

Dystonia Medical Research Foundation

Calgary Chapter

ISSUE # 73

March 2008

CHAIRPERSONS' CORNER

Despite the inclement weather, we were pleased at the turnout at our meeting on Jan. 19/08. Thanks to Heather for arranging our guest speaker, Ken Grandia, who showed us a video that was made by some grad students who are working with the Dean of Kinesiology at the U of C. The video showed tests done on Ken's mom and another lady who are both suffering from E.T. (essential tremor) Each lady was asked to use the "mouse " which was developed specifically to measure the tremors and to see if the patients were able to follow the outline of a square and the diagonal lines within.

Ken is interested in encouraging people to be part of the test, however one must be off meds when testing. The tests are being done at the Human Performance Lab at the U of C and are being funded for 2 years by the Federal Government.

We invite you all to our next meeting (March 15) to hear our speaker, Natalie Reeves- a movement and massage specialist who also teaches yoga.

Teresa Ebbeling and Lil Faider

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EDITOR'S NOTES

Marg is still away in the southwest of the US, which is undoubtedly warmer than it has been here! For the month of February, she and Gord are moving round various time-shares in Las Vegas, Phoenix and Palm Desert, and will not be near a computer, so we have no letter from Marg this time.

We are looking for volunteers for two research projects. It is exciting that we can help scientific study now and know that we will be helping fellow sufferers in the future.

Firstly, Ken Grandia and his team are hoping for volunteers to test his experimental computer mouse. This mouse is designed to differentiate between intentional movements and those which are the result of tremors. The team is looking for anyone with tremors. The tests will be done at the University of Calgary, take about an hour, and Ken says they are completely pain free! If you can help, please contact Ken at kkgrandia@shaw.ca or call him at 278 8217.

Also, Brian was talking to Dr. Kiss recently and she too is asking for volunteers. Dr. Kiss is the neurosurgeon who does Deep Brain Stimulation surgeries at the Foothills Hospital in Calgary. She has now asked me to put the following in this newsletter:

Researchers at the University of Calgary are considering doing a research project on people with focal hand dystonia (writer's cramp) and are looking for an estimate of how many people in the support group have this condition. If you do have this focal hand dystonia and may be willing to participate, then please contact Sue Nelson (in Dr. Kiss's office) at 220-5572 or email at nelsons@ucalgary.ca

And now some sad news: we lost Roy's dad, Wally Schneider, at the end of January. Wally had been sick for a few months and in a hospice for the last few weeks. A few of us visited him in the hospice, and he was pleased to see us. He wasn't able to speak very much, but when I was there he shook my hand with a firm grip which reflected his former strength.

I was sorry that I was unable to attend the funeral. Lil, Teresa, and Brian went, and were all glad that they did and said that it was a very nice funeral. The room was packed and more chairs had to be found. Wally's trademark cowboy boots were on display, along with a bowl of vegetables. An old friend talked at length and everyone learned a lot of interesting things about Wally's life after he came here long ago from Switzerland. Wally could turn his hand to pretty much anything, and in the winter when he couldn't work in his market garden, he took part in theatrical productions.

Roy wrote a beautiful poem to his dad.

They played "Amazing Grace," "Those Were the Days My Friend," and "I Did it My Way."

We are all thinking of you Roy, and are so sorry that you have lost your dad.

Our next meeting is Saturday March 15th, usual time and place. Natalie, the speaker at our next meeting, works at the Centre I go to for massage and for postural reconstruction physiotherapy. She is new there and does Thai massage and hot stone therapy. I haven't met her yet, but my masseur and physiotherapist speak very highly of her.

Heather MacLellan

ITEMS OF INTEREST

ITEM 1

This article was in the Spring 2007 issue of Dystonia Dialogue, and I found it most interesting. HM

Written by Jennifer Pader, MDIV, STM, Mental Health Advisory Committee

STICKS AND STONES, Stigma and your Sense of Self

You might be sitting in a restaurant having a cappuccino. Getting on the bus. Waiting in line for an ATM.

Suddenly you sense that you are being stared at. When you look up, people avert their eyes or continue to stare. For people with dystonia it can feel like being under a microscope. Symptoms—tremors, grimaces, a shaky voice, blinking, muscle spasticity—can become more intense while you are being stared at, whispered about, watched, or overtly treated with rudeness because of the way you move or sound.

Those painful moments when individuals with dystonia are made to feel freakish or odd are hard to forget and sometimes hard to forgive. Those tactless questions—“What happened to you?” or “What’s wrong with you?”—create a sense of shame. The embarrassment and humiliation are especially keen when intrusive remarks or stares come from people who are otherwise well meaning and have no idea that their attention is unwanted. They “just want to help,” but they make everything feel worse.

Stigma and Shame

It is from the ancient Greeks that Western civilization developed its concept of stigma—literally, the mark of the inferior or enslaved. Associated with disgrace, disownment, even repugnance, the original Greek word ‘stigma’ referred to a tattoo or brand mark that was put on each slave and proclaimed his ownership for all to see. The mark invited all free Greeks to recognize the slave’s lowly status and consider him inferior.

Persons with dystonia are made to feel powerless, helpless, and may (consciously or unconsciously) internalize society’s low expectations of persons with a disability. Additionally they may feel ‘marked’ and visibly different. They may even worry that others can see their fears or inner shame, but usually that is not the case. Unlike the Greek slaves, dystonia patients are usually expert at camouflaging their worst symptoms and accessing medical care that can improve their impaired abilities.

The Role of Stigma in Society

Stigma (or discrimination against or devaluation of another person) has played a role throughout the history of humanity. People with any medical condition, including dystonia, are at risk for being stigmatized. Throughout time, societies have identified and marginalized (with either physical exile or other methods) individuals who appear to threaten—biologically, socially, politically, psychologically—the ‘greater good.’

For example, in societies where natural resources such as food, water, or shelter were scarce, the designation of any individual as ‘too dependant’ or ‘disabled’ may have improved the chances of biological survival for the non-stigmatized. The group would cast out those members unable to carry a full workload such as the aged, the injured, or those with disabilities. Excluding those persons from eating and living among the group would enable the physically healthier members to live.

The stigmatization of people with dystonia serves multiple purposes. Primarily, it unconsciously reduces the anxieties of those without dystonia. Like the mythical ostrich that buries its head in the sand to avoid a threat, the flawed logic of stigma suggest that by distancing oneself from, for example, someone with apparent dystonia symptoms, the greater population that is not familiar with the disorder will not have to acknowledge or deal with it. Of course, in reality, ignoring people with dystonia does not make the needs of the community any less urgent or important.

Fighting Stigma

Whoever first said “sticks and stones may break my bones, but words can never harm me” obviously had not felt the pain of social stigma. Whether dystonia patients are going for a job interview, a blind date, or watching a play at their child’s school, there is always that internal hesitancy when entering a room and waiting for others’ reactions. Trust your instincts. If you feel that you are being treated differently, you probably are. The question is: what to do about it? People with dystonia and their medical providers can make it clear to the non-dystonia community that dystonia is not contagious and (in most cases) not life threatening. The majority of persons living with dystonia live, work, raise families, and live full and productive lives.

Fighting stigma may also mean:

Carrying DMRF brochures with you to politely educate those who behave rudely or make you feel uncomfortable. Suggest that they at least take a brochure and learn what dystonia is, so that they don’t reveal their ignorance to others!

What doesn't work against stigma is staying home and hiding. Far more effective in changing the behavior of others is educating them to who you are and what you can do. Don't let them pigeonhole you—and don't do it to yourself—as merely a 'dystonia patient.'

Let the world know who you are: that you are first and foremost a parent of twin girls or a mountain biker, a top salesperson, a film maven, a soldier, a brother, a beautician, a weekend painter, a dog lover, a proud newlywed, a chess master, a software engineer, a passionate gardener.

Don't let others define your identity for you. Who we are and how positively we feel about ourselves are the best defenses against the feelings of being stigmatized.

Jennifer Pader is a psychotherapist who works in New York City. She is affected by spasmodic dysphonia.

ITEM 2

I don't know how many of you know that Sarah Smith, the National Director of Dystonia Medical Research Foundation Canada, has resigned. She has done great work for us, building on and expanding the solid foundation laid by Shirley Morris, our pioneer in DMRF Canada. The following letter is from Sarah:

Dear Members,

Over the past two years, I have enjoyed serving the dystonia community and working in partnership with you to help build this organization. Without your participation and support, this organization could not sustain itself. Thank you for your tireless efforts and all you do to support DMRF Canada and all those affected by dystonia.

Much has been accomplished to advance our mission in Canada in a short period of time. DMRF Canada continues to cultivate a partnership with the Canadian Institute for Health Research to fund matching grant dystonia fellowships in Canada. We have established an annual 5 km Run to help increase the visibility of dystonia and raise much needed funds for research. We have launched a dystonia awareness campaign by bringing *TWISTED* to educational sites across the country.

We now have the *Dystonia Canada* newsletter, which is released to the membership twice a year and highlights Canadian research, awareness, and Support Group activities across the country. We continue to influence legislation on the Hill and increase funding for dystonia research on a federal level by

growing our Advocacy Day activities, creating a Private Member's Bill, and growing our MP/Senator dystonia caucus on the Hill every year. We continue to partner with the Ontario Neuromodulation Coalition to advocate for a Centre of Excellence for Neuromodulation Therapies in Ontario.

Having said that, there is still so much that needs to be done to get dystonia heard and continue to grow DMRF Canada so that we are competitive with other charities across the country. My recuperation from pneumonia over the past few months and other health issues over the past year, have been a wake-up call for me. And so, it is with mixed emotions that I announce my resignation from DMRF Canada. My last day will be January 25, 2008. The Foundation is currently in the process of recruiting a new Director.

Dystonia has been a cause worth fighting for and I am grateful for the opportunity I have had to serve the dystonia community in Canada. I do hope one day, we can find a cure for dystonia which will enable a life free of pain and discomfort to you all.

With appreciation,

Sarah Smith
National Director

INTRODUCING - Teresa Ebbeling

I am married to Ken, have 2 children , Mike and Roberta and a dog named Tippy. Calgary has been my home since 1969. I grew up in Cranbrook, B.C. where my parents settled when I was 9. We are an immigrant family from Poland where my folks and siblings were born, but I was born in Germany after the war. Dad came to Canada in 1949, followed by Mom and the 4 kids in 1950. How she managed to travel across the Atlantic and then across Canada by train with 4 kids in tow, plus all our belongings and not speaking English is a wonder to me. I was 4 at the time. I attended the University of Victoria where I got my BEd and taught for 2 years. That's where I met Ken -- at his 21st birthday party. After we were married, I taught for the Public School Board in Calgary. Parenting kept me home until I started substitute teaching once the kids were 6 and 9. I continued to do that until 1997 when my Dystonia first appeared.

It started with one toe on my left foot that I first noticed was curling under when I was golfing one day. For a while it was just a problem only when I wore enclosed shoes but not sandals. Then it progressed and my foot started twisting inwards. At that point I started using crutches so as not to put weight on my foot. I had those darn things for a year but then got a brace for my leg. The brace would only fit in a man's runner because of it's width so needless to say my shoe wardrobe was pretty limited. I remember when I could start wearing ladies shoes

again, what a blessing that was. During the 2 years after my diagnosis I tried many different treatments- acupuncture, physio, chiro , and also went to see Dr. Terry Willard, a naturalist. Nothing seemed to help so one day I decided to try and do without my brace to see how things would go. Well, they went pretty darned well. I put the brace in my storage room and hope to never use it again.

I had to give up golf, skiing and other activities that required walking or being on my feet a lot -- at least to begin with. That was hard but I got over it. Eventually I took up golf again, which was great, but not skiing. I enjoy reading, doing cross stitch, walking the dog, traveling, playing bridge and volunteering with Habitat For Humanity as a family partner.

I feel very lucky that I was directed to our support group, because that too is a blessing. Seeing everyone at the meetings and hearing how everyone is doing gives me comfort and hope.

QUIZ TIME

This was from Teresa,

There is one bus with seven girls in it. Each girl has 7 backpacks and each backpack has seven big cats. Each big cat has seven little cats. How many legs are there all together?

Answer later in the newsletter



ON THE LIGHTER SIDE

Teresa emailed me this one, and I love it:

The Seniors Breakfast Special

We went to breakfast at a restaurant where the "seniors' special" was two eggs, bacon, hash browns and toast for \$1.99.

"Sounds good," my wife said. "But I don't want the eggs."

"Then I'll have to charge you two dollars and forty-nine cents because you're ordering a la carte," the waitress warned her.

"You mean I'd have to pay for not taking the eggs?" my wife asked incredulously.

"YES!!" stated the waitress.

"I'll take the special then," my wife said.

"How do you want your eggs?" the waitress asked.

"Raw and in the shell," my wife replied.

She took the two eggs home.

And this emailed from a friend in the UK:

WET PANTS

Come with me to a third grade classroom..... There is a nine-year-old kid sitting at his desk and all of a sudden, there is a puddle between his feet and the front of his pants are wet. He thinks his heart is going to stop because he cannot possibly imagine how this has happened. It's never happened before, and he knows that when the boys find out he will never hear the end of it. When the girls find out, they'll never speak to him again as long as he lives. The boy believes his heart is going to stop; he puts his head down and prays this prayer,

"Dear God, this is an emergency! I need help now! Five minutes from now I'm dead meat." He looks up from his prayer and here comes the teacher with a look in her eyes that says he has been discovered. As the teacher is walking toward him, a classmate named Susie is carrying a goldfish bowl that is filled with water. Susie trips in front of the teacher and inexplicably dumps the bowl of water in the boy's lap.

The boy pretends to be angry, but all the while is saying to himself, "Thank you, Lord! Thank you, Lord!" Now all of a sudden, instead of being the object of ridicule, the boy is the object of sympathy. The teacher rushes him downstairs and gives him gym shorts to put on while his pants dry out.

All the other children are on their hands and knees cleaning up around his desk. The sympathy is wonderful. But as life would have it, the ridicule that should have been his has been transferred to someone else - Susie. She tries to help, but they tell her to get out.

"You've done enough, you klutz!"

Finally, at the end of the day, as they are waiting for the bus, the boy walks over to Susie and whispers, "You did that on purpose, didn't you?" Susie whispers back, "I wet my pants once too."

May we always see the opportunities that are around us to do good.

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Membership fees for 2008 are now due. Please bring them to a meeting or mail them to our treasurer Brian Larke, address at the end of this newsletter.

Please remember to let me know if you change your street address or email address. Please also let me know if you have an email address and could receive the newsletter electronically in future, each mailing costs us about \$1.50 per newsletter. Thanks a lot! HM

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May the sun bring you new energy every day. May the moon softly restore you by night. May the rain wash away your worries. May the breeze blow new strength into your being. May you walk gently through the world and know its beauty all the days of your life. --Apache Blessing—from Natalie, our March speaker.

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Answer to QUIZ TIME = 10990

**DYSTONIA MEDICAL RESEARCH FOUNDATION, CALGARY CHAPTER
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NEXT MEETING

TIME 10 am to 12 noon

DATE Saturday, March 15th 2008

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

GUEST SPEAKER. Natalie Reeves

MEMBERSHIP FORM - 2007

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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