



There is Hope Through

'CONTACT'

Printed in the interest of those affected by Myasthenia Gravis

"Could It Be MG?"

Quarterly News

Volume 45 Issue 1

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Lins O'Connor hosting an International Press Conference at the Groote Schuur Hospital, Cape Town, South Africa with Sir Desmond Tutu publicizing Cataracts work.

MG Journey of Radio and TV Host

Lins O'Connor

It's hard to believe that it was three years ago I was diagnosed with MG, and what an interesting journey it has been. It all started when I was on air — I started slurring my words and my eyelids began to sag — my producer asked me how much I had to drink yet I hadn't had a drop!

The next day I was watching the Super Bowl and Cont. on Page 2

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1 March 2021

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Myasthenia Gravis

Myasthenia Gravis Society of Canada

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my eyelids began drooping again so I used some tape to pull them up so I could keep watching the game — I didn't think much of it. Everything was slowly getting worse over the next few days. I was having trouble chewing and swallowing which finally made me realize something was wrong. Did I have a mini stroke? Was it my throat causing problems from broadcasting all these years?

I was sent to Doctor Murray at the Intestinal Health Institute where they did a scope procedure and ice test on my eyelids.

That was the night my journey began.

My wife got a call informing us that we needed to go to Sunnybrook Emergency immediately. I was admitted and rushed to Doctor Zinman, Head of the Neurology Department. He decided he wanted to monitor me overnight. I thought it was unusual when doctors that weren't assigned to me were coming and taking photos of my face in emerge — I'm sure it had nothing to do with my good looks as I have been told I have a face for radio!

The next day I had the pleasure of Doctor Zinman running all these electrical probes on me. He came back happy to inform me he had good news – you have Myasthenia Gravis! It's a rare disease and there's no cure, but it's treatable, so no need to worry! That was a shock to my system because I had never heard of MG before.

Where did I catch it I asked?

I was kept in hospital for eight days under the care of Doctor Zinman and his excellent team. Things seemed to be going along great; the good doctor was reducing my steroids, took me off Mestinon, and I was close to remission. A few months on then bang! I had a crisis on a long weekend.

I ended up in ICU as a result at Markham-Stouffville hospital on life support. After two days I flat lined and had the experience of crossing over just to be sent back – the first thing I heard was the nurses talking loud to me, but then I heard my wife's voice!

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It was quite an experience and it renewed my faith that there is more after life on earth. After 10 days in ICU all the tubes were pulled out of me and finally I could talk instead of using a clipboard to communicate to the nurses (which I'm sure pleased them).

It was time for the next part of the journey; to get me out of bed and sit me in the chair. How could this be done I asked myself as I couldn't walk. My limbs were paralyzed and my neck was weak. The next phase reminded me of my media trips to Africa where I witnessed an elephant being lifted onto a truck in a huge harness. It's a bit embarrassing but that's what happened to me each day.

The next stage was going to rehab and getting my limbs working again. After 50 days I was kicked out just to be greeted by the C19 virus. I've been in isolation since March because of my low immune system. I'm now on Imuran and a reduction of the Prednisone steroid. I hope to be off the Prednisone soon.

I have been strong throughout the journey and am motivated to get back to being my old self, and hope I can inspire others to stay strong and do the same as well.

I ask everyone to support the research of MG and the MG Society of Canada to support and get the word out on this disease. Tell your MP, MPP, and media about the disease.

I hope to be back on air in the New Year.

Lins O'Connor

Life is a Balance of

Holding On and Letting Go

.... Rumi







Editorial "Engaged"

"Myasthenia Gravis Canada
is Your National MG Patient
Advocacy". I get many calls and Emails as
your MG Canada President and Newsletter
Editor. Primarily Canadian MG patients
and their caregivers. Occasionally from

elsewhere. Each call reminds me of how important our Canadian patient advocacy is, especially with the help of Social Media. Now distance is only a click away. Questions like "Are the currently approved COVID Vaccines safe for MG patients? – Apparently yes but never hurts to confirm with your healthcare advisors and so forth." MG engaged conversations 24/7.

Patient Engagement: What has changed the most in the last 10 years, is the remarkable increase in Canadian MG patient engagement with each other. Example: I received a memo from one of our long standing Directors, recovering from an MG crisis attack. Part of the treatment was IVIG. The problem was delay for arrival of second IVIG treatment. Delay caused touch and go recovery. The question became whether or not this was an isolated incident or the early warning of Canadian IVIG supply shortages, which could be a serious issue for many MG patients.

MG Canada National IVIG Survey

Immediately we initiated a request for information through our Myasthenia Gravis Canada Facebook group. Within hours we had active personal reports from across Canada, representing all regions of our country. No one was experiencing any delays on their IVIG appointment schedules so far. That doesn't mean there's a stock pile of IVIG, but it does mean our Canadian MG IVIG supply chain is holding up, so far so good. Canadian MG patient engagement. It's about helping each other by being engaged with our fellow MG National patients. We hope your new MG Canada Website will help us all engage even better in future. Thank you for all that.

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





21 Tips for You & Myasthenia Gravis ... Things I've Learned!

Things I've learned in the past three years with MG by Pat Hayles

- 1. You can have a very good life, but no question its different from the old one
- 2. Build your own support network actual and virtual
- 3. Truly understand MG has a range of impacts for each individual, and yours may be very different from someone else you know with MG
- 4. Truly understand your own body and its reactions (differently day by day and sometimes hour by hour)
- 5. **Medications are your friend**, but you need to be actively involved in monitoring their affect on your body. (It helps if you have a doctor who encourages you to be an intelligent patient partner)
- 6. Muscle weaknesses are broader than you think (spending an hour talking to friends or family can be as tiring as going to the store), and certain activities may take a lot more energy than you expect. (Driving tires eyes far more than reading a book)
- 7. Fatigue is cumulative so plan when to do things and limit the number of things you plan to achieve in a day
- 8. **Don't beat yourself up** (a.k.a. as Manage Your Guilt)
- Knowing your own body and its capacity is the key strategy that gets you through
- 10. You can overdo things one day, but you may have to "give back" twice the energy used in recovery time the next day
- 11. A knowledgeable neurologist is worth their weight in gold, (especially one that lets you email concerns and responds in a timely manner)
- 12. **Contact with other MG warriors** (in groups, facebook, etc.) is useful in getting tips, and understanding others are much worse off than you



Continued from Page 5—Things I've Learned

- 14. Sleep and rest are your best friends. Plan for an afternoon nap, go back to bed after breakfast if that's how you feel, and occasionally treat yourself to a whole day in bed if That's what you feel is a fit for you
- 15. **Stretch things by taking bite-sized chunks** shower, then pause before trying to dress for the day; dampen hair and shampoo head before showering off (exposing yourself to as little heat and steam build up as possible). Build in digestion time after eating before getting on with other things
- 16. **Figure out quality of life priorities, and plan them into schedule,** allowing enough time to savor them, before trying to rush on to something else
- 17. Be so thankful for supportive family and friends
- 18. **Find little treats** that give you something to look forward to
- 19. Reach out to those less fortunate than you don't end up defining yourself by the fact you have MG
- 20. Accept the way you look physically: wear clothes that are comfortable, but dress-to-please on occasion (even if only to show you can),
- 21. Don't panic crises are rare and preventable By Pat Hayles

Myasthenia Gravis Antibody Subtypes: What do they mean?

By Dr. Cheryl Zimmer

As sufferers of myasthenia gravis (MG), we have been told that our disease is an autoimmune disorder caused by autoantibodies to the neuromuscular junction that prevent the transmission of messages from our nerves to our muscles. But what does that actually mean? Let's discuss antibodies and the subtypes responsible for MG. Cont. on P. 7



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Continued from Page 6 Myasthenia Gravis Antibody Subtypes:

What is an Antibody Anyway?

The Encyclopedia Britannica (Did you know there is still an Encyclopedia Britannica? Check out www.britannica.com), describes antibodies, also known as immunoglobulins (Ig), as proteins created by the immune system in response to an invader called an antigen. Antigens may include microorganisms like bacteria or viruses, or they may be cancer cells, as examples. Antibodies attach to these antigens to neutralize them, rendering them powerless and unable to perform their intended destructive action.

Autoantibodies are produced by the body and mistakenly interfere with normal biological processes by binding to or attacking receptors.² Autoantibodies result in autoimmune diseases. Some autoantibodiesmay be very specific and only affect one organ or organ system.³ For example, in Hashimoto's Thyroiditis and Grave's Disease only the thyroid gland is affected. Other autoimmune diseases are systemic, affecting much of the body, like systemic lupus erythematosus (SLE).

The Neuromuscular Junction

MG is an organ specific autoimmune disease of the neuromuscular junction. Normal muscle movement requires a message from the nerve to pass to the muscle so it can move properly. Basically, nerves release acetylcholine (Ach) which is recognized by the acetylcholine receptor (AchR) of the muscle, resulting in movement.

However, the process is actually quite a bit more complicated, with several other receptors involved in the chain reaction that leads to muscle movement. A protein called agrin is released from the nerve and binds to low-density lipoprotein receptor-related protein (LRP₄), which then binds to and activates muscle specific kinase (MuSK), which causes AChR clustering. Clustering results in a higher concentration of AChR in one location, increasing the efficiency of the neuromuscular junction.

As it turns out, any of these proteins and/or receptors, AchR, MuSk, LRP₄ and agrin, may be targeted in MG.^{5, 6}

MG Subtypes

MG can be classified based on the autoantibody implicated. The most common type of MG is due to the AchR autoantibody, also known as the anti-AchR antibody, which

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Continued from Page 7 Myasthenia Gravis Antibody Subtypes

has a prevalence of 80-85%. Anti-MuSK antibodies are seen in 4-6% of cases, and anti-LRP4 antibodies occur in 2% of tested MG patients. Those who have no antibodies in their blood serum pointing to MG are known as seronegative, which occurs in approximately 2-10% of cases. This doesn't necessarily mean that these 'myasthenics' don't have autoantibodies. It just means that the antibodies causing their MG may not be known yet or can't be detected with current testing. Anti-agrin antibodies can be found in 10% of MG patients in conjunction with and without the other known MG autoantibodies.

There are some known differences in the presentation of MG in those with the different autoantibody subtypes. For example, AchR autoantibody positive MG may be associated with thymus gland abnormalities or thymomas. This is not the case in the other autoantibody subtypes. In those with anti-MuSK autoantibodies, MG symptoms tend to be more severe and include more facial, bulbar (throat) and respiratory weakness. Because of its selectivity for the respiratory muscles, anti-MuSK MG is more commonly associated with myasthenic crises. Unfortunately, acetylcholinesterase (AChE) inhibitor medications such as pyridostigmine bromide (Mestinon) may be less effective and cause more side effects in anti-MuSK MG.

A recent study found that those patients that had anti-LRP₄ MG had milder symptoms and responded well to treatment, with a later onset than other subtypes. On the other hand, those with anti-agrin MG had an early onset, a large range in symptom severity and only a moderate response to treatment. The same study found that the seronegative group of patients tended to have milder symptoms, with less predominant bulbar involvement, greater limb involvement and a worse response to treatment. Of note, there were very few subjects included in the study, so these generalizations need to be taken with a grain of salt. More research into the variation in disease symptoms and severity by subtype needs to be conducted before we can make definitive conclusions on the differences.

Targeted Treatment

Medications to manage MG include AChE inhibitors, prednisone, plasmapheresis, IVIG, immune suppression with drugs such as azathioprine (Imuran) or mycophenolate (CellCept or Myfortic), and rituximab. However, there is no magic formula for who is prescribed

dyasthenia Gravis

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which treatment when and at what dosage. Much of the treatment planning seems to be individualized and conducted by trial and error.

The most common treatment for MG is pyridostigmine bromide (Mestinon) which is an AChE inhibitor. It aims to keep more Ach in the junction, between the nerve and muscle by preventing the chemical breakdown of unused Ach into smaller parts called choline and acetic acid. 4,7 This medication is short acting and effective at retaining available Ach, but it doesn't get to the root of the autoantibody issue at the neuromuscular junction. We know, as stated previously, that anti-MuSK MG is less responsive to AChE inhibitors, however these patients respond very well to plasmapheresis and rituximab. 4Other specific management strategies for the different subtypes are not well known. Targeted treatment, based on the autoantibody in question, AchR, MuSK, LRP₄, agrin and potentially others, is the holy grail of MG therapy. As more MG antibodies are uncovered and studied, we will gain more insight into the variation between MG subtypes. Perhaps we will be able to selectively remove just the implicated autoantibodies in a process similar to plasmapheresis or suppress the offending antigen using targeted immunosuppresives. ⁴ Time will tell, but hopefully subtype-oriented, patient-specific therapy is on the horizon. We just need to be patient.

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Dr. Cheryl Zimmer, Medical Writer for MG Canada



Zoom **Meeting** **Myasthenia Gravis Society of** Canada, MG Canada Support "National Journey of Hope" Sunday, March 14, 2021 at 3 pm

ZOOM meeting invitation link by Email hosted by Cap Cowan, MG Canada medical advisory and others. Email Membership@MGCanada.org for your invitation link. MG Canada members will get a personal invitation link by Email.

> Zoom **Meeting**

MG Support Group Meeting Ottawa & Region. Sunday, February 28, 2021, at 3pm

Anyone that wants the link can email mgottawa@yahoo.com

Online

Facebook Website

Connect With Others from Across

Canada Sharing Their Experience of Living with MG. Join our Myasthenia Gravis Facebook Group (Canada) Support through postings, discussion, and comments from patients and families. Online at www.MGCanada.org

> **Phone** Support

Myasthenia Gravis Telephone Support. These members welcome calls from those wanting to connect.

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



MG Core Strengthening

By Julia Naumes. Article arranged by Garry Morehouse, MG Canada

Like so many people around the world, my workout habits and locations changed drastically with the pandemic. Prior to March 2020, I was playing handball for a few hours 2-3 times a week, doing yoga at the YMCA once a week, and going on the occasional short hike. I was in the best shape since diagnosis with MG and had finally gotten back into playing handball tournaments. I was also preparing for my wedding and had extra motivation to be at peak shape.



During the time period when it was unknown how the virus was being spread, I was home completely and just utilizing the equipment I had on hand. Below are exercises that require no special equipment and pack a lot of "bang for your buck" so to speak. I hope these are helpful for those that have not returned to the gym or are looking for different

exercises to spice up their routine.

Bird Dog - This exercise is great for core and back strength and also develops balance. Begin in quadruped and then simultaneously extend the opposite arm and leg. The goal is to form a straight line from fingertips to heel. If you have weakness or compensatory movement patterns, you may find your back tilting; try to correct this. Sometimes it's helpful to think of a water bottle on your back and trying to keep it there by staying level. If it is too difficult to perform this exercise with both arm and leg extending simultaneously, you can do one at a time. When my MG is not behaving I often have to do this.



Plank - This is the ultimate core exercise, and one I find many people with MG struggle with, as it requires an extended isometric hold. This exercise is typically done with the elbows extended, hands and toes on

Continued from Page 11—Congenital Myasthenic Syndrome

had the ground, and a straight line from the crown of your head to the heels. This not only requires significant core strength, but it also requires significant strength from the triceps muscles to keep the elbow straight. A modification to the plank that I often have to use is going down so my forearms are on the floor; this takes the triceps out of the equation. Even with this modification I often have trouble with this exercise and sometimes will modify so my knees are on the ground. If I need more modification, I will do the plank against the wall. I place my hands on the wall slightly below shoulder height with my feet 2-4 feet away from the wall and then hold that straight line from the crown of my head to my heels. The farther away from the wall you are, the more resistance you will feel with this exercise.



Dead bug - On face value this exercise does not seem like it would be that difficult, but man do you feel the burn and/or fatigue set in quickly with this core exercise. Begin lying on the ground with your arms and legs in the air. Then simultaneously lower the opposite arm and leg to the ground. Make sure your lower back stays flat during the exercise and is not rounding excessively.

Again, if this exercise is too difficult you could modify it by only lowering one limb at a time, or by bending your knee and elbow, decreasing the length of the lever.



As always, discuss these exercises with your healthcare team before participating.

Picture sources

https://www.popsugar.com/fitness/How-Do-Bird-Dog-Exercise-Your-Back-40441615

https://greatist.com/fitness/perfect-plank#fix-commonmistakes

https://www.pinterest.com/pin/481463016405626394/ Julia Naumes is an occupational therapist and certified hand therapist.

Smile!

There was the person who sent ten puns to friends, with the hope that at least one of the puns would make them laugh. No pun in ten did.



"Lazy Baby" Had Congenital Myasthenic Syndrome by Linda Scanlon

The Myasthenia Gravis Society of Canada, has a few members that have a different type of Myasthenia Gravis called, Congenital Myasthenic Syndrome or (CMS).

Congenital Myasthenic Syndrome is an inherited disease of muscle weakness. It is similar to Myasthenia Gravis but is not autoimmune and is therefore treated differently. CMS is caused by a genetic defect at the neuromuscular junction and usually starts at birth or soon after and presents with numerous symptoms of weakness. A chemical called Acetylcholine should release from the nerves and tell the muscle to contract but in CMS the chemical is either missing or not working and allowing the muscle to contract. There are several different types of CMS and they are specifically diagnosed with an EMG and often DNA testing.

My daughter was born with CMS but was originally diagnosed as a "Lazy Baby" because there was no other reasonable explanation for her weakness at the time. At birth, she presented with a weak cry, poor suction, droopy eyelids, choking spells and overall body weakness.

There are a variety of drugs called Anticholinesterases that work for some types of CMS but may be harmful in others. These medications can also make the child weaker if either too much, or too little is given. 3,4 DAP is another medication that helps by increasing strength and allows the muscles to work longer. It is very important to always follow your doctors advice when administering these medications and always give them on time, which is usually every four hours.

The medication (Mestinon) used to treat her weakness, worked well for her and actually made her strong enough to begin crawling and walking by sixteen months. Because of her swallowing difficulties, we would crush her pill between two spoons and feed it to her mixed in apple sauce or a spoonful of jam. Over the years, we have had to change her medications many times, especially

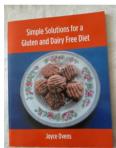


continued from Page 13—Congenital Myasthenic Syndrome as she got older and a bit more physical. We tried almost every medication available at different times but she is presently doing well on 3,4-Dap and Mestinon. As a parent of a child with CMS, the best advice I can give is to learn about and understand CMS and to realize the limitations your child is living with. Learn to listen carefully and recognize the difference between weakness and general fatigue, there is a difference that will tell whether they simply need to rest awhile or whether it's time to see the doctor for a change in the dose of their medication.

My daughter is an adult now, and has two children of her own. Both children are healthy and free of CMS.

Linda Scanlon

Achievements: Member Joyce Ovens Raising Funds for MG With Her Cookbook



"Simple Solutions for a Gluten and Dairy Free Diet "is a perfect introduction recipe book for anyone who has just been told that a gluten free diet or dairy free diet, or both, is necessary to maintain their health. The recipes are easy to follow for a novice or seasoned cook. Cooking is meant to be fun, so enjoy!

"As individuals with Myasthenia Gravis often have

dietary issues, I will be happy to donate \$5.00 to MG Canada for every book that is sold to a limit of \$300.00. The cost of each book is \$25.00 which includes shipping in Canada. Please send me an email at: joycewovens@gmail.com for payment options." Joyce Ovens

MG Canada's Newsletter "Contact" is published by Myasthenia Gravis Society of Canada

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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.





In Memory:

"Kind, Funny, Loveable, Giving"

Jill Dupuis, Georgetown, Ontario, 1977 – January 4, 2021,

Trafalgar General Hospital, Oakville from complications of COVID 19. Jill was diagnosed with Myasthenia Gravis about 3 years ago. Graduate, University of Guelph. Teacher over 20 years.

Jill was a passionate reader — even switching to audio books after her eyes were affected by her Myasthenia Gravis so she could keep expanding her knowledge and keeping her brain sharp. She would make lists of books she wanted to read in her lifetime, polishing them off in months, rather than the years it would take the rest of us.

In the last three years Jill faced Myasthenia Gravis and Cushing's Disease diagnoses, two major surgeries removing two tumours, one of which was cancerous, radiation treatments and then her last valiant battle with COVID 19.

Born and raised in Sudbury, Jill lived in Southern Ontario for nearly 25 years, after attending the University of Guelph, followed by teacher's college at Nipissing University. She was born to be a teacher and excelled at making her students feel loved and special. Being able to empathize with and relate to her students was her superpower. Jill spent the majority of her 20-year teaching career at Glen Williams Public School, Georgetown, Ontario, where she delved into her passion of art, expanding it most recently to digital art. Her talent was infinite, as was her kindness.

Jill began feeling under the weather at the beginning of December, 2020. At first she thought it was a cold, but decided to get tested for coronavirus to be safe. It came back positive — a result the family knew could have far-reaching implications as Jill was living with Myasthenia Gravis, a condition that causes muscle weakness and, at its worst, respiratory failure.

Over 20 memoriam contributions to the Myasthenia Gravis Society of Canada are **greatly appreciated.**

Neil Lalonde
Madelen& Dan Sweeney
Elizabeth Taylor
Lorraine Sweeney
Minh Trac
Eileen Sweeney Ward
Rochelle Turcotte
Betty Reed
Bryan & Heather Luren

Jenny & Eric Caetano Ruth & Brian Zanatta Lisa Daiber Saskia Jarvis Emily Candelora Debbie Krohn Diane Uram Carla Parisotto Sara Corkum Patrisha Brunet
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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

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905 642 2545



Inspiring architecture. Thank you Tony Watkins for your recent suspension bridge photo.

Myasthenia Gravis 24/7 personal healthcare preparedness, especially in current Coronavirus crisis.

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 when heading for emergency. Have your MG Canada Blue Card ready with "do and don't" recommendations regarding antibiotics and other treatments that might acerbate your Myasthenia Gravis. Ask for new cards at

membership@MGCanada.org &/or it's automatic when becoming a member or renewing your membership.





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
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Welcome March! Thank you to all our MG Canada front line volunteers.

That includes you, our Newsletter contributors, readers and influencers. Not surprisingly, MG Canada is now directly connected in various ways, to over 2000 Canadians. There are many ways to serve our fellow Canadian Myasthenia Gravis Patients, Caregivers, Healthcare Professionals, MG Researchers — especially, but not only in this continuing COVID 19 sur-reality. Day after Day. It takes a very large contingent of committed, to shepherd our Chronic MG condition. We're a dynamic interconnected circle of caring. Social media, Website, Newsletters, support sharing - all helps greatly. We've seen our Myasthenia Canada Facebook group continue to grow because we respect and share our experiences 24/7 with compassion and empathy. We're here for each other MG brothers and sisters. This is the season to say thank you for all that love and caring. Sincerely, MG Canada Board of Directors. We look forward to spring. Stay well and Safe.

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"Canada's National Myasthenia Gravis Patient Advocacy"