

# Dystonia Medical Research Foundation

## Calgary Chapter

ISSUE # 74

April 2008

### CHAIRPERSON'S CORNER

Hello everyone. Hope this winter has not been too harsh for you all. Yesterday I saw my first robin of the year and this morning we are in the midst of a blizzard, with promises of 20 degree C for the weekend. April is a crazy month weatherwise in Calgary, but nice to see the exciting signs of Spring.

As many of you know, I was away for several months this winter escaping the cold and snow in southern California. Thoroughly enjoyed my first stint at retirement. That was great, but nice to be back too. I sure appreciated the extra work that Lil Faider and Teresa Ebbeling took on over this period looking after meetings and my letters and such. Heather MacLellan of course did her usual fine work in putting our newsletters together and out to you. Sure helps to be surrounded by such willing and able members of our group, ready to jump into a void when needed. Thanks to all of you.

You will likely have seen some of the internet comments about potential problems with Botox injections and the ability of Botox to migrate to adjacent muscles. The American Food and Drug Administration are looking into reports of serious side effects from Botox and related products, but have not advised doctors to stop using the product. They are conducting a safety review and say the reactions may be due to overdosing. I would expect part of the problem is that the doctors injecting the Botox are not overly experienced in their applications. Certainly, neurologists have been applying medical Botox to Dystonia patients for some 20 years and have had no serious complications that I have ever heard about. Some people experience a dry mouth when injections are given, but even this is not particularly common. Also, this side-effect usually passes in a few days, I understand. Botox has been an exceptionally successful treatment in relieving muscle spasms or relaxing spastic muscles among Dystonia sufferers for a long time. Of course, we all continue to watch for new information. I do not mean to be overly simplistic about these concerns which do deserve further study, but I hope that fear will not undo any future help our people could receive from this well controlled and safely applied drug.

Lil Faider has been very busy getting our next Casino Days all lined up for us. I know that many of you have volunteered to work a shift in one of the varied capacities and she will be contacting you in the near future to make final arrangements. Your help is vital and much appreciated. As you know, this has been such a wonderful fund-raiser for us for many years now. Our own people and our dear friends are what make this event possible for us. Research funding is paramount to finding our cure.

We have a new National Director in Toronto. Diane Gillespie has taken over this very demanding position and we wish her well in her endeavours. Diane called me last week in her effort to introduce herself to all the Canadian leaders and get our feedback about what we might like to see her tackle. I was impressed with her personally and also with her background. She has been a major organizer and fundraiser with ALS Canada and also the Canadian Diabetes Foundation, and so brings great experience and skills to our Dystonia organization. Diane has many good ideas and is very keen to jump into our cause and see just what she can accomplish on our behalf. Loretta Jacques, who has done a great job of handling the operation of our national office for some time, continues on to aid Diane and provide continuity in the day to day workings of administration. They will be a strong team, I'm sure.

It is time to think of our annual Walk and Wheel. This is our twelfth year and a great tradition for our group. For those of you not familiar with this event, we hold a walk amongst our own members and their family and friends in early June. At this time we ask that friends, family, coworkers support us with a donation of \$10, \$20, etc., whatever they can provide. We take donations in a lump sum form, as it is not possible for our members to walk a prescribed distance or series of laps. Varied physical conditions dictate that we walk a distance suitable to the individual involved. Some people who are not comfortable with asking family and friends for monetary support, make this the time for their personal annual contributions to Dystonia research. This is just fine as well. You can lend your support to another of our walkers, or the whole group. In other years we have walked in Fish Creek Park in a lovely area with varied length trails, and then finished up with a pot-luck picnic. Last year the Park was undergoing extensive repairs following some earlier heavy weather damage, making it unavailable to us. We instead held our event out of our house and walked the Parkland neighbourhood, finishing with a pot-luck picnic in our backyard and house. This seemed to work well and so we will again centre our event out of Gord's and my place in Parkland. Very near the park actually, where we formerly gathered. Details are on a separate page as well as pledge sheets for your collections. This is an important fund-raiser for us and a great social, fun event as well. This will be our last gathering before our summer break. Do mark your calendars for June 14 and come join us for a great day.

In regards to our Walk pledges, we are trying something new this year to help our computer savvy contributors who are not in day to day contact with their friend or family member who walks, but still want to support us. There is an organization on the internet, [www.canadahelps.org](http://www.canadahelps.org) who aid Canadian charities in fund-raising. Donations can be made electronically to them, they immediately issue receipts with our Federal charity number, and then forward the funds on to us. There is an administration fee of 3% for this service. Sharlene Claerhout tipped us on to this group and I understand that DMRFC in Toronto has been using them for a while now. You will find our Calgary Chapter listed under Dystonia Medical Research Foundation. This could be a real help to us in raising funds from our supporters at a distance, but because of the fee, I would ask our own people and your supporters that you see regularly, to continue to bring your monies directly to us in Calgary. The more full donations we can keep, the better for our cause.

Our next meeting will be at our usual spot, the Developmental Disabilities of Calgary building, 10 am to noon, Saturday, April 26. Please come join us. If not possible to come that day, do let one of us know how you are faring as you will certainly be in our thoughts.

Marg Roy

## ITEMS OF INTEREST

### ITEM 1

*Syedda emailed me this article. It was in the UK newspaper Daily Mail on-line March 11<sup>th</sup> 2008. Please note that the author stresses that the FDA is not stopping the prescription of Botox, but is conducting a safety review. Also, the doctors interviewed emphasize that Botox is safe when administered by a competent physician. I know there are people in our support group who have been having Botox shots regularly for fifteen years or so with marvelously beneficial results and no adverse effects. However, this is a story we should watch as the research progresses. HM*

### **Can Botox injections poison your body?**

By THERESA DEVEREUX - March 2008

Just how safe is the anti-wrinkle drug Botox? That's the question raised by new research which found that, contrary to popular belief, the toxin can spread in the body - potentially putting patients' health at risk.

Botox is one of the fastest-growing cosmetic treatments in the world and is also increasingly being used as a medical treatment for a range of conditions, including excessive under-arm sweating, incontinence, migraine, stroke, and muscle spasms in children with cerebral palsy.

The drug is made from a toxin produced by the bacterium *Clostridium botulinum*, one of the deadliest germs known to man. Botox is made from a toxin that causes botulism, the progressive paralysis of muscles, a severe and often fatal condition whereby the muscles become progressively paralyzed - the heart and breathing muscles stop, causing death.

It is this ability to temporarily paralyse muscles which has been harnessed by the medical profession. And while in large doses Botox can be fatal, using small, carefully applied doses to paralyse and therefore relax an overactive muscle can be useful medically. Relaxing the rigid muscles after a stroke can mean a patient may find it easier to dress themselves, just as relaxing the muscles of the head and neck can relieve the pain of certain types of migraine, or relaxing one of the muscles that controls the bladder will relieve incontinence.

Botox was first licensed for cosmetic use in 2002; tiny amounts injected into the face block nerve signals and cause paralysis, relaxing the muscles and smoothing out wrinkles.

It has been widely assumed that Botox stayed in the muscle and was therefore safe - but new research contradicts this. In the study, conducted at the University of Calgary, in

Canada, and published in the Journal of Biomechanics, it was found that the product is not as easy to control as previously thought.

The research was led by scientist Dr Walter Herzog, who received the American Society of Biomechanists' highest honour for his work last year. He had been using botulinum as part of his study into osteoarthritis when he noticed that the toxin didn't just affect the muscle in which it was injected.

Experimenting on cats, his team injected the toxin into a muscle at the back of the leg. Four weeks later, the time it takes for Botox to have its full effect, they measured the strength of this muscle, and that of a neighbouring muscle.

Herzog says: "What we found was that the toxin passed easily into the surrounding muscles and weakened all the muscles in the area." The results support other research that has already shown that botulinum can pass through muscle fascia (the packing tissue around muscles). "Our research showed that the toxin can also affect the working of the neighbouring muscles." He adds: "While I see the benefits of it as a therapeutic tool, its applications in humans are increasing and it is important we understand more about this product, which is a toxin."

This research comes amid investigations by the American Food and Drug Administration (FDA) into reports of children's deaths, and severe side-effects for others treated for a variety of medical conditions with Botox and related products.

The most serious cases were in children with cerebral palsy being treated for spasticity - rigid muscles. They experienced difficulty swallowing, muscle weakness and breathing problems - mimicking the symptoms of botulism poisoning - which appeared to be related to the spread of the botulinum toxin from the site of injection

The FDA is not advising doctors to stop prescribing the drug, but they are conducting a safety review and say the reactions may be due to overdosing. However, they are warning patients that they should receive immediate medical attention if they have worsening or unexpected difficulty in swallowing or talking, trouble breathing or muscle weakness following any injection of Botox.

According to Rajiv Grover, secretary of the British Association of Aesthetic Plastic Surgeons, the doses used cosmetically are 50 to 60 times less than those used to treat some medical conditions. "Along with my colleagues I've treated thousands of patients and if we saw a lot of diffusion to other muscles of the face we would see a lot of complications which we certainly do not. "The single most important factor in getting a good result from Botox is not the drug itself but the skill of the person who injects it."

Dr Antony Fulford-Smith, spokesman for Allergan, the manufacturer of Botox, says: "Dr Herzog's research was on cats and therefore it is inappropriate to make any conclusions at all about the safety of Botox in relation to humans. "It was a laboratory experiment using doses that would not normally be used in a therapeutic situation. Botox has been used worldwide to treat millions of people for many conditions for nearly 20 years, providing huge relief in many cases. We closely monitor any adverse reactions and if used as indicated and injected in the right dose it is very rare for there to be any serious side-effects in relation to the spread of the toxin."

## QUIZ TIME

Some greedy parents raided their daughter's piggy bank. They got out a grand total of \$8.20, with the same number of pennies, nickels, dimes and quarters. How many of each?

*Answer later in the newsletter.*

## INTRODUCING - Brian Larke

*Brian has been writing his autobiography for us, and for his own family history archives. I will serialize it as it is quite long. Here is the first episode:*

I was born in 1939 just after the second world war began. My birthplace was Redcar, Yorkshire on the north east coast of England, part of Teeside, which is known for steel, chemicals and ship building. My ancestors came north from Norfolk in the late 19<sup>th</sup> century, as the north attracted rural labour to develop the heavily industrial areas of Teeside. My earliest memories include being huddled in an air raid shelter listening to the sound of bombs dropping in and around our home, as the Teeside area has a heavy industrial concentration and as such was a prime target.

Our one claim to fame is that one Janet Larke had an illegitimate child with Cardinal Wolsey in about 1510/1520. Cardinal Wolsey was a powerful advisor to Henry V111 for many years and with the money he obtained from this position he built Hampton Court Palace. He later gave the Palace to Henry but this did not make up for his inability to arrange a divorce from Catherine of Aragon. Wolsey 's power was undermined by others who were jealous of his position and Henry ordered him to the Tower of London. Fortunately, for him at any rate, he died on the way to the Tower and thus probably cheated the executioners axe.

In the late 40's I used to go to the beach to rake up sea coal which is left on the beach at low tide. This coal came from a submerged coal seam and we used this to add to our regular source, which was rationed. Sea coal is very fine compared to lump coal and we used to fill conical packets made from newspaper and put them on the fire to burn. As the coal had a high moisture content it produced an enormous amount of smoke which, if we were unlucky, filled the house with a choking mist that hung around for days.

I am an only child and I followed the usual deprived childhood undergone by any child who grew up in wartime, I was 6 years old before I saw my first banana. I used to get a ration of 4ozs. of candy a week and I took great pains to get 2ozs. of hard candy and 2ozs. of soft. During the war we grew our own vegetables and we were lucky as we lived in a house which had a garden to grow them. We also had rabbits, chickens and ducks. My father made a little duck pond and I took pleasure in splashing the ducks and in the process got soaking wet. Not a problem today with electric dryers but then it was a case of hanging clothes on a line outside and hoping it didn't rain before they were dry.

At age 11 I took the 11+ exam, which was designed to sort out the high achievers from the others who were not. I passed the exam which afforded me the opportunity to go to the "Grammar School" in 1951. This was a source of pride for my mother because I was the only one of my 6 cousins to go. The down side for me was that I had to wear a uniform 7 days a week which meant that I was easy to identify and suffered a little bullying by those other guys who didn't pass the 11+. I had to learn French which I hated. I also learned to run fast. Uniforms made it easy for teachers to see who was in the local pool hall which was around the corner from the school and to which I was a regular customer.

I spent 5 years in a school system which was designed to make me into University material. This involved learning by rote with a heavy emphasis on a structured learning environment. Looking back I realise that we were never taught to think or explore for things ourselves. Discipline was meted out by prefects (older boys who delivered corporal punishment with great enthusiasm). After 5yrs. I took a 2 hour exam. in each subject that the teaching staff felt I had the best chance of passing, as this was another screening process designed to further refine university material. I passed 5 out of 6 subjects. Who needs Latin anyway!. Too bad if you were sick on the day of an exam. 5 years effort down the tubes.

I decided to leave school in 1956 and I started an apprenticeship in mechanical engineering. This involved drafting in a work situation together with practical hands-on experience in various engineering areas. Included in this was a 5 year part time academic program leading up to becoming a fully fledged engineer.

My mother was overjoyed with my choice as this meant we had 3 generations working for the same steel company and I was "on staff "which meant I would get paid when I was sick.

This is where it starts to get interesting . . . . .

*Episode two will be in the next newsletter.*



## ON THE LIGHTER SIDE

Pastor Norton woke up Sunday morning and realizing it was an exceptionally beautiful and sunny early spring day, decided he just had to play golf.

So... He told the Associate Pastor that he was feeling sick and persuaded him to give the sermon for him that day.

As soon as the Associate Pastor left the room, Pastor Norton headed out of town to a golf course about forty miles away. This way he knew he wouldn't accidentally meet anyone he knew from his church. Setting up on the first tee, he was alone. After all, it was Sunday morning and everyone else was in church!

At about this time, Saint Peter leaned over to the Lord while looking down from the heavens and exclaimed, "You're not going to let him get away with this, are you?" The Lord sighed, and said, "No, I guess not."

Just then Pastor Norton hit the ball and it shot straight towards the pin, dropping just short of it, rolled up and fell into the hole. IT WAS A 420 YARD HOLE IN ONE.  
St. Peter was astonished. He looked at the Lord and asked, "Why did you let him do that?" The Lord smiled and replied, "Who's he going to tell?"

*A friend emailed me this for St. Patrick's Day:*

An Irish priest is driving down to New York and gets stopped for speeding in Connecticut.  
The state trooper smells alcohol on the priest's breath and then sees an empty wine bottle on the floor of the car.  
He says, "Sir, have you been drinking?"  
"Just water," says the priest.  
The trooper says, "Then why do I smell wine?"  
The priest looks at the bottle and says, "Good Lord! He's done it again!"



Answer to Quiz Time: 20

## **DYSTONIA WALK AND WHEEL - 2008**

COME JOIN OUR WALK AROUND PARKLAND AREA TO RAISE FUNDS FOR MUCH-NEEDED RESEARCH INTO THIS "MOVEMENT DISORDER" DISEASE. THIS WILL BE OUR TWELFTH ANNUAL WALK. MONIES RAISED WILL GO TO THE DYSTONIA MEDICAL RESEARCH FOUNDATION FOR RESEARCH GRANTS. EACH YEAR WE GET CLOSER TO MUCH NEEDED ANSWERS.  
RECEIPTS FOR CHARITABLE DONATIONS OF \$10 OR MORE WILL BE AVAILABLE.

DAY:	SATURDAY, JUNE 14, 2008
TIME:	10 AM THROUGH 1 PM
WHERE:	MARG AND GORD ROY'S HOUSE, 119 PARKLAND HILL S.E., CALGARY

DIRECTIONS: COME EAST ON CANYON MEADOWS FROM THE MACLEOD TRAIL SIDE OR WEST ON CANYON MEADOWS FROM BOW BOTTOM TRAIL TO PARKLAND BOULEVARD (LIGHTS AT CORNER OF CANYON MEADOWS AND PARKLAND BLVD). COME ALONG PARKLAND BLVD QUITE A WAYS, PAST THE FIREHALL, PAST THE BIG CURVE AND ONE BLOCK PAST THE OVERHEAD CROSSWALK SIGN.(IF YOU GET AS FAR AS THE MORMON CHURCH, YOU HAVE GONE TOO FAR.) TURN RIGHT AT PARKSIDE DRIVE, GO ONE BLOCK, THEN RIGHT AGAIN ONTO PARKLAND HILL. THIS STREET IS ONLY TWO BLOCKS LONG AND WE ARE ON THE MIDDLE CORNER: CREAM COLOURED BUNGALOW WITH REDDISH BROWN TRIM. 119 PARKLAND HILL SE. PH 271-4438

**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, 48<sup>th</sup> 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, April 26<sup>th</sup> 2008

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

**GUEST SPEAKER.** None

**MEMBERSHIP FORM - 2008**

**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: DMRF Calgary Chapter

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



