

Ottawa / Gatineau Area Dystonia Support Group

Newsletter



By helping each other, we help ourselves!

April 2008

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

Do you know that approximately seventy percent of our support Group members are afflicted by cervical dystonia? Were you aware that three people in our Group have undergone DBS and another contemplating it? Another member underwent an early form of DBS back in the 1990's and afterwards suffered through 11 more brain operations to correct problems, non too successfully.

I like to inform people, particularly new members, about our support Group, including information that you might not be aware of before.

The Ottawa Dystonia Support Group, which was formed in 1991, consists of over 200 people with various forms of dystonia, including generalized, writers cramp, dysphonia, oromandibular, blepharospasm, and as I mentioned earlier, cervical. This movement disorder attacks people indiscriminately; our membership consists of a 50/50 split men and women. They range in age from 25 to 60 plus.

We have 4/5 doctors who inject Botox or provide other medical support to members with dystonia. Approximately 16 volunteers help keep the Group moving. We could use 10 more! These volunteers

provide such services as financial accountability, a telephone caller system, a quarterly newsletter, quarterly meetings, monthly coffee get-togethers, plus fund-raising and awareness programs. We are now updating our Web Site, developing a plan for Awareness, and attempting to provide other services that might assist you.

On a larger scale we estimate that we have from 23,000 to 50,000 people across Canada who are afflicted by dystonia. We have support Groups in most provinces that provide the same service as we do. Our efforts are coordinated by a Dystonia Headquarters in Toronto.

Today, as you read these few words you might be aware that there are others suffering the same frustrations are you, who are dealing with dystonia alone, or who have family members that have trouble understanding and accepting this condition...

I want to end this piece by emphasizing that you are not alone in coping with dystonia... As winter turns to spring, spring moves to summer, summer changes into fall and as fall brings back the snow/cold of winter, bear in mind that you are never alone.

We are here for you always, no matter what the season!

*The Ottawa / Gatineau Support group is an affiliate of the
Dystonia Medical Research Foundation, Toronto, Ontario.
You can reach Diane Gillispie, National Director Canada at 1-800-361-8061.
Come and join us at one of our meetings, at the
Carlington Community Centre, 900 Merivale Road, Ottawa
Group Coordinator, Stu Higdon, (613) 749-7401
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Editor, Branka Jovic



Drawing in the logo, Margaret Howard



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.

BOTULINUM TOXIN SAFETY ISSUES

According to "The Network News" an e-newspaper for volunteers of the Dystonia Medical Research Foundation, and dated February 27 2008, The US Food and Drug Administration (FDA) has issued an "Early Communication" regarding a safety review of botulinum toxins types A and B for both FDA-approved and unapproved (sometimes called "off label") uses in the United States. This review includes BOTOX® and MYOBLOC®.

The FDA is reviewing reports of serious side effects following the use of botulinum toxins, particularly for the management of juvenile cerebral palsy in which large doses of the medication are administered.

This posting of an "Early Communication" is a routine measure taken by the FDA to provide the public with early information regarding safety or other related reviews, often before any conclusions are or can be made.

The FDA made clear that "the posting of this information does not mean that there is a causal relationship between the botulinum toxins and adverse events. Nor does it mean that the FDA is advising healthcare professionals to discontinue prescribing these products. FDA is considering, but has not reached a conclusion about whether this information warrants any regulatory action. FDA intends to update this document when additional information or analyses become available."

The DMRF supports the FDA's efforts to ensure that treatments for all disorders, including dystonia, are safe and effective. We appreciate the manufacturers' efforts to cooperate with the FDA, putting patient safety above all.

Mahlon R. DeLong, M.D. Scientific Director of the Dystonia Medical Research Foundation (DMRF) commented on the use of botulinum toxins as a treatment for dystonia: *"The administration of botulinum toxin for neurological disorders such as dystonia is safe and efficacious because of the small amounts used in therapy. Botulinum toxin has been used as a treatment for dystonia since 1980 and worldwide thousands of patients have been treated with very few adverse affects. If anyone has questions about their treatment plans, they are urged to consult with their physicians."*

The manufacturers of botulinum toxins are working very closely with the FDA to ensure that it has all of the information necessary, including safety data from clinical trials, to make an informed and reasonable judgment regarding them. The DMRF will share further information on this issue as it becomes available.

As a service to our members, it is the policy of the DMRF to report on developments regarding all types of dystonia but not to endorse or recommend treatment.

We urge you to consult your own healthcare professional about your individual treatment plan.

DEALING WITH DBS

In this issue we wanted to give you insight in deep brain stimulation (DBS) through personal experience of our Group members. We are bringing four stories spanning through the process of waiting for DBS, midway after the operation, three quarters of the way along, and the final product. By doing this, we hope to help you to make an educated decision should you wish to be considered for this operation. Email or call Stu or the people who have undergone this procedure.

My Frustrations while Waiting for DBS

My name is Kathy Moorcroft, I am 47 years old and was diagnosed with Cervical Dystonia nearly 4 years ago. I was asked to write about the frustrations I am dealing with. I guess that is where I could start, in saying how frustrating this illness is.

...frustrated in how I look...

...frustrated in how I feel...

...frustrated how much sleep I need...

...frustrated in how people look at me...

I am on various types of pain medication which of course helps with the pain but does not help with the pulling or twisting. I feel like my face is in spasm and moreso when eating. It has become a habit to hold my face to get relief.

I am frustrated because I am not able to drive and therefore have not worked in just about 4 years. Therefore it has also become a financial frustration.

I am not able to do a lot of things that I used to do... it is almost like my life is on hold. I want to make sure that I try everything before I undergo surgery. And now I feel that I am at that point. I have read and watched about DBS and have to feel optimistic that it will work for me.

Over the course of the four years I have undergone various types of help including: chiropractor, physiotherapy, acupuncture, massage therapy, osteopath and other routes of pain management. Of course Botox was also tried three different times.

I even underwent a double blind "cancer medication" trial for cervical dystonia. I am frustrated that test results have gone missing. I even went for an EMG testing, on one day notice. One hour into the testing

the machine picked up a radio frequency and played "Amazing Grace" in a foreign language. If my 23 year old son was not sitting beside me, I would never mention this to anyone! To this day, I still have never received the results. I have often wondered if that song was telling me something.

Because I have some mercury fillings, I even had my mercury levels checked only to find that the levels are normal.

The hospital that I am with has asked that the following be done prior to DBS:

- brain MRI
- visit with their hospital Psychiatrist
- visit with their hospital's Neuropsychology Psychologist (this was a 5 hr. memory assessment), all of which have been done.

I am so fortunate to have a wonderful husband who has on many occasions taken time off work to drive me to Toronto for appointments. Without good family and friends I don't know where I would be today. Please don't get me wrong, I try to keep busy and when the weather is nice, I try to be outside as much as I can. It is a strange illness, as I feel better when I am raking or hoeing the garden, it is when I watch TV, or try to read, or writing, that I get all tightened up. I realize there are worse things out there, but I am ready to be better again.

I called the hospital last week to check my status and was told that I am now a candidate for the surgery although they can not give a time for it. I am anxious but frightened.

Kathy Moorcroft

Midway after the Operation

It has been just over a year ago that I had deep brain stimulation surgery and I have improved approximately 10% after having the surgery, possibly 15%. I have another appointment with Telehealth on March 20th. I'm hoping that Dr. Moro will have an alternative to try. So far she has pretty well exhausted all alternatives.

My hope is that eventually the surgery will improve my health a little more. One thing that has helped me about another 5 to 10 percent is the change from Ativin to Clonazepam. Dr Grimes and his associate changed that for me the last time I had botox shots on January 9th. My next shots are April 2nd. So, I'm back on botox shots and hoping a brighter future is ahead.

Cheryl Tanner

Kathryn Sullivan's DBS Story

by Rosalie Labelle

Speaking with Kathryn was a pleasure. One can't help but to be captivated by her upbeat nature, her sense of humour and contagious laughter.

Kathryn has both cervical and oromandibular dystonia. Kathryn has no knowledge of any root cause of her dystonia and has not had genetic testing done. Kathryn's dystonia came on about 10 years ago when she was about 46 years old. The onset of her symptoms began slowly. It started in her neck and within a few years it spread to her jaw. In 1999 to 2000 Kathryn had orthodontic work done when she found that she could not chew properly. Kathryn symptoms did not improve so she sought the help of other health professionals and was finally diagnosed in 2001.

Kathryn had deep brain stimulation surgery (DBS) because Botox® was no longer controlling her symptoms, especially her oromandibular dystonia. Kathryn had her DBS surgery done in May 2006. Kathryn had her surgery done at Toronto Western Hospital by Dr. Lozano. Kathryn was given a lot of information about the procedure by Dr. Elena Moro and her team, Dr. Grimes and his staff, and Ian a support group member who had had the surgery. Stu from the dystonia support group had given her the name of someone who had had it done and she talked to them as well. She also did her own research on the internet.

Kathryn has tried other treatments in addition to the Botox® such as acupuncture. The acupuncture helped her oromandibular dystonia, as it helped her overcome the difficulty she had when speaking on the phone. Kathryn explored other alternative treatments such as an osteopath and a holistic health care practitioner who works with energies. Kathryn says that the alternative therapies have helped her to manage her dystonia symptoms better, and have increased her energy and motivation.

It took about a year between Kathryn considering the surgery and having it done. Kathryn only had about two weeks notice prior to being called in for surgery. She did not consider this to be a problem. OHIP covered the cost of her operation which was about \$85,000.00. She had private hospital coverage.

Kathryn was considered to be a good candidate for the surgery because they felt that they could help her with her cervical dystonia. Psychologically she was

considered a good candidate to tolerate the eight hour surgery while wide awake. Kathryn also had a good support system. Her sister Marlene was with her the entire time she was in Toronto and while she was recovering at home.

The procedure started at six in the morning on a Monday. Kathryn had an MRI that took over one hour and was intensive. Kathryn did not feel that she had problems with this part of the procedure. The halo was then bolted into her skull which hurt although she was given a local anaesthetic which lasted all day. Kathryn felt that the halo was very heavy during surgery. Kathryn had trouble with neck support during the surgery. She had to use towels to support her neck. She felt stiffness in her neck a few days following surgery due to her head position. Kathryn found it to be cold in the surgery room and kept warm by wearing big socks.



Kathryn could hear the electrical activity being recorded as the electrodes were inserted into her brain and eventually placed into the globus pallidus of the basal ganglia. The doctor asked her to move her hands and feet and she was asked to count. Kathryn was shown pictures during the surgery that made her upset and made her cry and laugh. She found the speed at which the pictures changed to be upsetting, not the pictures themselves. She felt that the large amount of stimuli to which she was exposed resulted in a neuro overload.

Kathryn's sense of humour helped her during the surgery. The doctor had to drill three holes for the placement of her electrodes instead of just two because there was a big blood vessel exposed by one hole that had to be plugged. When he was finished she said "Way to go Black n' Decker Man." She said that she did not feel anything during the drilling just a sense of vibration yet there was so much vibration her teeth banged together.

Kathryn had one day between the first surgery and having the implantable pulse generator (IPG) inserted so she could participate in a research study. Kathryn felt that this gave her a unique opportunity to contribute to the body of knowledge about dystonia. On the Tuesday the wires were outside of her head wrapped in bandages. She remembers the researchers tracking her brain activity during this time for about two hours.

Kathryn had the stimulator put in on the Wednesday. Inserting the stimulator was what she called an easy surgery and only lasted an hour and a half. She was put out for the surgery and did not feel any pain from it when she awoke. Kathryn did not have any problems with her IPG site. It was comfortable and pain free. Kathryn recommends that women get a good sports bra to hold the IPG in place for a few days following DBS surgery.

Kathryn was only in the hospital for four days for her surgery. She did not have any unexpected problems with the surgery. She did feel sick immediately after surgery and started vomiting. Kathryn did not have cognitive problems after surgery. On the Thursday Kathryn was on her way home. She recalls stopping for a coffee and a donut whilst wearing a weird hat and having a shaved head. She said that she felt like Mike Tyson on a bad day. Once again Kathryn's sense of humour shines through.

Kathryn now wears a medical alert bracelet stating that she can't have a traditional MRI because of the DBS procedure. She can only have an MRI done at Toronto Western Hospital where they have specialized MRI equipment.

Ten days following surgery she could talk and eat normally again just like she did before the onset of dystonia. Kathryn could walk better after surgery because her neck was much more comfortable and not twisting.

To date Kathryn has had approximately eight programming sessions. Kathryn felt relief from her symptoms after her first programming session but it was not until after the fourth programming that she had the greatest alleviation of symptoms. After the fourth programming session she had a "Honey Moon" period where she had no symptoms for about two weeks; she felt like she had prior to having dystonia. Kathryn has had more alleviation of her cervical dystonia symptoms than her oromandibular dystonia symptoms following surgery. Kathryn feels that she had

a 50% success rate with the surgery; her neck having been helped and her jaw being more of a challenge. Kathryn said that she definitely feels better after having the surgery and that she would do it again.

Prior to and following surgery Kathryn has had brief periods where she has no symptoms. She feels that when she has distractions her speech is better. For example at her brother's wedding she felt her symptoms were alleviated for the whole evening.

Kathryn has gotten used to the ups and downs after living with her dystonia over 10 years and thus has adapted to the ups and downs of the DBS programming process. Kathryn can relate to the man in the documentary "Twisted" who was having challenges with the DBS programming following surgery for his dystonia. She could empathise with his emotional roller coaster ride as she has been on the same one herself. She says that you just have to flow with the ups and downs because what is the alternative? She said that it is important to have people to talk to and that a support network is critical. Kathryn feels like a "work in progress" and states that the surgery is still being tested and perfected and feels that in 10 years today's procedure may be considered to be archaic. Kathryn advises that it is an individual decision to have the DBS done and she recommends doing your own research on your type of dystonia and the likelihood that it can be helped with DBS surgery.

Kathryn is taking yoga again. She had to stop when she got dystonia. She has adapted the yoga exercises to be cautious of her neck. Kathryn is also playing an instrument for the first time; the piano. She has purchased her first digital keyboard piano and is now able to play her first song "When the Saints Come Marching In."

We would like to thank Kathryn for sharing her story with us and for being such an inspiration with her positive and forward looking attitude.

Keep on marching forward Kathryn!

Ian's Story

I had deep brain stimulation three years ago in Toronto at the Western general hospital.

Dr. Lozano was the one who performed surgery. I had generalized dystonia, the surgery went really well and then Dr. Moro programmed the stimulator to find the right settings for me. I was able to see some progression a couple of hours after the first programming session. I was able to keep my head straight for the first time in years and was shaking a lot less. After going for several programming sessions in Toronto they found the optimal settings for me just about a month after the surgery.

I'm really pleased with the results I got; I'm 100% better now and can have a normal life again. I was 25 when I had the surgery and was told that the younger you are you can expect better results. I spent 13 years of my life in pain and suffering and never thought I would be able to live a normal life one day, I'm blessed to have had this great team in Toronto.

Ian Boudreau

News, Events, etc...

Walk and Wheel

Provided we get additional help, we will once again hold a Walk and Wheel on Parliament Hill on Saturday, May 24.

Please let us know if you can help!

Awareness Week

We have just recruited a new Awareness Coordinator who is busy planning a series of events marking Dystonia Awareness week in late June, including the sign off for A Dystonia Proclamation.

Dystonia Advocacy Day

This will be the third such event on Parliament Hill to educate politicians about this devastating movement disorder. Once a National Director has been installed we will begin work on ensuring another success on the Hill, date to be announced.

Welcome...

Effective January 25, 2008, our former National Director resigned to take up new challenges. Our new National Director will commence on March 25 - her name is Diane Gillispie.

Comings and Goings

We lost our two members, Gerald Boisclair, early 2008, and Margurite Czuba, late 2007, due to causes other than dystonia.

What to do?

You, like so many who are burdened by dystonia, may have sought out different solutions to minimize those frustrating spasms. Unfortunately there are people out there who state they understand dystonia and promise you that they can help, but sometimes take your money and run, and you are no better off. One possible way of minimizing this from happening to you is to get the phone number of people that these people have supposedly helped so you can minimize the possibility of being hoodwinked.

Thank you / Merci

I would like to take this opportunity to thank those who have extended their support in a positive way in keeping the Support Group going.

Jean Durepos, Maryln Luffman, Diane Van DenHam, Judy Bates, Shirley and Ron Riopelle, Mary Higdon, Eleanor Mintz, Jacqueline Giorgi, John Heney, Audry Hoar, Theresa Momy, Branka Jovic, Kathryn Sullivan, Kathy Moorcroft, Louise Valiquette, Margaret Tait, Kelda Whalen, Cheryl Tanner, Ian Boudreau, Rosalie Labelle, Claire Gladman, and living in Beijing Jin Jie.

If I have forgotten anyone, please accept my apologies and thanks.

You do make a difference for others!

Get-togethers

The first get-together for 2008 will take place at the Carlington Centre, 900 Merivale Road, Tuesday April 22. You will be informed shortly who the speaker will be.



Coffee Get-togethers

We have selected four areas for Coffee Get-together which normally takes place on Tuesdays commencing at 11 am.

Schedule Dates	Places
April 15 May 20 June 17	<i>Tim Hortons</i> at the corner of Baseline / Woodroff (near the Home Depot store)
May 06 June 03	<i>Tim Hortons</i> at St Josephs Blvd immediately prior to the Orleans Shopping Centre
April 08 May 13 June 10	<i>Tim Horton's</i> on Bank Street near Riverside Drive
April 27 May 27 June 24	<i>Tim Hortons</i> at St Josephs Blvd in Hull near the 550 overpass

Please come join us for an afternoon of fun with your dystonia family!

Note: We will assess the need for coffee during the summer months.

The Ottawa Dystonia Support Group

Volunteers Needed

What is Dystonia?

Dystonia is a neurological movement disorder; similar to Parkinson's, that causes muscles in the body to spasm for more than 500,000 people across North America. At this time, there is no cure for Dystonia; only treatments that include drug therapy, Botox injections, and surgery for specific types of Dystonia. There is ongoing research.

What is the Ottawa Dystonia Support Group?

Our support group, which was founded in 1991, helps people in the Ottawa area cope with Dystonia. It's a non-profit organization supported by people with Dystonia and by volunteers like you. Our international headquarters is Chicago (Dystonia Medical Research Foundation) and our Canadian headquarters is located in Toronto.

Activities of the Group

Our Group is organized into three segments:

- 1) Well being of group members,
- 2) Awareness,
- 3) Fund-raising.

We hold monthly Get-togethers and Executive meetings at the Carlington Centre, 900 Merivale Road. At these Get-togethers, medical people update us on Dystonia research, and we hold coping sessions. In addition, we publish a quarterly newsletter, and we conduct fund-raising and awareness campaigns (These activities are expanded below).

Volunteer Needs

The work of the Ottawa Dystonia Support Group is supported with the help of people with dystonia and by volunteers. Without it, we could not exist. We need volunteer help in all the following activities:

- 1) Awareness - help in developing and publishing educational ads (2 - 3 hrs/month)
- 2) Fund Raising - help in organizing fund-raising events, such as our annual Walk and Wheel on Parliament Hill (2-3 hrs/month, more prior to W&W)
- 3) Updating Membership lists (2-3 hrs/month)
- 4) Helping to organize get-togethers (1-2 hrs/month)
- 5) Volunteer recruitment (2-3 hrs/month)
- 6) Assisting in the development of the "Dealing with Dystonia" booklet (3-4 hrs/month)
- 7) Updating our Support Group brochure (1-2 hrs/month)
- 8) Acting as a telephone caller (2-3 hrs/month)
- 9) Well being - help with organizing executive meetings, taking notes, and the newsletter (3-4 hrs/month)

There are other ways you can help as well. No experience required. Bilingualism is not necessary in most cases. The Group can help you if you have second language needs. Work can be done at home, or at regular meetings.

For further information, please contact Stu at (613) 749-7401.

Thank you for coming out to help us!