



There is Hope Through
‘CONTACT’

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

Quarterly News

Volume 43 Issue II

May 2019

June is Myasthenia Gravis Awareness Month in Canada

Many positive MG patients are generating activities to spread the word about Myasthenia Gravis in June. For the second year in Canada, June is Myasthenia Gravis Awareness Month. Myasthenia Gravis Canada’s goal is to advance MG education many ways: Seminars, support groups, walkathons, literature, other multi-media communications, social media articles and much more. Listed below are events happening this June to help spread the word!

**•Ottawa Support Group Meeting:
New Myasthenia Gravis Canada Support Group**
Sunday, May 26, from 3 pm to 5 pm *(Details on page 2)*



**• MG Canada Support
Meeting—**
Toronto Sunday, June 9, 2019
6-8 pm *(Details on page 3)*

**• 2nd Annual MG Canada
Walkathon in Courtney, BC**
Sunday, June 15, 2019
(Details on Page 2)

Continued on Page 2 & 3

Cont. from Page 1—Celebrating June as MG Awareness Month

New Myasthenia Gravis Canada MG Support Group Meeting Being Started in Ottawa

Support Meeting for those living with Myasthenia Gravis.
Meet caregivers, family, friends, interested others.

**First Meeting in Ottawa for new area
Myasthenia Gravis Canada Support Group
Sunday, May 26, from 3 pm to 5 pm
Greenboro Community Centre, Meeting Room A
363 Lorry Greenberg Drive,
Ottawa, ON, K1T 2R5**

**Contact Pat Griffiths.
Email: patgriffiths@rogers.com**

2nd Annual Courtney B.C. MG Canada Walkathon



**Courtney B.C. MG Canada
Walkathon
Sign Up for 2019!**

In 2018, Linda MacMullen and Jude Angione successfully ran a walkathon in Courtenay, B.C., which raised funds for the Myasthenia Gravis Society of Canada, as well as generating much publicity, getting the word out about Myasthenia Gravis. Linda has just announced the 2nd Annual Courtney MG Canada Walkathon will be held Sunday, June 16th, 2019. Contact Linda MacMullen at l.macmullen@shaw.ca

**Myasthenia Gravis Society of Canada
Toronto Area**

Support Meeting

Registration: 5:30—6 pm.

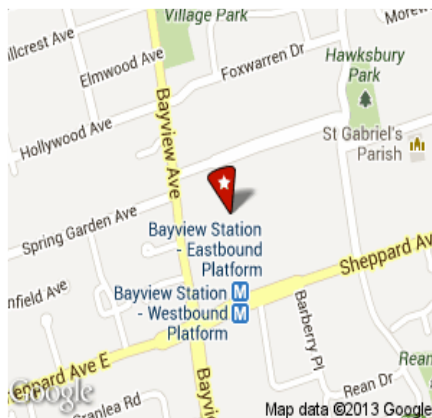
Sunday, June 9, 2019 6:00-8:00 pm

**Speaker Dr. James Scholey
Specialist, Internal &
Kidney Medicine.**

Toronto General Hospital, University Health Network

**“Effects of MG Prescription Drugs on
Internal Organs”**

Support Meeting for those living with Myasthenia Gravis,
Meet caregivers, family, friends, interested others.



***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,*

*For this meeting, we request those members who are able, with last name
starting M-Z 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

MG Newsletter Editorial May 2019. **Headline:** **“Finally, after 60 years. Promising new, original, MG research for treatment & cure!”**

NEW! Promising MG research for cure. For 60 years or more, Mestinon has been the only MG prescription product with full medical consensus. In the past 60 years, MG treatments have relied on products developed for more widely affected disease groups. Immune suppressants for organ transplant. IVIG for a wide variety of auto immune. Few products specifically for Myasthenia Gravis treatment have been developed since - until now.

Several Pharmaceutical companies have been in biological research development, and are now actively testing specific Myasthenia Gravis treatments – and results are very promising. New names like argenx, Alexion, UCB, Ra Pharma, CSI Pharmacy, Momenta are in multi stage patient tests. Some new products are already approved by FDA and Health Canada.

The good news is these new products are specifically for Myasthenia Gravis. However - the results and challenges of becoming mainstream products to help MG patients will be enormous – and not just about hard research costs.

Much larger patient sampling group sizes are needed to deepen validity of patient study test results. Instead of 15 to 50 per test study – rather 100 to 200 or more.



Spring Hope in the Garden

It is time to consider what we as Canada’s MG patient advocacy can do to help. Consider a few options. 1) Perhaps there is a need for a confidential “Myasthenia Gravis Canada Patient Registry”. 2) Perhaps there is a way to identify willing MG patients from different parts of Canada by creating a collaboration of MG treatment Health Professionals to support a larger patient participation than just their own MG patients. 3) Perhaps there are ways to create an MG patient and professional MG Researcher entity that retains patient

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Continued from P 4 - Editorial

For sure it is paramount that a much larger number of willing MG Patients support MG researchers. We are a geographically huge country. To offer the broadest universe of participants without geographic location limitations, requires our uniquely patient centric advocacy confidentiality to further minimize research bias. Can it be done? Yes. Are there benchmarks? Do we have the will to do it? It will depend on MG Canada member's and affiliate stakeholder's support, endorsement and funding to create – and sustain.

Myasthenia Gravis Canada is now Canada's established MG patient advocacy – exclusively dedicated to Myasthenia Gravis. We can be part of our own solutions for MG patient treatment and cure by making sure adequate research is done, and not delayed because of inadequate MG patient research. We can also vigilantly pursue fundraising.

We encourage this to happen. That's what Myasthenia Gravis Canada is partly about.



Cap Cowan, President, CEO and Newsletter Editor

Myasthenia Gravis Society of Canada

CapCowan@MGCanada.org



*“Then followed that beautiful season...Summer...
Filled was the air with a dreamy and magical light, and the landscape
Lay as if new created in all the freshness of childhood.”*

Henry Wadsworth Longfellow

• **First Annual Myasthenia Gravis Awareness Walk.**

St. Peters Road, St. Peters Bay, PEI.

Saturday, June 15th. 1:30—4:00 pm

St. Peters Road, St. Peters Bay, PEI

<https://www.facebook.com/events/412863779443565/?ti=ia>

An Incredible Journey from Crisis to Diagnosis

By Mary McCaw

It was a Saturday afternoon at the beginning of March in 2015 and I was on my way to a friend's birthday party near Trenton. I stopped in Colborne for a bagel and to my surprise I had a lot of trouble chewing and swallowing it. I mentioned this at the party where three nurses were in attendance. They kept an eye on me and at one point administered an epi pen thinking I might be having a reaction to something I'd eaten. My wine was even taken away from me!

Later, it was decided that I should be taken to Emergency at Trenton Hospital. I have no memory at all of being treated but what I do remember has become a gem in the events that followed. A young man in an EMT uniform came over to me, introduced himself and said that I had taught him grade 9 French at Clarke High School.



Mary McCaw out celebrating her Birthday.

I have no recollection of being treated, but was told they took x-rays of my chest which were inconclusive and had another epi pen injection. I didn't try to drive home and I remember little of the evening. The next morning, I insisted on driving myself to Emergency at the Northumberland Hills hospital in Cobourg. I told myself to stay in the outside lane and not speed. I remember circling the hospital trying to find the emergency entrance, parking my car and picking up the phone stating that my emergency was that I was choking and couldn't breathe. My brother rushed in and I gave him my jewelry and purse. The rest is a blank.

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Cont. from Page 6 - An Incredible Journey

The next ten days were spent in a coma and during that time I was intubated twice. I had aspiration pneumonia in both lungs. I have a very clear memory of my near death experience. There were nine bas reliefs of young Greek or Roman men in loin cloths on a wall of a cave. I was one of them! We were animated and told to fight hand to hand combat until only one was left standing. I fought so hard until there were only two of us. I prayed to die because I just couldn't fight any more. Then there was a light and I was brought up to the surface to be with my family and friends again.

I learned that after about five days in Cobourg, I was taken by ambulance to Peterborough where there was a larger hospital and



hopefully doctors who would know what to do with me. I continued to be in ICU for another five days in a coma. It was St. Patrick's Day when I woke up because my cousin brought me a shamrock scarf. I was stunned, having no idea what had happened to me. **I had lost a lot of motor skills.** They brought me chocolate pudding to learn to use a spoon again! I did crosswords to practise printing

At this time, the young EMT from Trenton popped in to see how I was and to tell me he had been part of the team that brought me to Peterborough. Once I didn't need to be in ICU any more, I was again taken by ambulance to Lakeridge Health Oshawa, my home hospital. Many tests were done, CT scans and MRI's. An ENT doctor was called in to see if I wasn't able to speak or swallow much because of damage done when I was intubated. I had a dietician and a speech pathologist. After less than two weeks, I was sent home.

During the next days I saw my family doctor who was quite unhappy that I hadn't been seen by a neurologist. By the end of the week, I couldn't even swallow a drop of water. On the Monday, I saw a speech pathologist at the Whitby rehab hospital. She took one look at me and said I had to be back in the hospital. She called the speech pathologist who had seen me there and my doctor who must have called local neurologists because I was seen by one within a couple of hours in Emergency. He did tests and eventually blood work was sent

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Cont. from P. 7 **An Incredible Journey**

to a lab in Toronto to confirm his suspicions of Myasthenia Gravis. I started taking mestinon and prednisone.

Over the next month, I watched Spring arrive from my ninth floor window which overlooked the city and Lake Ontario. This time I had a feeding tube through my nose so eating wasn't an issue. I was quite independent and even allowed to drag my pole over to the adjoining park to read and enjoy the sunshine. Therapists helped me with speaking and swallowing. Getting down a teaspoon of yogurt or pudding without choking was a triumph! I would write down on a pad of paper my end of a conversation.

Eventually, they wanted my bed and my neurologist said there was no reason why I couldn't continue at home. I wasn't so sure and was quite apprehensive. A tube was inserted in my abdomen to continue with tube feeding on my own. I'd have to grind and dilute my pills and insert the mixture into my tube with a syringe. It was arranged for me to have a nurse, dietician and speech pathologist come to my house. I'd look forward to visits from my cute male nurse! I had appointments again with a speech pathologist and over time started being able to swallow soft foods and happily added solids.

By the end of July, I had recovered enough to have the tube removed and I was on my own. Research online discovered that there was an expert in MG at Toronto General by the name of Dr. Vera Brill. I asked for a referral and have been seeing her every six months for four years. Medications have been reduced and I feel I am leading a pretty normal life. Fatigue is normal, but I feel very fortunate.

Mary McCaw, Courtice, ON



MG Society of Canada Director Tony Watkins thanks Dr. Carolina Tapia-Barnet for her attendance at the Myasthenia Gravis Society of Canada Support Meeting and for her presentation on the Patient Well Being Assessment Study. Dr. Tapia-Barnet is with the University Health Network at Toronto General Hospital.

Looking to Connect With Others Dealing with Myasthenia Gravis?

Prefer to talk to a real person?
Connect 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.

Tiina Elder, Mississauga. 905-565-5875

email: tiina.stuart@bell.net

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

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

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

Prefer “online life”? Try 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.

For The Record: We're Proud to Say Myasthenia Gravis Canada Support Groups are run by dedicated and enthusiastic MG patient volunteers.

For the record: We are Myasthenia Gravis Society of Canada and Myasthenia Gravis Canada Facebook Support Group. Myasthenia Gravis Society of Canada is Canada's only legitimate Federally Incorporated, Registered Charity, National MG patient advocacy. We serve Myasthenia Gravis patients in all of Canada's provinces and territories. No other Canadian MG patient advocacy organization serves every province and territory in Canada.

Even though we'll soon be 6 years old as MG Canada, we were previously MG Ontario Chapter of MDC for over 40 years. The decision to become National and independent as MG Canada, was based on the need for Canadian MG patient advocacy self determination, rather than being under the umbrella of Muscular Dystrophy Canada. Our Myasthenia Gravis Canada Facebook support Group will be 3 years old this June.

We are Myasthenia Gravis Society of Canada, (not just an Ontario chapter), our nation's equivalent in every way to the American MGFA, with which we have a friendly association. We are a completely separate independent entity – and it's very important to keep it that way. Mutually cooperative. Yes. Totally separate entity and administration. Yes

Unlike many other Facebook groups, we deliberately keep ours almost fully private by insisting on prequalifying to join and a fair but firm code of conduct. Myasthenia Gravis Canada Facebook Support group runs on mutual trust and good faith. **It is all our best interests to make sure our Canadian National status continues to fight for all MG Canadian patients, and sensitizes our unique Canadian universal health care system**

Soon then. Cap Cowan, President, Myasthenia Gravis Canada,
CapCowan@MGCanada.org



Smooth Summer Sailing!

Better Breathing Through Technology

From Conquer MG's Fall 2018 Patient Seminar presentation
by Sally O'Meara, RN

Myasthenia gravis can sometimes weaken diaphragm muscles and affect a person's ability to breathe; in November, 2018, Sally O'Meara, RN and nurse educator, described how technology can help one cope. .

Read the Signs

When MG affects respiratory muscles, it can cause acute respiratory failure (or an "MG crisis"). You also might have an ongoing problem with breathing (or **chronic respiratory failure**). If you can't swallow easily, food and liquids can go down your airway and get in the lungs, leading to **aspiration pneumonia**. And breathing issues related to **sleep disorders** (sleep apnea) are not unusual with MG patients.

These signs indicate MG is affecting your breathing:

- Shortness of breath with activity or rest
- Inability to breathe when laying flat
- Pausing to take a breath after every few words
- Single breath count less than 25
 - Take a deep breath in, count out loud as quickly as you can – saying each syllable of each number - while you exhale. (A healthy person can count to about 50)
 - Failure to count to 25 is a sign to seek immediate medical attention or call your neurologist
- Slurred speech with nasal, wet voice
- Waking during the night feeling short of breath
- Morning headaches & unexplained sleepiness

Technology to the Rescue

Several devices can help relieve MG-related breathing difficulties. Many have heard of C-PAP (continuous positive airway pressure) machines that are used to treat sleep apnea. C-PAPs are not recommended .

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Continued from Page 11 Breathing Better

to help with MG breathing issues. Instead, a BiPAP (bi-level positive airway pressure) helps with breathing in two (“bi”) ways. It delivers high pressure for inhaling and low pressure for exhaling. A BiPAP reduces the work of breathing.

A Bi-PAP works like a ventilator, without a tube down the throat. A tight mask is worn over the mouth/ or nose to regulate breathing. It can be used at home during the night to correct shallow breathing during sleep, and during the day to relieve shortness of breath. A BiPAP can be used to avoid intubation when breathing assistance is needed during myasthenic crisis.

To be able to use a BiPAP, a patient:

- Must be able to swallow, and
- Must be cooperative and alert.

Using a BiPAP machine at home can help you maintain a healthy oxygen level and improve daily living. It can promote your comfort, support ventilation, maintain oxygenation, and prevent hospitalization.

BiPAP criteria for MG:

BiPAP machines can be obtained by recommendation from your Doctor. You should qualify for a BiPAP without doing a sleep study if you have an MG diagnosis from a medical professional and one of the following:

- Pulse oximeter reading of less than 88% for more than 5 minutes during sleep
- Awake ABG (arterial blood gas) reading PaCO₂ > 45 mm Hg (you have a high level of carbon dioxide in your blood)
- FVC Forced vital capacity (FVC) (the amount of air you can force out of your lungs) < 50% of predicted level
- NIF (or MIP) reading (the strength to inhale) < 60 cm H₂O; normal reading is 90 to 100.

A BiPAP machine with a program called AVAPS is best for MG patients with chronic respiratory failure. This program adjusts to fluctuating muscle weakness and poor breathing during sleep.



Your Donations to Myasthenia Gravis Society of Canada Keep Us Going!

A Huge Thank You For Support
Myasthenia Gravis Society of Canada has received from Donations, “Celebration of Life” Memorium gifts, Memberships, & 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, the public & Healthcare Professionals. To encourage research into cause and cure for MG.

Donations can be mailed to
Myasthenia Gravis Society of Canada,
247 Harold Avenue, Stouffville, Ontario, L4A 1C2.
Or donate online at www.MGCanada.org

905 642 2545

Registered Charity#81155 1431 RR0001

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

Do you have an MG article of interest to “Contact”?

Please forward to 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.



Why “MG Fit?” National Fundraising Campaign?

**It is MG Canada’s goal to assist
MG Patients achieve the highest level of
“New” Normal—a Combination of Physical,
Mental, and Spiritual Well Being—
One’s Optimal MG Fitness.**

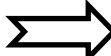
Canada’s MG Fit program tries to encourage MG patients to achieve wholeness in view of the changed dynamics of their bodies, minds and spirits. Those living with MG eventually realize that they have a “new normal” which changes their capabilities. MG Fit promotes the acceptance of MG chronic realities which will allow patients to pursue stability through treatment, and attain growth through the determination to live within their “new normal.” “MG Fit” gives patients a guideline vision of encouragement to achieve personal wellbeing to reach new levels of personal fulfillment and wholeness.

“\$tep Up For MG Fit”

Help the “MG Fit” campaign raise \$\$\$ to be used to improve awareness and support of MG patients, caregivers, health care professionals and MG researchers. The stronger we are financially—the more we can help. “Step up for the MG Fit” campaign helps fulfill the mission of MG Canada to promote the health of MG patients by providing access to information and support group programs; to advance MG education through seminars, literature and other multi-media communications; and to receive and maintain funds for qualified MG research, or researches for MG cure.

MG Canada, a registered charity, not-for-profit organization with Registered Charitable # 81155 1431 RR0001, estimates that about 30,000 Canadians may have MG, but many have never been diagnosed, or worse, have been misdiagnosed with other conditions which can become life-threatening if they suffocate due to severe weakness of the respiratory muscles. “\$tep Up for MG Fit!” In our fiscal year 2018, MG Canada support did 1,528,141 steps towards our goal of one billion steps from donations, “in Memorium” gifts and MG Walkathon.

To donate:

go to www.MGCanada.org or See Donor Form on page 15 

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

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

Or call 905 642 2545 or 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.

Several MG Canada Members Attended Myasthenia Gravis Conference in Atlanta, Georgia



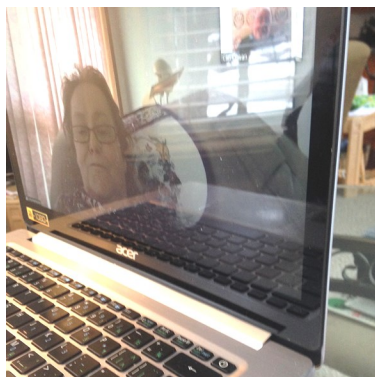
MG members Wilma Koopman, Cap Cowan, and Kathy Baer chat in the exhibition hall during a break in the sessions.

Several MG Canada members took part in the American MG Foundation Conference. Wilma Koopman, who recently spoke to our Support Group, was a speaker. She is with London Health Sciences.

Garry Morehouse was also a guest speaker at the MDFA Conference.

Garry gave a workshop to our Support Group on exercise and MG.

Testing ZOOM Technology Allows for MG Group Meetings Across Canada



Working out the ZOOM technology, Linda hosts an MG discussion with Cap and other MG Directors Tony and Aleem.





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

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 Facebook Quotes

IVIg yesterday had all new lot numbers ... Headache so bad last night. I've had migraines before which didn't even hold a candle to this headache ... better today though.

My EMG was done no caffeine or drug treatment. A warm blanket was put over me, and they shocked my hand and my neck and got the desired results. My neuro books the diagnoses appt and the EMG in the same day and if your GP hasn't done the blood test yet he sends you for that too. But I walked out that day with yes you have it blood, emg and my diagnoses tests say so here's some meds see you soon.

Time to celebrate ☐ saw my neuro today. He says he can't see any signs of my MG symptoms so he is calling me stable!!!! Lowered Prednisone from 15mg to 12.5mg and continuing with Mestinon 30mg/3 times a day instead of 60mg/3 times a day, and my blood pressure was down still ☐ it's been a long year and I am finally seeing the light at the end of the tunnel.

Having my thymectomy tomorrow. Any helpful tips would be appreciated. I am not sure what to expect, especially when it comes to recovery. Thank you
Wishing you all the best for a good recovery. I have my pre-op apt Friday am for robotic surgery May 22nd. Haven't been giving it much thought, just looking forward to the recovery and the final outcome!

Thank you everyone for well wishes. The surgery went very good, they were able to remove the tumour robotically and no nerve damage was done! So far recovery has not been easy, but I guess it was to be expected. I am being well taken care of by everyone here at VGH.

WELCOME NEW MEMBERS! 😊 :) We're glad you found this support group. We hope you'll find the support you've been looking for in our growing MG family.will get you get started in the group, and also help you find information about MG, treatments, specialists etc. Please go over the links and join the conversation. It's only through OUR PARTICIPATION that this support group becomes effective.



**Myasthenia Gravis
Society of Canada**

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