

# Dystonia Medical Research Foundation

## Calgary Chapter

ISSUE # 80

October 2009

### CHAIRPERSON'S CORNER

Hello everyone. I hope that Thanksgiving was a happy time for you with family and friends. A little early taste of winter, but hopefully we can soon get back to normal, whatever that is in Calgary.

I had the privilege September 30 of attending the Merz introduction of their new Botulinum Neurotoxin Type A drug, Xeomin. Drs. Karsten Schlemm and Jurgen Frevert of Merz Germany gave presentations on the background, research and development of Xeomin. Also Dr Kirk Dressler, Head of Movement Disorders Section, Dept of Neurology at Hannover Medical School came to give us a history of his experience with this toxin. Xeomin has been commercially available in Germany since 2005, so he had quite a history to give us. Glenn Block, President and GM of Merz Pharma Canada Ltd with his team organized this excellent evening. This was a dinner meeting for the neurologists, movement disorder clinic teams and pharmacists of Western Canada in order to introduce everyone to this new drug. Our own clinic's Dr Ranawaya and Dr Suchowersky along with two of their Fellows and senior nurse Karen were present: also Dr Martin of Edmonton's clinic and his key people. Also, I understand doctors from B.C. and Saskatchewan had come in for this presentation.

Great pains have been taken to remove the additional proteins that have been present in earlier versions of this toxin. Xeomin can be carried in house for extended periods of time without refrigeration and no reconstitution is required when the drug is to be administered. There seems to be great success with Spasmodic Torticollis (Cervical Dystonia), Blepharospasm and the spastic postures often caused by stroke. They have also used it successfully treating hyperhidrosis (excessive sweat gland production). To date no one has developed antibodies to this drug, which raises great hope for new patients. In earlier toxin recipes there was much more carrier protein and the thinking is that this was the cause of much of the antibody development. Of course, the toxin itself is a protein and so many people who became resistant to these earlier

toxins, may also have developed antibodies to the botulinum toxin itself. Time will tell, but certainly it is good to have another option for treating Dystonia. At this point, Merz has Canadian Government approval for the drug, but also has insurance coverage from private Blue Cross plans and other insurance groups. They are still working on the public or senior Alberta Blue Cross plans and hope to have that in place by next spring. They do, however, have a working plan with the various movement disorder clinics so that if a neurologist wishes to use Xeomin specifically and there is no appropriate insurance coverage, Merz will get involved to remedy the problem. Merz's Western Canada Medical Rep. is Damien King and he will be keeping us up to date on the latest patient information.

We have a date for our next Casino so mark your calendars: March 2 and 3<sup>rd</sup>, 2010 at the Elbow River Casino. This is a new casino location for us and as many of our regular workers live in the SW, it should work well for us. Lil Faider is again working her magic to make these two days come together and work smoothly for us. A lot of time and organizational expertise is required for this and we thank her for her ongoing efforts to keep this the amazing fund-raiser that it is for us. Even if you have not helped at one of these casinos before, there is easy and quick training available as we start our shifts. All work you do is with the assistance and overseeing of professional staff, so it is interesting and fun. You get to handle, count or distribute lots of lovely loot. Please add your name to Lil's list of workers.

Just a reminder to all of you that the generous gift of an hour's free counselling is still ongoing with Donna Piercy. Donna spoke at our winter meeting last year and is now completing her psychologist degree. She has been making a few hours on an afternoon available to us once a month for a while now. Her busy schedule is such that we don't always have a lot of time to organize these sessions, so we would appreciate knowing who among you would like the chance to have a sounding board for an hour. I understand that she is very easy to talk to. Her whole varied career has been in the medical field and so she has been making this wonderful offer to our group and your spouses of course, as they are certainly affected by our dystonias as well. Just let myself or Heather know of your interest.

Our next meeting will be our usual 10 am to noon at the Developmental Disabilities Bldg, **October 24th**. This is a meeting you don't want to miss. **Diane Gillespie, our National Director from Toronto** will be here to meet us and update us on her accomplishments in getting the Canadian Government's support for our research projects, her fund-raising successes, and the major gains we are making in awareness. She will be able to tell us about the work of other Canadian support groups and chapters and of course will bring us the latest new info about Dystonia itself. At this meeting, we will also have an update from Wes Teskey of the University of Calgary who with his team has been working on a special computer 'mouse'. This is being engineered to disregard the overriding, unintended jerky movements characteristic in patients with irregular dystonic hand or arm movements, Essential Tremor or Parkinsons. Only the slower intended movements of the 'mouse' will be recognized and acted upon.

This will open up the world of computers to many, many people who now find operating the mouse both frustrating and near impossible. Do try and join us October 24<sup>th</sup>. If you cannot make it, please let one of us know how you are doing as you will definitely be in our thoughts.

Marg Roy

## **INTRODUCING: Brian Larke**

*Here is the sixth part of Brian's story:*

Needless to say that I was away from home and after we were married it became a problem. I had managed to save enough for a down payment on a house by living on my expense account and saving all my salary for almost two years.

Unfortunately, my wife's mother was very ill with cancer and my continued absence during the week made things worse for my wife. So another change of direction in my career and I got the job back that I had lost two years earlier with the engineering company. My wife's mother died in 1965, a year after our marriage. I quit smoking again even though I had about 5,000 cigarettes in my office which had built up from the 3,000 a month that I was supposed to give away as samples. After the freedom of working for the cigarette company I found that working a five day week in an office was boring and I had to get out. So my father in law's input was called for again and this time he came up with a company called Oxo Limited.

Oxo was the distribution vehicle for the parent company called Leibig's, who were the largest cattle ranchers in the world based in South America. Everybody has heard of Oxo cubes and they also made a wide range of canned meat products sold under the name Fray Bentos. (Also known as "frayed bent 'oss".) Once again it was back to a company car and an expense account. This time I worked from home and was pretty well left to my own devices as long as I kept up with my sales quotas. This was not difficult as my predecessor was not very productive. My territory was from the east coast of Northern England around Teesside and west almost to the Lake District on the other extreme. It was quite a contrast from those "dark satanic mills" of the industrial revolution in Teesside to some of the most beautiful places in England in the Yorkshire Dales and the Pennines. This was the area that James Herriot made famous in his Vet. stories and things he described were still the same now as they were then and as they had been for centuries.

The weather was the same as it had been for centuries and that was bone chilling cold wind that went through rather round and no amount of warm clothes seemed able to keep out.

Coincidentally the head office of Oxo was in Thames House, London which is now featured in the BBC World TV series as the headquarters of MI-5/Spooks programs.

The economy in 1966 Britain was in a shambles and a wage freeze was in force. My income was basically salary compensation. I found myself in the awkward position of having increased my sales and not having any increase in salary. There was at that time the notion that selling on commission would lead to underhanded behaviour by pushy sales people selling inferior goods. So time to rectify my situation yet again.

My wife Sheila and I had talked about emigrating occasionally and we decided to check out South Africa as a friend of hers had recently come back from South Africa for a holiday in England and liked living there. Like most things, we never really followed through and I discovered that Sheila had a way of turning off an idea by saying "that gives me /or us something to talk about". This is the comment on which many a sales presentation has died on the vine. It is useful now when Sheila uses it I know she is not interested in the idea or product, so it's game over, let's get on with life.

It was in 1966 that a chance meeting took place which was to change our lives forever.

When working at the engineering company I met George Whitehead, who was on a drawing board adjacent to mine and life being what it is, we lost touch after I went to the cigarette company and he emigrated to Canada. He worked in Hamilton for a couple of years and he decided to come back to U.K by travelling west rather than east and travel around the world. On a cruise ship travelling back to U.K he met a Canadian girl called Lois and she would later become George's wife.

They both came to George's home town of Middlesbrough and while they were there we met them through a mutual friend and we told Lois of our thoughts about emigrating. She extolled the virtues of Canada and she suggested Calgary as a possible destination. She came from Medicine Hat and her sister was married and lived in Calgary. Her husband, Ed Madsen, was a detective in the Calgary Police Force and he became Deputy Chief some years later.

Stay tuned, we will be back after a few short weeks.

## ITEMS OF INTEREST

**The phenomenal power of the human mind.**

I couldn't believe that I could accurately understand what I was reading. According to research at Cambridge University, it doesn't matter in what order the letters in a word are, the only important thing is that the first and last letter be in the right place. The rest can be a total mess and you can still read it without a problem. This is because the human mind does not read every letter by itself, but the word as a whole.

Amazing huh?

## ON THE LIGHTER SIDE

*Wise words emailed to me recently:*

Time is like a river. You cannot touch the same water twice, because the flow that has passed will never pass again.

\* \* \* \* \*

*This quiz is from Teresa, it's a good one. I didn't do very well at it!*

### **Dementia Quiz**

Below are four questions and a bonus question to test your perception, reasoning and the quickness of your logical processing. They are stated simply so you should try to answer them instantly. To assure the accuracy of the results, you should not take your time, but instead, answer each of them immediately.

OK?

Let's find out just how clever you really are....

**First Question :**

You are a participant in a race. You overtake the second person. What position are you in?

**Answer :** If you answered that you are first, then you are absolutely **WRONG!** If you overtake the second person and you take his place, **YOU** are in second place!

Try not to screw up next time. Now answer the second question, but don't take as much time as you took for the first question, OK?

**Second Question :**

If you overtake the last person, then you are...?

**Answer :** If you answered that you are second to last, then you are **WRONG** again. Tell me, how can you overtake the **LAST** person??

You're not very good at this, are you?

**Third Question :**

Very tricky arithmetic! Note: This must be done in your head only. Do **NOT** use paper and pencil or a calculator.

Take 1000 and add 40 to it. Now add another 1000 Now add 30 . Add another 1000 . Now add 20 .. Now add another 1000 ... Now add 10 . What is the total?

Did you get 5000 ?

The **correct answer** is actually 4100 ...

If you don't believe it, check it with a calculator!

Today is definitely not your day, is it? Maybe you'll get the last question right... Maybe...

#### Fourth Question:

Mary's father has five daughters:

1. Nana, 2. Nene, 3. Nini, 4. Nono, and ??? What is the name of the fifth daughter?

Did you Answer Nunu? NO! Of course it isn't. Her name is Mary!!! Read the question again!

Okay, now the **Bonus Round**, i.e., a final chance to redeem yourself:

A mute person goes into a shop and wants to buy a toothbrush. By imitating the action of brushing his teeth he successfully expresses himself to the shopkeeper and the purchase is done.

Next, a blind man comes into the shop who wants to buy a pair of sunglasses; how does HE indicate what he wants?

It's really very simple. He opens his mouth and asks for it...

*I hope you did better than I did!*

*HM*

\* \* \* \* \*

*And I had this one in an email too.*

#### The Brick

A young and successful executive was traveling down a neighbourhood street, going a bit too fast in his new Jaguar. He was watching for kids darting out from between parked cars and slowed down when he thought he saw something. As his car passed, no children appeared. Instead, a brick smashed into the Jag's side door!

He slammed on the brakes and backed the Jag back to the spot where the brick had been thrown. The angry driver then jumped out of the car, grabbed the nearest kid and pushed him up against a parked car shouting, 'What was that all about and who are you? Just what the heck are you doing? That's a new car and that brick you threw is going to cost a lot of money. Why did you do it?'

The young boy was apologetic. 'Please, mister...please, I'm sorry but I didn't know what else to do,' He pleaded. 'I threw the brick because no one else would stop...' With tears dripping down his face and off his chin, the youth pointed to a spot just around a parked car. 'It's my brother,' he said. 'He rolled off the curb and fell out of his wheelchair and I can't lift him up.' Now sobbing, the boy asked the stunned executive, 'Would you please help me get him back into his wheelchair? He's hurt and he's too heavy for me.' Moved beyond words, the driver tried to swallow the rapidly swelling lump in his throat. He hurriedly lifted the handicapped boy back into the wheelchair, then took out a linen handkerchief and dabbed at the fresh scrapes and cuts. A quick look told him everything was going to be okay. 'Thank you and bless you,' the grateful child told the stranger. Too shook up for words, the man simply watched the boy push his wheelchair-bound brother down the sidewalk toward their home.

It was a long, slow walk back to the Jaguar. The damage was very noticeable, but the driver never bothered to repair the dented side door. He kept the dent there to remind him of this message: 'Don't go through life so fast that someone has to throw a brick at you to get your attention.'



*Another one I received as an email:*

## **JOKES THAT CAN BE TOLD IN CHURCH**

Attending a wedding for the first time, a little girl whispered to her mother, 'Why is the bride dressed in white?'

The mother replied, 'Because white is the color of happiness, and today is the happiest day of her life.'

The child thought about this for a moment then said, 'So why is the groom wearing black?'

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Three boys are in the school yard bragging about their fathers. The first boy says, 'My Dad scribbles a few words on a piece of paper, he calls it a poem, they give him \$50.'

The second boy says, 'That's nothing. My Dad scribbles a few words on piece of paper, he calls it a song, they give him \$100.'

The third boy says, 'I got you both beat. My Dad scribbles a few words on a piece of paper, he calls it a sermon, and it takes eight people to collect all the money!'



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An elderly woman died last month. Having never married, she requested no male pallbearers. In her handwritten instructions for her memorial service, she wrote, 'They wouldn't take me out while I was alive, I don't want them to take me out when I'm dead.'

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A police recruit was asked during the exam, 'What would you do if you had to arrest your own mother?' He answered, 'Call for backup.'

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A Sunday School teacher asked her class why Joseph and Mary took Jesus with them to Jerusalem. A small child replied, 'They couldn't get a baby-sitter.'

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A Sunday school teacher was discussing the Ten Commandments with her five and six year olds. After explaining the commandment to 'Honor thy father and thy mother,' she asked, 'Is there a commandment that teaches us how to treat our brothers and sisters?' Without missing a beat, one little boy answered, 'Thou shall not kill.'

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At Sunday School they were teaching how God created everything, including human beings. Little Johnny seemed especially intent when they told him how Eve was created out of one of Adam's ribs. Later in the week his mother noticed him lying down as though he were ill, and she said, ' Johnny, what is the matter?' Little Johnny responded, 'I have pain in my side. I think I'm going to have a wife.'

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You don't stop laughing because you grow old. You grow old because you stop laughing.



*Please remember to let me know if you change you address or email address, or if you no longer want to receive this newsletter.*

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**NEXT MEETING**

TIME 10 am to 12 noon  
DATE Saturday, October 24th, 2009  
LOCATION DEVELOPMENTAL DISABILITIES RESOURCE CENTRE  
4631, RICHARDSON WAY, SW, CALGARY  
SPEAKER Diane Gillespie, Canadian National Director DMRF  
And Wes Teskey from U of C

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**MEMBERSHIP FORM 2009**

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