



Dystonia Medical Research Foundation

Calgary Chapter

ISSUE # 83

September 2010

CHAIRPERSON'S CORNER

Hello everyone. Hope you have been making the most of our mixed up summer. It came a day here and a day or two there, so hope you managed to fit some outdoor fun into those scattered days.

Thanks to our last Casino Days, we were able to forward a cheque for \$64,798.00 to DMRFC in Toronto to help cover research programs. Following is an excerpt from a thank-you letter we received from Diane Gillespie, our Executive Director:

"More and more DMRF Canada is investing in Canadian research through our partnership with CIHR, and through our partnership with DMRF United States. The Canadian research that is being funded in 2010 through both partnerships is as follows:

1. Robert Chen, MD, PhD, Toronto Western Hospital, Grant (DMRF U.S.) Effects of Internal Globus Pallidus Deep Brain Stimulation for Dystonia on Cortical Circuits and Plasticity

2. William Hutchison, PhD, Toronto Western Hospital, Grant (DMRF U.S.) Activity dependent Synaptic Plasticity in Globus Pallidus of Dystonia Patients

3. Amanda Smith, PhD, Ottawa Hospital Research Institute, Fellowship (DMRF U.S. 2010, DMRF Canada 2011-2014) Investigation into the Cause of Myoclonus Dystonia

4. Bahzad Elahi, PhD, Toronto Western Hospital, Fellowship (DMRF Canada) Regulatory effect of intra cortical inhibition on Paired Associative Stimulation (PAS) induced sensory-dependent, motor cortex plasticity.

5. Ryan Scott, PhD, Ottawa Hospital Research Institute, Fellowship (DMRF Canada) Cytoskeletal linker proteins mediate organelle functioning neurons

6. Manon Le Bel, PhD, Universite Laval (Quebec), Fellowship (DMRF Canada), Study of the involvement of relaxing glutamate and expression levels of neurotransmitter transporters in dyskinesia induced by L-DOPA”

It is marvelous to see how much work is being done on our behalf and how our efforts and the proactive thinking of our Provincial Government are helping make all this possible. Alberta’s program for distributing gaming proceeds to non-profit groups like ourselves is highly commendable and greatly appreciated. Their new method trying to spread a little more through the rural areas and the downturn in the economy reduced our share this year, but it was still exceptional to receive these welcome funds.

We had our Walk in June and managed to get the only dry day in weeks. Those participating enjoyed our cruise of the neighbourhood and the delicious picnic that followed. The good weather was a two edged sword in that our numbers were down as people took advantage of the sunshine to have their own personal escapes. Our funds raised were about \$3,900 this year. As this is our one major personal fundraiser of the year, we will hope to involve more of you next year. It really is a fun way to raise research monies and a nice social event as well.

Enclosed in this newsletter in a poster you can take into any of your doctors or pharmacists that introduces our Calgary Chapter of DMRFC for support and information. This helpful page was provided by Toronto to aid in our awareness efforts. If you need extra copies, please contact Heather or myself.

This **next meeting will be Saturday morning September 25**, 10 am to noon at our usual spot, the Developmental Disabilities building. I will have pamphlets re the new Merz drug, Xeomin which is the newest Botulinum Neurotoxin Type A. This drug has been used successfully in the treatment of Dystonia for several years now in Europe and has been approved and available in Canada since last Fall. Good to have another option available for our Neurologists. Two of its benefits are that it is without the complicating protein carriers of earlier toxins and

it also does not require refrigeration until being reconstituted, usually at time of injection.

I will also have copies of the new Dystonia Canada Report available. The front cover shows two Torch bearers from our 2010 Olympic games with distinguished Dystonia credentials. Sam Belzberg, co-founder of our Foundation carried the Olympic Torch and Ross MacDonald, a Paralympic Wheelchair Basketball player with generalized dystonia carried the Paralympic Torch. Thrilling experience for each of them I'm sure.

One of our favourite people, Lil Faider, has been feeling a little off of late, not quite her usual bundle of energy. I have been visiting her and she is coming around just fine, but I know she would appreciate your kind thoughts and prayers.

We also have planned a meeting for October 30 at our usual time and place. We have a speaker on The Alexander Technique of movement and relaxation coming to speak with us at that time. Please mark your calendars for these two dates.

Try to join us September 25 as we always need your support and look forward to your personal updates. If you cannot join us please let us know how you are doing, as you will definitely be in our thoughts.

Marg Roy

ITEMS OF INTEREST

ITEM 1

"NECK CRISIS" by Jeremie Rethan

I am reading a book recommended to me by Rae and I am finding it very interesting. It is written by a neurophysiologist from Manitoba called Jeremie Rethan. His premise is that constrictions in muscles and blood vessels in the neck can cause all sorts of problems in our bodies like high blood pressure, tinnitus, hearing loss, and carpal tunnel, and he is particularly worried about our

younger generation who spend hours hunched over computers or texting on their phones. They are developing what he refers to as “computer hump.” His research concurs with the work of Dr. Zamboni of Italy whose findings pioneered the liberation procedure which is giving relief to many people all over the world suffering from MS. Jeremie Rethan believes that we can help ourselves with simple exercises, self massage, and some changes in sleeping positions. No drugs and no surgery.

The book is self-published, because Rethan did not want his ideas edited. Coles and Chapters are carrying his book and he is touring those stores and talking to people about his methods. Syeeda and I went to meet with him here in Calgary at Coles Market Mall in June. We found him helpful and interesting although he freely admitted that he doesn’t know much about dystonia. He had interviewed a woman with blepharospasm for the book. He was keener to impart knowledge of his research than to sell his book, which was quite refreshing. Neck Crisis is about \$25.

ITEM 2

NICK VUJICI

An ex work colleague sent me an email recently. Some of you may have seen it. It is a video clip of a young man called Nick Vujici who was born with no arms or legs. He is twenty-seven, obviously loves life, has a strong faith, is originally from Australia, and has a double Bachelors degree majoring in Accounting and Financial Planning. He now lives in California and is President of an international non-profit organization **Life Without Limbs**. He lectures in schools and he is inspirational. His messages are simple:

Forget what you don’t have or can’t do and concentrate on what you do have.
Be patient.
Be thankful.
Everyone is beautiful just the way they are.

And he says, ”If God can use a man without arms and legs to be His hands and feet, then He will certainly use any willing heart!”



ON THE LIGHTER SIDE

I had the following in an email from Brennan:

When Insults Had Class...These glorious insults are from an era before the English language got boiled down to 4-letter words.

The exchange between Churchill & Lady Astor: She said, "If you were my husband I'd poison your tea." He said, "If you were my wife, I'd drink it."

A member of Parliament to Disraeli: "Sir, you will either die on the gallows or of some unspeakable disease." "That depends, Sir," said Disraeli, "whether I embrace your policies or your mistress."

"He had delusions of adequacy." - Walter Kerr

"He has all the virtues I dislike and none of the vices I admire." - Winston Churchill

"I have never killed a man, but I have read many obituaries with great pleasure." - Clarence Darrow

"He has never been known to use a word that might send a reader to the dictionary." - William Faulkner (about Ernest Hemingway).

"Thank you for sending me a copy of your book; I'll waste no time reading it." - Moses Hadas

"I didn't attend the funeral, but I sent a nice letter saying I approved of it." - Mark Twain

"He has no enemies, but is intensely disliked by his friends.." - Oscar Wilde

"I am enclosing two tickets to the first night of my new play; bring a friend.... if you have one." - George Bernard Shaw to Winston Churchill

"Cannot possibly attend first night, will attend second... if there is one." - Winston Churchill, in response.

"I feel so miserable without you; it's almost like having you here." - Stephen Bishop

"He is a self-made man and worships his creator." - John Bright

"I've just learned about his illness. Let's hope it's nothing trivial." -
Irvin S. Cobb

"He is not only dull himself; he is the cause of dullness in others." -
Samuel Johnson

"He is simply a shiver looking for a spine to run up." - Paul Keating

"In order to avoid being called a flirt, she always yielded easily." -
Charles, Count Talleyrand

"He loves nature in spite of what it did to him." - Forrest Tucker

"Why do you sit there looking like an envelope without any address on it?"
- Mark Twain

"His mother should have thrown him away and kept the stork." - Mae West

"Some cause happiness wherever they go; others, whenever they go." -
Oscar Wilde

"He uses statistics as a drunken man uses lamp-posts... for support
rather than illumination." - Andrew Lang (1844-1912)

"He has Van Gogh's ear for music." - Billy Wilder

"I've had a perfectly wonderful evening. But this wasn't it." - Groucho Marx



*I found this in the AARP magazine, and thought it was lovely. Its
by Donna L. Gestri and it is titled:*

About May Flowers

I was 6 years old and visiting my grandmother one May weekend. In her garden, tulips were fading, roses were full of promise, and anemones were swaying in their glory. But I was entranced by the yellow flowers that grew all over the front yard. Unaware that they were weeds, I gathered a luscious bouquet of dandelions for Grandma and proudly marched into the house.

Aunt Jennie, Grandma's unmarried sister who lived with her, saw me first. Childless, Aunt Jennie lacked for macaroni necklaces, finger-painted portraits and lopsided Play-Doh figurines, but she never tired of prepping her nieces and nephews for special occasions, from the Easter bunny's visit to recital bows and curtsies. She specialized in big hugs and kisses.

Aunt Jennie sat in her arm chair reading a magazine, a cup of tea by her side. With a flourish I thrust the bouquet of weeds at her. "Look at what I picked!" I shouted excitedly. Aunt Jennie's hand fluttered to her chest. "For me?" she exclaimed. "They are beautiful. Thank you so very much. I'll get a special vase to put them in."

I blanched, I'm sure, but there was no way I could tell Aunt Jennie that the flowers were meant for someone else. Her eyes shone as she ran to show my grandmother. I followed, afraid that Grandma might be hurt by my betrayal. I found Grandma with her arm around Aunt Jennie, who was wiping her eyes with the back of her hand. Grandma nodded at me with approval for the kindness that I had unintentionally spread. I learned that day how simple, thoughtful deeds can turn winter into spring and weeds into vibrant May flowers.

I read these wise words recently. They made me think.

From the Talmud: We do not see things as they are; we see things as we are.

Words said by the 14th Dalai Lama: Happiness is not something ready made. It comes from your own actions.



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

DYSTONIA MEDICAL RESEARCH FOUNDATION, CALGARY CHAPTER
CONTACTS

Chairperson: Margaret Roy 403-271-4438 email: roymg@telusplanet.net

Treasurer: Brian Larke 403-281-5562 email: angela07@telus.net

Newsletter Editor and for change of address or email address:

Heather MacLellan 403-289-0736 email: hethmac@telus.net

NEXT MEETINGS

TIME 10 am to 12 noon

DATES Saturday, September 25th
and Saturday, October 30th

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

SPEAKERS Sept 25th None
Oct 30th Larissa Makila talking about Alexander Technique

MEMBERSHIP FORM 2009

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
29, 275 Woodridge Dr. S. W.
Calgary, Ab T2W 4S4

