



*There is Hope Through*  
**'CONTACT'**

*Printed in the interest of those  
affected by Myasthenia Gravis*  
**"Could It Be MG?"**

Quarterly News

Volume 43 Issue I

February 2019

## 5th Year Anniversary!

Birth of Myasthenia Gravis Canada  
Canada's National MG Patient Advocacy.

*The promise of Love and Hope for all Canadian Snowflakes*

January 2014, the MG Ontario Chapter after 40 years, by unanimous vote of all current executive at that time and endorsed by previous executive unanimously, several years earlier, finally started the process to become Canada's voice for MG patients, MG caregivers and MG medical treatment and research Healthcare Professionals. It was time for us to become a proud Canadian National MG patient voice. It was time for establishing our own identity and to formally establish Myasthenia Gravis Canadian National patient advocacy self-determination.

**With a member couple guarantee for legal fees if we proceeded to proof of completion,** we retained a Toronto Corporate law firm who were willing to proceed to get us national incorporation as a not-for-profit and also registered charity status. Finally, after 40 years as an Ontario regional MG patient group with no legal status, we began the process to become legally recognized, with self-determination and permanent ability to truly be dedicated for and to, all Canadians affected by Myasthenia Gravis.



Our application, submitted for Federal non-profit incorporation as "Myasthenia Gravis Society of Canada", was initially

Cont. on Page 2

## MG Canada Support Meeting

Sunday, March 3, 2019 6-8 pm

See Page 3 For details

*Cont. from Page 1—5th Year Anniversary*

rejected and with it hope for Registered Charity Status. Details of CRA Directors and purposes had to be modified to their satisfaction without compromising our ambitions.

**Over 1 year later we were finally approved for National incorporation as “Myasthenia Gravis Society of Canada” a.k.a. MG Canada and eventually a.k.a. Myasthenia Gravis Canada.**

**The next process to become a Registered Charity was even more challenging.** Finally, we received Registered Charity Status 3 years ago this June. We have come a long way in 5 years + 40 years before. It is a huge leap of service for all Canadians affected by Myasthenia Gravis. In the end our generous donors covered all related expenses – and of course a proper Registered Charity Donation Tax receipt was issued.

In this five-year period our active membership participation has grown substantially, representing many of Canada’s communities in all of Canada’s provinces and territories from Atlantic to Pacific, from Windsor to the Arctic. We have a long way to go but we’ll get there – with all your help, encouragement and support. Thank you all. Together we are strong! Together we serve our Canadian MG brothers and sisters! 24/7.

**Happy 5<sup>th</sup> Birthday, Myasthenia Gravis Canada!**

Cap Cowan, President, CEO  
and Newsletter Editor  
Myasthenia Gravis Society of Canada  
[CapCowan@MGCanada.org](mailto:CapCowan@MGCanada.org)



Betty & Cap Cowan



*A cheque was presented to Wilma J. Koopman, our December meeting speaker. Her message of hope and managing Myasthenia Gravis was very well received. In appreciation, a cheque for the London MG Health Services was presented by Directors Tony Watkins and Aleem Remtulla.*

# Myasthenia Gravis Society of Canada MG Support Meeting

Registration: 5:30—6 pm.

**Sunday, March 3, 2019      6-8 pm**

**“Tell Your Myasthenia Gravis Story”  
and open discussion of issues facing  
the MG Patient.**



**Annual Meeting  
Celebrating 5 years for  
Myasthenia Gravis Society of  
Canada.**

**Support Meeting for those living with Myasthenia Gravis,  
caregivers, family, friends & interested others to meet.**



***Loblaws Community Meeting  
Room, Bayview Village Mall,  
2877 Bayview Avenue, North  
York, M2K 2S3.***

*(Meeting Room is located upstairs, S/W corner  
of the store, Elevator access.) Public Transit  
Access, subway access at Bayview Station on the  
Sheppard Subway. Free Parking,  
Bayview Village Mall.*

***For this meeting, we request those members who are able, with last name  
starting A—L bring a food item to share. Loblaws has  
asked that any food served come from their store.***

**Info at 905 642 2545**

**[www.MGCanada.org](http://www.MGCanada.org)**

## # 94 The Art of Positivity

*It seems to be so easy for people to say keep a positive attitude, but as we all know that isn't always easy to do.*

*How you might ask, do I do this?*

To use an example of one of our fellow snowflakes, “I was so embarrassed when I could not lift the 40 lb bag of dog food out of the shopping cart and I had to ask my 13 year old for help.”

**Maybe we need to make some things “family oriented or family responsibilities”** When we go shopping for things like heavy bags of pet food, take one of our children with us and take the food out of the cart together. Try “okay, on the count of three lift” and put it on the conveyor together. Even better, leave the heavy things in the cart and ask the cashier to scan them in the cart.

**If you are worried about the response of people when your partner carries the heavy bags,** try taking the groceries out to the car in the shopping cart and then others won't notice.

### Being Prepared



**Perhaps you could make meal prep and baking a family affair** with everyone taking part according to their age and abilities. “Okay, Mom or Dad is having a bad day today so if we want cakes or cookies we have to do it together” ...hopefully it works.....

**For those absolutely rude people who challenge you on using a disabled spot, why not invite them to walk with you for 15 or 30 minutes** (whatever your limit is) and maybe then they will understand why you are using these spots.

Just before Christmas I had an experience where I stumbled on the stairs in Union Station in Toronto, Ont. A young man behind me who was in a hurry uttered the comment “Oh, another senior who can't hold their liquor.” I was mortified at the time but this won't happen again as **I will take the elevator and avoid those staircases.**

**We need to try and have some responses in store to curb the degree of humiliation and upset we suffer at times like this.** If the other person does not seem to be pacified with our response

Cont. on Page 5

## Cont. from Page 4 - The Art of Positivity

then we need to just let it go and continue on. It is not worth the effect the upset will have on our system if we let it.

**Before undertaking an activity, I try and think how I can respond in a positive way if “things” do not go well.**

**As we all know, life really is fragile, try and prepare ahead of time how you think you may respond.**

*Blog submitted by an MG Snowflake who wished to remain anonymous.*

## “Could It Be MG?” ©

*(Slogan of MG Canada initiated in 2016  
and launched at World Congress on Neuro  
Muscular Research, Toronto, July 2016)*



Article from Myasthenia Gravis Foundation of Illinois a.k.a. ‘Conquer Myasthenia Gravis’ found on their web site reproduced by reciprocal permission understanding. In addition are excerpts from the Mayo Clinic on diagnosis procedures and some current treatments for our May issue.

**Myasthenia Gravis (MG) can be difficult to diagnose** because weakness is a common symptom of many disorders. Add to this the fact that symptoms may be vague, fluctuate or only affect certain muscles. And MG doesn’t “perform” on demand; the eyelid that droops at 7 p.m. may not show for a 9 a.m. doctor appointment. Identification may be complicated further when more than one autoimmune disorder is involved. It’s not unusual for Myasthenia Gravis Diagnosis to be delayed – sometimes up to two years, *(much longer or never- often mis-diagnosed and often symptom treated without diagnosis such as ‘stitching up drooping eyebrow’ surgical procedure.)*

### **These steps may be taken to confirm a diagnosis of MG:**

**Neurological exam:** This may include testing your reflexes, muscle strength, muscle tone, senses of touch and sight, gait, posture, coordination, balance and mental skills. Impaired eye movement or muscle weakness may prompt a doctor to evaluate further.

**Blood tests to measure myasthenic antibodies in the blood:** About 80 to 85 percent of MG patients test positive for AChR antibodies – antibodies to the acetylcholine receptor – in their blood. A positive

Cont. on Page 6



Cont. from P. 5 **Could It Be MG?**

antibody supports the diagnosis of MG, but a higher number or titer of this antibody does not correlate with more severe disease. Another 5 to 10 percent are found to have antibodies to muscle-specific serum kinase (MuSK), a protein that helps organize ACh receptors on the muscle cell surface. This antibody also can be tested for in the blood. A blood test for the LRP4 antibody is not yet commercially available. Some MG patients have normal antibody levels, especially with the restricted ocular form of MG.

**Ice Test:** Cooling of muscles affected by MG may transiently improve weakness. This test is simple and easily performed on a droopy eyelid, often helping to confirm a diagnosis of MG.

**Edrophonium Test:** A short-acting drug called edrophonium chloride (Tensilon®) is given intravenously. If weakness, especially in the eye muscles, briefly and temporarily improves, it indicates you may have MG. The drug does this by blocking an enzyme that breaks down acetylcholine, the chemical that transmits signals from nerve endings to muscles. A trial use of oral pyridostigmine bromide (Mestinon) is an alternative approach.

**Nerve conduction studies/repetitive nerve stimulation:** A small electrical impulse is applied to a nerve resulting in muscle contraction. Muscles in patients with MG fatigue easily and don't bounce back from repeated stimulation as well as those of a healthy person.

**Single fiber electromyography (EMG):** A sterile needle electrode is inserted into a muscle which the patient gently contracts or activates. Computer analysis of several recorded electrical signals in that muscle may show abnormal neuromuscular transmission, found in MG as well as some other neuromuscular disorders.

**Imaging:** Computed tomography (CT) or magnetic resonance imaging (MRI) is often done to identify an abnormal thymus gland or a thymus gland tumor (thymoma).

*(There is no one foolproof method of diagnosis for MG. Sometimes test results are inconclusive, even when your examination and story seem to point to a diagnosis of the disease. If this happens, it may be appropriate to track symptoms and repeat testing over time until your diagnosis can be clarified.)*

**This information was abstracted from these sources:** [The Myasthenia Gravis Fact Sheet](#) published by the National Institute of Neurological Disorders (updated February 19, 2016) and retrieved April 27, 2016.

Reviewed by the Conquer MG Medical Advisory Board, April 2016. Unless otherwise stated, the information provided here is of a general nature, composed by non-medical personnel. It is meant to be accurate and helpful advice for MG patients. It is not intended to be medical opinion, nor is it a substitute for personal professional medical care.

Found on Web site <https://www.myastheniagravis.org/about-mg/diagnosis/>

# Total Frustration

## Recent Blog on the Current Frustrations of Sero Negative MG Diagnosis by a Myasthenia Gravis Canada Support Group Facebook Participant.

### **“An informational post about Seronegative Myasthenia Gravis.”**

This is something I am passionate about spreading awareness about, as it has been so difficult for me to receive a diagnosis and now treatment... as many of you have witnessed.

**Yes, I tested negative to AChR as well as the MuSK blood test. Yes, I have Myasthenia Gravis.** 80% of the people with MG test positive to the AChR blood test. The other 20% who test negative, and show clear signs of MG, are possibly Seronegative Myasthenia Gravis. 40% of those who have Seronegative MG will test positive for MuSK antibodies (Study is being done for free at UBC if interested), and the others have antibodies not yet discovered. The newest antibody found as a possible cause for MG is the LRP4 antibody (Study being done in Georgia, Oxford, and Sweden if interested).

**Those who are suspected for MG but test negative to the blood work, often test positive** in the nerve studies such as EMG, RNS, and SFEMG. SFEMG is 98% accurate for aiding in the diagnosis of MG, but 2% still test negative even though they are MG positive. It is also only as good as the doctor performing the SFEMG. Response to medications is often used as an aid in diagnosing Seronegative MG as well. Often at the end of the day, Myasthenia Gravis is a clinical diagnosis until the antibodies that are causing the MG are found, or the right diagnostic tests are performed.

**So many patients like myself, (600 of us now in the Seronegative MG Facebook group)** are often denied life saving treatments due to doctors not being knowledgeable in Seronegative MG. They assume AChR is the only test. This is quite worse in Canada.

**Yes, there are lots of great neurologists who treat MG. No, there are not lots of great neurologists who treat Seronegative MG.**



I flew to Florida (like so many of us SNMG patients do) to be diagnosed by a top specialist who is on the board of the MGFA. Cont. on P. 8

Cont. from P. 7 - **Here's a Recent Blog**

**Yes, it was a clinical Diagnosis until I was able to receive the LRP4 blood test and SFEMG here. His words were "I would have to research a symptom of MG that you DON'T have, there is nothing else this could be."** I was sent home with a treatment plan. I have had no doctors willing to treat me due to a negative AChR and MuSK blood test, even while going to the hospital on the verge of crisis.

**Yes, I tested negative for the blood work (So far), and yes, I have Myasthenia Gravis.**

I have lots of research for anyone requesting."

<http://myasthenia.org/WhatisMG/TestDiagnosticmethods.aspx>

<https://www.facebook.com/groups/785255948165687/>



**Celebrate Spring!**

## **Difficult Journey**

### **My Journey with Myasthenia Gravis by Tony Watkins**

A diagnosis of Myasthenia Gravis has taken many years to be finalized. My journey covered many stages: initial symptoms, medical issues, and the final diagnostic phase. Some symptoms were evident in late December (2007) which included double vision, drooping right eye lid, and difficulty in swallowing. I was finally diagnosed in January 2014 by Dr. Hans Katzberg.

**Initial Symptoms:** Droopy eye lid, shortness of breath, difficulty with breathing, problem with swallowing, fatigue, moodiness, not feeling 100%

#### **Medical Issues**

**2008 (April)** Surgery for a prolactin pituitary adenoma. I was hospitalized for removal of the tumor at the Trillium hospital. Unfortunately complications followed after the surgery.

**2009.** Prolactinoma resection at Trillium Hospital

**2010-** Swallowing reflux not functioning normally

**2011- 2012** Swallowing problems, choking problems, and breathing problems are significantly worse.

Cont. on P. 9



**Continued from P 8 - My Journey by Tony Watkins**

**2012** - The prolactinoma adenoma on the pituitary showed a recurrence. This time medical management was provided.

**2012-2013 (March-April)** I was hospitalized in the Toronto Western Hospital with aspiration pneumonia. Further testing indicated that the upper esophageal sphincter muscle was extremely weak. I also received Botox treatment for my throat for my swallowing problem. It helped for about 2 weeks. Little did I know, Botox is not recommended for Myasthenia patients.

**May (2013)** I had a repeat episode of aspiration pneumonia. With further consultation it was decided to insert a G - J feeding tube, to prevent further aspiration pneumonia episodes.

**2013 (June – July)** I was hospitalized at the Toronto Western Hospital for severe aspiration pneumonia. With this serious condition, I was incubated and admitted to the ICU unit for breathing support.

**2013 (July - August)** I was hospitalized at the North York General Hospital with bilateral vocal cord paralysis. The surgeon performed a cricopharyngeal myotomy and inserted a breathing tube.

**2013 (September)** I was hospitalized at the Toronto Western Hospital for a repeated episode of aspiration pneumonia. Some of the problems were related to blockages in the feeding tube.

**2013** - The feeding tube was exchanged for a different type during 2013 but my issue with blockages continued.

**2013 (October November-December)** Due to many bouts with pneumonia and feeding tube problems, my weakened condition required a 3 month stay at Bridgepoint. In this weakened state, I experienced severe muscle weakness, eye drooping, weakness in the extremities, and coughing large amounts of phlegm.

**2013 (December)** My condition was definitely deteriorating! I was exhibiting shortness of breath, decreased oxygen saturation levels, increased respiratory secretions, and many choking episodes.



Continued on Page 10

Continued from Page 9 - My Journey with Myasthenia Gravis

## MG Diagnosis Final Stage

My journey as an MG patient was very complicated and required vigilant reporting of my ongoing symptoms. MG effected my eyes (double vision) breathing and ability to swallow.

**January 2014** I was finally diagnosed with Myasthenia Gravis by Dr. Hans Katzberg. I was sent to T W H where I went into an M G crisis resulting in 4-5 month stay in I C U requiring breathing supplementation and oxygen support. After this, I was sent back to Bridgepoint Rehab Centre.

**In 2015 and 2016** I was once again admitted to T W H with complications from pneumonia. The feeding tube had perforated my upper intestine resulting in 3 operations. I finished my journey with a 3 month stay at the Bickel Centre.

My journey was long, tedious and at times stressful, but I have to thank Dr. Hans Katzberg and his staff for the final diagnosis of MG.

**Thanks to:** Catherine and my family

**Most importantly** I have to thank my partner of almost 35 years Catherine for her caring and unwavering support during this most difficult time. Without Catherine, and visits from family I might not be here today, writing about my journey with Myasthenia Gravis.

**Tony F Watkins**



*The message is "Hope".*

*Aleem Remtulla won this heart shaped stone donated by speaker Wilma J. Koopman of London MG Health Services Network at our December Support Meeting. Aleem is a Myasthenia Gravis Director.*

*It's a Fact!  
If we didn't  
have our  
crazy  
weather, how  
would  
Canadians  
start a  
conversation?*

**Thank You for the Support**  
Myasthenia Gravis Society of Canada has  
received from “Celebration of Life”  
Memorium gifts, Memberships, Donations &  
MG Fit pledges.

All gifts help to realize the goals of Myasthenia Gravis  
Society of Canada

- To help those with Myasthenia Gravis,  
a chronic condition.
  - To educate caregivers, family, public &  
Healthcare Professionals.
  - To encourage research into cause and cure for MG.
- Your support is greatly appreciated.

*Donations can be mailed to*

*Myasthenia Gravis Society of Canada,*

*247 Harold Avenue, Stouffville, Ontario, L4A 1C2.*

*Or donate online at [www.MGCanada.org](http://www.MGCanada.org)*

905 642 2545

Registered Charity#81155 1431 RR0001

**“In Remembrance” Donations Received**

Marguerite Marie “Margie” Hatt

Peter Nightingale

Elizabeth Strathlee

Sally Weisfeld

Mary Perry

Robert Donald Duffy

Maureen Sheane

Catherine Marguerite (Tillie) McDonald

Norma Duffy

Alma Myer

Barbara Smith

Lucien St. Martin

Maria Orfanos



# Looking to Connect With Others Dealing with Myasthenia Gravis?

## Connect by Phone:

**BY PHONE: MG Peer Support Group.** *Whether you have recently received the news that you have Myasthenia Gravis, or you have been living with MG and want to share your experience, these members have offered their support. Please feel free to contact them to discuss your experience.*

### **Ages under 40**

**Tiina Elder**, Mississauga. 905-565-5875

email: tiina.stuart@gmail.com

**Jill Thomson**, Calgary, AB. T2J 0V6 403-286-0056

### **Ages 41 - 60**

**Phillip Sanderson**, Harriston, ON, N0G 1Z0. 519-338-3356

### **Ages Over 61**

**Florence Pye**, Carleton Place, ON, K7C 1P8. 613-257-1847

**Vikki LeDez**, Sunderland, ON, L0C 1H0 705-357-0377

email: vledez@yahoo.ca

**Fernanda Nascimento**, St. Catherines, ON. 905-937-9762

**Pat Griffiths**, Ottawa, Ontario. 613-237-1649

## Connect by Facebook

### **Interested In Joining the Myasthenia Gravis Canada Facebook Support Group?**

On Facebook, you can connect with others affected by Myasthenia Gravis through the Myasthenia Gravis Canada Facebook Support Group page, another way to learn more through discussion, posting and comments. Use this URL:

<https://www.facebook.com/groups/1380379838949713/> and link text is Myasthenia Gravis Support Canada.

# MF Fit Is Your National Fundraising Campaign

## Donor Form “I am \$tepping Up for MG Fit!”



Name: \_\_\_\_\_

Address: \_\_\_\_\_

City \_\_\_\_\_ Prov. \_\_\_\_\_ P. C. \_\_\_\_\_

Phone \_\_\_\_\_

Email: \_\_\_\_\_

**I support MG Fit by donating:** (Please select one)

\_\_\_ 1,000 steps = \$10

\_\_\_ 2,000 steps = \$20

\_\_\_ 5,000 steps = \$50

\_\_\_ 10,000 steps = \$100 Silver

\_\_\_ 50,000 steps = \$500 Gold

\_\_\_ 100,000 steps = \$1,000 Platinum

Please indicate \_\_\_ Online donation \_\_\_ Cheque donation

For online donations please go to

[www.MGCanada.org](http://www.MGCanada.org)

*online donations will receive an automatic receipt*

For cheque donations please write cheque and mail to:

**Myasthenia Gravis Society of Canada**

**247 Harold Avenue, Stouffville, On., L4A 1C1**

**Further information Email [Give@MGCanada.org](mailto:Give@MGCanada.org)**

**Or call 905 642 2545 or [www.MGCanada.org](http://www.MGCanada.org)**

Myasthenia Gravis Society of Canada

is registered charity #81155 1431 RR0001.

Tax Receipts for donations of \$10 and over

are issued unless otherwise specified.



# Shawn Wins Gold!

At Parasport Ontario “My Team and I got the gold medal and we won all 4 games we played. ... So many people asked me how it felt when we won in the 8th end with my awesome sweeping to keep the rock from curling for our takeout and I was scared when I saw the rock curling off our line. However, I managed to correct it perfectly and I said “Man it feels so surreal” and they said **“Wait till they put the medal on you and it will sure feel real” and it did!** It was worth every blister on my hand as I didn’t have curling gloves and getting up at 5:30 am in the last three days as I am so not a morning person.” (At Oshawa Curling Club, Durham Region.)



Opening Ceremonies



Shawn Creelman With His Team



Shawn & Metal

## Toronto Globe and Mail Article Published February 12, 2019 on Toronto Researchers Who Have Discovered How Immune Cells Use Neurochemicals to Fight Infection and the Role of Acetylcholine

A brief review of Ivan Semeniuk’s article in the Globe and Mail reveals encouraging progress. Myasthenia Gravis Canada encourages a more in depth look at this research in future.

... “scientists have wondered why blood cells that are crucial to the body’s defences against infection also produce a molecule that is better known for its role in conducting signals within the brain.” ... “researchers at the Princess Margaret Cancer Centre in Toronto think they’ve found the answer: **The molecule, called acetylcholine, is used by immune cells to trigger a chemical chain reaction that loosens blood vessels, opening a doorway into infected tissues.**”... “it speaks to an emerging connection between the nervous system and the immune system.” ...**“It tells us why [acetylcholine] may be involved in so many important chronic diseases,”**

Currently this research is done using mice. More work is needed for human body’s immune response to chronic infections. We will follow up on this in the future.

# Notes for MG from the Mayo Clinic to Help Cope with MG

## Lifestyle and home remedies

(especially in the early days of MG Diagnosis Treatment.)

Supplementing your medical care with these approaches may help you make the most of your energy and cope with the symptoms of Myasthenia Gravis:

- **Adjust your eating routine.** Try to eat when you have good muscle strength. Take your time chewing your food, and take a break between bites of food. Small meals eaten several times a day may be easier to handle. Also, try eating mainly soft foods and avoid foods that require more chewing, such as raw fruits or vegetables.
- **Use safety precautions at home.** Install grab bars or railings in places where you may need support, such as next to the bathtub or next to steps. Keep your floors clean, and move any loose rugs out of areas where you may walk. Outside your home, keep paths, sidewalks and driveways cleared of leaves, snow and other potential debris that could cause you to stumble.
- **Use electric appliances and power tools.** You may lose energy quickly when conducting tasks. Try using an electric toothbrush, electric can openers and other electrical tools to perform tasks when possible.
- **Wear an eye patch.** Consider wearing an eye patch if you have double vision, as this can help relieve the problem. Try wearing the eye patch while you write, read or watch television. Periodically switch the eye patch to the other eye to help reduce eyestrain.
- **Plan.** If you have chores, shopping or errands to do, plan the activity to coincide with the time at which you have the most energy. Also, try to reduce extra walking in your house when working on projects, as it may reduce your energy.

## Coping and support

For people with Myasthenia Gravis and their family members, coping with the disease may be difficult.

If you have Myasthenia Gravis, find ways to relax. Stress may worsen your condition.

Cont. on Page 16

## Continued from Page 15 - MG Patient Coping & Support

Also, ask for help with tasks if you need it. Your family and friends may be able to assist you with tasks that are difficult.

If you're a family member of someone with myasthenia gravis, try to be understanding of your loved one's emotions as he or she adjusts to the condition. Read about Myasthenia Gravis and learn about what your family member is experiencing.

You and your family members may benefit from participating in a support group. A support group may offer a place for you to meet people who understand what you and your family members are going through.

Suggestions as outlined by The Mayo Clinic.

## Myasthenia Gravis Events

### Coming Up!

**Myasthenia Gravis Society of Canada Support Meeting, Sunday, March 3, 2019**, Loblaws Community Meeting Room, Bayview Village Mall, 2877 Bayview Village Mall, North York, M2K 2S3. 6-8 p.m.  
Info: 905 642 2545 [www.MGCanada.org](http://www.MGCanada.org) for more information.

**The Myasthenia Gravis Association of BC** hosts Support Group Meetings twice a year.. Contact Information email: [MyastheniaGravis@bc-cfa.org](mailto:MyastheniaGravis@bc-cfa.org) or call 604 451 5511 for 2019 dates.

**MG Victoria Support Group**, Monthly Meetings.  
Email: [shipeleys@shaw.ca](mailto:shipeleys@shaw.ca).

MG Canada's Newsletter "Contact" is published by

**Myasthenia Gravis Society of Canada**

c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2

Phone 905 642 2545 [www.MGCanada.org](http://www.MGCanada.org)

**Do you have an MG article of interest to  
"Contact"?**

Please forward to [CapCowan@MGCanada.org](mailto:CapCowan@MGCanada.org)

*Articles in the Myasthenia Gravis Society of Canada Newsletter express the views of the author and are for information only, not medical advice. Patients should consult with their physicians for medical treatment.*



# Myasthenia Gravis Society of Canada

## New/Renew Your MG Canada

### MEMBERSHIP APPLICATION

Date \_\_\_\_\_ New Member \_\_\_\_\_ Renewal \_\_\_\_\_

Last Name \_\_\_\_\_ Male \_\_\_\_\_ Female \_\_\_\_\_

First Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

Address (Include Suite #) \_\_\_\_\_

City \_\_\_\_\_ Postal Code \_\_\_\_\_

Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Cell Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Name of Spouse, Partner or Significant Other (Optional)  
\_\_\_\_\_

E-mail Address \_\_\_\_\_ @ \_\_\_\_\_

In order to reduce postage costs I would like to receive the quarterly newsletter "Contact" via e-mail, rather than by regular mail: Yes \_\_\_\_\_ No \_\_\_\_\_

Would you like us to call you? Yes \_\_\_\_\_ No \_\_\_\_\_

**For "Myasthenics Only" and for statistical purposes (held in strictest confidence):**

My Neurologist is Dr. \_\_\_\_\_

Neurologist's Telephone No. \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

**ANNUAL MEMBERSHIP FEE**

\$ 20.00 + \$2.60 HST = \$ 22.60 \$ \_\_\_\_\_ (12 months – Individual or Family)

**or** \$ 50.00 + \$ 6.50 HST = \$ 56.50 \$ \_\_\_\_\_ (36 months – Individual or Family)

Donation \$ \_\_\_\_\_ (optional)

Total \$ \_\_\_\_\_

***Please complete as much of the form as possible.***

***All information will be kept in the strictest confidence.***

*It is important to keep your membership and record of information up to date and accurate each year. Please advise any changes during your renewal period.*

**Questions or Changes?** Call 905 642 2545 or e-mail to [membership@MGCanada.org](mailto:membership@MGCanada.org)

Mail completed form and payment to:

**Membership Coordinator – Myasthenia Gravis Society of Canada**

**c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2.**

## Myasthenia Gravis Canada Support Group Recent Comments

### **“For those that have had Plasma exchange. How did you feel afterwards?”**

*Comments: “I used to get it once a week... it never made me feel better but I didn't feel worse- my neuro felt it held me steady to allow other meds to work... never had problems or side effects besides having trouble waiting to pee”. “It was very effective for my husband's symptoms and he has said that he felt stronger physically after each treatment. The treatment was a little tiring but the great effects made it worth it for him. He is now on Prednisone and Mestinon & doing well 5 months post treatments. The Dr. is pleased and is going to slowly start weaning him off his Prednisone this month.”*

**“Re MGFA Atlanta Patient Education conference March 30-April 2.** I'm overdue to go to an informative MG Education conference. A lot of changes in a very short time. Example: Self Administered IVIG no longer just a trial... Would be awesome to have a Canadian team there. From Toronto, Ontario it's about 1500 km each way to drive Atlanta. 16 hours nonstop. I have a mini van that can handle up to 7. If we had a few from TO it might save a bit. Share rooms. We might also be able to do a group discount deal? A team approach strategy could cover all the speakers and workshops. Maybe even video blog reports from there?” *Comment: “I've already booked my flights and Via to Toronto (on points and Black Friday deals). Would love to have a Canadian contingent! Many direct flights Toronto to Atlanta every day if that helps.”*

**“Travelling in New Zealand, so far so good.** The Mestinon was discontinued before we left and Dave's vision so far is holding, which is a good thing as double vision would not be good on these narrow windy roads in the motor home! I am thankful for the moments with every beach we walk on, we don't know the future so we revel in the present!” *Comment: “That's amazing for you and your family. You're right, relish the good days because you never know (for any of us, not just us with MG) how many you will have. I'd love to see New Zealand some day. It sounds amazing! Enjoy!!!”*



c/o 247 Harold Ave.,  
Stouffville, Ontario,  
L4A 1C2