

Dystonia Medical Research Foundation

Calgary Chapter

ISSUE # 75

September 2008

CHAIRPERSON'S CORNER

Hello everyone. I hope this summer has been a pleasant and fun one for you all. We got off to a rocky start with a very wet June, but then weather progressed a little better. One of those things we have no control over, so I'm sure you enjoyed your holidays and family and friend get-togethers as planned. Summer is so short and we Canadians do have to cram so much living into them as the outdoor season seems to fly by. Yes, I know outdoor winter sports are wonderful, but the same groups of people do not gather in the same way.

We started the summer off with our Walk and Wheel in mid June and that turned out to be a great day for us. We based our walk from my house again this year and this seemed to work out fine. We had a lovely walk through our neighborhood of Parkland and followed up with our traditional pot-luck picnic. We enjoyed great company and delicious treats as usual. Thank you to all who took part in the walk and picnic and to all those who supported us monetarily. Our own people and our family and friends were most generous as always. We raised nearly \$8,000 and that is something to be very proud of. This goes a long way in supporting the research and awareness projects we hold dear. For those of you who missed this opportunity to gather and support our cause, please keep this Walk in mind next year. It is very important to all of us.

Late June, we again had an opportunity to work at the Calgary Casino for two days and thereby receive a portion of the proceeds of the Alberta Gaming Commission for that quarter. Many of our own people and their families, as well as many outside friends support this opportunity for us and the return to our research monies is always quite staggering. Lil Faider does such a wonderful job of organizing and coordinating our efforts in these Casino Days. This has been her specialty for many years now and we sure appreciate the great time and energy she devotes to this project. We have now received our portion of the proceeds and it is an exciting \$80,287. This was in spite of the fact that two new

non-contributing casinos opened their doors this spring. The two Casinos operated by local Native Indian Bands of course keep their proceeds to help their own people. Thanks to each of you who helped us with this endeavour and thanks to all the Calgary people who unwittingly helped us as well.

Now Fall is approaching, hopefully at a slow pace, and we all get back to our normal activities. Our next meeting will be September 20, Saturday, 10 am to noon at our usual spot. This is a chance for us all to get together and show the kindness, caring and support we all rely on. This will be a general catch up time for us. We have been in contact with some new people afflicted with Dystonia and certainly hope to meet you. You will see how easy and helpful it is to be among those who understand only too well what you have been living and coping with.

I was speaking with our foundation's National Director in Toronto, Diane Gillespie, and she has been very busy fundraising, working with the Federal Government to raise awareness for Dystonia, and making up a new Canadian version of the What is Dystonia brochure. We have a supply of these coming to us, so will be able to provide some to the Movement Disorder Centre and various doctors you think might be interested. She also has someone designing a Canadian Web Page for us and there will be a link to each local group so that we could post our Newsletter or other information we deem important, like our notice of meetings and such. This is an exciting thought, isn't it?

Just a reminder that Gord and I will be escaping for a good part of the winter in Southern California again this year, and so I will need help with meetings and ideas for our group while away. If you feel you have some new and exciting thoughts and would like to take over our group, that too can be discussed. Please give this some thought and lend your special strengths to your friends and supporters. I assure you the personal returns and opportunities for growth are worth any effort you might expend on our behalf.

Take care, be well and happy and come out and spend a couple of hours with us in September. As always, if you cannot join us, you will be in our thoughts, so please let us know how you are doing.

Marg Roy

ITEMS OF INTEREST

ITEM 1

This was in Laurie Bell's Hamilton Area Dystonia Support Group News of February 2008. It's a report of discussions they had at their last meeting, and I found it interesting:

Eleven members came to participate in a casual discussion about how our dystonia symptoms affect our families & friends. We realized that it is their job to understand that we must expect a little more physical limitation, modify our lifestyles, and that we do the best that we can. Generally, family members can be a great support system. Unfortunately, that is not always the case. Sometimes family members are more traumatized than the patient, and cannot give the needed strength. If this is the case, the patient must look elsewhere for support & encouragement. There are support groups of all kinds, on line & in gathering spots. Sometimes a little support happens in a kitchen over a cup of coffee, sometimes a meeting can occur in a coffee shop.

If the patient is able to reach out to other gatherings like a volunteer group, yoga class or a bowling group, he/she can find positive support there. Without it, one can lose a sense of purpose and suffer more emotional stress which will create more havoc with dystonic spasms. **It is a huge struggle to overcome the initial embarrassment and depression that comes with any severe life crisis, whether it is physical or an emotional shock.** We each need to find help wherever we can. The first step is always the most difficult.

Laurie Bell and the Hamilton Group

So, please come out to one of our Calgary meetings or give one of us a call or an email. We are here to support each other. HM

ITEM 2

I was looking on the internet to see if I could find any recent information about Botox for this newsletter. I didn't find anything related to dystonia, but I was interested to read that research is being done into using Botox for some other medical conditions.

The first find was a piece about enlarged prostate. St. Joseph's Health Care in London was looking for men 50 or older experiencing the symptoms of benign

enlarged prostate. London is one of five Canadian centres involved in a worldwide trial investigating the use of Botox injections into the prostate gland to shrink it and relieve symptoms.

Reference: <http://lfpres.ca/perl-bin/publish.cgi?x=articles&p=242790&s=health>

The second article I came across was about research being done into using Botox to shrink cancer tumors. A study from the Université de Louvain in Brussels, Belgium led by Bernard Gallez, PhD is exploring how Botox might be used to treat cancer patients. They have injected Botox into tumors in mice and it caused the tumors' cellular vasculature to open. This improved circulation of the tumor and made traditional chemotherapy and radiation treatments more effective at killing off the cancer cells. Reference:

www.bestsyndication.com/Articles/2006/Nicole-WILSON/Health/02/021506-botox

I always feel optimistic when I see any kind of research being done, whether it is related to Dystonia or not. There are so many clever and talented researchers working hard all over the world. Surely one of them will find something to help us one of these days. HM

QUIZ TIME

Nick is one-fourth his grandfather's age. Five years ago, he was one-fifth his grandfather's age. How old are Nick and his Grandfather now?

Answer later in the newsletter.

INTRODUCING - Brian Larke

Here is the second part of Brian's story. He has been writing his autobiography for us, and for his own family history archives.

In 1958 I joined the Young Conservatives, a group for the under 30's within the national party. It was more a social organization, although we did work at elections and we had great "weekend schools". These consisted of getting away from parental scrutiny and to have a good time in a posh hotel.

A Purity Patrol ensured that the correct males were linked up with the appropriate females, in theory anyway. In practice since it was 2 of the same sex to a room so it was virtually impossible to achieve anything other than staying up till dawn and feeling like hell in the morning. During this period I was introduced to some

people who changed my outlook about life that existed beyond my limited experience.

In 1959 I became VP of the Redcar branch and I had become romantically involved with the secretary of the branch. This relationship progressed over a year and I was really happy and looking forward to it continuing. Then on my 21st birthday we all went out for a party and she gave me a Parker 51 fountain pen with a gold top (which I still have). This was the gift that truly marked my coming of age at the time in 1960. I had managed to buy a car with my increased income and I was sitting pretty, a good job and a great relationship. I had got a Higher National Certificate in Mechanical Engineering so my future was looking good but I really didn't want to spend my life as an engineer.

After my 21st. party I dropped my girlfriend off at her home and that was the last time I saw or spoke to her from that day to this.

I was able to find out that she had left the area to start training as a nurse and my efforts to talk to or see her were in vain. This came as a complete surprise to me.

I was devastated to put it mildly. My little world had come tumbling down around my ears in less than 24 hours.

I was so upset that I had to do something to change my life and take my mind off my broken heart!

I was working in a drawing office (or drafting, if you prefer) which employed about 120 people, some of whom had done their National Service in the merchant navy. I had missed having to do my time by three months as the cut off was in September 1960 and my birthday was in December 1960. I had always been intrigued by the thought of going to India as I had a relative who had been in the Army in India and he had told me quite a lot about the country. The jewel in the crown and all that.

As luck would have it I talked to a fellow worker in my office who had been in the merchant navy working for a company which traded between India and continental Europe. I was impressed with what he told me about life in the merchant navy. This was just what I needed to get away from home and start a new life. The company was called T&J Brocklebank, part of Cunard Shipping Co. By coincidence a previous girl friend of mine worked in the Middlesbrough office of that company. I gave her a phone call and I asked her what I had to do to obtain a position with them and she arranged for an interview with the local Engineering Superintendent whose office was across the street from mine. I went to the interview and was offered a position of junior engineer with a start date immediately I passed a medical. This was the break I needed to mark a fresh start and so a couple of week's later I started as junior engineer with a sailing

date on day one of my new position. This was the first of several times in my future employment when I was hired on the initial interview.

I had no idea what I was getting into when I joined my first ship, the SS Maturata. I was the 5th. Engineer and it was my job to assist the 2nd. Engineer on the 4 to 8 watch, twice a day, am/pm. We left port on a very stormy night in January 1961 on a three day trip to Rotterdam. The heat and smell of the engine room was overpowering and I was seasick for the whole trip. I wanted to die, as anyone who has been seasick knows only too well.

So ended the first trip.



ON THE LIGHTER SIDE

This is from Teresa

The Children's Bible in a Nutshell

In the beginning, which occurred near the start, there was nothing but God, darkness, and some gas. The Bible says, 'The Lord thy God is one,' but I think He must be a lot older than that.

Anyway, God said, 'Give me a light!' and someone did. Then God made the world.

He split the Adam and made Eve. Adam and Eve were naked, but they weren't embarrassed because mirrors hadn't been invented yet.

Adam and Eve disobeyed God by eating one bad apple, so they were driven from the Garden of Eden. Not sure what they were driven in though, because they didn't have cars.

Adam and Eve had a son, Cain, who hated his brother as long as he was Abel.

Pretty soon all of the early people died off, except for Methuselah, who lived to be like a million or something.

One of the next important people was Noah, who was a good guy, but one of his

kids was kind of a Ham. Noah built a large boat and put his family and some animals on it. He asked some other people to join him, but they said they would have to take a rain check.

After Noah came Abraham, Isaac, and Jacob. Jacob was more famous than his brother, Esau, because Esau sold Jacob his birthmark in exchange for some pot roast. Jacob had a son named Joseph who wore a really loud sports coat.

Another important Bible guy is Moses, whose real name was Charlton Heston. Moses led the Israel Lights out of Egypt and away from the evil Pharaoh after God sent ten plagues on Pharaoh's people. These plagues included frogs, mice, lice, bowels, and no cable.

God fed the Israel Lights every day with manicotti. Then he gave them His Top Ten Commandments. These include: don't lie, cheat, smoke, dance, or covet your neighbour's stuff.

Oh, yeah, I just thought of one more: Honour thy father and thy mother.

One of Moses' best helpers was Joshua who was the first Bible guy to use spies. Joshua fought the battle of Geritol and the fence fell over on the town.

After Joshua came David. He got to be king by killing a giant with a slingshot. He had a son named Solomon who had about 300 wives and 500 porcupines. My teacher says he was wise, but that doesn't sound very wise to me.

After Solomon there were a bunch of major league prophets. One of these was Jonah, who was swallowed by a big whale and then barfed up on the shore. There were also some minor league prophets, but I guess we don't have to worry about them.

After the Old Testament came the New Testament. Jesus is the star of The New. He was born in Bethlehem in a barn. (I wish I had been born in a barn too, because my mom is always saying to me, 'Close the door! Were you born in a barn?' It would be nice to say, 'As a matter of fact, I was.')

During His life, Jesus had many arguments with sinners like the Pharisees and the Republicans.

Jesus also had twelve opossums. The worst one was Judas Asparagus. Judas was so evil that they named a terrible vegetable after him.

Jesus was a great man. He healed many leopards and even preached to some Germans on the Mount.

But the Republicans and all those guys put Jesus on trial before Pontius the Pilot. Pilot didn't stick up for Jesus. He just washed his hands instead.

Anyways, Jesus died for our sins, then came back to life again.

He went up to Heaven but will be back at the end of the Aluminum. His return is foretold in the book of Revolution.



And these from Marg:

Disorder in the Court

These are from a book called Disorder in the American Courts, and are things people actually said in court, word for word, taken down and now published by court reporters who had the torment of staying calm while these exchanges were actually taking place.

ATTORNEY: What gear were you in at the moment of the impact?

WITNESS: Gucci sweats and Reeboks.

ATTORNEY: What was the first thing your husband said to you that morning?

WITNESS: He said, "Where am I, Cathy?"

ATTORNEY: And why did that upset you?

WITNESS: My name is Susan!

ATTORNEY: Is your appearance here this morning pursuant to a deposition notice which I sent to your attorney?

WITNESS: No, this is how I dress when I go to work.

ATTORNEY: Now doctor, isn't it true that when a person dies in his sleep, he doesn't know about it until the next morning?

WITNESS: Did you actually pass the bar exam?



Teresa sent me this one a while ago:

Subject: **SEVEN WONDERS OF THE WORLD**

A group of students was asked to list what they thought were the present "Seven Wonders of the World." Though there was some disagreement, the following received the most votes:

1. Egypt's Great Pyramids
2. Taj Mahal
3. Grand Canyon
4. Panama Canal
5. Empire State Building
6. St. Peter's Basilica
7. China's Great Wall

While gathering the votes, the teacher noted that one student had not finished her paper yet. So she asked the girl if she was having trouble with her list. The girl replied, "Yes, a little. I couldn't quite make up my mind because there were so many." The teacher said, "Well, tell us what you have, and maybe we can help." The girl hesitated, then read, "I think the 'Seven Wonders of the World' are:

1. To See.
2. To Hear
3. To Touch
4. To Taste
5. To Feel
6. To Laugh
7. To Love."

The room was so quiet you could have heard a pin drop. The things we overlook as simple and ordinary and that we take for granted are truly wondrous.

This was a thought in an email from a friend recently:

Do you realize that in about 40 years, we'll have millions of old people running around with tattoos and pierced navels? (*Now that's scary!*)



Answer to Quiz Time:

Nick is 20; his grandfather is 80.

**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, September 20th, 2008

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

GUEST SPEAKER. None

MEMBERSHIP FORM - 2008

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DYSTONIA: _____

Please check off one of the following: New _____

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

