



Dystonia Medical Research Foundation

Calgary Chapter

ISSUE # 84

October 2010

CHAIRPERSON'S CORNER

Hello everyone and welcome to Fall in Calgary, a little more stable weather and the beautiful vistas of gold and green.

Some of you may have seen the program on CTV that highlighted Dopamine Responsive Dystonia. A child of 3 or 4 months began exhibiting clenching fists, tightening body muscles and general discomfort and was diagnosed with Cerebral Palsy. The mother just couldn't accept this diagnosis and hunted until she found a Neurologist who recognized that indeed her child did not have this disease, but in fact was showing signs of this rare form of Dystonia. He recommended a trial of leva-dopa, a dopamine supplement, be administered to the child and almost immediately all the symptoms disappeared. Dopamine is a chemical we all produce in varying amounts and in some cases the body produces so little that dystonic symptoms appear. It is quite miraculous to see the difference in the lives of these people: normally children, but not always. There was also a man in the video who had been given a reprieve from his dystonia finally with a correct diagnosis and administration of this drug. I remember seeing a video at a DMRF Symposium several years ago of two children who were in wheelchairs and in constant pain and contortions. After finally receiving a correct diagnosis of DRD, they were in a matter of days up and running around like children should. It would be hoped that all neurologists when recognizing the symptoms of generalized dystonia would immediately give

dopamine to the patient to see if all the symptoms would simply go away. I know many do, but it may not be the common practice it should be. I know personally, when I was diagnosed with Writers', my doctor gave me dopamine to see if this would change things for me. He said I would immediately get better or worse, and in my case I got worse, but of course only for as long as the drug was in me. It was a simple experiment and gave us a fast answer that my dystonia was not dopamine responsive. All this makes one wonder just how many people are misdiagnosed that could be given back a normal life by taking this drug several times a day forever - such a small price to pay for the freedom to move.

I met recently with the Representative, Drew Smith, of Merz Canada the maker of Xeomin the new botulinum toxin drug. It is from the same strain of toxin as Botox. As I have mentioned earlier, there is great hope that people starting on this toxin will not develop the antibodies against it that have been seen in the past. It was developed to require no extra protein carrier and that is thought to be the main culprit in spurring antibody growth. Alberta Blue Cross has now approved Xeomin for insurance coverage and once this happens, most private plans follow along as well, taking their lead from the provincial plan. Xeomin has been available in Canada for over a year now, and has just received its approval from the FDA in the USA. The more people using the drug, the better the price should be. It is just slightly less expensive than Botox at the moment.

As I mentioned last month, I have a supply of the new DMRFC Report which is always a wealth of information. Good article in there about the Calgary team we have been following to develop the electronics and mathematical theory behind producing devices such as a computer mouse that would be capable of ignoring the quick jerky movements of dystonic hands, or the tremors of Essential Tremor or Parkinson Disease. Ken Grandia also gave us a little rundown of the current directions of this team. If you have not received a copy of this report from Toronto, I will bring another supply to the next meeting or you can drop me an email or give Teresa or Heather a call.

Our last meeting was a very small group, but good discussions, support and information. Even when the sun finally shines in Calgary, it would be nice to see a good turnout for these gatherings. Next meeting will be October 30, Saturday morning, the usual place and time 10 am to noon. Our speaker will be presenting information on the Alexander Technique, which is about making our movements and muscles more efficient and hence our bodies happier. This technique was devised by F M Alexander more than 100 years ago. Look forward to seeing you for this most interesting presentation.

As always, if you cannot join us, please let one of us know how you are doing as you will be in our thoughts.

Marg Roy

ITEMS OF INTEREST

ITEM 1

I found this on the web. Its written by a young woman called Wallis Brozman and it is about her and her black Labrador service dog, Caspin. I hope they are both doing just fine!

"I have dystonia, which causes abnormal, uncontrollable movements and twisted posturing of your body. Recently, dystonia has seemed like something I cannot escape. Then in February 2009, I was paired with a Service Dog Caspin, and my life has changed in amazing ways. I feel like my dystonia matters less with Caspin by my side. I can focus on my goals and dreams, and he always seems to make the pain more bearable.

I have been back home in Davis for four days now, although it seems like I've had Caspin for so much longer than a couple of weeks. Already in these few short days, so much has changed for me. People smile at my dog, instead of looking at me with a mixture of pity and curiosity. They ask me about Caspin, tell me how wonderful he is, instead of asking what's wrong with me. I live alone, 3000 miles from my family. It was so hard to be alone sometimes. I feared for my safety, and I was incredibly lonely. I can feel safe now.

Just tonight, I found myself outside walking Caspin, and I had left my phone in the house. I had thought that there was no reason to bring it. I was wrong. The cool night air triggered a dystonic attack. I was stuck in the dark, completely rigid and in spasm. I began to panic. Why hadn't I brought the phone; and would I have even been able to push a button if I had? Who would I call? In my panic, I looked to Caspin. He saw my anguish, my discomfort, and sought to comfort me. He put his head on my spasming legs, licked my tremoring hands, reassured me with a gentle lick on my cheek. I knew Caspin was ready to help in any way he could. Since this was supposed to be a night time bathroom run, I hadn't thought to dress Caspin in his pulling harness. If only I had, I thought. He could have pulled me. He looked up at me and I knew what to do. I grabbed his collar softly and whispered, "Caspin, pull". Easily, like it was meant to be that way, Caspin pulled me lightly towards my door. He glanced at me every few steps as if making sure his pace wasn't hurting me. As we reached the door, I unlatched the lock and told Caspin to push. He had never pushed open my door, but I knew he would tonight. We made it inside, and Caspin turned out the light. I had stopped spasming, but I was still rigid. I called Caspin onto my bed, and he sat there,

licking my rigid arms, easing my muscles back into a more useful state. I was in my bed and I was safe.

I hate to think what would have happened to me “before”. Would someone have come to help me? Would I have sat there for hours until perhaps by some stroke of luck, the spasming stopped? Who knows. What I do know is that Caspin was my lifesaver tonight. It has been four days since we left the CCI campus in Santa Rosa, and Caspin has already saved me.

I applied for a service dog from Canine Companions for Independence two years ago, almost to the day. I knew the benefits of having a service dog; I have volunteered with Dogs4Diabetics in Concord for over two years now. However, had someone told me that a dog would get me safely home one night, I never could have believed them. Had they told me that this black dog would be there to comfort me when I was in pain, or sad, or lonely I would never have imagined how true it would be. Caspin is always there to listen to me rant, or sob, and in two weeks he has witnessed both. He lends a non-judgmental ear when I need one, and a strong and comforting shoulder when I need to cry.

Caspin has provided me with so much more than a capable set of paws, eager to retrieve my dropped keys; more than just a strong dog to pull my wheelchair when I’m tired. He has even provided more than a sense of security far from home. Caspin is my constant companion, my loyal friend. It has been four days, and so much has happened. If in only four days, my life has changed this much, I cannot wait to see what will happen in the next four weeks, months, and years. It’s bound to be just as wonderful.”

* * * * *

Brian has decided that the episode of his autobiography which appeared in the last newsletter and ended with their arrival in Calgary is a suitable time to call it a day. However, he has an interesting alternative. Read on:

Do you believe in coincidence? Maybe this will change your mind.

By Brian Larke

In 1979 my parents were visiting from the UK and my father used to take our family dog, Duchess, a Sheltie, for walks around the neighbourhood. On this particular day as he walked by a home a few minutes into his walk, a Sheltie ran down the path of a house to greet my father and Duchess. Moments later a lady came out from the home to call off her dog. They started to chat and the lady was from the UK and was interested in where my parents came from. My father noticed there was a sign with the name of Ditchburn by the front door. He mentioned that he had a cousin named Ditchburn whom he hadn't seen for many years. The lady asked for his first name and my father said, "Derek". She said, "That is my husband's name."

Further investigation revealed some interesting information.

Derek and I had lived about half a mile from each other in England and we grew up without either of us knowing about the other. There is a ten year difference in our ages which may be part of the reason for that. Derek's wife, who came from the same town, is called Sheila. After getting married they moved about 3 miles down the coast from Redcar, located on the north east coast of England, to a small town called Marske. They lived there until they emigrated to Winnipeg with two boys, Stephen and Tony. (I'm not sure when they arrived in Calgary). Derek got a job working for RGO, a company selling all types of office design and equipment in the Calgary market. They eventually moved to Victoria in 1981 where we visited them from time to time. To my shame, we have lost touch with them over the years.

This is where it gets interesting. As you probably know, my wife's name is Sheila and she comes from the same town as Derek and I, as did Derek's wife.

When Sheila and I were married we moved down the coast to a small town about 3 miles from Redcar to Marske, the same place as Derek and his wife.

We lived there until we emigrated to Canada in 1967 and arrived in Calgary. In 1967 we bought a three bedroom in the Palliser subdivision where we lived until 1988 when we moved to Woodlands.

After a couple of false starts I in 1970 got a job selling office equipment and where I worked for almost 30 years in Calgary and surrounding area with various companies. At times I was in competition with RGO as our markets overlapped now and then but we didn't know it.

We have two children, a boy named Stephen and a daughter named Susan, she has lived in Victoria since 1992. We families lived in similar 3 bedroom bungalows and we both had reclaimed brick fireplaces of similar design.

Life can be stranger than fiction at times.



QUIZ TIME

1. Do they have a 4th of July in England?
2. How many birthdays does the average man have?
3. Some months have 31 days; how many have 28?
4. In baseball how many outs are there in an inning?
5. Is it legal for a man in California to marry his widow's sister?
6. Divide 30 by $\frac{1}{2}$ and add 10. What is the answer?
7. If there are 3 apples and you take away 2, how many do you have?
8. A doctor gives you three pills telling you to take one every half hour. How many minutes would the pills last?
9. A farmer has 17 sheep, and all but 9 die. How many are left?
10. How many animals of each sex did Moses take on the ark?
11. How many two cent stamps are there in a dozen?

Answers later in the newsletter



ON THE LIGHTER SIDE

From a friend in an email

These are allegedly real notes written by parents in the Memphis school district.

Spellings have been left intact.

1. My son is under a doctor's care and should not take PE today. Please execute him.
2. Please exkuce lisa for being absent she was sick and i had her shot.
3. Dear school: please ecsc's john being absent on ja n. 28, 29, 30, 31, 32 and also 33.
4. Please excuse gloria from jim today. She is administrating.
5. Please excuse roland from p.e. for a few days. Yesterday he fell out of a tree and misplaced his hip.
6. John has been absent because he had two teeth taken out of his face.
7. Ca rlos was absent yesterday because he was playing football. He was hurt in the growing part.
8. Megan could not come to school today because she has been bothered by very close veins.

9. Chris will not be in school cus he has an acre in his side.
10. Please excuse ray friday from school.. He has very loose vowels.
11. Please excuse Lesli from being absent yesterday. She had ~~diahre~~ ~~dyrea~~ ~~direathe~~ the runs.
12. Please excuse tommy for being absent yesterday. He had diarrhea, and his boots leak.
13. Irving was absent yesterday because he missed his bust.
14. Please excuse jimmy for being. It was his father's fault..
15. I kept Billie home because she had to go Christmas shopping because i don't know what size she wear.
16. Please excuse jennifer for missing school yesterday. We forgot to get the sunday paper off the porch, and when we found it monday. We thought it was sunday.
17. Sally won't be in school a week from friday. We have to attend her funeral.
18. My daughter was absent yesterday because she was tired. She spent a weekend with the marines.
19. Please excuse Jason for being absent yesterday. He had a cold and could not breed well.
20. Please excuse mary for being absent yesterday. She was in bed with gramps.
21. Gloria was absent yesterday as she was having a gangover.

22. Please excuse brenda. She has been sick and under the doctor.

23. Maryann was absent december 11-16, because she had a fever, sorethroat, headache and upset stomach. Her sister was also sick, fever an sore throat, her brother had a low grade fever and ached all over. I wasn't the best either, sore throat and fever. There must be something going around, her father even got hot last night.

Answers to QUIZ TIME

1. Yes. It comes after 3rd of July!
2. Just one and we celebrate it using 'birthday' which means anniversary.
3. All of them.
4. 6, three per side.
5. No, because he is dead.
6. 70. 30 divided by $\frac{1}{2}$ equals 60!
7. 2. You took them!
8. 60 mins. Start with the first pill, 30 mins later take the second pill then 30 mins later take the 3rd pill.
9. 9
10. None. Moses didn't have an ark, Noah did.
10. There are 12 two sent stamps in a dozen!

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 MEETING

TIME	10 am to 12 noon
DATES	Saturday, October 30 th
LOCATION	DEVELOPMENTAL DISABILITIES RESOURCE CENTRE 4631, RICHARDSON WAY, SW, CALGARY
SPEAKER	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