



Dystonia Medical Research Foundation

Calgary Chapter

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CHAIRPERSON'S CORNER

Hello Everyone, Hope you are well and that you will enjoy your celebrations of Passover and Easter. These are such signals of spring for each of us and after this current winter, a much-awaited season, I'm sure.

This last February marked the 35th anniversary of the Dystonia Medical Research Foundation. At its beginnings with Samuel and Frances Belzberg, the medical knowledge and research were virtually nonexistent. Their daughter Cheri had finally been diagnosed with Dystonia and after the initial shock and relief of having an answer to her strange set of symptoms, the question was what now. Problem was, noone had any idea how to tackle this problem and noone was researching it. They then contributed a major personal sum of money, teamed up with Dr John H. Menkes who had diagnosed Cheri and dedicated their time and energy to organizing our Foundation. Dr Menkes became our first scientific director. Together these pioneers promoted research and raised visibility and knowledge within the medical community. In 35 years we have learned so much, discovered the genetic components of many forms of Dystonia and generally made it possible for us to be diagnosed within a reasonable time frame and not just be told it is "all in our heads," imaginary, stress related or some other fool excuse. We certainly owe a huge debt of gratitude to the Belzberg family, Dr Menkes, Nancy Harris-office guru, and all the dedicated doctors, researchers and patient's families who have made these strides possible. We don't have all the answers yet, but we have a very advanced list of questions and each year we get closer to an outright cure.

We have a date for our next Casino Days and we need your help. We have been assigned July 22 and 23, Friday and Saturday. Lil is doing the early organising as she always has, but we need someone to step up and work with her learning the ins and outs of this our major fundraiser. Please advise me of your wish to volunteer as this very important leader. We also as always need volunteers for day and night shifts as cashiers, bankers, chip runners and all the other positions we must fill. Please step up for us.

Our next meeting will be April 30, Saturday morning 10 to noon as usual. I look forward to seeing many of you and hearing how you are thriving, coping or both. Do try to join us. If you cannot do so, please let one of us know how you are doing as you will certainly be in our thoughts.

Marg Roy

I found this on the DMRF website. Its written by Janet Heishetter, and it follows on from Marg's words about the 35th anniversary of the Foundation.

I'm sure we all can feel alone with our own private version of dystonia, so its good to know that there are hundreds of people in many countries working on our behalf. Janet Heishetter mentions some of them in this article:

At the Foundation's annual meeting, we recognised 35 years of dedication to achieving our goal of a cure for dystonia, 35 years of stimulating research, promoting awareness and providing support for dystonia-affected persons and their families. The meeting was productive and we look forward to announcing the grants we will be funding this year and to providing a report on the progress we have made over these past three decades toward achieving our goal.

Throughout the meeting I was struck with the dedication of every person there. The members of our Medical and Scientific Advisory Council, people who are incredibly busy, but who gave us their time to thoughtfully review and discuss the merits of the grant and fellowship applications. There were our recently funded investigators who presented on their research and then engaged in discussions regarding where best to direct research to advance our knowledge. The Foundation's Board Members - people who work tirelessly to provide financial support and guidance so the DMRF can be there for those who turn to us for information, support and help. We were fortunate to have a number of guests, people who have made significant contributions to the field by reviewing grants

through the Department of Defense Peer-Reviewed Medical Research Program or who have worked hard to create dystonia awareness and lead support groups. We were pleased to welcome Fiona Ross, the Chairman of the Board for the Dystonia Society in the UK - reflective of the community desire to work collaboratively if we are to be successful in battling dystonia.

Many of these people have been there from the very beginning - and they reiterated that they are not going anywhere until we reach our goal of a cure. The anniversary provided DMRF with the opportunity to acknowledge the extraordinary people who have been with us on this journey. People who have worked selflessly to help us end dystonia. We recognised these amazing individuals with the DMRF Distinguished Service Award.

It is my honor to announce that the DMRF Distinguished Service Award was given to the following people:

Stanley Fahn, MD - Mark Hallett, MD
Mahlon DeLong, MD - Xandra Breakefield, PhD
Laurie Ozelius, PhD - Susan Bressman, MD
Samuel Belzberg - Frances Belzberg
Dennis Kessler - Rosalie Lewis
Joseph Jankovic, MD - Claire Centrala

We thank each of these wonderfully dedicated people for their commitment to the DMRF and the dystonia community. The DMRF continues its work. Our commitment to the community remains steadfast. The DMRF is not going anywhere until we achieve our mission.

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INTRODUCING Pat Leswick

As Heather asked me to write a short story of my life for the next newsletter -----
Here we go:

My name is Pat Leswick and I was born in London, England in 1949.
We immigrated to Canada when I was 12 and everything was going along just fine till around 1991, when I noticed that my neck was turning slightly to the right.

Each year it seemed to get worse and each year I hunted out another person to help me with my problem. I started with physiotherapy and massages; then moved on to the hypnotist; as I was told that it was most likely a habit that I had acquired over time and I had to train myself to stop doing that. So there I was sitting in chairs in front of the TV forcing myself to turn my head to the left in order to watch TV. Nothing was working and the neck was turning more and more.

The more upset I got the worse my neck turned.

Then one day I saw a short clip on TV with regard to a neurological disorder called "Dystonia" and off I headed to my GP to tell him that I was sure that was what I had. With trepidation he checked and found a neurologist in town - Dr Ranaway who dealt with this disorder.

I always remember my visit to his office; back then on 8th Avenue and 8th Street. To my surprise there were no big tests or scads of forms to be filled out and questions to be answered. He calmly asked me to walk down the hallway to the end then turn around and come back. After a few minutes he said that the way my neck turned with the shoulder up etc was a clear indication that I had "Spasmodic Torticollis" I really could not believe my ears. Somebody actually told me what I had and it was not a habit that I had developed nor was it just in my mind.

He told me about the Botox shots, made an appointment for my first set of shots then told me about a support group, which was being run by a now good friend---- Marg Roy. When I got home that night I gave her a call and she actually came over that night and described to my husband and I the type of Dystonia that I had and all the other types and how lots of people walk around for years without a diagnosis.

Twenty years later and I still get my Botox shots every 3 months from Dr Ranaway .

Eight years ago I developed a sharp stabbing pain in the side of my mouth when I talked or the wind blew on the side of my face. After telling Dr Ranaway he diagnosed my next disorder called "Trigeminal Neuralgia" this is when the blood vessel that comes out of the basil ganglia in the brain for some reason hits the nerve and causes the most debilitating pain in the side of your face. I finally had this operated on in Winnipeg last year by Dr Anthony Kaufman who now is known as one of the best micro vascular neurosurgeons in North America. He goes into the back of the brain and places a piece of Teflon between the vein and nerve. He said that I was the first person he had ever operated on who had Dystonia and Trigeminal Neuralgia which at this time he said did not seem to have any correlation but the operation is new and only time will tell.

Well there I am. I feel very blessed to have found the people with the expertise to solve my problems and allow me to continue on as normal as I can be without having to take heavy duty drugs etc.

I have to add that I may not always show up to all the support group meetings but without them I would have been lost.

Thank you all.

Pat Leswick



ON THE LIGHTER SIDE

I had this from Teresa last week:

Newfie Password

The Bank of Montreal was running a recent Password Audit and found Stevie O'Toole from Conception Bay (Newfoundland) using the following password:

MickeyDonaldMinnieGoofyDaffyBugsElmerPlutoOttawa

When Stevie was asked why he had such a long password, he replied, "Lard t'undering Geesus! Are yez blind er' stupid? I wuz told me password hd to be at least 8 characyters long wit' one capital."

This was from Teresa too:

Law of the Garbage Truck

One day I hopped in a taxi and we took off for the airport.

We were driving in the right lane when suddenly a black car jumped out of a parking space right in front of us.

My taxi driver slammed on his brakes, skidded, and missed the other car by just inches! The driver of the other car whipped his head around and started yelling at us.

My taxi driver just smiled and waved at the guy. And I mean, he was reallfriendly.

So I asked, 'Why did you just do that? This guy almost ruined your car and sent us to the hospital!'

This is when my taxi driver taught me what I now call, **'The Law of the Garbage Truck.'**

He explained that many people are like garbage trucks. They run around full of garbage, full of frustration, full of anger, and full of disappointment. As their garbage piles up, they need a place to dump it and sometimes they'll dump it on you. Don't take it personally.

Just smile, wave, wish them well, and move on. Don't take their garbage and spread it to other people at work, at home, or on the streets.

Life's too short to wake up in the morning with regrets, so ... Love the people who treat you right.

Pray for the ones who don't.

Life is ten percent what you make it and ninety percent how you take it!

Have a blessed, garbage-free day!

Someone emailed me this one too:

Medical Humour: Dr. Smith and Dr. Jones

Best friends graduated from medical school at the same time and decided that, in spite of two different specialties, they would open a practice together, to share office space and personnel.

Dr. Smith was the psychiatrist and Dr. Jones was the proctologist; they put up a sign reading: "Dr. Smith and Dr. Jones: Hysterias and Posteriors". The town council was livid and insisted they change it.

So, the docs changed it to read: "Schizoids and Hemorrhoids"

This was also not acceptable, so they again changed the sign.

"Catatonics and High Colonics"....No go.

Next, they tried "Manic Depressives and Anal Retentives"... thumbs down again.

Then came "Minds and Behinds"...still no good.

Another attempt resulted in "Lost Souls and Butt Holes".. unacceptable again !

So they tried "Analysis and Anal Cysts"...not a chance.
"Nuts and Butts"...no way.
"Freaks and Cheeks"...still no good.
"Loons and Moons"...forget it.
Almost at their wit's end, the docs finally came up with:
"Dr. Smith and Dr. Jones--Odds and Ends"

Everyone loved it.



Great Puns

A man's home is his castle, in a manor of speaking.

Dijon vu - the same mustard as before.

Practice safe eating - always use condiments.

Shotgun wedding - A case of wife or death.

A man needs a mistress just to break the monogamy.

A hangover is the wrath of grapes.

Dancing cheek-to-cheek is really a form of floor play.

Does the name Pavlov ring a bell?

Condoms should be used on every conceivable occasion.

Reading while sunbathing makes you well red.

When two egotists meet, it's an I for an I.

A bicycle can't stand on its own because it is two tired.

What's the definition of a will? (It's a dead give away.)

Time flies like an arrow. Fruit flies like a banana.

In democracy your vote counts. In feudalism your count votes.

She was engaged to a boyfriend with a wooden leg but broke it off.

A chicken crossing the road is poultry in motion.

If you don't pay your exorcist, you get repossessed.

With her marriage, she got a new name and a dress.

The man who fell into an upholstery machine is fully recovered.

You feel stuck with your debt if you can't budge it.

Local Area Network in Australia - the LAN down under.

Every calendar's days are numbered.

A lot of money is tainted - Taint yours and taint mine.

A boiled egg in the morning is hard to beat.

He had a photographic memory that was never developed.

A midget fortune-teller who escapes from prison is a small medium at large.

Once you've seen one shopping centre, you've seen a mall.

Bakers trade bread recipes on a knead-to-know basis.

Santa's helpers are subordinate clauses.

Acupuncture is a jab well done.

Another from an email:

The Best Wal-Mart Greeter Story:

Charlie, a new retiree-greeter at Wall-Mart, just couldn't seem to get to work on time.

Every day he was 5, 10, 15 minutes late. But he was a good worker, really tidy, clean-shaven, sharp minded and a real credit to the company and obviously demonstrating their "Older Person Friendly" policies.

One day the boss called him into the office for a talk. "Charlie, I have to tell you, I like your work ethic, you do a bang up job, but your being late so often is quite bothersome." "Yes, I know boss, and I am working on it." "Well good, you are a team player. That's what I like to hear. It's odd though your coming in late. I know you're retired from the Armed Forces. What did they say if you came in late there?" Charlie answered, "They said, "Good morning Admiral, can I get your coffee, sir?""

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While I was watching the Oscars a few weeks ago, there was a special tribute to Lena Horne, a pioneering African American performer I greatly admired, who died in 2010. The following words are attributed to her, and I rather like them:

It's not the load that breaks you down. It's the way you carry it. Lena Horne

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Membership fees for 2011 are now due. *Its normally \$20, but any contribution would be welcome. We have expenses running the support group and there is a cost to mailing the newsletters by Canada Post, so annual dues are very useful to us. Please bring to a meeting or mail to our treasurer Brian whose contact info is at the end of this newsletter. Please let me know if you no longer want to receive the newsletter or if you move and change your address or your email address. Thanks!*

HM

**DYSTONIA MEDICAL RESEARCH FOUNDATION, CALGARY CHAPTER
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NEXT MEETING

TIME 10 am to 12 noon
DATE Saturday April 30th
LOCATION DEVELOPMENTAL DISABILITIES RESOURCE CENTRE
4631, RICHARDSON WAY, SW, CALGARY
SPEAKER None

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

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