom!



HOW DO YOU DECIDE WHOM TO MARRY?

1. HOW DO YOU DECIDE WHOM TO MARRY? (written by kids)

You got to find somebody who likes the same stuff. Like, if you like Sports, she should like it that you like sports, and she should keep the chips and dip coming.

-- Alan, age 10

No person really decides before they grow up whom they're going to marry. God decides it all way before, and you get to find out later who you're stuck with.
-- Kristen, age 10

2. WHAT IS THE RIGHT AGE TO GET MARRIED?

Twenty-three is the best age because you know the person FOREVER by then.
-- Camille, age 10

3. HOW CAN A STRANGER TELL IF TWO PEOPLE ARE MARRIED?

You might have to guess, based on whether they seem to be yelling at the same kids.
-- Derrick, age 8

4. WHAT DO YOU THINK YOUR MOM AND DAD HAVE IN COMMON?

Both don't want any more kids.
-- Lori, age 8

5. WHAT DO MOST PEOPLE DO ON A DATE?

Dates are for having fun, and people should use them to get to know each other. Even boys have something to say if you listen long enough.
-- Lynnette, age 8

On the first date, they just tell each other lies and that usually gets them interested enough to go for a second date.
-- Martin, age 10

6. WHEN IS IT OKAY TO KISS SOMEONE?

When they're rich.
-- Pam, age 7

The law says you have to be eighteen, so I wouldn't want to mess with that.
-- Curt, age 7

The rule goes like this: If you kiss someone, then you should marry them and have kids with them. It's the right thing to do.
-- Howard, age 8

7. IS IT BETTER TO BE SINGLE OR MARRIED?

It's better for girls to be single but not for boys. Boys need someone

to clean up after them.
-- Anita, age 9

8. HOW WOULD THE WORLD BE DIFFERENT IF PEOPLE DIDN'T GET MARRIED?

There sure would be a lot of kids to explain, wouldn't there?
--Kelvin, age 8

And the #1 Favourite is.....

9. HOW WOULD YOU MAKE A MARRIAGE WORK?

Tell your wife that she looks pretty, even if she looks like a dump truck.
--Ricky, age 10



Had this in an email the other day, its by Vivian Greene:

Life is not about waiting for the storm to pass, its about learning to dance in the rain!



Please remember to let me know if you change you 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
CONTACTS**

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Treasurer: Brian Larke 403-281-5562 email: angela07@telus.net

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NEXT MEETING

TIME 10 am to 12 noon
DATE Saturday, February 27th 2010
LOCATION DEVELOPMENTAL DISABILITIES RESOURCE CENTRE
4631, RICHARDSON WAY, SW, CALGARY
SPEAKER We will show the movie about guitarist Billy McLaughlin

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: Brian Larke, Treasurer
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