



Newsletter of the Ottawa Area Dystonia Support Group

By helping each other we help ourselves

AUGUST 2001

JOIN US!

Doing "Something" About Dystonia!

We begin our fall program with a Get-Together on **TUESDAY, SEPTEMBER 4**, at the Carlington Health Centre, 900 Merivale Road, commencing at 7 pm. Come and join us in this warm exchange of experience about dystonia. Apart from our September meeting, we will be holding our monthly Get-Togethers (except for January and February) the fourth Tuesday of each month until June 2002. Commencing in October the date of our Get-togethers will be:

- **October 23**
10th Anniversary of the Ottawa Support Group
- **November 27**
- **December Xmas party**
(date to be announced)

There will be no Get-Togethers in January or February. In 2002 our Get-Togethers will be held on:

- **March 26**
- **April 23**
- **May 28**
- **June 25**

Please note these dates on your calendar.

On September 22, at 12:30 pm, we will be holding our annual **WALK AND WHEEL ON PARLIAMENT HILL**. Over the past five years we have collected \$25,000 for Dystonia research. If you want to help defeat Dystonia, please approach your family, friends, neighbours to sign the enclosed donor sheet. We need your support on the Hill on September 22 to help defeat our greatest enemy: Dystonia. Canadian groups are now supporting a research project to the tune of \$99,000. Many thanks to all of you who made this happen.

October 15-22 will be **NATIONAL DYSTONIA AWARENESS WEEK**. This is when we try and educate professionals, the general public on Dystonia. Let us make sure that no one else, like you, will be misdiagnosed. With your help we can ensure that everybody in the Ottawa region is aware of this crippling disease. Please support our Awareness Program by calling Stu at 749-7401.

Stu's Corner

As you receive this newsletter, we are about to leave one season and enter another. I see beautiful flowers still in bloom, birds chirping cheerily, the shimmering sun shining brightly. In a few short weeks we will be fortunate to see the fantastic changing colours of fall.

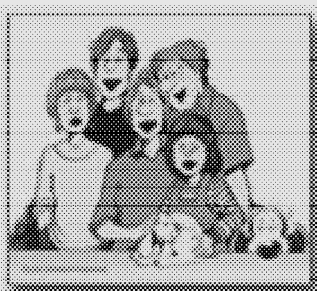
But as we prepare to enter the new season, with all the things we want to accomplish as a Support Group, I must share with you the thought that coordinating a Support Group is quite a challenge.

How do you develop a positive feeling in people like you when you've been told there is no cure for dystonia? What is the best way to help you in your lonely battle against dystonia? You are already dealing with pain, medications and all other kinds of challenges you face in your daily living. You are going about minding your own business and here I come, asking you to help me out with the Support Group! The nerve of the guy! You can see, it is a daunting challenge.

But if we want to beat dystonia, and I am sure you do, we must take certain actions. I say we because we need your support. We need your help with raising awareness about dystonia, with raising funds for research, with making better services available to you. More importantly, we need your help in weaving the web of contact and support between all of us so that no one is left on his/her own.

So what is the solution to this challenging problem? Well, I've learned from my numerous friends among you that you are already "doing something" about dystonia, trying this or that, whether individually or together with others. That is your way of not giving in. Well, the Support Group is also not giving in! Helping us with the Support Group is also

From Stu's Corner ... p. 3



What, you never heard about dystonia?!

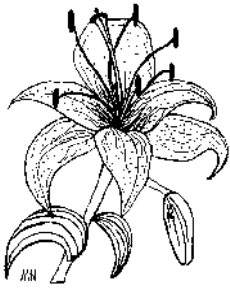
September 22, 12:30 pm Walk and Wheel on Parliament Hill

Raising funds for dystonia research

October 15-22 National Dystonia Awareness Week

"What, you never heard about dystonia?!"

For information call Stu at 749-7401.



Newsletter of the
Ottawa Area
Dystonia Support Group
P.O. Box 229, Stn. B
Ottawa, ON K1P 6C4

Editor

Yvon Breton
(819) 770-5296
yvonbreton@videotron.ca

Research

Cameron MacLeod
jcmacleod@perth.igs.net

*Have also worked
on this issue*

**Stu Higdon, Mary Higdon
Linda Chapman, George
Winges, Angelina
Mangone**

Group Coordinator

Stu Higdon
(613) 749-7401
seaward.h@sympatico.ca

Regular Get Together

Held on the fourth Tuesday
of every month at 7:00 pm at
the Carlington Community
Centre, 900 Merivale Road.

Dystonia is a neurological disorder characterized by involuntary, 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.

The Ottawa Support Group is an affiliate of the **Dystonia Medical Research Foundation**, Chicago, IL, (312) 755-0198. The Canadian representative for DMRF is Shirley Morris (1-800-361-8061).

Publication of information and opinion in this newsletter does not constitute endorsement by the Ottawa Area Dystonia Support Group. Readers are urged to check with appropriate authorities in each facet of living with dystonia.

LOGO: The drawing in the logo is by Margaret Howard.

My story...

Inspired by You

Stu Higdon

I decided nine years ago, after working 39 years, that I did not want to work anymore, and I subsequently retired. Although I had been volunteering for 25 years with Blind bowling, Saint Vincent's Hospital, UNICEF, and several other organizations, I had no hesitation when asked by Cam MacLeod to take over the Dystonia Support Group. My *raison d'être* for all my volunteer activities is simple – it was my way of saying 'thank you' to my Maker for granting me good health. When I accepted the role of coordinating the Support Group in 1994, it was a continuation of my volunteer work.

Yet it was somewhat different than other volunteer work in which I was involved. There have been stressful moments, i.e., organizing Walk and Wheels, trying to acquaint the medical profession and general public about dystonia during the National Awareness Week, or getting a replacement editor for our Newsletter. When things get real bad I go out in my workshop and make things. I quit UNICEF and two other volunteer jobs to increase my time with you. Overall though, things have

Cam MacLeod, a founding member of the Ottawa Area Dystonia Support Group, recalls:

"One event I shall always remember is the first phone call I received one day in 1994 from Stu Higdon. That call changed the course of history for our support group.

"My dystonia had become much worse. I was having personal problems, including having to leave my profession. Other members of our executive all had dystonia

worked out reasonably well. I have been able to carry on with volunteering at four other organizations in addition to the Dystonia Support Group.

Fortunately I have three great helpers: a dedicated, supportive wife, a great executive, and my good health. To begin with my wife, she works quietly behind the scene, correcting my many errors, working on the Walk and Wheel, mailing out the newsletter, and many other things. Thanks, Mary! Also, I have been very fortunate to have a great executive, that go out of their way make the support group work. Thanks guys! Finally my health has permitted me to work with your great organization. My wife may not quite agree, but my humble attitude, handsome looks and youthful energy keep me going...

I am a person who likes to work with people so it is only natural for me to find ways to encourage all group members to become more active. If more of you get involved so many positive things could be accomplished.

My brother Gordon, who has generalized dystonia,



and who is in a wheelchair has just driven 1900 kilometers to visit me. Some years ago he was lying on an operating table with two probes in his brain to help alleviate his dystonia. The operation did not work. At first my brother was quite discouraged. One day he was interviewed with a young lady suffering terribly with MS. At that point in time he realized that although he was dealt a bad deck of cards, he did not get the worst card. Since then he has taken hold of his life and has become involved with the battle against dystonia. Also a young lady in our Group has had 12 brain operations, none of which was really successful. In spite of these setbacks she is an active part of our Executive. This is what I call faith and a positive attitude in dealing with dystonia.

In closing, this is my story, the wonderful people I have the good luck to work with and to know. Have a nice week!

From the Editor

which gave them equal challenges. Our support group desperately needed help.

"Stu had just returned with his wife Mary and his brother (who has dystonia), from a North American dystonia conference in Houston, Texas. He obtained my phone number at the conference and called

to offer his help.

"That telephone call was a prayer answered. Stu, with the support of Mary, has enabled our group to survive and to move ahead in many ways – including being there to help those many others in the Ottawa area, suffering from the daily challenges of dystonia."

VOLUNTEER OTTAWA/PATHWAY PROGRAM

On behalf of our members we would sincerely like to thank the people at these two programs for their support throughout the years. They continually attempt to find volunteers for our Support Group. Many thanks!

My story...

An Active Approach to the Treatment of Spasmodic Torticollis

Linda Chapman

My spasmodic torticollis appeared suddenly about four years ago without any previous injury to my neck of which I was aware. I went to several clinicians who were puzzled by my symptoms and finally to a neurologist who immediately diagnosed the condition and asked me why I had waited so long before seeking help! By this time my neck was whipping uncontrollably to the left and I was barely able to continue working as a medical secretary.

There followed a year of Botox injections and Clonazepam tablets which were of little help and I was feeling quite depressed when I attended Dr. Avi Nativ's presentation to our Dystonia Support Group in November, 1998. Avi, a kinesiologist and physiotherapist, described his approach to the treatment of ST which involves the use of active biofeedback techniques coupled with an upper extremity muscle strengthening program. As I've always been a physically active person, I was interested in his work and have been under his care for the past two and a half years.

One of the first things Avi told me was that I would have to work out (in a gym) for the rest of my life to strengthen the muscles of my neck and shoulders. Therefore, I do gentle workouts with weights at least twice a week, following a program he designed for me. Several times a week I have also been hooked up to



a computer via the muscles of my neck and, using special software, have undergone training to correct the movements of my neck and increase its range of motion. This is called biofeedback.

Avi and his team at the Neurogym - Louise, Eric and Heather - have given me the support and hope that is so needed by one who suffers with this difficult condition. I am glad to report that, as a result of their efforts, I am functional with my ST and work full-time, drive, dance, and practise yoga. I have learned not to become discouraged with the fluctuations in the condition and feel sure that, with perseverance, I'll overcome it some day. To some extent each of us must be our own therapist because we are the ones who know our dystonic muscles best and we can use all our understanding to help us when these muscles are painful.

In closing, I would like to mention the work of the French physiotherapist, Jean-Pierre Bleton, who published a monograph on spasmodic torticollis in 1994. He has developed a series of exercises which can be practised at home on a daily basis, and I have found them to be most helpful in relieving my symptoms.

Best wishes to all and heartfelt thanks to the Dystonia Support Group, without whose presence I would never have heard about the Neurogym.

No Need to Say it, She Knows it!

George Wings, caregiver

Coping with someone in your immediate family requires a great deal of patience and understanding, plus a knowledge of dystonia. In the beginning (15 years or so ago), it was very difficult to find someone even in the medical profession who knew what dystonia was.

I think the whole family should become familiar with what the affliction is. My son Ken was a tremendous help to me and his mother Helen.

Numerous trips to Toronto, many phone calls to Chicago, Vancouver, plus many Botox injections, helped us to face the facts: there was no cure, at least not in the foreseeable future.

We decided to stop telling her that her tongue kept on protruding, which is her main problem at this time. Her eyes had stopped blinking and closing a great deal, but dystonia had moved down to her jaw and tongue. As a result it became very difficult to chew her food, as her tongue would throw it out.

We decided not to even mention it anymore to her, letting on we did not even

see it. I kept myself busy doing housework for her, Hoovering, etc., also NOT being overly sympathetic! I am convinced that had it not been for Helen's strong faith, things would have been much different (worse!).

We then became aware of a local dystonia chapter that was holding meetings once a month, which was

being conducted by a gentleman named Mr. Stu Higdon. He would arrange for guest speakers, relating of course as much as possible to dystonia.



We learned a great deal from some of these guest speakers about dystonia, coping, etc.

I also learned not to continually tell her about what was happening - she knew it! That is, that her tongue was protruding a lot.

Other than that, I just help her as much as I can with her housework and doing errands, like at the drug store, and doing various messages for her (appointments with doctors, etc.) She also has a heart condition, for which she is taking a lot of medication and which of course limits her physical activities.

FROM STU'S CORNER... continued from page 1

"doing something" about dystonia. Some of you have come forward already and it is heart-warming.

So think about it. Let us "not give in" together. Let us succeed together. It's so much better.

The flowers will remain bright, the birds will sing cheerily, the sun will shine ever brighter when your individual battle against dystonia becomes our battle.

COPING WITH DYSTONIA

Trouble Falling Asleep?

Angelina Mangone

Whenever sleep does not come as easily as you would like, there is another option to counting sheep or drinking warm milk. I have found that meditation can help. It is not a guaranteed success for everyone but there are many other benefits you can derive from doing it on a regular basis. These benefits can range from lowering your blood pressure to calming your over-hyper nervous system. Hopefully though, sleep might come more easily.

Now for a few pointers on the "how" of meditating. Your spine should be straight as you sit on your bed, cross-legged with hands resting on your legs. If you have torticollis or find it difficult to hold yourself up straight, try propping a few pillows behind you and one to support your neck and head. After you have positioned yourself, close your eyes and focus on your breathing. Notice it either at the chest or the stomach level. Notice the expansion

and contraction - the filling and the emptying, etc. Other thoughts will undoubtedly bombard your mind while you are doing this but gently and non-judgmentally, just notice when this is happening and go back to focussing on your breathing. If you do not feel comfortable focusing on your breathing, you may focus on environmental sounds. Hopefully those sounds will not be too loud if you are trying to fall asleep.

It will be difficult to do this at first, especially if you haven't ever meditated before, so start with 5 minutes and work up to 20 or 30 minutes. It sounds easy enough to do but don't expect too much from yourself. Be happy with whatever happens and make sure you persevere. The more you practise the more your mind can calm down from the hustle and bustle of daily living and the easier it should become to fall asleep. Good luck!

LEADERSHIP SYMPOSIUM IN CHICAGO

A Cure for Dystonia May Not Be Far Away

Stu Higdon

On your behalf I attended a three-day leadership symposium organized by the Dystonia Medical Research Foundation (DMRF) in Chicago on July 12-15. The next issue of the newsletter will provide more details of the interesting outcome of the symposium, but I will highlight a few items. Attempts are being made in the U.S. to actually confirm the number of people who have Dystonia (this will assist us, for example, in obtaining federal funds for research). It is estimated that there are 300,000 people with dystonia in North America and 10,000 in Canada but these numbers are old and are more a guess than an estimate.

Thalamotomy, pallidotomy, and Deep Brain Stimulation (DBS) are still being used to reduce the effects of Dystonia for some patients. The DBS surgery has much improved in recent years. A 20/20 Program on ABC TV on Friday, August 17, highlighted the positive effects of DBS on a young man with generalized dystonia. Also, Myobloc (a new strain of botulinum toxin, like Botox) is being used in the U.S. to treat dystonia patients. We are trying to get Myobloc approved in Canada. It provides similar relief as Botox, but has different make-up qualities.

Regarding research, DMRF noted it needed \$100,000 before the end of August to cover research grants. The real good news

is that we were told there is light at the end of the tunnel, that *there may be a cure for Dystonia within 2-3 years*. DMRF President, Rosalee Lewis, said: "Time is quickly approaching when we will be able to say 'Dystonia Was' and not 'Dystonia Is'!"

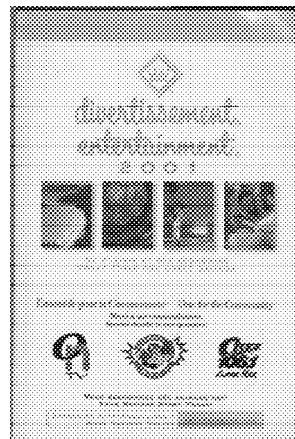
Phil Thomas, PhD of the DMRF Scientific Advisory Board gave an excellent presentation on the research being done. In a nutshell, research is targeting a particular protein that is believed to affect motor functions. They need to know what precisely the target is, how it is altered and how it can be changed or altered to achieve normalcy again. First they want to be able to have a "model" system in a test tube, such as a cell or a chemical agent that mimics at least some of the aspects of dystonia. This enables the researchers to do testing, etc. that could never been done on a human. Remember, this is the molecular basis of the disease.

Once this is learned, a drug can be developed that will target all areas of this abnormal motor function and return the function back to normally. We all know that new drugs can take up to 15 years to be approved for use on patients. But researchers believe that there is already a drug on the market, or a combination of several drugs that can be combined together to affect this protein and maybe provide a cure for dystonia!

New Entertainment Books Are Out!

The Ottawa-Hull area entertainment book for 2002 is now available. The sale of these books helps finance the Ottawa-Hull Dystonia Support Group. If you wish to purchase a book(s) please call Marg Pranschke at 225-2401 or Stu Higdon at 749-7401.

The book contains information as well as coupons for rebates on restaurants, hotels, shopping malls, sports and leisure activities.



Save up to 50% on your entertainment expenses and help finance the Dystonia Support Group at the same time!

This newsletter is partially funded by Allergan, who developed Botox for the treatment of Dystonia. Many thanks for your support.