



# The Mystery Behind the Thymus Gland By Dr. Cheryl Zimmer

Your thymus gland (if you still have one) is part of your body's immune system. It is tasked with protecting you from autoimmune reactions. It is often implicated in Myasthenia Gravis (MG) when it goes awry. However, truth be told, the relationship between the thymus gland and MG is not completely understood.

# Your thymus gland is located in your upper chest, just behind your sternum, separating the right and left lobes of your lungs.

Before you were born and throughout your childhood, your thymus gland produced thymosin, a hormone responsible for the formation of T lymphocytes, also known as T-cells, a type of white blood cell that is stored in your lymph nodes.<sup>1</sup> By the time you reached puberty your thymus gland was just a vestige of its former self and was no longer functional. Like your appendix or tonsils (if you still have those), it is no longer required for survival, let alone everyday life, but it can become a nuisance.

Thymic hyperplasia is an enlargement of the thymus gland, while a thymoma is a thymus gland tumor, which may either be benign and



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**due to an immune response or malignant, meaning cancerous.**<sup>2</sup> Only 1% of thymomas are thymic carcinomas.<sup>2</sup> Thymic hyperplasia is found in 50-60% of acetylcholine receptor (AChR) antibody positive MG, while thymomas are found in approximately 15-20% of MG patients, <sup>3,4</sup> but the prevalence of MG is 50% in those with a thymoma.<sup>2</sup> This means that just because you have MG, doesn't mean you'll have a thymoma, only 1 in 5 MG patients do. However, if you have a thymoma you have a 50/50 chance of having MG. In contrast, thymus abnormalities are not seen in anti-muscle specific kinase (anti-MuSK) MG.<sup>3</sup> On the other hand, in some patients with the newly discovered anti-low-density lipoprotein receptor-related protein 4 (anti-LRP4) MG serotype, thymic hyperplasia has been observed but not sufficiently studied.<sup>3</sup>

The evidence is clear that if you have thymic hyperplasia or a thymoma, your thymus gland should probably be removed.<sup>2</sup> What is much less certain is what to do with the thymus gland in the case of non-thymomatous MG. In other words, should the thymus gland be removed in people with MG with a normal thymus gland?

The best way to look at the evidence is to examine systematic reviews. These are studies that use a methodical approach to

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### MG Support Group Meeting Ottawa & Region

The **Next Zoom meeting will be Sunday September 27th at 3 p.m.** Anyone that wants the link can email.

Email Contact: mgottawa@yahoo.com

### Myasthenia Gravis Society of Canada MG Canada Support "National Journey of Hope" Meeting

Zoom meeting will be Sunday, October 4th, 2020, at 3 p.m. Email <u>Membership@MGCanada.org</u> for your invitation.

#### Myasthenia Gravis Society of Canada

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collecting and appraising multiple clinical studies on a topic, then synthesizing the findings. In 2017, a systematic review of 26 papers of thymectomy outcomes in 640 patients with non-thymomatous *ocular* Myasthenia Gravis found that thymectomy was an effective treatment with a complete stable remission rate of approximately 50%.<sup>5</sup> These studies were not randomized controlled trials (RCT), meaning that MG patients were not divided into 2 groups, one group that had a thymectomy and one group that did not, then compared.

An RCT was finally published in 2016 in the New England Journal of Medicine, with a follow-up study published in 2019 in Lancet Neurology, comparing the long-term effect of thymectomy and prednisone in patients with non-thymomatous AChR antibody positive MG with those treated with prednisone alone.<sup>6,7</sup> After 3 years, there was a statistically significant improvement in clinical status, lower requirement for alternate day prednisone dose (44 mg versus 60 mg), fewer patients that required azathioprine (17% versus 48%) and fewer hospitalizations for exacerbation (9% versus 37%) in the group of 66 patients that underwent thymectomy as compared with the group of 60 patients that did not.<sup>6</sup> After 5 years for those that continued the study, the 35 patients in the thymectomy plus prednisone group continued to demonstrate improved clinical status compared to the 33 patients in the prednisone alone group, lower average alternate-day prednisone (24 mg versus 48 mg) and fewer hospitalization for exacerbation (6% vs. 30).<sup>7</sup> So, the effect of thymectomy was sustained.

A word about the thymectomy procedure itself. The traditional approach has been trans-sternal, which is highly invasive. Trans-cervical video-assisted or robotic-assisted thymectomy is minimally invasive, offering a substantially reducing recovery time with no significant difference in MG outcomes from the trans-sternal approach.<sup>8,9</sup> Because it is less invasive, there is an increasing acceptance of the benefits of trans-cervical thymectomy over its risks for AChR antibody positive MG.<sup>8</sup> Uncertainty remains however, with regard to the advantages of thymectomy for *all* types of MG.

### This review is based on research, but every case of MG is different.

We are snowflakes, after all. No two of us are the same. If you have AChR antibody positive MG, discuss the Continued on Page 4



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possibility of a thymectomy with your neurologist.<sup>10</sup> If you have anti-MuSK, anti-LRP4 or seronegative MG, the jury is still out on the benefits of thymectomy. We will just have to wait and see what future research tells us.

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#### Dr. Cheryl Zimmer, Medical Writer for MG Canada.



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 Patient Volunteers Our Best Hope for Positive MG Research.

This **article is an expansion of Myasthenia Gravis Facebook Group** (Canada) post below from Cap Cowan, September 17 & 18, 2020. My personal "MG Journey of Hope" volunteer contributions continue. Third time volunteer at Toronto General Hospital (TGH) to help research for treatment of Myasthenia Gravis. First time for comparative trials of IVIG suppliers. Second time as volunteer patient for more definitive referencing MG patient psychological assessment study. This time as patient volunteer for "rozanolixizumab" 3<sup>rd</sup> phase clinical trial. Diagnosed and treated by Dr. Bril, for fairly severe Generalized Myasthenia Gravis patient for approximately 15 years.

**Current personal prescription daily regime**. (I also took 'Imuran' for several years but stopped about 2 years ago to lower risks of skin cancer basil and squamous cell carcinomas. 6 removed by plastic surgery so far. None since cessation of Imuran).

#### Cap's Daily Meds: September 2020

Myasthenia Gr

- 5 Mestinon (Pyridostigmine Brom) With food
   60 Ml. 11/2 breakfast; 1 lunch; 1 ½ dinner; 1 evening
- 2 Cellcept (Mycophenolate sod) Before eating
   360 ml. 1 breakfast; 1 dinner
- 3 **Prednisone** with food 5 mg. 1 breakfast
- 4 Tamsulosin HCL RD With food 4 ml. 1 lunch
- Atenolol (Beta Blocker) With food Prescribed by cardiologist.
   50 ml. ½ dinner
- 6. Rosuvastatin 5 ml. With food 1 evening
- 7. Vitamin D 1000 iu breakfast. With food
- ASA Enteric 81 mg. coated aspirin (blood thinner) breakfast.
   With food
- 9. Vitamin C (chewable) 500 ml. 1 breakfast, 1 dinner
- 10. Omega 3 1000 ml a day; 1 lunch
- 11. Multivitamin for Sr Men 1 evening
- 12. Calcium & Vitamin D 650 ml; evening.
- 13. Iron (Dr. Rasul) Ferrous Gluconate 1 lunch (every other day)
- 14. **Perindopril Erbumine** 2 Mg. With food **1 Lunch** (Fairly recent to help lower blood pressure)



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**PERSONAL NOTE:** It's fair to say our bodies are constantly changing with or without prescription medications. Myasthenia Gravis treatments so far remain very patient subjective. My personal prescription meds and supplements above are a result of both MG specific treatment, my age, the side effects of medications, food eating habits, positive mental attitude and the ongoing monitoring of my overall metabolism by my personal doctor including blood tests periodically. I'm trying my best to remain active and do exercise versions I can manage. General consensus of my MD is I'm doing better than average for my age. There's hope I can maintain a high degree of Quality of life. It will help if my current diet reduces my weight to a goal of 32 pounds less and of course if a cure for MG is found.

**Facebook blog September 17, 2020:** "Started yesterday as a volunteer for a 3rd phase clinical trial through Dr. Bril at Toronto General Hospital Prosserman clinic. Always amazed at the high calibre of clinical staff on her team. Considering the fact that they primarily concentrate on Myasthenia Gravis and GSB, relatively rarer neuro muscular conditions, their team has 4 full fledged Neurologists, all professor or assistant professor status, currently 5 visiting fellows from around the world plus support staff who often are at least MD status or higher themselves. Lubna, who will be my clinician for the 20 or so visit trial period, was a surgeon in Dubai. MG Canada's Fall Newsletter and/or online, will try to give updates on current trials across Canada. If you wish to receive the next MG Canada Newsletter, drop an email to <u>Membership@MGCanada.org</u> We will also try our best to advise



you on the closest trials to where you live if you are interested in participating."

Facebook blog September 18, 2020: "The trial is for "rozanolixizumab". I will receive infusion (subcutaneous, my choice of either waist area or upper leg) at visits 2, 4, 5, 6, 8 and 9. I counted about 20 visits with an additional built-in study with my permission. I agreed, hopefully for all of our benefit or I would be a hypocrite to be constantly encouraging all MG patients to assist MG research when and where we

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can. We can give you the contact information for this one if you Email us at <u>Membership@MGCanada.org</u>. Strictly volunteer. Travel expenses & parking are paid for. It's a triple study method. Random 1) 7mg/kg rozanolixumab 2) 10mg/kg rozanolixumab 3) a placebo dose. (A placebo is a product which looks like rozanolixumab, but does not contain any medicinal substance and will not have similar effect.) Which one of 3 is about 33%. Double blind manner. Neither me or trial doctor will know which study treatment is given. I'll add more details in our MG Canada Fall Newsletter "Contact" now in production. Email us at <u>Membership@MGCanada.org</u> if you wish to be on the MG Canada Newsletter email list. Wish me luck."

#### What is 'rozanolixizumab' and how does it work?

According to the UHN study information, Study MG patients have medium to severe generalized Myasthenia Gravis. Currently the usual study treatments are acetylcholinesterase inhibitors, corticosteroids, non-steroidal immunosuppressants, plasma exchange, intravenous immunoglobulin, and some biological agents. All of these study treatments have potential side effects, and some may not work for some MG patient conditions.

Rozanolixizumab is a type of antibody that helps break down circulating antibodies (proteins circulating in the blood stream) including harmful antibodies, lowering their levels in blood. This therefore may put patients at risk of infections. The purpose of this trial is to help us understand how effective rozanolixizumab may be in patients with MG, see how safe the drug is and how well MG patients are able to tolerate it.

So here we are in the midst of a global pandemic continuing to move forward with MG research. As Myasthenia Gravis patients, it's up to us to support this research everyway we can. There is real hope that several new treatments are already starting to show signs of significantly improving MG quality of life. Volunteering for MG research is one way we can truly help each other and Health Care Professionals caring for us. There is hope for MG cure.

Sincerely,

Cap Cowan, President and Newsletter Editor Myasthenia Gravis Society of Canada CapCowan@MGCanada.org 905 642 2545





# **Taking Charge of Your Wellness**

### **By Garry Morehouse**

In October 2018, I had to suddenly wear a patch over one eye to prevent double vision, use a walker and a neck brace for weak muscles and wear a bike helmet in case I fell. I could not hang-up my bathrobe on a hook, lift a litre of milk from the fridge or sign my name. I had difficulty chewing and swallowing. Due to my lip muscles being limp, I wore a bib as food and liquids spewed from my mouth. A fall outdoors sent me by ambulance to the hospital. Following a two -week period of many tests I was diagnosed with MG.

I honestly believe the reason I am now doing so well, playing pickleball five days a week, is that I took charge of my wellness and set measurable goals with timelines. I researched the best exercises for me with a goal of getting back in the game of pickleball. The exercises which worked best for me once my symptoms stabilized were sit-to-stand squats, urban pole walking, resistance bands, Yoga positions like bridge and plank, and breathing exercises. Combined, these exercises improved my endurance, and mobility.



Garry at Pickleball

# I researched IVIG treatment versus drug therapies like Imuran and

**Prednisone.** I requested IVIG which I have undergone every eight weeks for the past two years. My Neurologist suggested I switch to Imuran but I refused. I said: "if it ain't broke let's not try to fix it". So, I remain on IVIG with zero side effects. I am off all drug prescriptions.

I became mindful of eating well. I began to eat a nutritious and balanced diet. Healthy foods I have come to love are beets, blueberries, liver, halibut, eggs and milk. I consume peach flavored Boost about two hours before having vigorous exercise.

#### Myasthenia Grav

#### Myasthenia Gravis Society of Canada

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I did not accept moving to a "new normal" when the "same old, same old" was what I wanted. I still have some balance issues but am not sure if they are MG related or due to a strained and weak Gluteus Medius as my psyotherapist diagnosed or if it's a part of the aging process. In December I will celebrate being 75 years. Some pickleball players were teasing me of looking drunk on the court! I am going to pull out a flask the next time they comment.

The medical profession is competent and well-intended but usually too overburdened to provide undivided attention. Become your own advocate. Research the best medication and improvement program to cope with MG. Create a collaborative relationship with your medical team by preparing for appointments. Use your time wisely with the busy doctors. Inform them what you think is necessary then listen to your doctor and assess the response. Seek a second opinion if you think necessary. Respect your MG while becoming more proactive in your wellness programs. It makes a world of difference in your overall health.

This article is based on my personal experience and research. MG, as we know, varies greatly from person to person. For some people, the ability to exercise may be limited -- especially during flare ups or exacerbations, but it is always good to know what is possible. One should consult with appropriate professionals before embarking on a vigorous wellness program. It is with immense gratitude that I write of my personal success.

Garry Morehouse



A Promising New Day at Balsam Lake in Ontario



# **On Facebook?**

# **Connect With Others from Across** Canada Sharing their Experience of Living with MG

Join our Myasthenia Gravis Facebook Group (Canada) Hear from others affected by Myasthenia Gravis through this Support Group - another way to learn more through postings, discussion, and comments from patients and families living with Myasthenia Gravis.

### Myasthenia Gravis "Help Line" **Telephone Support with an MG Patient**

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 telephone them to discuss your Myasthenia Gravis experience.



Aleem Remtulla, Toronto, ON 647-390-0522 Tiina Elder, Mississauga, ON 905-565-5875 Jill Thomson, Calgary, AB. 403-286-0056 *Phillip Sanderson,* Harriston, ON 519-338-3356 Vikki LeDez, Sunderland, ON 705-357-0377 Fernanda Nascimento, St. Catherines, ON 905-937-9762 Pat Griffiths, Ottawa, ON 613-237-1649

We need Telephone Support Contacts across Canada. Interested? Inquire 905 642 2545



### The Bright Side is our Best MG patient Choice!

Keep going Canada! "Try a new level of strength and community consciousness!"



### **Positive 'Wellness' Ideas Help You Thrive**

#### *Try these for your personal conscious science of wellbeing.*

Starting the day off fresh
It's a brand-new day. Take a deep breath.
Focusing on the positives
Write down 3 things that went well today.
Getting outdoors
Play. Move. Unwind. Walk. Bicycle.
Seeing the bigger picture
Jot down one thing you can do to make a positive difference in your community
Treating yourself
A new plant. Some food you like perhaps like dark chocolate. Try some music ideas. Lots of possibilities. Read a book.
Embracing culture
Celebrate your cultural roots.
Being active
Head out to a local park or activity centre.
Using your personal resources
What or who has helped you positively. Make a list. Now, add things you do for your self!
Learning
Go online to learn how to do just about anything on YouTube. Or go out in the world and take that course you've meant to try.
Finding meaning
Get in touch with a sense of your purpose? What excites you? What do you feel passion- ate about?
Enjoying yourself
Spend 1 hour today doing what you want.
Connecting
Call a friend or someone you like and arrange to meet.
Disconnecting from all video screens
Really? Yes, to stay connected you need to disconnect. Enjoy this time without any
interruptions. Try no screens while eating meals. Light a candle instead.
A moment just to rest
Give yourself a moment to just close your eyes and let go of your thoughts.
Time out to breathe
Take 3 minutes to focus on consciously breathing deeply to relax.
Nature
Take a walk in a natural setting. Re-connect with the natural world around you! dapted from CAMH.ca 2020 article.

### **Lavender Field Memories**

Myasthenia Gr

"Every year Josh and I go back to Serenity Lavender Farm, which is where we had some of our wedding pictures done, and we take a picture to mark our anniversary.

Making a donation in memory of my Grampa around the time of our anniversary has been something that I have wanted to do, and I hope that we can continue to do it annually now." Emily Huffman



Josh and Emily Huffman married on June 25, 2016

June 25, 2017



Thank you, Josh and Emily, for your kind donation to the work of the Myasthenia Gravis Society of Canada in Celebration of your marriage and in Memory of your grandfather.

# Have You Recruited Anyone to Donate Blood Lately? Better Still, How About Donating Plasma?

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**Canadian Blood Services is a non-profit charitable organization that is independent from the Canadian government.** The Canadian Blood Services was established as Canada's blood authority in all provinces and territories except for Quebec in 1998. Headquarters are in Ottawa. Motto: Together, we are Canada's lifeline.

Join Canada's Lifeline. Book now to encourage your friends and family to donate blood. Find a Donor Centre near you. Blood Donation can make a lifesaving difference. Even better, for making IVIG which many MG patients depend on, donate plasma.



#### Here's an example of procedure in August 2020 Stouffville, Ontario Blood Clinic with extra COVID 19 precautions.

**"Subject:** Stouffville Lions Club Status Report - CBS Clinic of August 1, 2020 The August 1, 2020 clinic was held in Stouffville, with changes to accommodate the COVID 19 environment. The clinic took



clients from 9:00am to 2:00pm.

All clients were Booked in advance (walk-ins were not accepted).

The budget was 61 units, 54 were collected.

The Lions Contribution was: Lion Ivan: 2 hrs on site, Lion Roy: 5 hrs (4 on site, 1 prep). Total: Lions volunteer hours : 7

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#### Here's a few notes on how the clinic was handled.

- Four beds were set up, spaced apart as you would expect.
- The PPE being worn were masks (a couple of face shields were in evidence). No gowns were seen.
- Donors lined up at the door and were interviewed in detail at the door on their COVID status. After that they started progressing through the donation process (wearing masks and distancing at all times). As all donations were booked in advance, the lineup was never longer than 2 people, and observing distancing was straightforward.
- After donation, donors were taken to the recovery area where they sat on a chair for the required 5 minute recovery and observation time. Although they were allowed to select cookies, munchies and the like, they were not allowed to eat them inside (to munch, they had to remove their mask). They were requested to not 'root' through the various items, because of the touch factor. Also, CBS did not supply coffee.

Three volunteers are required at each shift - one at the entry door to direct people, one at the recovery area, and a standby to take over if required.

Lion Roy O'Boyle, Stouffville Lions CBS Volunteer Coordinator "Printed with permission"





"One of the things that has helped me as much as any other, is not how I am to live but how much I can do while living."

George Washington Carver, Scientist and Inventor

Thanks to MG Member Judy Neilson for forwarding this quote.

# Roy Loach, Supporter of the Myasthenia Gravis Society of Canada, and husband of MG Patient Marny Loach. A Life Well Lived.



Myasthenia Gravi

ROY LOACH came to many GTA MG Canada Support meetings with Marny Loach, who struggles with ocular MG. They came by subway, enthusiastically waiting for the meetings to congregate. Roy and Marny acquired an electric cart, which they promptly decided to sell for proceeds to MG Canada.

Roy was born on September 13, 1928, in Leaside, Toronto. He earned a Bachelor of

Applied Science, Mechanical Engineering, 5T2, at the University of Toronto after returning from WW 2. Roy met and fell in love with St. Michael's Hospital nursing student, Marion Joy Dyson. They married in 1954. Had three children, John, Keith and Claire. Many of Roy's children's friends refer to him as their second father. In the eighties and nineties Roy became "Grandpa Roy" to 6 grandchildren. In 2016 he twice became a great-grandfather.

**Professionally, Roy started as a design engineer** with his father in their machine shop, S.W. Loach & Son. Roy developed several unique machines for the printing industry. Both sons, John and Keith, helped Roy expand "Loach Engineering" into a successful industrial supplier and manufacturer. Roy was a charter member of the North Scarborough Rotary Club and "worked out" every morning at The Fitness Institute. Music was an integral part of Roy's life. Many parties ended with sing-songs around various keyboards played by Roy with friends and family.

**Eight years ago, Roy and Marny moved to "The Dunfield"** (near Eglington and Yonge Street in Toronto). After retirement, Roy became known as "Toy Doctor" volunteer repairing and customizing countless toys at the Bloorview MacMillan Children's Centre. Roy was a Sunnybrook Hospital Odette Cancer Centre greeter. Roy passed away peacefully Family Day, February 17, 2020.

A life well lived. He is missed by all who knew him.

**Raymond "Guy" Jardine** 

### DONATIONS

We appreciate all donations received to aid the work of Myasthenia Gravis Society of Canada.

Donations have also been received in loving memory of:

Samantha Cove

"Margot"

Ø

Linda Thorne

Roy Loach Bill Vik

Laura Vanderwal

Barbara Smith

Peter Winnett

# Donate to Myasthenia Gravis Society of Canada.

Help Keep Us Going and Growing A Huge Thank You For Support

Myasthenia Gravis Society of Canada receives Memberships, Donations, MG Fit Pledges, "Celebration of Life" Memoriam Gifts, and other charitable donations.

All donations 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.org905 642 2545Registered Charity#81155 1431 RR0001Is your membership due for update? Please email Membership@MGCanada.org



16 September 2020

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Wyasthenia Gravis Society of Canada	Myasthenia Gravis Society of Canada	
Myasthenia Gravis Society of Canada	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 #)	
	Postal Code	
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	, 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		
	is to call you? YesNo	
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\$ 20.00 (	1 year) \$ (12 months – Individual or Family)	
<u>or</u> \$ 50.00	(3 years) \$ (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 <u>Membership@MGCanada.org</u>		
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# Myasthenia Gravis emergency preparedness, especially in current Coronavirus crisis. (See example Page 5.)

Have several complete printed copy updates of your current prescription meds and dosage amounts with daily times. List supplementary treatment such as IVIG & other supplements you may take such as 81mg Aspirin and vitamins. Keep at least 5 days of daily meds ready to go if at all possible. Have your MG Canada Blue Card ready with "do and don't" recommendations regarding antibiotics and other treatments that might acerbate your Myasthenia Gravis. Try your best to stay calm.

# MG Canada's Newsletter 'CONTACT' is published by:



Myasthenia Gravis Society of Canada c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2

905 642 2545 www.MGCanada.org membership@MGCanada.org

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

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