



# Dystonia Medical Research Foundation

## Calgary Chapter

ISSUE # 93

March 2013

*Hi Everybody,*

*I hope you are all doing well, avoiding the nasty flu that is around, and coping with winter. Our weather hasn't been bad in Calgary, not so far anyway, we've had only a few short sharp wintry periods.*

*Marg is away enjoying the mild winter in California and other warmer climes. She is not writing her usual Chairperson's Corner this time, but she sends her best wishes to you all.*

*This brief newsletter is just to keep in touch, give you some information about dystonia research, share a few jokes, and to wish you and your families a happy and healthy 2013*

### NEWS ABOUT OUR CASINOS

*Lil Faider organised another successful casino for us in February. We all give her a great big THANK YOU for all her dedication and hard work on our behalf over the years. We will not know exactly how much we have raised for DMRF research funds this time until they do the next three-monthly reckoning. Lil has done this for us for over 20 years. She has overseen our participation in Calgary casinos many times and raised a little more than \$750,000*

*(yes, more than a quarter of a million dollars) for DMRF funds. A terrific achievement!*

*One time Lil even received a separate cheque for \$52 which was our share of tips big winners had given the cashier!*

*Lil, we are SO grateful.*

*Its time for Lil to hand the over the reins for this big organisational task and Sheila, Brian's wife, has very kindly offered to take this responsibility from her. Yvonne will assist her and perhaps we can find another person to help coordinate everything the casino requires and have a small Casino Committee headed up by Sheila. If anyone would like to help us by taking up this position please contact Sheila, me, or Marg. Lil worked so hard to get us a spot on the casinos' calendar and we must keep this great event going. There are now so many charities and agencies vying for casino dates we cannot afford to let this lapse. Please think about volunteering for the next casino which will be in approximately 18 months. Or you may know a friend, neighbour or relative who would be generous enough to come and swell our numbers. Lil will, of course, be on hand to offer her abundance of knowledge and expertise to our new Casino Committee. We will discuss all this at our next meeting.*

*Our next meeting will be in the later part of May after Marg gets back to Calgary. I will send another newsletter before then with a firm date.*

*Heather MacLellan*

## **ITEMS OF INTEREST**

### **ITEM 1**

*I found this on the DMRF Chicago website. Its from December 2012*

#### **Teams of Researchers Discover Gene for Spasmodic Dysphonia**

Christine Klein, MD, Professor of Neurology and the Schilling Professor of

Clinical and Molecular Neurogenetics at the University of Lubeck, Germany, was the principal investigator of an international study group that has identified the DYT4 gene associated with a dominantly inherited form of dystonia called whispering dysphonia. Dr. Klein is a past member of the DMRF's Medical & Scientific Advisory Council and guest author for the Dystonia Dialogue. Whispering dysphonia caused by the DYT4 gene is an inherited form of dystonia, causing muscles to contract uncontrollably first in the vocal cords and then progressing to the neck muscles.

Expanding on previous work on DYT4, Dr. Klein and her team conducted genome-wide linkage analysis in 14 members of a large Australian family followed by genome sequencing in two individuals. The findings were published online in December in the *Annals of Neurology* along with a second article describing another research team's work on this gene, led by Henry Houlden MD, MRCP, PhD, Professor of Neurology and Neurogenetics, The National Hospital for Neurology and Neurosurgery Institute of Neurology Queen Square, London.

Symptoms of spasmodic dysphonia (sometimes referred to as laryngeal dystonia) include involuntary contractions of the vocal cords muscles, causing interruptions in speech and affecting voice quality. One of the most characteristic features of spasmodic dysphonia is the patterned, repeated "breaks" in speech, causing a strangled-sounding or breathy voice. Treatment may include botulinum neurotoxin injections, voice therapy, and breathing techniques.

The DMRF congratulates Dr. Klein, Professor Houlden, and the outstanding investigators who contributed to this exciting discovery. Each new gene associated with dystonia provides a potential new target for therapeutics and adds to science's growing understanding of all the dystonias.

## ITEM 2

*I have been reading the current issue of Dystonia Canada Report. It includes some exciting and hope-filled items about research, some of which I shall include below.*

In the last quarter of each year, the DMRF in the United States invites investigators to submit applications for dystonia research funding. Recent grant cycles have generated more proposals than ever before, and the field of dystonia has never been more active.

### **Pursuing Drug Targets**

The DMRF is working with BioFocus, a biotechnology company, to identify new drug targets. These efforts may ultimately lead to a whole new generation of dystonia therapies that interrupt or alleviate dystonia at the cellular level. The project has successfully progressed through the first two stages, identifying

several potential targets. While no one can predict where these results will lead, this development is very encouraging. The next step is to validate and confirm the preliminary data. The DMRF is partnering with Tyler's Hope for a Dystonia Cure in this effort. (DMRF Canada partnered in this project in 2012).

## **New Stimulation Methods**

In addition to deep brain stimulation, other therapeutic stimulation methods such as cerebellar and premotor cortical stimulation are under investigation. This is the direct result of a growing understanding of how specific brain areas are involved in dystonia. "None of us think of dystonia as just a basal ganglia disorder anymore," explains Scientific Director Mahlon DeLong, MD of Emory University School of Medicine. "Dystonia is a network disorder - much more complex." Research is demonstrating that in addition to the basal ganglia, other areas of the brain are implicated in many cases of dystonia including the cerebellum, motor cortex, thalamus, and corpus callosum. Each of these brain structures represents an area for investigating new therapeutic approaches, and simultaneous advances in neurostimulation are presenting opportunities for less invasive techniques.



## **ON THE LIGHTER SIDE**

**I am giving you a Daily Survival Kit to help you each day.....**

Toothpick ... to remind you to pick the good qualities in everyone, including yourself.

Elastic band ... to remind you to be flexible. Things might not always go the way you want, but they can be worked out.

Band-Aid ... to remind you to heal hurt feelings, either yours or someone else's.

Eraser ... to remind you everyone makes mistakes. That's okay, we learn from our errors.

Candy Kiss ... to remind you everyone needs a hug or a compliment everyday.

Mint ... to remind you that you are worth a mint to your family and friends.

Bubble Gum ... to remind you to stick with it and you can accomplish anything.

Pencil ... to remind you to list your blessings every day.

Tea Bag ... to remind you to take time to relax daily and to go over your list of blessings.



*This is my excuse - - - -*

Ever walk into a room with some purpose in mind,  
only to completely forget what that purpose was?

Turns out, doors themselves are to blame for these strange memory lapses. Psychologists at the University of Notre Dame have discovered that passing through a doorway triggers what's known as an event boundary in the mind, separating one set of thoughts and memories from the next.

Your brain files away the thoughts you had in the previous room and prepares a blank slate for the new locale.

It's not aging, it's the darn door!  
Whew! Thank goodness for studies!



*Punographs. They came in an email from a friend*

I changed my iPod name to Titanic, and now It's syncing.

Jokes about German sausage are the wurst.

A soldier who survived mustard gas and pepper spray is now a seasoned veteran.

I know a guy who is addicted to brake fluid. He says he can stop any time.

I stayed up all night to see where the sun went. Then it dawned on me.

This girl said she recognized me from the vegetarian club, but I'd never met herbivore.

I'm reading a book about anti-gravity. I can't put it down.

Why were the Indians here first? They had reservations.

Energizer bunny arrested. Charged with battery.

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*Our \$20 memberships are now due for this year. Please mail to our treasurer Brian at the address below, or bring to the meeting in May.*  
*Thank you*

## CONTACTS

Chairperson: Margaret Roy 403-271-4438 email: [roymg@telusplanet.net](mailto:roymg@telusplanet.net)

Treasurer: Brian Larke 403-281-5562 email: [sheilaandbrian@shaw.ca](mailto:sheilaandbrian@shaw.ca)

Newsletter Editor and for change of address or email address:

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## NEXT MEETING

DATE Sometime in the spring, probably late May.

LOCATION DEVELOPMENTAL DISABILITIES RESOURCE CENTRE  
4631, RICHARDSON WAY, SW, CALGARY T3E 7B7

SPEAKER

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## MEMBERSHIP FORM 2013

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

PHONE: \_\_\_\_\_

EMAIL ADDRESS: \_\_\_\_\_

TYPE OF DYSTONIA: \_\_\_\_\_

Please check one:

New \_\_\_\_\_

Renewal \_\_\_\_\_

MEMBERSHIP FEE \$20

**Please mail cheque payable to: DMRF Calgary Chapter**

**To: Brian Larke, Treasurer  
19 - 2121, 98 Ave SW  
Calgary, Ab T2V 4S6**