

Dystonia Medical Research Foundation

Calgary Chapter

ISSUE # 72

January 2008

CHAIRPERSON'S CORNER

Happy New Year to you and yours! Hope this has been a fun, happy, and healthy holiday season for you all spent reliving special memories and creating new ones. We had our holidays in California: very different, but nice just the same. Palm trees with lights wound up their trunks is a new and cheerful sight. Lots of new friends to make. Certainly this retirement bit is a new way to start out a year, but I think I can just handle it. Fun to think of all the new things Gord and I can get ourselves into.

Our last meeting brought us a talk from Dr Ranaway. He was excellent and we all learned new information about Dystonia and were reminded of things we perhaps hadn't heard about for a while. Great to hear about Dystonia from a specialist's perspective and he is so warm, relaxed and open to questions about this subject so dear to all our hearts. You will see a write-up further into the newsletter about his talk. Impossible to cover all he explained, but it will give you an idea of his presentation.

This has been a very busy year for us with our support meetings, our Walk and our Casino days. We represented our Foundation at the Hotchkiss Brain Awareness Day this March showing a short video on Dystonia and making information available for attendees. Some of us joined the writer of Twisted, the new film about Dystonia when it was first aired this spring at the Calgary Disabilities Film Festival. All events were very productive and enjoyable. We in Calgary were able to send an amazing amount of money to Toronto to be used for research grants and awareness projects. Along with the \$100,000 from these fundraising, volunteer efforts, we were able to send a further \$20,000 that was so generously donated to us by the family of one of our members. They wish to remain anonymous, which is certainly the true face of charity. Our gratitude is enormous for their kind gift. It is wonderful for us to be able to help in supporting the huge effort being expended by so many medical people and scientific researchers. Many more people each year are approaching our Foundation with ideas and proposals for research projects to find answers to our Dystonia puzzle and it's eventual cure. As you know, all proposals and requests are studied by our Scientific Board to ensure all our funds are expertly and purposefully applied. It is quite amazing to see the variety of genetic, pharmacological, and cellular research studies in progress for us.

Thanks to all of you who have taken part in our fund-raising projects and our support and awareness missions this year. We learn so much from each other about dealing with our own version of Dystonia. We represent many different varieties of Dystonia, but so many of the problems and challenges are common to us all, that our varied experiences and coping techniques can touch and strengthen each of us. We owe a special thanks to the following people who go the extra mile for us all. Lil Faider has again been amazing in her organization of our Casino days and also in the many assorted jobs she handles for us and the support she gives us all. She is gearing up again for our next Casino days scheduled for late June. We are lucky to have this warm and energetic member of the Canadian Board among us. Heather has once again excelled as Editor of our Newsletter. She definitely has a knack for finding new and important information for us, and incorporating her warm sense of humour and insight into the bundle that keeps us all aware and uplifted. Brian Larke has done a great job of handling our finances, keeping track of memberships, and also starting a group album for us complete with pictures and a little information about ourselves. This last is of course an ongoing project, and he adds to our book at each meeting. There is always someone we haven't seen for a while who comes along to share a little time with us. Teresa Ebbeling remains our point of first contact for our group and welcomes any newcomers with kindness and any information they might require. She and Lil are often also the bakers of treats for our meetings. Our phone committee of Libby Graham, Brian Larke, Teresa Ebbeling and Yvonne Adams kept us reminded of our meetings and any last minute information we needed dispersed to all. Our National Director, Sarah Smith has made marvelous headway with awareness efforts at the Federal and Ontario government levels and accomplished much in fund-raising in Canada. Her Toronto Walk and Run that included the general public for the second time this year was a resounding success raising \$30,000. Leading the whole of Canada necessitates a special person to keep working with all the many Support groups and Chapters across the country with our varied needs, ideas and inputs. My thanks to you all, as you are an amazing group of people!

Our next meeting will be January 19, Saturday morning 10 am to noon, at our usual spot. As I will be away playing Snowbird, Teresa and Lil have graciously agreed to organize your meeting. Come out and support them and each other. Do let us know how you are making out as you start this brand new year.

Marg Roy

I had a brief email from Marg on Christmas Eve. She said they were getting organized, and were pleased to be there, but that it was a little cool. However, it was warm enough to be in the pool each afternoon. Have fun Marg and Gord!

HM

WINTER CHAIRPERSONS' CORNER

In Marg's absence, we want to take this opportunity to express how we feel about her and how much she does for us behind the scenes. She keeps us up to date on all the information from both sides of the border. Also, she attends as many conferences as her job allowed her to and upon her return, gives us a comprehensive account of what she has learned. As for at our meetings, in addition to greeting everyone with a big smile, she arranges for our speakers, films and guides our discussions. Coffee is always ready thanks to Marg and many times she brings the treats as well. She sets up our annual Walk and Wheel and with Gord's help it is always a great get together- it gives us all a more relaxed atmosphere to meet in. When it looked like rain, they invited us to their home which was very enjoyable. Marg keeps in touch with many members of our group between meetings and is always interested in how everyone is doing.

Enjoy your retirement Marg and Gord and we look forward to your homecoming.

Lil and Teresa

ITEMS OF INTEREST

ITEM 1

*The following article was in **Dystonia News** from the Dystonia Association of Northern Alberta in Edmonton, November 2007. It really caught my imagination.*

The Image of Dystonia by Margaret Miller

An image is like a word picture, so as a person with Dystonia I am the image or picture of Dystonia. For most people the word Dystonia does not provide visual information, so people who are unaware of Dystonia do not know Dystonia when they see it. However, in an instant, a stranger can look at me, and instantaneously I can see their emotional response to Dystonia. For me this is the most challenging experience of this disease. It is a wordless situation, a motionless moment in a line-up at the bank or in the grocery store. In this moment, there is no recognition, no realization, no revelation, and this situation is repeated many times.

I do not know what people feel when they look at me, I do know how I feel when they look at me, and I think you know how I feel too. In the future, I would like to think that when someone looks at me they know what they are looking at:

a woman with Dystonia. I would feel better about that. Well, I am going to do something; call it grassroots awareness. For the next year, my goal is to inform 100 people - a modest number - about Dystonia. I will report my progress in the newsletter.

Here is my final thought; you may be asking what the point is or why do this? Like me, you have probably seen people whom you believe have Dystonia. Like you, I recognize the postures and behaviours of the disease because I am well acquainted with its image. When I see Dystonia, I see, in that moment how fate has conspired to make the trip to the grocery store, or anywhere else, a difficult voyage. I see someone, regardless of unfortunate circumstances, meeting life with courage. I feel the strongest desire to will them strength, and I hope each of you receive these thoughts through this newsletter.

Remember DANA [*Edmonton support group*] encourages hope. We do not want anyone with Dystonia to do this alone, and our support group needs your help to grow and move forward.

To date, I have informed 2 people about Dystonia - a government worker and a dental hygienist - 98 to go!

This really made me think. We have about one hundred members in our Calgary support group. What if each of us informed only ten people about dystonia in the next year? Then a thousand new people would understand a little more about this strange condition we deal with every day. At every Christmas gathering I went to this year, I talked to somebody briefly about dystonia. That's a total of three people informed so far. It's a start! HM

ITEM 2

DR RANAWAYA NOV 2007 Submitted by Marg Roy

Dr Ranawaya gave us an excellent talk at our last meeting. He spoke of his own background as a family doctor in Saskatchewan and then going on to become a Neurologist. He then studied under Dr Tony Lang, a renowned movement disorder specialist in Toronto. That is where he learned about Botox injections and the difference this could make for their Dystonia patients.

When Dr Ranawaya came to Calgary, he was the only doctor in Alberta to administer Botox injections and had an immediate patient list. Prior to this, Albertans had been sent to Vancouver for their injections. Initially the injections were for Spasmodic Torticollis only, but later this was found successful for people with Blepharospasm as well. Injections for Writer's was attempted as well, but

often there were so many muscles involved in the hand and forearm, that the Botox weakened the muscles so much that other required strengths and movements were compromised. (Botox is now used of course for Spasmodic Dysphonia and other dystonias, just not by Dr Ranaway.)

There are a series of drugs that are still used successfully for Dystonia symptoms. These are not always tolerated well by the patient as normal cognitive skills are affected. Many people have trouble dealing with the memory loss, or slower brain reactive times that can be affected. Interestingly, children often have a much higher tolerance to drug affects than do adults. Their bodies seem to adjust better. Botox has been used successfully for many patients over the years. Some people develop antibodies over time that nullifies the effectiveness of this toxin. It was learned that limiting injections to no oftener than three months helped slow the development of these antibodies. Also, Allergan the producer of the original toxin has changed the way it is mixed and delivered to the doctors. Product is now more stable and there is less of the protein carrier that supports the toxin. A new version of the toxin was developed as Myobloc, but is no longer available in Canada as the original company sold off this drug line and new company has no distributor in Canada. At any rate, it appears from conducted drug trials, that people with antibodies to Botox, soon show the same resistance to Myobloc. Myobloc also required a much higher portion of toxin to be effective and may start antibody production in patients quickly. There is a new toxin being used in Europe, but not approved here as yet.

One of the good things that came with the Botox injections was the regularity of seeing his patients. Much can be learned when the progress of Dystonia can be seen every 3 months or so. Many times, once the various drugs were tried successfully or otherwise, the patient might not be seen other than yearly or occasionally not again if there seemed to be nothing to be offered them. All of the movement disorder specialists share their information on what is working or not, what trends and changes they are seeing in their patients. This is done through their own networking, but also through the Dystonia Study Groups who are organized all over the world working on our problems.

Dr Ranaway is so impressed with all the research going on about Dystonia and spoke very highly of our Dystonia Medical Research Foundation and the support it gives scientific researchers. We asked about any research he might be involved in, bearing in mind that he has his own patients, works with the Movement Disorder Clinic, and also teaches neurology. His research is hands-on and mostly limited to what can be learned and shared from his ongoing experience, and partaking in clinical trials and dystonia study groups. Most of the deep research now must be done by PhD's, people with doctorates in genetics, or microbiology working at the cellular level. Amazing what is coming out now that the human genome project was completed, and we are so lucky to have so many brilliant researches working for us. He spoke of the various genes found to be involved and explained about how the original gene DYT1 is autosomnal, occurring in about half of off-spring, but only presenting actual

dystonia in about ¼ of children. Such a mystery as to why it shows itself or why not. Much research aimed at determining what medical or environmental factors might be coming into play.

He spoke of the many versions of dystonia and how they are continuing to see more and more “vocational” type dystonias. These are the ones that affect dexterous movements repeated over a lifetime like a writer’s hand control or a musician’s dystonia where a pianist’s fingers or a trumpeter’s mouth might suddenly develop peculiar movements that can render their career’s impossible. There are a large group of musicians working together under the DMRF umbrella, to support each other and help in awareness among their peers.

He spoke of so many things, bringing each of us some new information, and a reminder of something we haven’t heard about for years. Dr Ranawaya is a natural teacher: relaxed, open, and generous with his knowledge and experience. We all appreciated his time and effort on our behalf.

QUIZ TIME From the Giant Book of Mensa Mind Challenges 2003

Get the Scoop

Ken and Terry’s, the local ice cream shop, will be giving away free cones some time this year. Because they want to limit the lines a bit, they have given out three clues as to the date of their giveaway. Can you figure out when it will be?

- 1) The giveaway will be in the first week of a month without an A in it.
- 2) It will be on a day of the week that has a U in it
- 3) The month has no E but the day of the week contains an E

Answer later in the newsletter

INTRODUCING - Darol Wigham

Darol James Wigham was born on the 25 September, 1930 at the Royal Alexandra Hospital in Edmonton, Alberta to Winnifred Wigham (nee Hobson) and James Wilson Wigham. I was the youngest of three children, with a sister Jean Annie 9 years older and William, 3 years older. I was raised in a rather typical blue collar home. My father was a truck driver for Swift Canadian Meat Packers and my mother was a seamstress. As a consequence we never lacked

for food and our clothes were often made over hand me downs. As far back as I can remember my mother was never really well, suffering from pelvic cancer.

I attended Highlands school from grade one to nine and was always an above average student, although skipping grade 6 took it's toll in high school. From the age of seven I wore ever thicker spectacles and was the typical four-eyes. As a result I was not that active in school sports, both because of being so short sighted and breaking too many pairs of glasses. While in grade nine my mother passed away from her very painful cancer. In the fall of 1943 I moved to the Norwood district with Dad and brother Bill, and enrolled in grade ten at Eastwood High School. Throughout high school I was only an average student, and in retrospect I think the passing of my mother played a large part in the lowering of my academic standing. In the summer after grade eleven I worked at Swifts in the Smoked Meat Department. At first I wrapped bacon and hams, I then moved to the pickling cellar where I pulled bacons and hams from large wooden barrels filled with brine, then hung them on racks to go into the smoke house for curing. After grade 12 my summer job was as a truck driver delivering bread for Alberta Bakery, which was owned by the father of my close friend Dave Shecker.

After High School I worked as a rodman on a City of Edmonton survey crew for 6 months. In December of 1948 I went to Camp Borden for 6 months to take a reserve army officers course at the Infantry School. On my return to Edmonton I enrolled in first year engineering at the University of Alberta. By January it was obvious that I hated engineering, and in September I switched to geology. I found geology much more to my liking, with much more freedom of thought than engineering. After my first year I had a summer job as a roughneck on a drilling rig in the Viking- Kinsella gas field, along with 2 other students. After second year I again worked as a roughneck, this time on a deep Devonian test called BA Gateway Morningside, just north of Lacombe, Alberta. At the completion of 3rd year I received my BSc. in Geology and went to work for Canadian Gulf Oil for the summer. My roll was that of a geological assistant on a 3 man surface geology party in NE. BC. We worked by boat along the Peace River from Findlay Forks to Hudson Hope, then we flew into small lakes in a Dehavilland Beaver float plane to examine Mississippian and Devonian rock outcrops. To round out the season we looked at geological exposures along the Alaska Highway as far north as mile 500. In September I returned to U of A for a fourth year of geology. On graduation in May 1954 I went to work for Gulf and did surface geology between Jasper and Nordegg utilizing a 27 horse pack string. In the winter of 1954-55 I sat on wells in the Stettler- Big Valley area. May 1955 again found me in the Nordegg- Jasper area looking at Devonian reef exposures.

On October 22, 1955 I married Evelyn Linke, one of my geology classmates. On return from our honeymoon we moved into a house we had built at 5808 Elbow Drive SW in Calgary, where our son Ronald Cameron was born August 2, 1956. We lived in our new 3 bedroom home until a transfer with Pan American Petroleum took us to Regina, Saskatchewan in June 1958. Our daughter Patricia was born in Regina May 6, 1959. After a very happy year and a half in Regina we

were transferred to Edmonton, where we lived for the next four years. This was a wonderful time for Ron & Patricia to get to know my father and Ev's Mom and Dad. Then in the fall of 1963 we moved back to Calgary with Pan Am, and a year later I joined Western Decalta Petroleum, a small Canadian Independent. It was at Decalta that I met Alastair Ross who became my mentor and then became my business partner 16 years later.

Al Ross and I had a private joint venture exploration company for the next 8 years, then in 1988 we formed a Canadian company for Pacific Lighting of Los Angeles. A condition of forming this company was that I was obligated to stay for 2 years, then I left on September 25, 1990. Since then Ev and I have traveled extensively, looked after our own oil and gas production, and worked within the non profit sector in Alberta.

About 1985 I noticed trouble signing my name and holding onto a wine glass or coffee cup. Dr.Doug Thorsen referred me to Dr. Ranawaya who diagnosed my focal dystonia in about 3 minutes and hence my presence in the group today.



ON THE LIGHTER SIDE

Someone sent me this in an email recently:

Every sixty seconds you spend upset is a minute of happiness you'll never get back.

Life is short. Break the rules. Forgive quickly. Love truly. Laugh uncontrollably. And never regret anything that made you smile.

Life may not be the party we hoped for, but while we're here we should dance.



A husband and wife attended counselling after 15 years of marriage.

When asked what the problem was, the wife went into an impassioned, painful tirade listing every problem they had ever had in their 15 years of marriage. She went on and on and on on: neglect, lack of intimacy, emptiness, loneliness, feeling unloved and unlovable, an entire laundry list of un-met needs she had endured.

After allowing this to go on for some length of time, the therapist finally got up, walked around the desk and, after asking the wife to stand, he embraced her, then kissed her passionately.

Speechless, the woman quietly sat down as though in a daze.

The therapist turned to her husband and said, "This is what your wife needs at least three times a week. Can you do this?"

The husband thought for a moment then replied,.. "Well, I can drop her off here on Mondays and Wednesdays, but on Fridays, I play golf."



And this from Marg, (author unknown):

I Am the New Year

I am the New Year
I am unused, unspotted, without blemish.
I stretch before you three hundred and sixty-five days long.
I will present each day in its turn, a new leaf in the Book of Life,
for you to put upon it your imprint.

I am the New Year
Each hour of the three hundred and sixty-five days,
I will give you sixty minutes that have never known the use of man.
White and pure, I present them; it remains for you to fill them with sixty jeweled
seconds of love, hope, endeavour, patience, and trust in God.

I am the New Year.
I am here - but once past, I cannot be recalled.
Make me your best.

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Answer to QUIZ TIME: Free ice cream will be on the first Tuesday in July

**DYSTONIA MEDICAL RESEARCH FOUNDATION, CALGARY CHAPTER
CONTACTS**

Chairperson: Margaret Roy - 271-4438

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

Newsletter Editor (and for change of address, or email addresses)

**Heather MacLellan
1327, 48th Ave N.W.
Calgary, Ab. T2K 0J6
phone: 289-0736
e-mail: hethmac@telus.net**

NEXT MEETING

TIME 10 am to 12 noon

DATE Saturday, January 19th 2008

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

GUEST SPEAKER. None

MEMBERSHIP FORM - 2007

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: Dystonia Medical Research Foundation, Calgary
Chapter**

**Attn. Brian Larke, Treasurer
29, 275 Woodridge Dr. S.W.
Calgary, Ab T2W 4S4**

