



Dystonia Medical Research Foundation

Calgary Chapter

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CHAIRPERSON'S CORNER

Happy New Year to each of you! I hope this last holiday season was filled with the warmth and happiness that loved ones can bring or send you. May 2012 be a happy and healthy year for you and all the special people in your lives.

New Year is always a great time to think of all the members of our group who have generously supported us with their time and energy: Heather MacLellan who organizes, publishes and distributes our Newsletter and does such a fine job of it; Brian Larke who has once again been our able treasurer, handling that myriad of duties for us; Teresa Ebbeling who was our long-time contact for new members or their families who needed information and an understanding person. Lil Faider has once again organized and overseen our Casino Days this year along with anything else she could think of to do for us. Lil, of course, also serves as a Director of the Dystonia Medical Research Foundation Canada as she has for many years. We owe a special thank you to all these people and more. Many of you support in other ways as well, be it our phone committee, contributions to the newsletter, monetary gifts or just being there for someone who needs a friendly ear and open heart. Within our group, we support or lean, teach or learn from each other in turn depending on our feelings any particular day - these are great gifts to be able to receive or give.

Our casino days went smoothly this year again thanks to Lil and her friends who aid us in all the lay positions we must fill. Happy to report we had 13 of our own group members volunteer shifts over these two days. Thanks to each of you, we all know how important this event is to our research efforts into Dystonia. We were able to send \$77,000 to DMRFC this year from this event. Wonderful system our province has for distributing the proceeds from the Gaming/Lottery

Commission. As I expect you know, the distribution formula changed this last year or two to allow more funds to go to rural areas rather than keep all the urban proceeds for urban groups. They are trying to make the system more equitable, but of course it spreads the funds wider and thinner. Still, this is an amazing infusion of cash for the work of our Foundation.

Teresa Ebbeling has now retired out to the Cranbrook area and so has handed her contact duties on to Brian Larke. We thank her for all her years as our first contact and the personal support she has been to us all. Hopefully she and Ken will make it back some time to coincide with one of our meetings.

As we are now meeting only twice a year, we will not get together again until April. This does not mean you are not in my thoughts and I look forward to hearing from any of you about how you are doing in the meantime. I know this goes for the others in our group as well. You can always contact one of us listed in the newsletter if you are trying to reach someone in our group.

Take care and know I wish you and yours a happy and healthy 2012.

Marg Roy

And a big THANK YOU from all of us to you too, Marg!

ITEMS OF INTEREST

ITEM 1

**Highlights from the 5th International Dystonia Symposium
October 20-22, 2011 - Barcelona, Spain**

Thanks to Diane Gillespie for sending me this information.

"This is a momentous year," remarked Stanley Fahn, MD on day 1 of the 5th International Dystonia Symposium held on October 20-22, 2011 in Barcelona, Spain. "The first definition of dystonia was published exactly 100 years ago in 1911." So it was all the more fitting that this year was marked by the most comprehensive scientific symposium on dystonia to date. Dr. Fahn went on to praise the debate and discussion that was taking place at the symposium, commenting that this is what is needed to move the field forward.

The 5th International Dystonia Symposium (IDS5) represents the latest chapter in a definitive series of international dystonia meetings organized by the Dystonia Medical Research Foundation (DMRF) since 1975, the last of which was held in 2002 in Atlanta with 150 attendees. This year, the symposium attracted 560

dystonia clinicians and researchers from 38 countries. The audience was an encouraging mix of established dystonia experts and up-and-coming movement disorder specialists.

The symposium was a joint organizational effort of the European Dystonia Federation, the National Institute of Health funded Dystonia Coalition, and the Dystonia Medical Research Foundation (DMRF). Individual dystonia patient groups funded travel scholarships for young investigators and industry sponsors provided additional support.

IDS5 brought together renowned researchers and clinicians for an extensive, three-day program of presentations and discussions on multiple topics including clinical issues, functional anatomy, pathophysiology, genetics and molecular biology, treatments, and the very latest developments in treatment approaches. The Symposium was the most comprehensive meeting on dystonia to date.

The purpose of the meeting was not simply to rehash what is known about dystonia but to challenge current thinking, explore controversial topics, and push forward into a deeper understanding of the disorder and how to treat those who are affected. Sessions and topics were designed to spark discussion between speakers and the audience, and at least one especially controversial topic was scheduled for debate every afternoon. In addition to oral presentations, poster sessions presenting preliminary findings of ongoing research were scheduled each day. The breadth of topics, from primary and secondary forms and beyond, included what fundamental lessons specific forms of dystonia can teach us about all the dystonias. Discussions consistently circled back to how the topic at hand was relevant to benefiting patients. Each section of the program concluded with a panel discussion of issues raised during the presentation and important considerations for the future.

It was not uncommon to hear attendees remark that this was the best dystonia symposium they had ever attended. The symposium demonstrated how much is known about dystonia, and challenged how to best apply what we know to develop and discover new treatments.

INTRODUCING BRENDA (CURREY) LEWIS

President Edmonton Support Group

Living with Generalized Dystonia

In 1974 when I was seven years old, my muscles forced me to walk on the outside of my right foot. I was extremely lucky to be diagnosed with generalized dystonia within six months from the start of my symptoms. It usually takes years

and not months to be correctly diagnosed. Considering it was 1974 my speedy diagnosis was even more of a miracle.

After my diagnosis, my dystonia progressed quickly and in less than a year of the first symptoms; my right arm, leg and torso were twisting and pulling me in many directions. It began with weird posturing of my foot, and moved upward from there. Medication was not helping me significantly and there were no other options than a brain surgery called a Thalamotomy. I had this surgery combined with others including orthopedic surgery.

With the surgeries I have experienced some serious side effects including a stroke and the development of a tremor from left shoulder to my hand. Many of my symptoms on my right side have been relieved from the after-effects from the stroke. I still feel the dystonic pulling if I try to strengthen those muscles. My left leg, torso & arm tremor are still active.

I was diagnosed one year before the Dystonia Medical Research Foundation was founded in 1976. My mother was thrilled to find that there was now somewhere to go for information and support. At that time awareness and help were lacking, keeping many people in the dark. What is dystonia? Where did dystonia come from? What can we do about it?

In 1993, I joined the Edmonton Dystonia Support Group as co-president and am now President with a focus on fundraising working alongside Connie Zalmanowitz, DMRF Canada board member. It has been a rewarding job. I held meetings, wrote a newsletter at least three times a year and met some really great people. I did do small fundraisers but that changed when I got the call from Connie. Connie's son Laurie had been diagnosed with dystonia and she wanted to help through fundraising. Connie volunteered to take charge of a Run, Walk and Wheel event and I enthusiastically said YES!

With Connie's organising skills and hard work and great helpers, we raised \$16,000 and 300 people turned out for a walk through Edmonton's beautiful Hawrelak Park. We held the event for two more years and have kept up the level of donations with letter writing campaigns. We now organize *profitable* casinos every two years through the Alberta Gaming Commission.

My symptoms still fluctuate. I've gone through times of struggle and total dependency to times of fair manageability. I'm fairly independent now. I use an electric wheel chair and can transfer from it and take a few steps here and there with relative ease. My mom and dad are a constant source of help and encouragement. I live alone in my home with family, friends and neighbours helping me tremendously with maintenance and home care. I am not in pain, which is a great blessing, but I know it may not always be the case. I believe my enjoyment of laughter and humour contributes a great deal to helping me.

I feel strongly about dystonia awareness. That is why I have written a book about my life before and after the onset of dystonia. Hopefully I will find a publisher soon. Considering I have had the disease for 37 years yet it still surprises me that dystonia is still relatively unknown. Let's all keep our hopes high!



ON THE LIGHTER SIDE

Trivial Pursuit

Can You Guess Which Of The Following Are True And Which are False?

Answers later in the newsletter

1. Apples, not caffeine, are more efficient at waking you up in the morning.
2. Alfred Hitchcock didn't have a belly button.
3. A pack-a-day smoker will lose approximately 2 teeth every 10 years.
4. People do not get sick from cold weather; it's from being indoors a lot more
5. When you sneeze, all bodily functions stop, even your heart!
6. Only 7 per cent of the population are lefties.
7. Forty people are sent to the hospital for dog bites every minute.
8. Babies are born without kneecaps. They don't appear until they are 2-6 years old.
9. The average person over 50 will have spent 5 years waiting in lines.
10. The toothbrush was invented in 1498.
11. The average housefly lives for one month.
12. 40,000 Americans are injured by toilets each year.
13. A coat hanger is 44 inches long when straightened.

14. The average computer user blinks 7 times per minute.
15. Your feet are bigger in the afternoon than any other time of day.
16. Most of us have eaten a spider in our sleep.
17. The REAL reason ostriches stick their head in the sand is to search for water.
18. The only two animals that can see behind themselves without turning their heads are the rabbit and the parrot.
19. John Travolta turned down the starring roles in 'An Officer and a Gentleman' and 'Tootsie.'
20. Michael Jackson owns the rights to the South Carolina State Anthem.
21. In most television commercials advertising milk, a mixture of white paint and a little thinner is used in place of the milk.
22. Prince Charles and Prince William NEVER travel on the same airplane, just in case there is a crash.
23. The first Harley Davidson motorcycle built in 1903 used a tomato can for a carburetor.
24. Most hospitals make money by selling the umbilical cords cut from women who give birth. They are used in vein transplant surgery. 25.
25. Humphrey Bogart was related to Princess Diana. They were 7th cousins.
26. If coloring weren't added to Coca-Cola, it would be green.

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Saskatchewanians have the lowest stress rate because they do not take **medical terminology** seriously.

Saskatchewan's Medical Dictionary

Artery..... The study of paintings
Bacteria..... Back door to the cafeteria

Benign..... What you be, after you be eight
 Caesarean Section..... A neighbourhood in Rome
 Cat scan..... Searching for Kitty
 Colic..... A sheep dog
 Coma..... A punctuation mark
 Enema..... Not a friend
 Fester..... Quicker than someone else
 Fibula..... A small lie
 Labour Pain..... Getting hurt at work
 Medical Staff..... A Doctor's cane
 Morbid..... A higher offer
 Node..... I knew it
 Outpatient..... A person who has fainted
 Pelvis..... Second cousin to Elvis
 Post Operative..... A letter carrier
 Recovery Room..... Place to do upholstery
 Secretion..... Hiding something
 Seizure..... Roman emperor
 Tablet..... A small table
 Terminal Illness..... Getting sick at the airport
 Tumour..... One plus one more
 Urine..... Opposite of you're out



Enclosed with this newsletter is a coloured **Avoidable Medication List**. Its from Care4Dystonia.org and is self-explanatory. *I hope you find it useful.*

*Please note: Subscriptions are now due for 2012. Please mail to Brian, contact info below. Thank you.
 Happy New Year to you all!*

Trivial Pursuit Answers:

Allegedly they are ALL true!!!!

CONTACTS

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NEXT MEETING

DATE WILL BE SOMETIME IN THE SPRING.

MEMBERSHIP FORM 2012

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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