Myasthenia Gravis Society of Canada

Myasthenia Gravis Society of Canada

There is Hope Through

'CONTACT'

Printed in the interest of those affected by Myasthenia Gravis

"Could It Be MG?"

Quarterly News | Volume 44 Issue 2 | June 2020

MG CANADA DECLARES 2nd Annual

"JUNE IS NATIONAL MYASTHENIA GRAVIS AWARENESS MONTH"

and how you can help get the word out.

"We can't ever do enough public and health professional education awareness about Myasthenia Gravis. Ask anyone who's been in an emergency ward line-up, barely able to breath, unable to swallow or chew – in MG crisis. Scared. Then admitted. Then left on a gurney for several hours, unattended without treatment."

The good news is that 6 years ago in Canada there was no national organization. Welcome MG Canada. *"Canada's National Myasthenia Gravis Patient Advocacy".*

-No Canadian MG Facebook groups –official or unofficial -Now there is.
-Very little social media focus on Myasthenia Gravis, in any serious way—Now we are evolving MG awareness in several social media platforms.

-But actual Canadian National engagement and proactive awareness has a long way to go.

Myasthenia Gravis awareness in every province, every territory, every city, town, village. Every hospital, medical clinic, medical student memory bank. Nurses. Doctors. Healthcare professionals including family medical. Health specialists. Optometrists. Physiotherapists. Dentists. Cont. on P.2

Continued from Page 1 - June is National Myasthenia Gravis Awareness Month

MG awareness for all Canadians at large. We have only begun. It's a huge story of symptoms, diagnosis, treatment, stability, 'new norm' acceptance and getting on with being productively happy.

We still don't know:

-What causes MG. We have suspicions – but we still don't really know.
-We don't know how to cure it. Treat it, but not cure it.

We do know:

-**MG** is not contagious, not transmitted. Good to be aware of in this current pandemic.
-**MG** for the most part is not genetic like many other conditions can be. Reassuring for family and friends.

-**We know** MG is an Auto-Immune condition.
-**We know** MG patients are in all ages and both genders.
-We know MG can be treated, once diagnosed.
-We know the treatment for diagnosed MG has many variables, many predicated on other pre-existing health conditions.
-We know that Canada has the capabilities to treat MG but many Canadian MG patients live beyond convenient treatment clinics.
-We know that diagnosed and treated MG patients can usually be self-medicated with proper guidance and ongoing regular check-ups.
-We know there are between 15,000 and 20,000 diagnosed or probable MG patients in Canada and it could be higher because its symptoms are masked with many other conditions or many never get proper diagnosis.
-We know we can lead a positive, productive quality of life (HR QOL) with treatment.
-We know there are new MG treatment pharma products being approved by Health Canada and on trial for approval.
-We know the average treated MG patient looks very normal and can remain highly productive.
-We know there are many reasons to have hope for improved treatments and potential cure.

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Continued from Page 2— June is National Myasthenia Gravis Awareness Month

We need your help to get the word out on MG. Whatever skills you have can help. Share your personal story – send it to us - and give us permission to use it. membership@MGCanada.org Send us your photo also. If you have personal reasons and prefer not to use your name or photo – no problem, as long as you verify. Many of you have amazing social media skills. Use them this month to publicise MG – and mention MG Canada and our web site www.MGCanada.org. Generate a Myasthenia Gravis story in your community, your professional association, your family doctor's office, your service club, your church. Share it on your social media page.

Join your Canadian MG brothers and sisters at MG Canada, to build more Canadian MG awareness. It's patriotic. It helps you and everyone.

MG CANADA DECLARES 2nd Annual *"JUNE IS NATIONAL MYASTHENIA GRAVIS AWARENESS MONTH"*

Editorial: MG PATIENT COURAGE QOL COPING WITH COVID-19

Be proud of yourself for MG managing 'Self Isolation'

You're doing brilliantly. We're proud of you. 'Quality of Life' for Myasthenics, particularly now, takes effort and attitude. We have been self-isolating since mid- March. At least it gives us a fighting chance to avoid this new health monster, COVID-19.

A friend sent me at terrific exposure risk guideline created by three writers with NPR – (National Public Radio). "Assuming safe distancing practices, a panel of infectious disease and public health experts rated the risk of summer activities, from backyard gatherings to a day at the pool to sharing a vacation house with another household. Personal risk depends on your age and health, the prevalence of the virus in your area and the precautions you take during any of these activities.

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Continued from Page 3—Editorial—MG Patient Courage

Also, many areas continue to restrict the activities described here, so check your local laws. There's no such thing as a zero-risk outing right now. As businesses and public areas reopen, decisions about what's safe will be up to individuals. It can help to think through the risks the way the experts do.

(Editor's Note: Myasthenics are particularly at high risk of infection, so add at least one risk level to everything outlined with safe distancing. For now always wear a face mask away from home.) **1. A backyard gathering with one other household: low to medium risk. 2. Eating indoors at a restaurant: medium to high risk. 3. Attending a religious service indoors: high risk. 4. A popular beach or pool: high to medium risk . 5. Outdoor celebrations such as a wedding with more than 10 guests: medium to high risk. 6. Public restroom: low to medium risk. 7. Friend uses your bathroom: low risk. 8. Vacationing with another family: low risk. 9. Hotel: low to medium risk. 10. Haircut: medium to high risk. 11. Indoor Mall: risk varies. 12. Nightclub: high risk. 13. Outdoor Camping: low risk. 14. Outdoors Exercising: low risk**." *(Editor's Note: 15. Grocery Shopping: low to medium risk at responsible stores.)*

We've had a few personal safe distance visits to our home, outdoors only – at a distance. 6 to 30 feet. None indoors so far. We go for occasional walks sticking to open areas. It's hard not to be a little hyped by endless days indoors. Even in colder days some time on the porch is uplifting. I've chatted by phone with many of you. I admire your calmness. It seems a good idea to show the check list derived from Canadian Mental Health Association. See Pages 11-13.

The hardest part for us is the daily schedule – or lack thereof. Recently I've started to set my alarm. Trying to get back onto a more regular eating schedule. One of the best things you can do is call someone. Connect. Engage. Empathize. Exercise anyway you can. Please stay in touch. Cap.

Cap Cowan, President and
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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.

A Side Effect of MG Meds: Immunocompromised:

By Dr. Cheryl Zimmer

Autoimmune diseases, such as Myasthenia Gravis (MG), occur when the body's immune system mistakenly identifies itself as a foreign invader, creating autoantibodies to attack and destroy normal cells. Autoimmune diseases do not render a person immunocompromised. In fact, one would consider that people with autoimmune diseases actually have a highly active immune system. The problem is that it is attacking the wrong organism. So, what makes people with MG immunocompromised? The answer is the medications they take to combat their disease.

Immunosuppression is often the treatment of choice for MG to control symptoms, and may include corticosteroids (prednisone), azathioprine (Imuran), mycophenolate mofetil (CellCept), mycophenolic acid (Myfortic), biologics, and plasmapheresis.[1] A 2018 study by Pedersen et al., found that 75% of patients with MG had been treated with immunosuppressants at some point following their diagnosis, with prednisone and azathioprine being prescribed most frequently.[2] Although immunosuppressants are effective at treating MG, they carry a range of other consequences. As compared to the symptoms and daily grind associated with MG however, it is often worth the risk to take these drugs, in conjunction with careful monitoring.

Prednisone is a glucocorticoid that suppresses the immune response by decreasing antibody production. This is achieved by inducing T lymphocyte cell death (apoptosis), preventing the action of inflammatory cytokines, and impairing antibody production of B cells.[1,3]Because it is a broad immunosuppressant, it can make a person more susceptible to infections. Other side effects include high blood pressure and blood sugar; weight gain and edema; issues with mood, sleep, and memory; cataracts and glaucoma; and, osteoporosis.[4]

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Continued from Page 5—Immunocompromised : A Side Effect of MG Meds

Monitoring of blood pressure, glucose, weight, potassium, and bone density are required. Calcium and vitamin D supplements are recommended to reduce the risk of fractures.[3]

Azathioprine has a targeted specificity for lymphocytes, inhibiting DNA and RNA synthesis and cell proliferation.[1] Like other drugs used to treat MG, it was initially used as an antirejection drug following organ transplantation. Unfortunately, it has a long latency, taking 6 to 12 months before becoming effective, with a peak impact at 24 months. Significant limitations of azathioprine are liver toxicity (hepatotoxicity), bone marrow suppression (myelosuppression), and low white blood cell count (leukopenia).[3]Mycophenolate mofetil is a prodrug of mycophenolic acid, meaning that it is converted into the pharmacologically active agent once it is metabolized by the body. Mycophenolate selectively interferes with lymphocyte function by inhibiting *de novo* purine synthesis.[3]Long term adverse effects also include myelosuppression and malignancy. Regular blood tests are important for MG patients on these medications, including monitoring complete blood count (CBC) and liver function. Malignancy and skin cancer screening should be done on a regular basis, with measures taken to reduce sun exposure.

New monoclonal antibody biologics, such as eculizumab, a complement inhibitor, and rituximab, a B-cell depletion therapy, are being used more frequently to treat MG.[5]Adverse events include immune-medicated end organ dysfunction and acute systemic inflammatory syndrome. Eculizumab carries the additional risk of meningococcal infection. Rituximab may cause progressive multifocal leukoencephalopathy (a disease that affects the white matter of the brain), myelosuppression, and hepatitis B reactivation, with the need for CBC and differential/absolute neutrophil count monitoring. Plasmapheresis is a short-term treatment for MG that filters antibodies from the blood. Because of the depletion of immunoglobulins during plasmapheresis, transient immunodeficiency may result for several weeks.[6] Fortunately, intravenous immunoglobulin (IVIG) can restore plasma to normal, reversing immunosuppression.Plasmapheresis is a short-term treatment for MG that filters antibodies from the blood. Because of the depletion of immunoglobulins during plasmapheresis, transient immunodeficiency may result for several weeks.[6] Fortunately, intravenous immunoglobulin (IVIG) can restore plasma to normal, reversing immunosuppression.

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Continued from Page 6—Immunocompromised : A Side Effect of MG Meds

…So, what about the elephant in the room: COVID-19?

Infections, in general, can exacerbate MG, even in patients who are just taking pyridostigmine (Mestinon), without the use of immunosuppression agents. Those with swallowing (bulbar) and breathing (respiratory) difficulties may be at an even higher risk of complications from their MG, when confronted by illness or stress. According to an article published in *Neurology* on May 5, 2020, there is a theoretical increased risk of developing COVID-19 in patients with MG who are on immunosuppressant therapies.[7] The authors indicated that those taking high doses of immunosuppressants, or multiple immunotherapies concurrently, were at a higher risk of contracting COVID-19, with the potential for more severe symptoms. However, a recently published guidance document in the *Journal of Neurological Sciences* stated that MG patients should continue their current treatment, unless approved by their healthcare provider.[8]

Vaccine development has ramped up to combat COVID-19. It is Important to remember that live vaccines can result in significant complications in immunocompromised patients and should be avoided.[3] Inactivated vaccines, which are safer, may be less effective,[7] but will be necessary to reduce the risk of contracting the virus.

To put things in perspective, in Canada on May 24, 2020, there were approximately 37.7 million people, of whom approximately 83,600 had contracted COVID-19.[9] That is only 0.2% of the population. An epidemiology study published in 2016 determined that the prevalence of MG in Ontario was 32/100,000 population.[10] Extrapolating, approximately 12,000 Canadians have MG, but only 24 (0.2%) will have contracted COVID-19. So, the risks are extremely low. ***Just to be safe, those on immunosuppressant medications should be extra-vigilant about practicing physical distancing[8] and wash their hands frequently.***

Good Friends 2020

Dr. Cheryl Zimmer.

Continued from Page 7—Immunocompromised : A Side Effect of MG Meds

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MG Puns for MG Educated Minds

- *I wondered why the baseball kept getting bigger. Then it hit me.*
- *I thought I saw an eye-doctor on an Alaskan Island but it turned out to be an optical Aleutian.*
- *A dog gave birth to puppies near the road and was cited for littering.*
- *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.*

IVIG SHORTAGE CRISIS PENDING!!!

COVID-19 strategy of self isolation has created another medical treatment crisis. Blood/Plasma donations are down dramatically. Strategy planning for a Canadian national multi-teared patient priority for blood and plasma shortages is now underway. Our Canadian National Emergency Blood Management Committee (NEBMC) co-chairs have invited MG Canada to engage on the development of an interim immunoglobulin shortage management plan. All our MG Medical Advisors have agreed to help. You can help, too. Here's how.

Encourage Family and Friends to donate Blood and Plasma. Your local donation centre may be closed but there are other locations available. Seek them out.

Your Myasthenia Gravis Society of Canada represents all Canadian MG patients from coast to coast. We are now active stakeholders with 'Canadian Blood Services'. **All our Medical Advisors are helping. Many MG patients rely on IVIG for treatment at one time** or another. Immunoglobulin is derived from plasma. Without it we have a much larger problem than just the pandemic. Some MG patients rely on IVIG only in early stages of MG treatment. Many rely on IVIG long term. **MG Canada asks for your help to increase blood/ plasma donations now!**

MG Canada Support Group Meeting

The MG Canada GTA Support Meeting for June 2020, cannot be held due to *current social distancing guidelines and self quarantining . Meetings will be resumed when the guidelines allow .*

905 642 2545 Email Contact: CapCowan@MGCanada.com

MG Support Group Meeting Ottawa & Region

Email Contact: mgottawa@yahoo.com

Carry On.... 2020

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

CMHA's Toolkit on Mental Health.

Check In On Your Mental Health Using Canadian Mental Health Association's "2020 Toolkit"

While people with Myasthenia Gravis may have varying symptoms from day-to-day or hour-to-hour to contend with, we thought it helpful to consider the following overview thoughts from CMHA.

"There are many schools of thought on mental health. So, at the Canadian Mental Health Association, we (CMHA) waded into everything from western psychology to Indigenous knowledge, and here is what we found: when we look at various descriptions of mental health, the overlaps are striking.

We (CMHA) found that, while feeling well means different things to different people, some things might actually apply to all of us: in order to thrive, we all need a good sense of self, and we all need purpose, contribution, hope, resilience and belonging. We've condensed that knowledge into an informal list that you can use to check your own mental health. (You can find the sources we consulted below.)

Read each statement, and consider whether you "Agree" or "Disagree" with it. It's not a scientific tool, or a way to diagnose yourself. It's just one way to check in with yourself about your mental health, and maybe guide you on how to support and improve it.

Your sense of self

- I feel confident about my own opinions, even if they're different from what other people think or believe.
- I think people respect me, but I can disagree with others and still feel ok about myself.

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- I feel that I am the expert on my own life.
- I consider myself to be a good person.
- I deserve to feel well.

Your purpose and sense of meaning

- I feel like I'm reaching my potential.
- I feel I am growing as a person.
- I challenge myself and my thoughts about the world.
- I have a sense of purpose and meaning in my life.
- It is a better world with me in it.
- I am good at things that matter to me.
- I get something out of the things I do.

Belonging

- I get along with others, and I feel good about my personal relationships and social interactions.
- I feel like I am part of something bigger than myself.
- I feel like I belong.
- I have people in my life to support me.

Contribution

- What I do matters a lot to others.
- I feel useful and productive.
- I make the world a better place in my own way.
- I am making a difference.

Hope and enjoyment

- I am optimistic about my future.
- I feel good about myself.
- I like and accept myself.
- I usually expect good things will happen.
- I enjoy life.

Resilience

- Things are hard sometimes, but I think I deal pretty well.
- I know I can't control everything, but I take action where I can.
- If you knock me down, I get back up again.

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Are you looking for services or supports in your own community? Visit cmha.ca/find-your-cmha to find your local Canadian Mental Health Association. **If you are in a crisis or need Immediate assistance, Visit www.crisisservicescanada.ca or call directly at: Canada: 1-833-4566 Quebec: 1-866-APPELLE (277-3553)**

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Inspiring Sunset Near Tweed, Ontario

Photo Kelly Cowan

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.

"My Personal Myasthenia Gravis Journey" by David Reid,

an MG Canada Facebook Member. Printed with permission.

In 2012, after several years of doctors trying to diagnose the cause of my many health issues, they finally figured out my primary medical issue is an autoimmune disease called "Myasthenia Gravis". In the course of finding this out they discovered several other issues.

Myasthenia Gravis is an autoimmune disease that affects the communication between my brain and my muscles. Symptoms can include getting tired very easily, slurred speech, vision changes, difficulty breathing, difficulty swallowing, burning in feet or hands. Sudden muscle fatigue and/or weakness.

By the time I was diagnosed with Myasthenia Gravis in 2012 I was a complete mess. I weighed 538 lbs (244.5 Kg) at my heaviest. I could no longer swallow solid foods. My speech was so slurred only my wife could understand what I said. Liquid multivitamin and 'Boost' was all I could swallow to survive on. I guess one good side effect was I started dropping weight. I could no longer walk more than a few feet, breathing was very difficult. I had such severe pain in my back I was on high doses of morphine and had lost much of my mental acuity. I had significantly reduced short term memory. I could watch a movie and 2 days later watch it again with out the tiniest sense of familiarity.

When the specialist diagnosed me, he sent me straight to the ER. A CT scan showed an existing and fractured Thymus. Normally we all lose our Thymus after puberty when our immune system is fully established. The Thymus becomes atrophied and is absorbed back into our bodies. My acetylcholine levels were all out of whack, my immune system was attacking my own body. I will discuss treatments I've received in subsequent postings.

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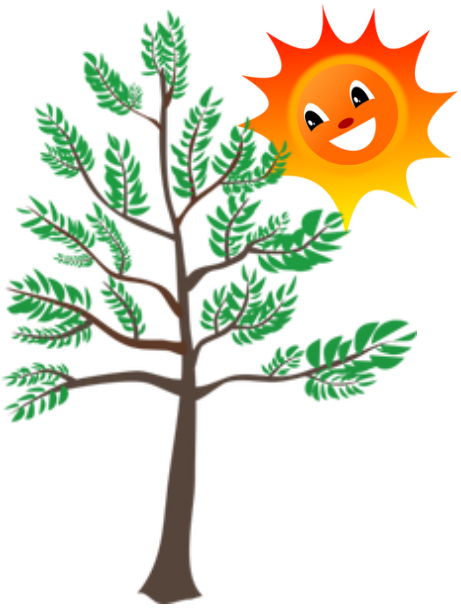
Continued from Page 14—"My Personal Myasthenia Gravis Journey."

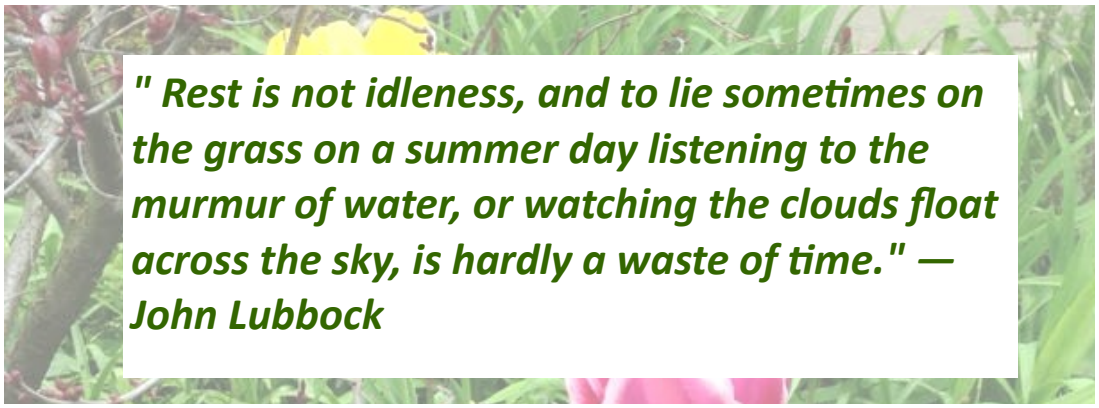
My GERD (Gastroesophageal Reflux Disease) resulted in severe heartburn and caused my teeth to begin melting away from the acid. Eventually I had to have the remnants of my teeth surgically removed. Walking was made even more difficult by the numbness in my feet from the neuropathy. **From the onset of early symptoms it took over 3 years for complete diagnosis.** This was caused by many factors. Several doctors told me to just lose weight and all would be well. It wasn't until I confronted my GP and asked "Does obesity explain slurred speech and numb feet?", that he started to take me more seriously. My GP then finally ordered an MRI to test for MS. When I could not fit in a standard MRI machine Alberta Health spent almost 2 years arguing over what department was going to pay for sending me to a large format MRI. It wasn't until completing an MRI with a negative result for MS and a colleague of my wife from her work (Speech Pathology) suggesting I needed a specialist, that they sent me to a neurologist in Edmonton.

That neurologist sent me to a specialist in autoimmune disease who then diagnosed me with Myasthenia Gravis. Before this diagnosis they were telling me it was MS, after the MRI was negative for MS, they were thinking ALS. To be fair, I had told the doctors that I had been diagnosed by my pediatrician at 13 with Myasthenia Gravis and referred me to a specialist. In the 6 months before that appointment my mom researched and put me on mega-dose vitamin therapy. By the time I went to the specialist all signs of Myasthenia Gravis had disappeared. Because western medicine does not believe Myasthenia Gravis can be cured by vitamins and diet they dismissed the childhood diagnosis and did not look for Myasthenia Gravis.



This becomes important later as a trigger to start looking for non traditional treatments for Myasthenia Gravis.

Regards,
Fuzzee Dee (David Reid)



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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:
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247 Harold Avenue, Stouffville, Ontario, L4A 1C2.
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Questions or Changes? Call 905 642 2545 or e-mail to membership@MGCanada.org

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

Please make cheque payable to: Myasthenia Gravis Society of Canada

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Myasthenia Gravis emergency 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 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
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905 642 2545 www.MGCanada.org membership@MGCanada.org

Do you have an MG article of interest to MG Canada's Newsletter 'CONTACT'? Please forward by mail or email at membership@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

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"June is MG Canada National Myasthenia Gravis Awareness Month"