

# Dystonia Medical Research Foundation

## Calgary Chapter

ISSUE # 76

October 2008

### CHAIRPERSON'S CORNER

Hello everyone. I hope you have had happy Thanksgiving celebrations filled with family and friends and thoughts of all the blessings that have come your way. It is good to stop and take stock once in a while. No matter what complications life throws us, there are usually so many things and people to be thankful for when we look around. People for us to love, appreciate and remember who support us as we struggle with Dystonia or any of our other life challenges. Seems a nice tradition to start into Fall with all its showy grandeur. We have certainly had wonderful weather to help ease our transition from summer.

We had a small but informative and supportive meeting in September. As you know, Ken Grandia has been working with students in the Geomatic and Kinesiology Departments of the University of Calgary developing a computer device similar to a 'mouse'. A special one that would be able to differentiate between our slower intended movements while recognizing and ignoring the more rapid involuntary movements generated by a tremor or movement disorder. One of these students, Wes Teskey a PhD student, came and gave us an update of their study. They are having people with tremors as well as control subjects come in so they can gauge the variety of movements that the device will have to accommodate. They have engineered the special monitor needed and are progressing through the complicated mathematics that will differentiate between normal movements and tremors. We were happy to learn more about this project and Wes and Ken were pleased to be able to learn from us about how our arms and hands are affected by our various dystonias. We again volunteered to help in any way we could, knowing you would all feel the same way about this.

I have copies of the new Dystonia Dialogue and also the new Canadian brochure "What is Dystonia". Will bring a supply of these to the next meeting, but if you

won't be able to join us and don't already receive these from Foundation, please give me a call after October 20<sup>th</sup> and I will be happy to mail you a copy of same.

As you know, I will be disappearing for most of the winter again this year and so Heather, Lil and Teresa will be organizing a meeting in January or February for you. Please help them with any meeting ideas or newsletter features you may think of. Aside from that Jan. or Feb. meeting, the consensus at our last gathering was to have that one winter meeting and then meet again in mid April when I return. We would appreciate any comments or thoughts you might have in this regard.

I have wonderful news in that we have been approved for a generous donation towards our research by the Calgary Area City Council of Beta Sigma Phi. We will be receiving \$10,000. Special thanks to our own Irene Anderson for helping us apply for and receive this amazing support.

Our next meeting will be November 1, Saturday morning 10 until noon, at our usual spot, the Developmental Disabilities Resource Centre. We are looking forward to hearing from Laura McDougall who is a masters student in the Faculty of Kinesiology at the University of Calgary doing a project on people with cervical and focal hand dystonia. This should be extremely interesting and Laura has included some information about this special study further into this newsletter. Please come out and join us. We will learn a new perspective and she will no doubt be hoping to learn more about the presentation and effects of our Dystonias.

I look forward to seeing you all. If you cannot join us, please let us know how you are doing. You will be in our thoughts.

Marg Roy

\* \* \* \* \*

## ITEMS OF INTEREST

### ITEM 1

*The following is from Laura McDougall who will be our speaker at the meeting on November 1<sup>st</sup>. It explains the study they are doing at U of C and how we may be able to help them with their research.*

**NEW RESEARCH! Masters Research Project at the University of Calgary:  
Is the uninvolved hand affected in dystonia: A transcranial magnetic stimulation (TMS) study**

Laura McDougall, Drs. Timothy Welsh and Zelma Kiss

A common feature in our brain is “surround inhibition”. It relaxes or inhibits groups of muscles that are not involved or oppose an intended movement and allow movements to occur in a controlled and organized manner. However in dystonia, opposing muscles do not relax. In fact, opposing muscles co-contract with the intended muscles resulting in the twisted and contorted limb postures. It is thought that these problems arise due to abnormalities in the basal ganglia - a deep structure in the brain. This abnormal output of the basal ganglia in dystonia causes excessive excitation of the motor cortex - the area of the brain responsible for sending signals to the muscles to begin movement. Surround inhibition may be one way that increased excitation overflows to affect muscles that would normally be inhibited during specific movements. It is not known, however, if the problem with surround inhibition affects only the limb affected by dystonia or if it is generally present throughout the body.

Our research at the University of Calgary is designed to examine surround inhibition in the hands of people with cervical dystonia or focal hand dystonia and people without dystonia. Our goal is to determine whether abnormalities in surround inhibition are specific to the limb affected by the dystonia or whether it is a generalized issue. While this research will not directly change how the subjects involved are treated, a better understanding of how the brain works in dystonia is critical to develop new treatments in the future.

The Cognitive and Motor Neuroscience Lab at the University of Calgary is looking for men and women with focal hand dystonia or cervical dystonia to volunteer for this study. We are also looking for individuals without dystonia to be part of a comparison or control population. The study will involve the application of single pulses of transcranial magnetic stimulation (TMS) over the motor cortex while participants make simple finger movements. TMS is a relatively new and exciting technology being used in dystonia research. It is a magnetic coil placed on the head and stimulation activates finger muscles to twitch; it is painless and non-invasive. We will also record the muscle activity in the fingers by pads placed on the skin surface. By examining the size of TMS-evoked muscle contractions in resting finger muscles, we will assess surround inhibition in the hand. All participants will receive financial compensation (at \$10/hr) for their time (time commitment ~ 1.5hrs). Transportation costs (i.e., bus fare or parking) will also be covered.

Come and help us understand dystonia! Please contact:

Laura McDougall

403-585-1863

lmcdouga@ucalgary.ca

## INTRODUCING - Brian Larke

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

My second trip was to India via the Mediterranean, the Red Sea and across the Arabian Sea and on to Ceylon eventually arriving in Calcutta. The trip took about 3 weeks as we called on various ports on the way. I was so naive that I thought that we would be eating a lot of salads as we did in UK when the weather got warm.

The food was like nothing I had been used to back home. Three meals a day with up to a 7 course menu served by East Indian mess boys and 24 hour room service complete with company silverware. Unfortunately the menu was to become rather monotonous and we could tell the day of the week by looking at the menu. I later found out that the quality of the food improved significantly on our homeward voyage.

We sailed with 22 white officers and an Indian crew of about 50. The ship was owned by T&J Brocklebank, part of Cunard, and was about 8,000 tons. We traded between European ports and the middle East. I had my own cabin and I had boy who took care of my cabin and did my laundry etc..

I was on the 4/8 watch again and as we went down the Bay of Biscay I was sea sick again and had serious doubts about my choice of a sea going career.

Once we hit the Med. I recovered and this was the last time I was ever sick.

At Port Said we docked before going through the Suez Canal. This was my first encounter with "business men" as they came on the ship selling everything from soup to nuts. I bought a shirt which, when I undid the wrapping, had only one sleeve. The vendor was nowhere in sight, of course. So showing a remarkable degree of initiative, I repacked the shirt and I traded it to another "businessman" for a couple of stuffed animals. I also came into contact with what we called the "Fuzzy Wuzzies" who had very spectacular hair styles which were held in place with camel dung. Needless to say I didn't stand down wind as the smell was overpowering. They were the only opposing force which defeated the British "square" form of defense strategy. Maybe the smell had something to do with it.

As we passed through the Suez the temperature went up and the engine room became very uncomfortable and trying to stay cool was a major problem. The vessel used steam propulsion provided by 3 scotch boilers which powered a triple expansion turbine engine. The temperature in the engine room was about 120 Fahrenheit with 100% humidity.

Drinking ice water was not a solution to replace the lost fluid as this was supposed to cause stomach problems. We still had lime juice at 11am every day

which was to replace vitamin C lost in sweating (hence the nickname for British sailors as “limeys”) We also drank gin & tonic ,as the gin was supposed to hide the taste of the quinine in the tonic which provided protection from malaria. The most popular by far was beer. This was lager in cans and was kept in a fridge until consumed at any time throughout the day or night. When I came off watch at 8am I used to drink shandies before breakfast.

*Part four will be in the next newsletter - - - -*



## QUIZ TIME

Complete the couplets below with words that are pronounced the same but spelled differently:

It's not permitted, not \_\_\_\_\_  
To read your paperback \_\_\_\_\_

Her haircut left her almost \_\_\_\_\_  
She grabbed a tissue and she \_\_\_\_\_

My broker called me on his \_\_\_\_\_  
To tell me not to buy, but \_\_\_\_\_

The transit worker wasn't \_\_\_\_\_  
And made me pay an extra \_\_\_\_\_

*Answers later in the newsletter.*

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## TIME FOR A RHYME

*I felt creative last week while on a long walk and penned this*

**Ode to Dystonia:**

I have dystonia, such a bore.  
It makes me twitch and sometimes sore.  
Yet, even if its quite perverse  
I'm glad that its not something worse.  
If I couldn't smell the flowers  
Or feel the sun or hear the showers  
Life for me would be quite grim  
But as it is, I'm hangin' in.  
So just for now I must endure  
Until Research can find a cure.

Some strangers treat me differently.  
They don't realize that I'm still me  
But friends all know that I'm not changed,  
Although my neck is rearranged.  
I truly bless my family,  
For they are always here for me,  
But should they not quite understand,  
Support is always close at hand.  
Our Calgary group has been a boon,  
So please come out and join us soon!

*Heather MacLellan*



## ON THE LIGHTER SIDE

From Marg:

*Some more from a book called Disorder in the American Courts.  
These 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: The youngest son, the twenty-year-old, how old is he?

WITNESS: Uh, he's twenty-one.

ATTORNEY: This myasthenia gravis, does it affect your memory at all?

WITNESS: Yes

ATTORNEY: And in what ways does it affect your memory?

WITNESS: I forget.

ATTORNEY: You forget? Can you give us an example of something you forgot?

ATTORNEY: Were you present when your picture was taken?

WITNESS: Are you kidding me?

ATTORNEY: So the date of conception (of the baby) was August 8th?

WITNESS: Yes.

ATTORNEY: And what were you doing at that time?

WITNESS: Uh.... I was gett'in laid!

ATTORNEY: She had three children, right?

WITNESS: Yes.

ATTORNEY: How many were boys?

WITNESS: None.

ATTORNEY: Were there any girls?

WITNESS: Are you kidding me? Your Honor, I think I need a different attorney.

ATTORNEY: How was your first marriage terminated?

WITNESS: By death.

ATTORNEY: And by whose death was it terminated?

WITNESS: Now whose death do you suppose terminated it?

ATTORNEY: Doctor, how many of your autopsies have you performed on dead people?

WITNESS: All my autopsies are performed on dead people. Would you like to re-phrase that?

ATTORNEY: All your responses MUST be oral, OK? What school did you go to?

WITNESS: Oral.

ATTORNEY: Are you qualified to give a urine sample?

WITNESS: Huh....are you qualified to ask that question?

*And this in an email from a friend:*

### **The Tomato Garden**

The Italian lived alone in New Jersey. He wanted to plant his annual tomato garden, but it was very difficult work, as the ground was hard. His only son, Vincent, who used to help him, was in prison. The old man wrote a letter to his son and described his predicament:

**Dear Vincent,**

I am feeling pretty sad, because it looks like I won't be able to plant my tomato garden this year. I'm just getting too old to be digging up a garden plot. I know if you were here my troubles would be over. I know you would be happy to dig the plot for me, like in the old days.

**Love, Papa**

A few days later he received a letter from his son.

**Dear Pop,**

Don't dig up that garden. That's where the bodies are buried.

**Love, Vinnie**

At 4 a.m. The next morning, FBI agents and local police arrived And dug up the entire area without finding any bodies. They apologized to the old man and left.

That same day the old man received another letter from his son.

**Dear Pop,**

Go ahead and plant the tomatoes now. That's the best I could do under the circumstances.

**Love you, Vinnie**

*A friend emailed this to me. Something to think about:*

## **Stress Management**

A lecturer, when explaining stress management to an audience of business people, raised a glass of water and asked, "How heavy is this glass of water?" Answers called out ranged from 20g to 500g. The lecturer replied, "The absolute weight doesn't matter. It depends on how long you try to hold it. If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case, it's the same weight, but the longer I hold it, the heavier it becomes." He continued, "And that's the way it is with stress management. If we carry our burdens all the time, sooner or later as the burden becomes increasingly heavy, we won't be able to carry on. As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden. So, before you return home tonight, put the burden of work down. Don't carry it home. You can pick it up tomorrow. Whatever burdens you're carrying now, let them down for a moment if you can."

So, my friend, put down anything that may be a burden to you right now. Don't pick it up again until after you've rested a while.



**Here are some great ways of dealing with the burdens of life:**

- \* Accept that some days you're the pigeon, and some days you're the statue.
- \* Always keep your words soft and sweet, just in case you have to eat them.
- \* Drive carefully. It's not only cars that can be recalled by their maker.
- \* If you can't be kind, at least have the decency to be vague.
- \* If you lend someone \$20 and never see that person again, it was probably worth it.
- \* Never put both feet in your mouth at the same time, because then you won't have a leg to stand on.
- \* Nobody cares if you can't dance well. Just get up and dance.
- \* Since it's the early worm that gets eaten by the bird, sleep late.
- \* The second mouse gets the cheese.
- \* When everything's coming your way, you're in the wrong lane.
- \* Birthdays are good for you. The more you have, the longer you live.
- \* Some mistakes are too much fun to make only once.
- \* We could learn a lot from crayons... Some are sharp, some are pretty and some are dull. Some have weird names, and all are different colors, but they all have to live in the same box.
- \* A truly happy person is one who can enjoy the scenery on a detour.



*Answers to QUIZ TIME:*

*allowed, aloud; bald, bawled; cell, sell; fair, fare*

*Please let me know if you change your address or your email.*

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

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**NEXT MEETING**

**TIME** 10 am to 12 noon

**DATE** Saturday, November 1<sup>st</sup>, 2008

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

**GUEST SPEAKER.** Laura McDougall

**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  
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