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 45 Issue 2 | June 2021

Forest Breathing—Dr. Julie Rowin MG Integrative Neurology

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Newsletter Highlights:

Continued from Page 1 Forest Breathing

It's Spring! And, I am a big proponent of the benefits of getting outside. Did you know that the health promoting effects of nature are backed by plentiful scientific evidence?

Research on Forest bathing, or Shinrin-yoku as it is known in Japan, has shown positive effects on immune health, mental health, stress reduction, and cardiovascular health.

What is Forest bathing?

Forest bathing is immersing yourself in nature in a mindful way. This could be a slow walk through a forest path taking in all the sounds and smells and sights or it could be sitting on a park bench and observing your breath.

Why Forest Bathe?

When you spend time in the forest, you are actually bathing in the substances released from the plants and trees known as the phytoncides. Phytoncides are what create the 'aroma' of the forest. Trees like conifers emit these phytoncide oils and compounds to protect themselves from pathogens. These molecules are beneficial for our immunity too.

Breathing the forest air boosts the number and function of natural killer cells in our blood.(1,2) Natural killer cells fight infections, cancers and tumors, so spending time with trees is a special form of bathing.

Various studies have shown the benefit of forest bathing on:

- **Memory**
- **Anxiety, fatigue and depression**
- **Blood Pressure (3)**
- **Immune function**
- **Cortisol levels**
- **Heart Disease & Metabolic Syndrome**

- **Increasing the activity of your parasympathetic nervous system and reducing the activity of your sympathetic nervous system, forest-bathing has anti-anxiety effects and reduces blood cortisol levels which has far reaching benefits to your overall health. (4, 5)**

How to Forest Bathe

Take a slow walk on a forest or park path or trail and tap into all five senses:

Listen carefully to hear the birds singing and the breeze rustling. Is there a body of water to hear? Can you hear your footsteps?

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Look at the various green colors. Are there waves in the water or is the water calm? Make sure to take notice of the shapes, colors and size of your surroundings. Notice the distance between yourself and the object(s)) you are observing.

Smell the aroma of the trees, soil, plants and water. Breathe in deeply.

Can you ***taste*** the air?

Feel the roughness of the bark on a tree, the sandy soil, the leaves. Are they damp? Are they dry? What textures do you feel?

The positive effects of forest bathing remind us of our intimate connection to nature. Our high paced, pressured and indoor lifestyle with high reliability on technology has done little to improve our health. Take 20 minutes a day to breathe in nature and notice the profound effects it has on your psychological well-being as well as your physical health.

If you cannot get outdoors, bring a bit of nature inside such as a plant or some flowers or some twigs. Use your senses to explore these objects. Even a small indoor green space can help with stress and anxiety.

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Dr. Julie Rowin MD is board certified in Neurology, Neuromuscular Medicine and Integrative Medicine. *She is unique amongst neurologists in that she practices holistically and has additional training in Medical Acupuncture, Yoga and Ayurvedic Medicine. Her holistic healing approach to the treatment of adult neurological conditions integrates nutrition, acupuncture and mind-body energetics with conventional medical management.*

Her treatments are designed to promote the most gentle way to help you restore your body to balance. www.julierowinmd.com

This article and photographs were arranged by Garry Morehouse, MG Canada

MG Canada June 2021 Newsletter Editorial

Editor Cap Cowan

"Myasthenia Gravis Canada Announces *"3rd Annual June Myasthenia Gravis Awareness Month"* *How you can help get the word out?* MG engaged conversations 24/7 at Myasthenia Gravis Facebook Group Canada. Time to let out all the stops. Send a copy of our June 2021 Newsletter 'Contact' to family, friends, personally connected Health Care Professionals. Organize an MG Canada Fund Raiser such as an MG Golf Tournament or MG Walkathon.

MG Canada Patient Engagement: In March we discussed what has changed the most in the last 10 years of MG Canada's Patient Advocacy. i.e. The remarkable increase in Canadian MG patient engagement with each other. Example: Tony Watkins has been an MG Canada National Executive Board member for several years. Tony also monitors our Myasthenia Gravis Canada Facebook Group. Tony says: 1) COVID concerns are still at the top of the current list of MG patient issues. 2) Remarkably faster Myasthenia Gravis diagnosis and treatment. 3) Inconsistent spectrum of national diagnosis by regional geography. 4) Significant increase in female participation in MG conversation. 5) Sharing reveals persistent need for early MG symptom information. 6) Often early confusion with Multiple Sclerosis (MS) symptoms and other Auto Immune conditions such as ALS, GBS/CIPD, LUPUS. 8) Fear of probable and confirmed MG, coupled with need for early patient reassurance, is still cause of big hurdles for newly diagnosed MG patients, coping with MG diagnosis and their treatment options.

Myasthenia Gravis Canada National 2021 Awareness Campaign: *"Why it's more important than ever! Because when you tell someone you've got Myasthenia Gravis you still get the blank stares. Because rarely can anyone spell it, never mind be aware of it. The fear is there by everyone including Health Care Professionals. No, it's not contagious. No, it is not genetically inherited. Yes, it can be treated."*

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We have to take our MG Awareness message to the streets. Canadian MG patient engagement. It's about helping each other by being engaged with our fellow Canadian MG patients, families, friends, public and Health Care Professionals. We know our MG Canada Awareness Campaign helps tremendously. With your help, we know all our asserted efforts including social media and our website www.MGCanada.org will help us all engage Super CalafragilisticlyExpealidosiously even better.

"Let's just do it!"

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

Welcome Lindsay Peets New Member of Your MG Canada Board of Directors Team

My MG Story by Lindsay Peets

My name is Lindsay Peets and I am a newly appointed MG Canada Director .

It's a pleasure to (virtually) meet you! I know it is always difficult to get a true sense of someone from a blurb, but hopefully this will give you at least some sense of why I am so excited to be involved with this society.

Before starting my journey with MG, I studied Cognitive Science then International Development at McGill University, where I also worked as both a Research and Teaching Assistant. In my spare time, I was the President of the McGill Savoy Society, a light opera company. Before leaving the workforce, I worked as an Operations Manager and COO specializing in change management and rapid growth. I have a (very nerdy) love for organizational optimization, outreach/growth strategy, and people-focused support. Before MG, I spent my time singing opera, doing DIY home renos and playing roller derby. Now, you can almost always find me sewing, doing digital art or editing videos.

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Much more important than my work experience, though, is my dedication to advocacy. Even before my diagnosis, I was passionate about patient advocacy and medical reform. I am particularly interested in intersectional identity and its impacts on health access. As a young, queer woman who has experienced mental health issues, I have seen first-hand how one's experience with the healthcare system is affected by one's identity and presentation. As research and medicine evolve to overcome these challenges, dedicated to contributing to long-standing, community-informed change.

My journey with MG is relatively new but nonetheless eventful. Since my diagnosis with AChR+ generalized myasthenia gravis in July 2020, I have had to stop working, have undergone a thymectomy and have had five MG crises. As a new MG patient myself, I can appreciate the trials and setbacks we face when seeking and first adjusting to our diagnosis. As with any chronic health issue, a support network is vital to succeeding in our ongoing health struggles. This is all the more true with myasthenia gravis, whose rarity and complex presentation threaten to isolate its patients. Speaking with other people who really *get it* has been critical to keeping me going through this difficult first year. In the most basic, vital sense, it reminds me that I am not alone.

During my first year with MG, I also experienced some of the unique ways in which MG impacts the life of a young woman like myself. From career impacts to being invalidated by doctors and dealing with my new identity as a chronically ill person, every aspect of my life has been touched by this disease. Having seen the impact that community support has on us as patients, my hope is to develop new resources and support networks specifically focused on the experiences and needs of both young and female myasthenics. Like every group, we face our own unique challenges with MG and all that comes with it. It is my sincerest hope that I can use my new position to advocate on your behalf and develop resources to address your biggest needs. **Lindsay Peets**

The First of Two Parts. To be continued in the September issue of "CONTACT" You can reach Lindsay through Membership@MGCanada.org.

Myasthenia Gravis Society of Canada "National Journey of Hope"

Sunday, Zoom Meeting: June 13 at 2-5 pm EDT

Meet Lindsay in person during 2-3 pm Open Mike, followed by 3-4 pm feature guest Dr. Carolina Barret-Tapia, and 4-5 pm Questions & Answers.

Email Membership@MGCanada.org for your invitation link.

"What Does "Being Better Mean?"

Remission, stability, refractory disease. What do we know about long-term outcomes in MG?

Carolina Barnett-Tapia, MD, PhD
Assistant Professor of Neurology. Department of Medicine, University of Toronto

A question on every patient with a new diagnosis of myasthenia is what to expect going forward. What is the prognosis? How long will they need treatment for?

Carolina Barnett-Tapia, MD, PhD

When we look at a large series following hundreds of people with MG, approximately 1 in 10 reach full remission.[1] In MG, this means absolutely no signs or symptoms for at least one year, and no use of pyridostigmine (Mestinon)—if you need pyridostigmine then you have some symptoms.[2] **Despite this low rate of complete remission, the majority of people with MG do get better with treatment, even if they are not in remission.**

But what does "being better" mean?

Most research studies rely on physicians' impressions to define good outcomes, but we know that often the views of physicians and patients differ.

In an electronic survey of 124 people with MG attending the Prosserman Family Neuromuscular Clinic at Toronto General Hospital, we asked them if they were satisfied with their current disease status. 80 individuals (65%) said they were.[3]The satisfied group had less symptoms than the group that was unsatisfied with their status, but most satisfied patients still reported some MG symptoms. Few had no symptoms at all. This means that for many people living with MG, It is possible to have good quality of life despite some persistent

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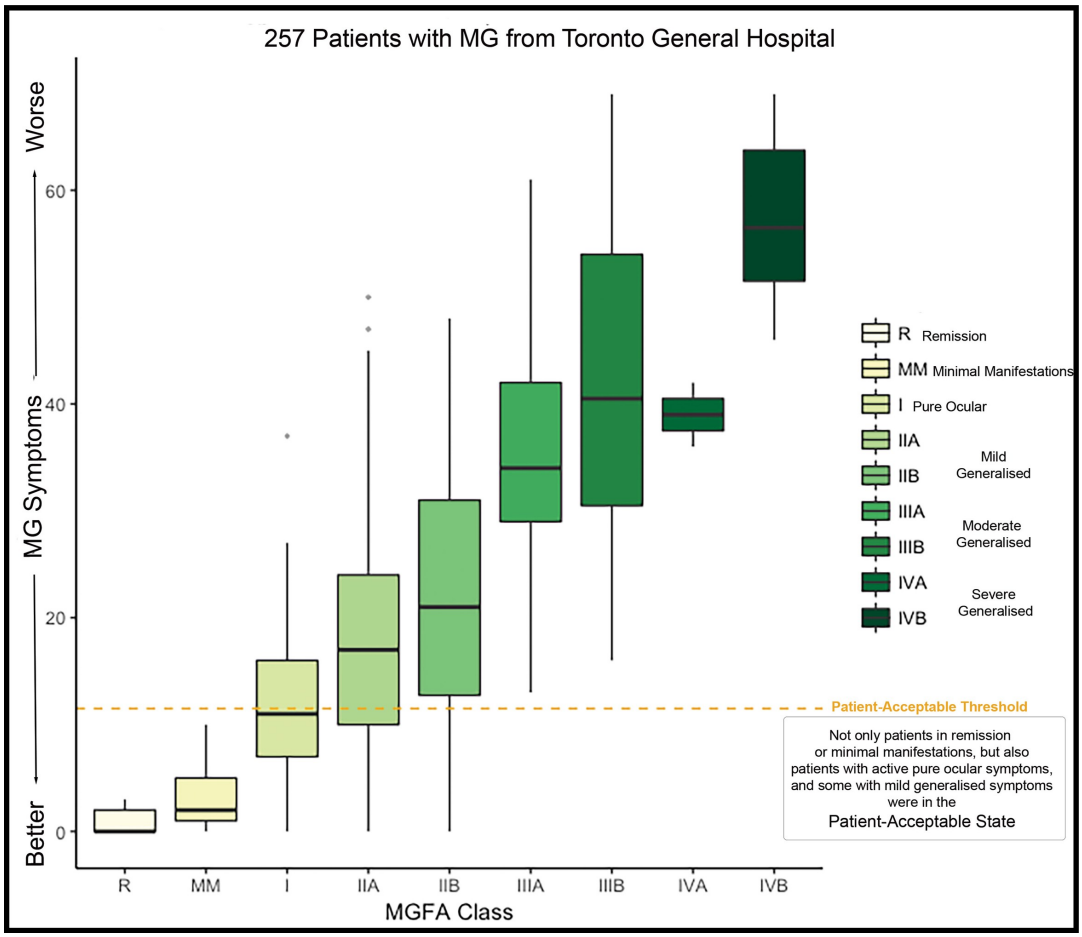
MG symptoms. When we looked at a larger group of patients (n=257) we found that many patients with active symptoms were in the acceptable symptom state. We also found that more men were in the patient-acceptable state than women. Previous studies have also found that women with MG may have worse quality of life than men, tend to have worse fatigue and disease scores. We don't know if this is related to biological differences (i.e. women having more severe disease) or if there are social factors at play, for example women having delayed diagnosis or having more adverse effects from treatments.



I think this concept of patient-derived acceptable states is important, because it brings a patient-centric lens to clinical practice and also research studies. That way we can focus on finding treatments that not only help patients feel better, but that can provide enough improvements so that patients also feel overall well. For example, we applied our thresholds for patient-acceptable symptoms in MG to the study of thymectomy in MG, and we found that the thymectomy group was not only better over time than the non-thymectomized patients, they had in average below the threshold of patient-acceptable symptoms, meaning that thymectomy helped patients not only to improve, but to reach an overall good state. And this is what we aim for in our patients.

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One symptom that is very concerning for people with MG is fatigue. We have found that fatigue is not only extremely important as it worsens quality of life, but it can improve with appropriate MG treatment.[4] People living with MG know that they have physical fatigue but many also report mental fatigue, with difficulties concentrating. We have also found that in MG fatigue is not only caused by MG itself, but is also associated with anxiety and depression. This is so important and sometimes forgotten in our clinic visits when we are often so focused on the disease itself, but we know that having a chronic disease can impact mental health.

Another source of concern for patients is the term "refractory MG", and we get several referrals each year for patients who are suspected of being refractory to treatment. Some people with MG have, unfortunately, disease that is hard to treat or does not respond with standard treatments, and we call this refractory myasthenia. Depending where you read about this, you can find that 1 in 10 to 3 in 10 patients with MG are refractory. This variability in numbers is because in different studies there have been different definitions of what it means to be refractory. We recently compared 5 different definitions in a group of patients and the rate of refractory disease ranged between approximately 5% to over 30%.[5] However, using newer definitions, the actual rate of refractory disease is probably around 5-10%, meaning that this thankfully occurs in a minority of patients. For people with refractory disease there is hope, as new medications have either been approved or are being studied in clinical trials.

Treatment Choices

I want to also note that we often discuss outcomes or symptoms in abstraction of treatments, but in reality, they are linked. For many people, some adverse effects of treatment are worse than some MG symptoms, whereas in other cases disabling symptoms may warrant more aggressive treatments. Patients should be able to discuss these trade-offs with their physician to decide upon the best course of treatment for them. We have little research into how people with MG make treatment choices and this information is important for physicians, drug developers (to produce medications that have a side effect profile that aligns with patients' preferences) and policy makers (to make decision regarding drug coverage). We are now studying this, and I hope to be able to share this with the MG community in the next year.

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Carolina Barnett-Tapia, MD, PHD. **Requested for MG Canada**

June is Myasthenia Gravis Canada's National Awareness Month

From Stable to Crisis -

The Spectrum of Exacerbation

By Dr. Cheryl Zimmer

Myasthenia gravis has its ups and downs. Muscle weakness may fluctuate overtime, even throughout the course of the day. Regardless of how long you have had the disease, stability may be elusive, particularly in cases of refractory MG. And, of course, we have all heard of, or even had, a myasthenic crises, when the respiratory muscles fail and the sufferer fights to breathe. But what about in between stability and crisis?

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Some MG patients may feel well for a while, whether on medications or not, and then experience a slow or rapid decline. Is it just a bad day? Are you experiencing a flare that requires medical management? Or is this a life threatening emergency? Lets review the spectrum from stable to crisis with a focus on exacerbations.

Let's review the spectrum from stable to crisis with a focus on exacerbations.

Across the Spectrum

Symptom-free, complete stable remission is the mecca that we all strive for, but according to a 2018 publication, up to 80% of people with MG fail to achieve this goal.[1,2] This is indicative of most chronic diseases. It is manageable but does not go away completely. This means that most people with MG experience it for life.

10% of MG patients have what is known as refractory MG.[1,2] These patients have persistent symptoms, that may be severe, and fail to respond to conventional MG treatments such as pyridostigmine (Mestinon). They require chronic rescue treatments (intravenous immunoglobulins [IVIG] or plasma exchange [PLEX]). Another definition of refractory MG is the Inability to reduce immunosuppressive medications such as prednisone, azathioprine (Imuran), or mycophenolatemofetil (CellCept), without a clinical relapse or the need for ongoing rescue therapy.[1,2]

A Myasthenic Crisis

A myasthenic crisis is defined as a severe weakness of the bulbar-innervated muscles or the respiratory muscles.[3] Breathing, swallowing, chewing or speech may be restricted over the course of a few days, or more rarely, a few hours. Supportive feeding, BiPAP, endotracheal intubation or mechanical ventilation may be required.[3,4]

A Severe Exacerbation

More common than a crisis, is a severe exacerbation. This is a clinical deterioration of MG requiring acute medical intervention or inpatient treatment but without the need for mechanical ventilation.[2] An article

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published in 2018 used the following three criteria together to define a severe exacerbation:[3]

1. **Progressive deterioration of MG** over recent days, but no longer than 30 days.
2. **A restriction** of the bulbar-pharyngeal functions, head-neck muscles or extremity strength affecting everyday life or beginning breathing weakness with reduced cough impulse.
3. **A Quantitative Myasthenia Gravis (QMG) Score[5] of at least 8 points,** with no more than 5 points resulting from the ocular findings. The QMG score is a standardized quantitative strength scoring system on a scale from 0 to 39, with a higher score indicating a greater severity. A 3-point change may also be significant for a severe MG exacerbation.[6]

Frequency and Triggers

In a study published in 2020, the frequency of myasthenic crises in patients without refractory MG was 7.1%, while the rate of crises in the refractory group was 14.3%.[2] The difference was much more extreme with regard to exacerbations, where in the refractory group, an alarming, but expected 64.3% of patients experienced exacerbations, whereas only 26.8% of patients in the non-refractory group had these experiences.[2]

Two risk factors that contribute to exacerbation include late onset MG (over 50 years of age) and the presence of additional autoimmune diseases.[7]Other triggers are respiratory infections, stress, micro-aspirations (inhaling small particles of food or fluids), changes in medication, surgery, and trauma.[7]Certain medications including fluoroquinolone, macrolide and aminoglycoside antibiotics, magnesium, betablockers and others, also contribute to acute MG exacerbations.[8]

Of note, and apropos of the time we are in, a recent study showed that there were no adverse effects or exacerbations as a result of vaccines in patients with MG.

Gauging Your Symptoms

There are several tools that you can use to gauge your exacerbation to determine if you are heading towards a crisis. Some signs to look for, as published in the Emergency Management of Myasthenia Gravis brochure

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Gauging Your Symptoms continued:

- **Rapid shallow breathing** to compensate for weak respiratory muscles.
- **Retraction of the supraclavicular fossa and intercostal spaces** as indicators of respiratory accessory muscle usage.
- **Paradoxical breathing and the inability to lie down on your back or speak more than a few words** are indicators of diaphragm weakness.
- **Severe slurred speech and difficulty managing secretions.**
- **Weak neck flexion** also correlates with diaphragmatic dysfunction. This can be tested by lying down on your back and attempt to lift your head off the bed and tuck in your chin.
- **A single breath count test** is conducted by counting out loud after taking a deep breath. The ability to reach 50 indicates normal respiratory function. A single breath count of less than 15 typically correlates with low forced vital capacity (FVC) and respiratory muscle weakness. Recent studies have used a cut-off of 25 to indicate an MG exacerbation.[9.10]

Note that pulse oximetry is NOT a good indicator of respiratory strength in MG patients as abnormalities in this parameter often develop only after life-threatening respiratory failure has already occurred.[4]

Conclusion

MG is a balancing act. Listen to your body and get to know your MG, realizing that fluctuations are normal and some days, you'll feel like a rubber chicken. Advocate for yourself by avoiding triggers that may result in exacerbations***. If you are noticing a decline, call your doctor to help you manage the flare with the appropriate rescue medication. And if you are having a crisis and can't breathe, don't play games. Call 911.***

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Dr. Cheryl Zimmer, Medical Writer for MG Canada

My Journey with Congenital Myasthenic Syndrome (CMS)

It all started with a "cute little wiggle". This is how my parents, family and family friends described the way I walked as a toddler and into my early years. As time went on, they began to notice I wouldn't run with other kids, would never walk up the stairs (I would crawl as a baby would even at the age of 5 or 6), and that I struggled with lifting things. My mother reported her concerns to our family physician. He felt I was just lazy and that my mother was being paranoid in thinking I had some ailment.

I was nine years of age when our physician finally started to listen to her concerns. This was because my grade 5 school teacher started to notice my differences.

My teacher, Mrs. G, reported that I really struggled in physical education. The basketball would fall far below the net when I would throw it. I was always last in any running or walking activities (Track & Field) or would only complete one round of the track instead of the ten we were assigned to complete. Mrs. G also noticed my "cute little wiggle", however, to her it was a struggle and not really "cute".

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She said it looked like I was limping when I walked. I recall her and the school nurse making me walk up and down the hall while they observed. Stairs were a struggle and I also recall falling down a lot as my legs would just give out for no apparent reason.

From here, referrals to specialists, hospital stays and lots of unpleasant testing began. It was determined I was rare, as children do not often present with auto-immune diseases, but I had something called Myasthenia Gravis. My body was working against itself with an attack or block at the neuromuscular junction causing the weakness I was experiencing. But there was GREAT hope!! In 80% of the cases seen where a child presents with MG, removal of the thymus gland pretty much cures all. So, surgery was scheduled and my thymus was removed at the tender age of nine. Unfortunately, this did nothing to improve my condition.

I took Mestinon, prednisone and had uncountable rounds of plasmapheresis. Mestinon was about the only thing that made a difference, however, I was still very weak. The next suggestion was to start IVIG treatments. By this time, I was now sixteen years of age, my parents were discouraged and felt a second opinion would be best before starting yet another new treatment.

My referral to the Head of Paediatrics, Dr. Haslam, at The Hospital for Sick Children was a blessing as he collaborated with Dr. Bril at Toronto General who helped get me to see a specialist at the Mayo Clinic in Rochester, Minnesota, Dr. Andrew Engle. This wonderful neurologist had been studying and treating a handful of patients who did not respond to the above therapies yet presented with what seemed like Myasthenia Gravis. He conducted all the unpleasant tests again, plus I had a surgery where he took a large piece of my intercostals muscle (rib area) to do extensive testing to try to determine what it was that was affecting me.

Here it was finally determined I did NOT have an autoimmune form of Myasthenia Gravis, rather I had a super rare disorder called Congenital Myasthenic Syndrome. This presents similarly to Myasthenia yet is so rare and unknown that many neurologists would just assume autoimmune MG.

NOTE: Part 2 of Cynthia Davidson's journey and treatment will continue in the Fall Edition of "CONTACT".

Patient Interest for British Columbia Study 3rd Phase. Must be MG patients.

Interested? Contact membership@MGCanada.org. All expenses paid by Study.

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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.

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Myasthenia Gravis Society of Canada
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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.

Sincerely, MG Canada Board of Directors. We are enjoying these spring & summer months. Stay calm. Stay well Stay Safe.

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

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"Canada's National Myasthenia Gravis Patient Advocacy "