



# Newsletter of the Ottawa Area Dystonia Support Group

By helping each other we help ourselves

MAY 2002

## APRIL GET TOGETHER

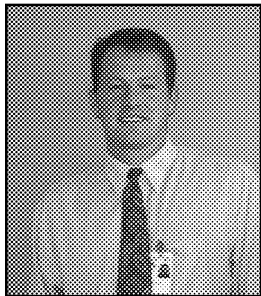
### Dr. Grimes Outlines Genetic Research

Dr. David Grimes, of the Ottawa Hospital Research Institute and medical advisor of our Ottawa area support group, applied for and was recently awarded a nearly \$60,000 research grant by the Dystonia Medical Research Foundation (DMRF). It is the first such grant to an Ottawa doctor. Congratulations, Dr. Grimes! The exact title of the research is "Candidate Gene Sequencing in a Novel chromosome 18p11 locus in Inherited Myoclonus Dystonia."

At our April get together Dr. Grimes outlined his grant to investigate the gene or genes involved in *Inherited Myoclonus Dystonia*. Genes, he pointed out, supply the instructions our cells follow for doing everything. Astonishingly, a chromosome, which is made up of many genes, if stretched out would reach two metres.

The dystonia Dr. Grimes is looking at is called *autosomal dominant* because only one

parent needs to have the gene in order for 50 percent of the children to inherit the gene and thus the chance of getting the inherited monoclonus dystonia. Most dystonias, though, are not inherited, as far as researchers know now, Dr. Grimes said.



The controlling gene appears to be on chromosome 18. Dr. Grimes' research has been greatly aided by a large family, 14 of whom have inherited monoclonus dystonia, who have been willing to have their blood examined. Having access to a large family like this provides a wonderful research opportunity where the inheritance of the faulty gene can be traced.

In response to a question from a member, Dr. Grimes said that once a faulty gene is found it can be cloned and its particular activity identified. Then drugs could possibly be developed to deal with the specific difficulties the gene is responsible for.

## Dystonia Picnic

June 15, Noon to 4 pm - Vincent Massey Park

We will be celebrating our second annual picnic on Saturday, June 15, at Vincent Massey Park. This will be a pot luck affair, so bring your favourite dish as well as something to drink. We will be having games and will be entertained by a local quartet. Come out and join us in having some fun..

## Stu's Corner

As I write these few words I wonder if the summer will ever arrive. It has been a cold spring for such a long time which makes me wonder if there will be a time when the weather will be warm, the sun bright and our spirits high.

If I had dystonia, I would also wonder if a cure would ever arrive. After all it has been such a long time that research has been going on. Surely they would have found a cure by now!

Finding a cure for a disease like dystonia is not easy. In fact finding a cure for any disease is time-consuming and expensive. Otherwise they would have found a cure for diseases such as cancer long ago, especially since the disease is fatal.

At the present time there are approximately sixteen doctors conducting dystonia research across North America, not to mention the many other medical researchers in Europe and elsewhere. The Dystonia Medical Research Foundation (DMRF) funds such research to the tune of over \$800,000 each year. Incidentally, a local neurologist, Dr. David Grimes, recently received a DMRF grant to conduct dystonia research, the first such grant to a medical researcher in the nation's capital.

Each of these researchers is working on a specific area of interest. All of the researchers have one thing in mind - to find a cure for everyone suffering from dystonia. These people are very dedicated, and spend many hours each day finding and isolating certain genes, or confirming other possible causes of dystonia.

In many instances these efforts have paid off. The isolation of the DYT1 gene a few years ago for early onset dystonia has proved that this research is worth the funds expended. I believe firmly in such research. To back up my belief, for the past five years I have organized a Walk and Wheel on Parliament Hill that has yielded over \$32,000 for dystonia research. Again, this year we will attempt once again to

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Newsletter of the  
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#### **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.

## **A Strong Support System of Family, Friends and Professionals — the Key for Living with Dystonia**

By Paul Anderson

Margo Williams' struggle with dystonia began in 1992 when, at 48, her neck began to twist uncontrollably to the left. She thought it was because she was working at a computer all day in her job at an engineering firm. Consequently, she met with her family physician. The doctor sent her to physiotherapy where she underwent massage and other treatments. This only made her problem worse. Diagnosis from another doctor was that her neck was turning because of strain — caused by carrying her purse on her left shoulder. Yet another doctor told her it was the result of menopause. A whole year after the manifestation of her first symptoms, by then feeling she was losing her mind, Margo finally went to see a neurologist at her husband Michael's insistence.

After simply watching Margo walk into the office, the neurologist diagnosed her on the spot. She had spasmodic torticollis, a form of dystonia affecting the neck muscles, turning her head to the side.

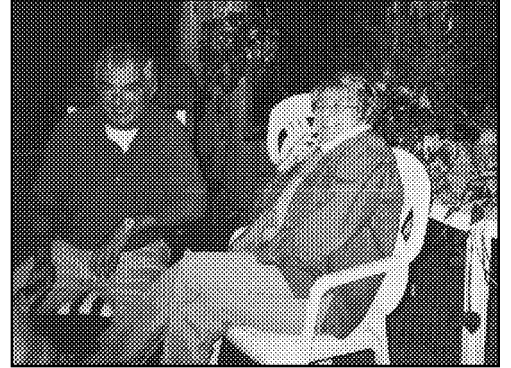
Once Margo was diagnosed, she thought the doctor would give her a pill to cure her illness. Only then did she find out there was no cure. Next, she went to the Civic Hospital to get treatment. Margo tried different medications that made her sleep a lot and even when she was awake she felt like a zombie. Eventually she was weaned off of those drugs and now takes only Tylenol

3s when needed. While she is trying botox treatments, they have worked only sporadically for her.

At the time Margo was diagnosed, her elderly mother, who is blind, was living with her and her husband. Margo didn't want to cause her mother to worry, so for a long period of time she kept her condition a secret from her. Eventually her mother was told, but Margo still doesn't tell her mother the degree to which she is suffering.

Margo's dystonia affects every aspect of her life. The things that we all take for granted, like walking and reading, became a chore. She emphasizes that everything she once did freely must now be improvised. For a long time Margo would use her left arm to control the turning of her neck. She no longer does this because the nerves in her left arm at the elbow are damaged from the consistent strain. She wears a special magnifying glass around her neck for reading. Thanks to the powerful lens, she still manages to see the words as her head moves. She is able to drive a car, but prefers to go only short distances.

Looking back, Margo believes she may have had mild dystonia as a young



Mike and Margo at their home in Gloucester.

adult, because when she looks at her wedding photos and other pictures she always has her head tilted slightly to the left.

Despite her condition Margo has a positive outlook and has kept her sense of humour. When she meets with other sufferers of torticollis at a restaurant, she describes the manoeuvring around the table as almost comical. Each person, according to the particular nature of their own disorder, orients his or herself for a moment before choosing a location at the table that is most manageable. Margo prefers to sit at the head of a table to compensate for her left-leaning torticollis.

Margo believes the key to dealing with dystonia is having a strong support system of family, friends and professionals. She advises new sufferers to talk to other people with the disorder. This way they can communicate with someone who actually knows what they are experiencing. She says, "Until you have dystonia, you don't know what it's like."

**Our sincere appreciation to three new volunteers who have joined us recently. They include Paul Anderson, Karen Hsu and Nicola Patterson. Thank you so much.**

# Surgery Updates

## Monica McCool



Monica with daughters Ashley (left) and Bryony (right) and mother Christine Langlow (back).

*Monica underwent the peripheral denervation operation by Dr. Bouvier in August 1998 at Notre-Dame Hospital in Montreal.*

I was apprehensive before surgery but also very confident because I was a good candidate. I had responded well to Botox injections in the past but had built up a resistance since I had been having them for so long. I did not feel I had anything to lose – my main thought was to eliminate the excruciating and constant pain. By this time I could hardly walk a few feet without my neck twisting to the left and my left shoulder was also elevated in an unnatural position.

The operation itself was uneventful except, that my neck and throat swelled abnormally and I was in intensive care with an airway inserted to help me breathe. Once I was back in a regular room and was not hooked up to machinery, the difference was amazing – absolutely no pain at all! I could walk up and down the hospital corridors in a fairly straight line and my head did not turn to the left, my shoulder did not rise and, most important, it did not hurt!

Having my head shaved at the back was traumatic as I had long hair – I knew it would be done but even

so it was a shock. Some people from the Montreal Support group came to visit me and gave me lots of encouragement. One person who was considering the surgery visited me and asked how I coped with the way I looked – i.e. my lack of hair or hairdo. I explained that my hair would grow back and I was so thrilled with the way I felt physically that vanity wasn't a concern.

After the surgery there were some physiotherapy treatments that were hard to do because my centre of gravity had changed – it felt like learning to walk and stand had to be done all over again – not as easy as it might sound. I went for regular physio when I came home and also did exercises at home. The hospital stay itself was not very long. After discharge I went back a week later to have staples removed – not a pleasant experience.

For months after surgery I found myself holding my breath waiting for the pain to kick in with each new thing I tried. It was incredible being pain free after all those years of suffering.

It has been almost four years since the operation & I have had two injections of Botox since then – very small ones but I was starting to have some discomfort. At present I know I will probably try Botox again because I am starting to have retrocollis where my head tips backward as well as turning to the left. At the time of surgery, Dr. Bouvier mentioned that I had a tendency to this and that he would like to perform another procedure at a later date. I really don't

know if I would have another surgery unless the pain came back and then yes, definitely.

Confidence in the doctor and the procedure, love and support of family, friends and fellow Dystonia sufferers, love of life and a firm belief in God – all of these factors contributed to

the success of my surgery.

My advice is "Go For It." The difference it made in my life was amazing. I would not have known how wonderful it could be to feel "normal" again.

I hope by sharing my thoughts and feelings it will encourage others to consider surgery a viable option.

## Nicole Bélanger

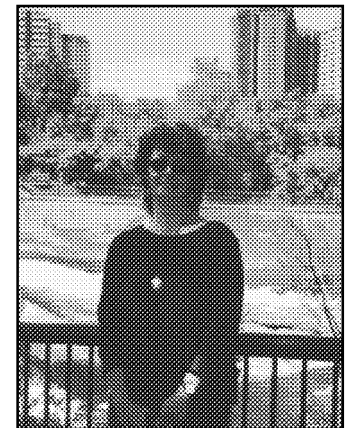
Interviewed by  
Karen Hsu

Hello, my name is Nicole Bélanger and I would like to tell you about my experiences before, during and after my neck operation. It seems like yesterday but it was seven and a half years ago that I decided to go to Montreal to have this operation. It was not an easy decision but I felt that with all the problems I was having it would be worth it.

Prior to going to Montreal I was having a lot of pain with my neck, my head was very heavy because of the ST and I needed to hold my head all the time. Of course this meant that my wrists were constantly sore, plus I could not use my hands when I needed them.

So with some trepidation I proceeded to Montreal. There, Dr. Molina assessed me to see if I was a good candidate. He then turned me over to Dr. Bouvier who performed the operation.

The actual operation lasted six hours during which I did not feel any pain, having been given a local pain-killer. However, since I had a new baby six months prior to the operation, I was not in as good a condition for the operation. Consequently it took me one year to get over the operation, whereas with most people it



only takes one month. In retrospect, they should have told me to wait one year after the baby was born.

To me the biggest advantage of having that operation is that I don't have any pain and I don't have to hold my head up any more. It is quite a big thing for me and now both my hands are free to do anything I want. I paint and I teach painting so this is quite an asset to have.

For people contemplating this operation I look at it this way. I believe there will not be a cure during my lifetime and I would say that it is really worthwhile to have this operation.

Looking back at what I went through and my life today, I would say that the operation literally gave me my life back. It took away most of the pain, and although I still have dystonia, my life is one hundred percent better right now.

## Caregivers' Corner

### Many Sides to Caregiving

By Paul Anderson

Boyd Gainsford has spent the better part of a decade as the caregiver to his wife, Joyce. This has made their marriage of 35 years even stronger. Boyd, 58, describes himself as someone who isn't afraid to help others. He didn't hesitate to change his lifestyle in order to give care.

"I used to go out with the guys. That changed. Now I stay home with the girl," Boyd says with a chuckle.

The Gainsfords live in Carlsbad Springs in a home surrounded by farmland. They have two adult sons who visit with them regularly.

Boyd believes the key to caregiving is patience and trying to understand what the sufferer feels. It's important for Joyce to have Boyd's assistance with many tasks and also his companionship. In a typical day Boyd may perform some light housework such as vacuuming, overlook any cooking Joyce undertakes, and help her put on her boots if they are going out. Most importantly, he spends time with her.

Joyce, 57, was diagnosed with dystonia in 1992. Her arms and face are affected. At times her arms twist uncontrollably. The dystonia also affects

her balance and coordination. She has to be careful and think ahead before performing simple acts. She does nothing spontaneously. Like most sufferers of dystonia, Joyce's symptoms get worse when she's tired, nervous or worried. Consequently, one of Boyd's main duties as a caregiver is to make Joyce's days as stress-free as possible.

Joyce worked as a typist clerk for National Defense for 30 years, but took early retirement in 1997 when performing her job became physically impossible. Due to her abrupt work stoppage and her dystonia, Joyce has suffered bouts of depression, making caregiving more complex for Boyd.

Caregiving is a two-way street for the Gainsfords. A few years ago Boyd injured his back and ribs, when he fell awkwardly while performing his job as a groundskeeper at a golf course. He tore the muscles in his rib cage. The muscle damage caused him to change from a 38-inch waist to a 44 in just over a month. Joyce helped him in his recovery in much the same way as he continues to assist her.

"We need each other... which makes for a healthier environment," says Boyd.

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

push forward with this fund-raising event.

You may feel that the summer that brings a cure for dystonia is a long way off. It might well be, but then again it might arrive sooner than you think. It will arrive early only if everyone like you who are suffering from this terrible

disease believes that a cure is possible, and does something about it. One day you will look out your window, the warm breeze of summer will comfort you; the bright sun will raise your spirits up into the heavens, and your dystonia will have gone out the back door.

## Dystonia Has Been Around

As dystonia becomes known in various circles, there are reports emerging of such and such historical figure, artist and ordinary folks down in history who may have had the movement disorder. Historians who study historical figures make the connection when they hear of the symptoms of dystonia. The following article was published by Reuters on April 9. Dating dystonia back to the Roman Empire is certainly the oldest link I've heard, but there are many other cases recorded.

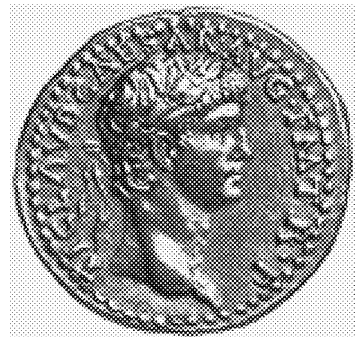
### Muscle Disorder May Be Clue to Claudius' Death

Although foul play has long been suspected in the death of the Roman emperor Claudius, a diagnosis nearly 2,000 years later suggests an underlying movement disorder may have made him vulnerable to poisoning.

Historical writings indicate that Claudius died just hours after a large meal that induced stomach pain and vomiting - and that featured one of his favorite delicacies, mushrooms. Many historians have speculated that Claudius' last wife, Agrippina, poisoned him so that her son Nero would become emperor.

But a new diagnosis, by Dr. William A. Valente of the University of Maryland School of Medicine in Baltimore, adds a twist. Valente suggests that a unique movement disorder rendered him more susceptible to poisoning by mushroom. He makes his diagnosis in the April 1st issue of *The American Journal of Medicine*.

According to Valente, Claudius' documented "nervous tics" of the head, leg weakness, "dragging" of his right foot and other symptoms are suggestive of dystonia, a type of movement disorder marked by prolonged muscle contraction. He suspects that this dystonia - which he dubs the "Claudian Complex" - could have arisen from a neurological abnormality



related to his premature birth.

Moreover, Valente speculates, if the mushrooms served at Claudius' last meal were of the muscarinic variety, the toxin in these mushrooms might have worsened the emperor's muscular contractions and ultimately led to his death. *Amanita muscaria* mushrooms, he notes, were among the ancient Roman favorites. Their toxin alone, however, would likely not have been fatal without some underlying disorder, according to Valente.

Of course, modern-day diagnoses of what killed Claudius are based on "random, anecdotal reminiscences" from antiquity, notes Dr. Richard J. A. Talbert of the department of history at the University of North Carolina, Chapel Hill. "We will never know," he writes in the same report, "if it was poison added by Agrippina that killed Claudius, or if it was 'bad' mushrooms, or just old age and a bout of illness."