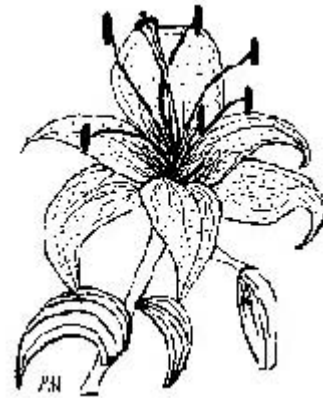


Ottawa / Gatineau Area Dystonia Support Group

Newsletter



By helping each other, we help ourselves!

Fall 2010

Dystonia is a neurological disorder characterized by in-voluntary, uncontrollable muscular contractions that force certain parts of the body into abnormal, often painful movements or positions. Important functions such as walking, talking, eating, writing and vision are often affected. Its extreme symptoms have a profound impact, holding its victims hostage, after removing them from society at large.

Stu's Corner

SIXTEEN YEARS OF WONDERFUL MEMORIES WITH YOU

Mid spring 1994 I was introduced to a life-changing experience. It was not something I expected and it caught me off-guard. To put the situation in perspective, my brother Gordon, who passed away last year, had suffered from a medical mystery called dystonia, in his case general dystonia. I thought he was the only person in the world who suffered with this malady.

Unexpectedly I found out that this was not true when my brother and I were invited to a dystonia medical conference in Houston, Texas. There we met many people who suffered from different forms of dystonia. I even found out there was a support Group back in Ottawa; when I returned I contacted Cam MacLeod.

Shortly after Cameron introduced me to people who suffered from many forms of dystonia including generalized, cervical, writers cramp, dysphonia, oromandibular and blepharospasm. I never heard of these terms before but when I met people with these afflictions I soon learned how much suffering there was in dealing with dystonia. Some of your stories on living with dystonia are told elsewhere in this newsletter. These situations startled me and convinced me,

more than anything, to volunteer and help people living with this difficult medical mystery.

When I took over the Group I felt we needed more awareness for professionals, so less people would be misdiagnosed and by the general public so there would be less unwelcome stares. We developed dystonia pamphlets and placed them in doctors' offices so newly diagnosed patients might be aware of our Support Group. With the help of others I organized an annual walk and wheel on Parliament Hill; last year was our 15th event at Canada's National Parliament. Thanks to the generosity of members and sponsors we were able to raise over \$80,000 toward dystonia research. Several years ago we involved federal politicians in our fight and now we have a private members bill that someday will declare the first week in June as National Dystonia Week. In addition, I felt that we needed and still need a strong national spokesperson to make the case for dystonia across Canada.

We were also successful in obtaining TV coverage which helped educate the general public about this difficult movement disorder.

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Newsletter of the Ottawa / Gatineau Area
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Cameron MacLeod, Chantal Bégin, Ian Boudreau,
 John Heney, Shirley Anne Sayle, Jean, Kathy,
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Publication of information and opinion in this
 newsletter does not constitute endorsement by
 the Ottawa / Gatineau Area Dystonia Support
 Group. Readers are urged to check with
 appropriate authorities in each facet of living with
 dystonia.

Stu's Corner

(Continued from page 1)

To keep the Group connected we put together a newsletter informing members about the latest research innovations plus other items of interest. We were fortunate to get speakers at monthly Get-togethers.

For the last two years we lightened up; less meetings and more fun things. So we organized Christmas parties, picnics, coffee get-togethers, and pub nights.

I had never been involved in such an undertaking before and was not sure how things would work out, but with your help we did succeed in all our efforts. I don't want to mention names since I might miss someone, but I am very grateful for the support of long-standing members of the Group, the Telephone Coordinator and her callers, our faithful treasurer, people who arranged coffee breaks and that special send-off for me; and finally a special merci for all dedicated volunteers such as the editor of this newsletter, my wife who has been so very supportive over the years, whether it was mailing out these newsletters, proofreading my errors, checking in people on Parliament Hill and many other things that make a Group function effectively. If I have omitted anyone please accept my sincere thanks.

My lasting wish is that soon we will have a national dystonia awareness week, a national dystonia spokesperson, continued national walk and wheels on Parliament Hill, and finally a national cure for dystonia. I will be very happy when I hear you cry out 'freedom to move'; free at last.

In conclusion, although I retired from the Group in February, I promised, with help of our very dedicated editor (who by the way as agreed to remain as editor), one last newsletter (this one) plus unofficial support in helping you deal with dystonia.

So in closing this long story, I want to tell you that you are the most courageous people that I know. I am very honoured to have shared in your daily difficulties for the past 16 years.

As always I will be here whenever you need me.

Stu

STORIES OF HOPE AND COPING

We are continuing series of stories about how some members of our Group are coping with dystonia.

STILL DANCING

By Chantal Bégin

My name is Chantal Bégin. I was diagnosed with right muscular hemidystonia in the fall of 1984 at 13 years of age. At that time, I was limping on my right leg and also could not write with my right hand due to uncontrollable muscular contractions. Luckily, I have been fortunate that I have not had any pain as a result of my dystonia. It took about a year for the doctors to diagnose me properly. School posed a different challenge as I had to start writing with my left hand instead of my right. My writing wasn't very legible as I was naturally right-handed and it would take some time to get accustomed to writing with my left hand. In recent years I have been able to write with my right hand for short periods of time by placing a pen or pencil between my index and middle finger. A neurologist taught me this writing technique and it has been very helpful.

When I was originally diagnosed with dystonia, I was prescribed Levodopa. This medication did not work for me. The next medication, Tegretol, fortunately worked for me. The Tegretol worked fairly well for about 6 years at which time my neurologist added Artane to the Tegretol. Artane was added to better control my limping. In 1997 (seven years later), I stopped Tegretol and continued only on Artane at the higher dosage level up until May of 2010.

Recently, I started a new monoamine depleting agent medication called Nitoman. I had to start

something new because Artane was no longer working effectively. I started having more severe uncontrollable contractions to my right leg making it very difficult to sit down at my desk while working. I need to stand up most of the day lately. Bedtime also became a challenge as I could not lie flat in my bed without my leg shaking uncontrollably. I could not easily fall asleep so I had many days where I felt anything but awake.

Presently, I have been taking Nitoman for just over one week. This is a brand new medication for me so I remain hopeful that it will help with my dystonia symptoms. If it doesn't work, Dr. David Grimes will recommend another medication, possibly Amantadine.

Although lately I cannot walk too long, two things that I enjoy doing are dancing and taking Zumba classes. While dancing or doing the Zumba dance exercise classes, I am able to enjoy myself without the usual dystonia symptoms. Of course, I also keep very busy with my 2 great kids, Yannick (4 years old) and Sarah (6 years old).

I wish to thank my husband Duane for being at my side for support since we have met. Also the Dystonia Support Group gives great support. Stu is always there to listen to us and coordinate events to promote support. Thanks for your great work Stu!

LOOKING BACK ON MY JOURNEY WITH DYSTONIA

By John J. Heney

Dystonia, by its nature, is an ongoing challenge. That can make it difficult to be mindful enough to stop along the way and reflect on one's journey with this puzzling physical interference.

Am I presumptuous to even think of placing my perceptions on paper? The unique forms and complexities of dystonia are so personal and so unique in the daily life of anyone coping with it. My reflections are mine as a person and mine in terms of my form of dystonia. Just as significant, they are mine in terms of what and who surround me that give it a context. If that context is a practical and gentle one, the limitations placed upon all the rich aspects of one's journey are reduced. Support from others is the key, and it is by no means guaranteed. Having a variety of activity options is significant too, as is the manner in how one balances coping, relaxing, letting go and keeping on.

My generalized dystonia came on suddenly in 1991, erupting when awareness of the condition in North America was so much more limited. Today, this makes me a veteran in some senses, in terms of longevity and in what I have lived to witness. I went public with my case when far fewer were doing so. Now, much later, my place in the scheme of things gives me the license to laugh.

A man who recently told me he had heard of dystonia instantly did a double-take, exclaiming, "Oh my God, it was you! *You* are the reason I know about dystonia!" Whether he was referring to my print, radio or television participation with others helping to create awareness is of no consequence. Whatever the case, *that's* what you call self-initiated support! It's at least worth a grin. Everyone with dystonia is a pioneer in awareness.

I have witnessed how dystonia has settled [Ha! Is *that* the word to use?] in my life and in the life of my wife Kathy, she equally flummoxed originally about what this mysterious collapse was and what it would mean in all manner of restrictions and new paths.

A slow return to my record of work in all manner of communication was part of that compromise and discovery. I am now at work on my fourth book. Along the way I developed what I call "the *Ladies and Gentlemen!* declaration" to bring hope to all who face challenging conditions but who, unlike me,

might not have the same support and options with which I continue to participate in the world. For me, a need to cope gradually shifted to become opportunities to demonstrate, including how I drew to myself various treatments that began to gradually build my strength and lower my incidents of the full-body convulsions I now refer to as "dystonic storms."

Hindsight reveals the swing in my life, back and forth, from determination to acceptance, pushing when it was wise to do so and pushing, alas, when it was probably not such a good idea. It means living a life scheduled differently, as many dystonics will recognize -- taking action in times of higher mobility in anticipation of future downtime, eventually enjoying downtime more, in the knowledge that the time will come for more activity. I liken it to speeding down an ice trail in a bobsled, but with no enclosure to keep things on track! If the training and dexterity one gains in a life with dystonia counted for anything, surely this would be an Olympic sport!

I have enjoyed the times when my involvement supporting dystonia awareness allowed me to apply my professional toolbox of communication skills. Those were not only victories. Now they are memories filled with new exchanges, interactions and exposures to different experiences.

We are all veterans of something. Part of the nature of being a veteran, be it in parenthood, war, peacekeeping, in a profession or a pastime, is that the very nature of what we are involved in evolves in itself and by itself, and we are destined to watch this happen around us. I vote for speedier diagnosis of dystonia, faster coordination of support for those faced with it, wider aid to and inclusion of those with dystonia in a social and financial sense. I seek wider options for those so challenged, supporting continued interaction that supports a sense of belonging and purpose. I have witnessed change in all these aspects, with some improvements and new hope for coordinated efforts. That has been gratifying.

Along with that has come more evidence of medical research to help alleviate suffering and perhaps, too, to prevent cases of the disease. There is always time to raise a glass [whatever be in it] to take stock of one's place in it all, and too find fulfilment for having made the journey in such a way that one was part of improving the outcome.

MORE TO LIFE THAN DYSTONIA

On a fall evening in 1991, while out for a walk I suddenly felt tightness on the side of my face. As weeks went by it became more severe and was also affecting my speech. My speech had in fact become more severely impaired. I now had great difficulty in communicating with my superiors, peers and clients. I was being asked questions like: "Have you had a stroke?", "Have you been drinking?" etc, etc. It was very humiliating to have to deal with all these questions, when in fact I had no idea what was happening to my state of health.

My physician referred me to a neurologist, and consequently numerous test were performed which also included an MRI. Results of all these came back clear. I was put on numerous medications to try to control the spasms, again to no avail. The illness was progressing and by this time my jaw and tongue were severely affected and as well had great difficulty in eating and chewing foods.

To make a long story short, it took almost two years for a qualified neurologist to confirm my illness. I had dystonia and it was more specifically known as "Oromandibular Dystonia".

I now had severe jaw spasms, facial contractions, slurred speech and trumpet mouth spasms. I was also unable to chew food, due to spasms, causing a major weight loss. I was unable to perform my job and had to go on LTD.

Soon I was getting Botox injections every four months in addition to medication which provided some temporary relief. There was no known cure and surgery is not an alternative. The botox was providing some relief for about two months out of four months and had to be administered under EMG guidance. My neurologist referred me to a Dystonia Support in Ottawa, in 1993. I found that I was not the only one affected and the group headed by Stu Higdon were very helpful in giving me the necessary support to deal with this illness.

I was in denial for quite some time, as well as, loosing a great job which I truly enjoyed and could no longer return to. I had to learn to live with this condition.

I had no intentions of going backwards and truly wanted to move ahead. Dusted off my film camera (in the 90s, digital wasn't out yet) and began to explore, quite aggressively the nature trails. It was like going to work, except there was no pay check at the end of the week, although I was getting lots of exercise and enjoying nature and getting some reasonable images. We should all take the time to "smell the flowers", so to speak. I found out that there was more to life than dystonia...

I have found that while out in the field (enjoying nature) with my camera that I get so much enjoyment imaging nature's diversity that my dystonia goes in temporary remission, during that period.

A recent interview (Ottawa Citizen, May 30, 2010) with Robert Bateman, the renown nature artist. He said, "Walk in the woods or somewhere beyond the concrete as often as you can. Not only is the exercise good for you, there's something intangible to be gained from being in nature."

Jean



LIVE NORMAL LIFE AGAIN

By Ian Boudreau

I've had dystonia since I was 12 years old. It started as cervical dystonia and progressed through the years into generalized dystonia. I have tried many treatments including medication, Botox, Myobloc, meditation... Nothing really worked so I then had DBS (Deep brain stimulation) 5 years ago. It worked out really well and I'm now able to live a normal life again. The only downside is I have to replace the battery on the stimulator every 5 years. Last month I went back to Toronto Western Hospital to get my battery replaced and everything went smoothly so I can now relax for another 5 years!

FREEDOM TO MOVE

Cameron MacLeod in Perth

In 1986 most doctors in Ottawa were not familiar with dystonia and I had no diagnosis or treatment until finally Dr. Preston, a very observant neurologist, was treating nerve loss in my injured hand. He looked at me carefully and said "You have spasmodic torticollis" and referred me to another neurologist, who still had no treatment for me.

My symptoms became worse including oromandibular and facial dystonia. I had to leave my position with the federal government. My neurologist could only prescribe tranquilizers. Doctors could not give me other patient contact names or any information that could help.

In 1991, I located the Vancouver office of the Dystonia Medical Research Foundation (DMRF) and the Movement Disorder Clinic at the University of British Columbia. There, Dr. Calne and Dr Tsui were doing early testing with Botox injections, which provided me with wonderful temporary relief. And..... through DMRF I was able to find 6 others in the Ottawa area who had dystonia. Then, everything moved forward in positive ways. We founded the Ottawa Area Dystonia support group. Volunteers, who did not have dystonia, came forward giving us great support and leadership, including Stu and Mary Higdon...and now... we have "*Freedom to Move*".

I WILL GO ON

By Shirley Anne Sayle

I waited a year to get to see the specialist at the General Hospital. Finally the day came when I would receive my botox injections in my vocal chords and I would be healed. Nothing happened!

Three times I went. I was terrified each time and I found it very painful. Finally they said: "Sorry, it is not going to work!" How could that be? It had worked for other people why not me?

I have experienced people on the other end of the phone ask if I am a prank call, have to repeat things three times and even in a restaurant the waitress had to call another waitress and some people think I am drunk because my words slur.

I have become very sad and speak less and less and retreat more and more from the world. I still have my true and dear friends and I thank God for them. This is a hard condition to bear and you are faced with reality each morning but I must go on and I will go on!!

DBS

I was not quite 42 when I was diagnosed with Cervical Dystonia, in 2004. I have held clerical positions since College, and it was at work that I first noticed the early signs. My head would jerk to the right and for a time it would straighten back, but then one day it "got stuck in this position" and there it stayed. My head always felt heavy. Unless I totally turned my body, I could only see things from my right side. Two of the first things that I had to give up were driving and my job..... My life was on hold.....

I was in tremendous pain. It felt like I had a charley horse in my neck that just would not go away. My shoulders were always in spasm. For a long time I was embarrassed to go out anywhere as I was always getting stared at. I had trouble walking, eating, reading and even doing basic household work was a real challenge. I tried everything to help alleviate the pain including physio / chiropractic and massage therapy, had gone to pain management clinics, even tried an osteopath. Temporary relief is all I ever got. Botox injections never helped either.

I read an article in Women's Weekly magazine about a girl in the USA who had undergone DBS for dystonia. I took this article with me during our next visit to Toronto Western Hospital where eventually my DBS was done in April of 2008.

The surgery was done and the only discomfort I really had was at the stimulator site. After the surgery we made trips back to Toronto for the next nine months for "programming". The only set backs that I have are the fact that my handwriting is quite illegible and my speech is strained.

I have now had this ailment for over 6 years, but at this point I feel that I am 85% better than I was before surgery. I have absolutely no pain whatever and even though my head is still tilted, I am able to function so much better. I went from taking several pain medications daily to having to take nothing at all. That in itself is a blessing.

I feel I am getting my life back and am so grateful that the surgery was as successful as it was and also for having such a wonderful husband who has stuck by me thru this long chapter of my life. I am fortunate to have so many great friends and family who have been there for me along the way as well.

Kathy

Living with Attitude

For me, dystonia has become about living with an attitude and not coping with a disorder. I have lived with dystonia for 14 years and underwent DBS surgery in 2006 which has helped to relieve some of my symptoms. The biggest shift for me has been how to approach life with the dystonia monkey on my back. I am pretty active and enjoy downhill skiing, cycling, kayaking, and swimming. I plan to continue piano lessons this fall and have begun to write poetry.

Doing these things makes me feel like my pre-dystonia self. I feel more in control of my life instead of having dystonia control me. Some people tell me - "well, your dystonia can't be that bad" or - "you are so lucky you can do these things". Perhaps this is true but it is a matter of perception.

I live with constant fatigue, muscle pain and dysfunction especially in my jaw and neck. I have trouble talking, eating and swallowing. Sometimes the effort to speak and eat is so daunting, I just want to lie down and be quiet. I never wake up refreshed and eager to jump out of bed. Being active takes a huge toll on my body and makes my symptoms worse. But the alternative is just too depressing.

I keep active and engaged socially in order to be happy and independent and I have absolutely no problem resorting to energy drinks and caffeine to get myself going. And some days I just rest, do nothing, give in. It's a balancing act and not an easy one especially when people don't understand and say things like - "you were so energetic yesterday, how come you can't go out today"?

The most important lessons I have learned living with dystonia are to be true to myself, have compassion for others and not let the disorder define me. Dystonia is the nasty card I have been dealt - the joker! I plan to play the game and never fold if I can help it. And, oh yes, I recently welcomed a one year old cockatiel named Koko into my life. She is a pet I can manage and is a delightful little girl and companion. She is the sweetest of the tweet!

KMS

LIVING WITH DYSTONIA

I have been living with idiopathic generalized dystonia and blepharospasm for 27 years. At first I was optimistic that I would soon overcome this affliction and would resume my career as a foreign service officer. However that was not to be. My career abroad was finished. I was devastated.

During the 1990's my condition worsened. I spent five years lying on my sofa reading and listening to music and taking untold numbers of different medications - some of which made me worse by exacerbating the symptoms.

I made the decision that I would not lie there for the rest of my life. I investigated dystonia further and eventually met experts in the field - a neurologist and a neurosurgeon in Toronto. I was willing to try anything and in the end I had eleven neurosurgeries. It worked for awhile.

From January 1997 until September 1997 I was virtually without painful spasms, I was almost completely still. I was euphoric; I could go for walks without becoming exhausted after a short block, I could sit through plays and films without becoming painful uncomfortable. It was wonderful! Sadly, however, it did not last and the spasms returned. The spasms were not as painful or as violent as they had been prior to the operation, but they were still there.

I thought about the activities I would be able to carry out without becoming exhausted. I joined Toastmasters and have given sixteen speeches. I am always on my feet to contribute with a joke or thought or the Roundtable where everyone contributes a short anecdote on the theme of that meeting.

Helping new immigrants and refugees with their conversational English is especially rewarding. I meet interesting people from all around the world and we simply have a casual chat without bothering with grammar rules and regulations.

My book club is a special joy as it offers me the opportunity to read books that I would never otherwise consider. We have very heated discussions.

Since I retired eight years ago I have travelled to twelve countries in Europe and Asia. I have a reasonably active social life - dinner parties are fine but receptions are very difficult as I am unable to stand still and talk. I start to sway and feel faint and as I prefer red wine this could prove disastrous. I must sit down at once.

I take weekly yoga lessons which I enjoy very much. I have taken an afternoon course at Carleton University on the history of opera. Yes at times I find it very difficult but with effort I manage. There are always those worse off than I am.

KAW

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There are a number of ways you can help

- *Leave a bequest in your will...
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Ask your financial advisor how, or contact DMRF Canada at:

TOLL FREE: 1.800.361.8061

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info@dystoniacanada.org

www.dystoniacanada.org



MY DYSTONIA, MY STORY

I was walking 3 miles every day with my dog Chablis and doing quite well losing weight and feeling great. Then I started to notice this tingling feeling from my neck to my mid back. I gradually got worse and then I noticed something else. I was watching TV in the den and all of a sudden I was watching out one eye, my neck was turning.

Finally after many doctors' opinions I was finally diagnosed with dystonia. I went to Dr. Barkley and started the Botox injections. After two years I found out they were not doing much good - so now I get the injections only when my shoulders are very painful. The last one was two years ago. I am now on strong pain medications. The first four years it was very hardly noticeable but it is now gradually getting worse.

I've had some hard falls fracturing my bones. The most embarrassing was in church when coming back from communion I fell flat on my face. Everyone rushed to help me. I wished the floor would open up and swallow me.

I can only walk about two blocks and my husband Paul now walks Oliver (Chablis has gone to doggie heaven). I know things could be worse but some days are really rough.

I advise anyone with a dystonia such as mine (every dystonia is different) to be very careful with every step they take and to hold onto whatever is near them.

I would also like to mention that the Dystonia Support Group has been very helpful to me as I deal with this medical mystery.

Good luck to each and every one of you!

Sylvia

Canadian Researchers Funded through DMRF Grants and Fellowships

The following Canadian researchers are being funded by DMRF United States and DMRF Canada grants. DMRF Canada fellowships are co-funded in partnership with the Canadian Institutes of Health Research, SHOPP program. DMRF Canada works in partnership with DMRF United States to fund the best world-wide dystonia research.

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

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

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

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

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

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

Profile in Courage – Gordon Wilson Higdon

Gordon, my youngest brother, was born with a medical mystery you probably never heard about. My parents and the doctor thought he had club foot, but that diagnosis changed after his neck turned to one side and his whole body began to struggle with painful muscle spasms. Later on we were to find out that these uncontrolled muscle spasms had a name, a strange name indeed.

Gord was twenty when he first heard of dystonia, a movement disorder that takes over and holds body muscles captive. A neurosurgeon in Montreal not only confirmed his condition, but offered to operate on his brain, the cause of his problem. This was an unknown condition, so this operation would be experimental. Had we known the outcome we might have had second thoughts about the operation.

In the Montreal hospital where the operation occurred, the doctor drilled two holes into Gord's skull while under local anaesthetic and put probes into his brain to control the spasms. His operation lasted over five hours all the while Gord was awake and telling the doctor what part of his body was affected by the probe. He was released from hospital a week later, and everything seemed great; he could walk straight, and he had no more muscle spasms. Then one month later, he suddenly collapsed, his body once again engulfed in painful muscle spasms. What happened next was interesting.

My brother went into a depression; who could blame him. After all the suffering he went through plus the pain of spinal taps and the brain surgery no wonder he would be down. But one day we went to a radio station in Montreal where they were interviewing people with different medical problems. That is when the change took place. Awkwardly sitting

across from Gordon, was a 16 year old girl with ALS. Her young body was distorted and she was in a lot of pain. During the interview she revealed she only had three months to live.

Gord knew he had been dealt a bad deck of cards but not the worst card. The girl sitting across from

him was much worse than he was.

Further, he knew that dystonia was not a death sentence; the doctor told him he would just have to deal with his spasms on a daily basis. ALS showed little mercy with the certainty of death at a young age.

My brother's attitude changed. If he was not going to die he might as well make the best of life. He returned to Newfoundland, and even though he was sometimes confined to a wheelchair, he found a job at the Hub, where

they hired handicapped people. He worked for 20 years as a dispatcher and in other jobs. He persevered and got his driver's license, met and married a young woman named Gloria from Millertown, who herself was dealing with a number of medical problems including Ricketts as well as an inherited brain disease. They were married in 1991. Sadly Gloria passed away May 25, 2010...

Gordon has always been an inspiration to me. We all need a hero to look up to and Gordon is mine. Even though afflicted by terrible muscle spasms, he never once complained. In the meantime, in addition to working he purchased and paid off a new house, took many trips with me and our wives

to the Caribbean, Alaska, and to Hawaii with my other brother, in each case in a wheelchair. In one instance, we did not get to Nashville after attending a medical conference on dystonia in Texas, however, one night six months later I received a call from him and Gloria. They were calling from Nashville, having travelled close to 4,000 km in a ten-year old van that carried only their wheelchairs and a few blankets. He told me he was then heading out to BC to see my

other brother. That was Gord; nothing could stop him, not his medical condition, not anything people might throw in his path.



For the past five years Gord has attended a Southside Road reunion with me and about 16 other guys. We would play darts and horseshoes up on the Southside Hills or at the Legion. On a number of occasions Gord would get out of his wheelchair and struggle up the 45 degree incline where the horseshoe pits were located. Gord participated in any activity he could, even when he had to hold onto his wheelchair with one hand and threw the darts with the other. Such was his determination. We played each year for an

unknown trophy. This year we played darts and horseshoes for two special trophies - the Gord Higdon trophies. These trophies, one for darts and one for horseshoes, will be awarded each year not necessarily for the best player, for the most determined played, in memory of Gord.

Yes, my brother Gordon said a final goodbye to all of us on August 27, 2009, leaving his wheelchair and spirit behind so the rest of us could inherit some of his determination and will power.

Stu Higdon

Freedom to Move

The Freedom to Move Ottawa/Gatineau Walk and Wheel was held on Sunday, June 13 at Vincent Massey Park. Diane Gillespie, DMRF Canada Executive Director, and Loretta Jacques DMRF Canada Office Administrator joined the group participants on the wonderful warm sunny day. The park was bustling with activity, and the participants enjoyed a walk, great conversation and a BBQ. Many thanks to all who attended and we look forward to seeing you next year.



*News, Events, etc...****New NHCC Web Site***

Neurological health Charities Canada (NHCC) has launched a new web site of which Dystonia Medical Research Foundation Canada (DMRF) is a proud member. There is plenty of valuable information, especially in relation to the national neurological studies being funded by the Canadian government.

DMRF Canada plan to post its major dystonia events on this web site in the near future.

www.mybrainmatters.ca

Twisted Showing

Please stay tuned for a showing of the film Twisted at the Ottawa Hospital in the fall in collaboration with Dr. David Grimes.

Birthdays

Many happy returns to all members celebrating their birthdays or anniversaries September 2010 to April 2011!

Research Update

DMRF Canada is funding two research projects at the Ottawa Hospital Research Hospital:

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

Dr. Ryan Scott, Ottawa Hospital Research Institute, Fellowship (DMRF Canada, March 2011) Cytoskeletal linker proteins mediate organelle function in neurons.

Dystonia Postal Box

Dystonia postal box has been discontinued effective June 30, 2010. Any mail should be forward to:

DMRF Canada
909-100 Adelaide Street West
Toronto, ON, M5H 1S3

Fall Pub Night

Will take place on Thursday, Sep 23, at 6 PM at a location to be decided. Please call if you would like to attend.

What is Dystonia?

“Dystonia is a neurological disease that results in uncontrolled muscle spasms”.



DYSTONIA

Call: 613-749-7401

<http://www.dystonia-foundation.org>