

Spring 2026



Spring Newsletter



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Spring AGM & Support Meeting

Sunday, April 19 th, 1:00pm

2805 Kingsway, Vancouver, B.C.

AGM 1:00pm to 1:30pm

Support Group Meeting 1:30pm to 4:00pm

- President Kelly Carson
- Special Guest Speaker TBA
- June is Myasthenia Gravis Awareness Month
- Disability Program
- Sharing our wins and concerns about our disease
- Social time getting to know each other
- Sandwiches and Healthy Food will be available for your enjoyment

Friends, Relatives, Health Professionals, and other interested parties are welcome to attend.

**PLEASE HELP US REDUCE PRINTING AND POSTAL COSTS
BY READING THE NEWSLETTER ONLINE ON OUR WEBSITE
<https://myasthenia-gravis.ca>**

*Articles contained in this newsletter are for information only.
The MG Association of B.C. does not give medical advice
in matters of medical treatment.
Members should consult with their physicians.*

Myasthenia Gravis Association of B.C.

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V5R 5H9

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@ext.1284



www.myasthenia-gravis.ca



OUR BOARD

- Kelly Carson
- Linda Briggs
- Kayo Devicic
- James Postnikoff
- LuAnn Burgmuller
- 3 Open Positions

A Word from our President

Spring has sprung, let's hope so anyway. Where I live there should have been a lot of snow, we didn't get much snow at all. During the winter time I normally go away somewhere warm, but, since finding my new found love of walking Caminos that seems to be my only focus for vacations.

In February I had the pleasure of speaking at the 101 Camino meeting, talking about having an illness such as MG and walking the Camino, the importance of listening to your body at the same time living a full life. I've kept my Camino Links in this newsletter for those who may not have checked them out and who may be thinking about a walking vacation. I think that my love for walking Caminos may have something to do with my MG. When you can walk for 100s of klm you tend to take advantage of it. While I am in remission, remission is still remission it is not a cure. As we know there is no known cure for Myasthenia Gravis at this time. That's why organizations like us exist, to support those newly diagnosed and those whom have had MG for a long time like myself.

I stay very aware and grateful that I am in as good as health as I am.

This past year we were able to help secure an RN for the Neuromuscular clinic at Victoria General Hospital by funding the 20% of their wage. If you attended our Fall 2025 meeting you would have had the pleasure to meet Kayla Holliston the RN working at the clinic and listened to how she spoke about the need for a full-time RN position. As this was a one-time funding commitment from us we were hoping that they were able to secure the 20% this year. Kayla let me know the last time we spoke they were not able to secure the extra 20% of funding for the RN wages, yet. I am hoping that we can help lobby Island Health to understand the importance of this clinic and the need for full time care. What we can do this year is to fund a piece of equipment to help the clinic work more efficiently. Currently my understanding is that the clinic shares with the hospital a spirometer, it tests for Forced Vital Capacity (type of lung function test). So, when the clinic needs it they have to go and find the one that is shared with the hospital.

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Spot Lite

My Clinical Trial Experience

Hello!

My name is LuAnn Burgmuller, and I am delighted to have found this supportive group just north of my home in Ferndale, Washington. I truly appreciate the warm welcome I have received and am honored to be serving on the board.

MG hit me fast and furiously in August 2022. I had spent a lovely morning picking blackberries and sat down for a quick lunch when, suddenly, I couldn't swallow or move my tongue. Speech difficulties and eye twitching soon followed. After an ER visit—where I was discharged with the mystifyingly incorrect diagnosis of a congenital jaw malformation and microcephaly that causes death in infancy—I proceeded to my PCP, who thought I'd had a stroke; an ENT, who thought I was a hysterical woman; and an oral surgeon's office, where the staff assumed I was drunk on the phone and hung up on me. I finally called my PA friend in Montana, who essentially diagnosed me over the phone.

I've been a nurse for 44 years, yet I had only seen MG in one patient many decades ago. I had to do a lot of reading to catch up on the latest treatments so I could adequately advocate for myself. I convinced my PCP to order specific MG labs and a brain MRI to help rule out other potential diagnoses. He listened to me and was able to get me in to see a neurologist sooner than most—though I still had to wait six weeks.

I was started on mycophenolate mofetil (CellCept), which I continue to take, and pyridostigmine (Mestinon), which became ineffective for me after about a year.

After the initial shock of diagnosis, I became determined to raise awareness about this disease and support others. For two years, my symptoms were somewhat managed with existing treatments, but my quality of life was still far from normal.

Online, I found an opportunity to participate in a clinical drug trial at Oregon Health & Science University (OHSU) in Portland, Oregon. After a rigorous screening process, I enrolled in a Phase III clinical trial testing a new medication for MG.

Beyond the possibility of accessing a promising new therapy, I was drawn to the idea of contributing to medical science. Many of the treatments we rely on today—from insulin to modern cancer immunotherapies—exist because volunteers agreed to participate in research. I wanted to be part of that continuum.

[continued on page 4]

RESOURCES



MG EMS Considerations & Triage



United Way
British Columbia

The informed consent process stood out most. The research team carefully explained the study's purpose, potential risks, possible side effects, and my right to withdraw at any time. I appreciated that transparency. It made me feel respected rather than like a "test subject."

Upon acceptance, I traveled to Portland for weekly and biweekly appointments over the next six months.

I was assigned a dedicated clinical trial assistant who was readily accessible by phone, text, and email. She met me at the door at OHSU and accompanied me throughout each appointment. Visits included routine lab work, EKGs, MG-ADL assessments, spirometer testing, strength measurements, administration of the study drug (via injection), and an examination by the study's primary investigator, a neuromuscular specialist at OHSU.

The study was randomized and double-blind. Neither I nor the clinical team knew whether I was receiving the experimental drug or a placebo. However, it became evident early on—based on lab results and improvement in my symptoms—that I was receiving the active medication.

The pharmaceutical company covered transportation to and from Portland, lodging, and meals. I typically traveled the day before my morning appointment and returned home that evening. They even allowed me to experiment with different modes of transportation to determine what worked best. I flew, rented cars, and took the train—the train ultimately being the most efficient option.

Participation required commitment. In my retired life, it was not a hardship for me, though I recognize it could be for others. There were days when I felt fatigued from the additional testing and times when I questioned whether the improvements I noticed were real or psychological. The consistent support from the study coordinators made a significant difference. They checked in regularly and treated me with genuine care.

Unfortunately, the study drug caused my cholesterol to rise to alarming levels. Because I am unable to tolerate cholesterol-lowering medications due to severe side effects, I had to discontinue the trial. I later learned the study was suspended nationally due to similar cholesterol elevations in other participants. A new formulation of the drug is now being tested and, so far, does not appear to cause that side effect.

Even though this particular drug did not work out for me, I gained a deeper appreciation for evidence-based medicine, greater confidence in clinical research systems, and a meaningful sense of contribution to future patient care. Participating in a clinical trial transformed how I view medicine. Every approved treatment on pharmacy shelves today once passed through hands and lives like mine.

I would participate again if the circumstances were right. Clinical trials are not for everyone and require thoughtful consideration. But for me, the experience was empowering, educational, and meaningful.

If you are considering participation, ask questions, review consent forms carefully, and speak openly with your healthcare provider. Clinical research is not just about testing drugs—it is a partnership between science and people willing to move medicine forward



MGABC SPRING NEWSLETTER

2026 Myasthenia Gravis Association of BC

Front Page Banner:
K. Carson photo
Pemberton BC

Editor: Kelly M Carson
Contributor: G. Skidmore
Grandview Printing

A Word from our President [continued from page 2]

Spring 2026

Our Board of Directors have voted in favor unanimously to purchase one just for the clinic. These are the kinds of things that we do with your generous donations. So please think about us when you have a few dollars to spare.

We have also been in discussion with a member in Victoria wishing to have support group meetings again if there is interest. Well, there is definitely interest so we are at the moment looking for space and deciding when these meetings will take place. If you are from Vancouver Island and I have not contacted you and you would like to attend support group meetings in Victoria please call the office and let us know, or you can write it down on your membership form when you mail it in with your payment.

I know our newsletter goes out to all of our members and you can't all make it to our Spring meeting although I wish I could meet you all. If there is anything specific you would like to see in our newsletters please let us know. Take Care and I hope to see you on April 19 th 2026.



ARE YOU INTERESTED IN VOLUNTEERING?

- * Are you an IT person?
- * Have Communication Skills?
- * Board Member Interest or Experience?
- * Interested in Fundraising?
- * Stuffing Envelopes?
- * Help with meeting set-ups?
- * Help with meeting teardowns?

Go to our web site, shoot us a message, or send us a message when you pay your dues. Help us ensure that no Myasthenic needs to feel alone!

A Message from our Treasurer

Did you know that our membership fee is only \$20.00 per year? This helps us to keep our office at the Center for Ability in Vancouver. The fees also make it possible for us to send out two newsletters a year to our members and to also hold two membership meetings per year?

You can pay for your dues at an in-person meeting, or mail it in to

2805 Kingsway, Vancouver, BC Canada V5R 5H9

Payment can also be made conveniently through Canada helps.

Canada helps is also a great way to pay any other donations as well, we even have monthly donors who conveniently pay through Canada Helps.

<https://canadahelps.org/>

Search Myasthenia Gravis of BC

Payments made at the Spring Meeting or by mail or through Canada Helps, will be valid until March 31st 2027

I would like to thank all of our members who pay their dues and also like to thank those who think of us when they make out their wills.

WELCOME TO ALL NEW MEMBERS

LINDA BRIGGS



ABOUT OUR MEMBERS

Our membership grows and shrinks at the same time. In the last few years we have lost some of our membership which is very sad. Another sad thing is our membership is also growing. We have some newly diagnosed folks recently, and we are doing our best to reach out to them.

In fact, one of our Board members met with Betsy Seet clinical education at Lions Gate Hospital to give MG information, and information about the Myasthenia Gravis Association of BC. And they have requested that we come and speak in the near future to speak with staff about Myasthenia Gravis. This is a passion of mine, being a Myasthenic and being able to speak about my experiences not only with this disease but with the trials and tribulations of getting diagnosed and treatment for my MG.

We are branching out more and more to get word out that we are here for those who are newly diagnosed and those who have had MG for a long while.

This is where our current membership reside. Most of our membership are from BC but we do have members from across Canada and of course we are happy to have a Board member from the US and other members also from the US. We may be the MGABC.... but that doesn't mean that we only help those from BC.

The Myasthenia Gravis triggers that will get you if you don't watch out

They show up in crowded rooms, emotional storms, even in the space of a heartbeat.

Living with myasthenia gravis means learning that some of the most powerful triggers aren't the ones anyone warns you about.

They're not always heat, or illness, or overexertion (though those matter, too). The hidden triggers are the ones you discover only by living inside a body that reacts before you can make sense of it. They show up in crowded rooms, in emotional storms, in moments of joy, and even in the quiet shifts of your own heartbeat.

Overstimulation was one of the first triggers I learned to recognize. Loud rooms, overlapping conversations, too many people talking at once, all of it made me cringe. I used to think I was just tired or overwhelmed, but the truth is simpler: My muscles don't have the reserves to keep up with the sensory chaos. I've had moments when my eyelids started to droop in the middle of a family gathering, or when my voice went hoarse and slipped away halfway through a conversation because the fight to be "normal" was too much. These aren't dramatic crashes. They are quiet unravelling.

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Practical sleep tips for people with MG

Everyone's sleep needs are different, but there are some tips for better sleep that may help if nighttime symptoms of MG are making it harder to rest.

Good sleep hygiene for chronic illness includes setting consistent sleep and wake times, building a calming bedtime routine that involves relaxation techniques like deep breathing, and creating a comfortable sleep environment.

Create a sleep-friendly environment

Making your bedroom more supportive and comfortable can help you fall asleep more easily and stay asleep longer.

Consider limiting noise and light by using blackout curtains, white noise machines, or earplugs to help reduce disruptions.

Adjusting the room temperature to stay cool can also make a difference, as overheating may worsen your MG symptoms.

MG-specific adjustments

Living with MG means you may need to adjust your routine with your symptoms in mind.

Some helpful strategies include:

- asking your doctor about timing your medications so they don't interfere with sleep
- avoiding heavy or late meals, especially if you have trouble swallowing or digesting
- elevating the head of your bed slightly or using supportive pillows to ease breathing

Information taken from Myasthenia Gravis News and is not meant to replace any instruction from your physician.

Donations

General Donations:

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Donations In Memory of:

Tom Barrett - Fiona McQuarrie
- Carol McQuarrie
- Ed and Sheila MacDonald
- DJ Sandhu
Janet Oliver - Susan Oliver

Donations in Honour of:

Kelly Carson Birthday - Gary Anderson

Distribution from Wills, Estates

Beverly Agnes Butler

*If we have missed anyone –
our deepest apologies.*

Living with Myasthenia Gravis

A myasthenia gravis (MG) diagnosis can be upsetting, but there are strategies you can learn to help you manage living with MG, a neuromuscular disease that causes muscle weakness and fatigue.

Different types of MG treatment can help control and alleviate disease symptoms that make everyday activities, such as talking and eating, difficult.

Establishing a daily routine, exercising, and nurturing your emotional health can help you maintain a good quality of life.

Although MG is more commonly diagnosed in adulthood, it can affect people of any age. When symptoms begin before age 18, the disease is referred to as juvenile myasthenia gravis.

How does myasthenia gravis affect daily life?

MG can interfere with daily living, given that muscle weakness can worsen within hours, potentially leading to fatigue and issues with vision, mobility, speech, and breathing.

The muscles of the eyes and eyelid are usually the first to be affected by the disease, which can make it hard to see and read.

Ocular symptoms of myasthenia gravis include:

- double vision
- droopy eyelids
- weakness or paralysis of the muscles that control eye movements.

Weakness in the arms and legs is another common symptom that can make everyday tasks, such as walking short distances or carrying shopping bags, more challenging.

There is also a link between myasthenia gravis and breathing problems. If the muscles in the neck or throat are affected, it can be difficult to speak clearly or even breathe. You or a caregiver should call your doctor whenever you are experiencing breathing issues.

Severe breathing issues may occur during a myasthenic crisis, when symptoms suddenly worsen, as the muscles that support breathing become extremely weak. If you think you're having a myasthenic crisis, it is important that you are treated as soon as possible in a hospital, so call 911 or go to the emergency room.

Creating a daily routine

For people living with MG, creating a daily routine can make a difference. Planning ahead, strategizing, and finding hobbies that are enjoyable may help you

cope with the symptoms of myasthenia gravis.

Figure out when you usually feel your best — keep track by jotting down the times, or the time of day — and plan to do your most energy-consuming physical activities, such as exercise or cleaning, during that time of day.

Scheduling your meals around those times is also a good idea.

Finally, try to enjoy life. Gardening, painting, reading, or doing puzzles are great ways to relax and boost your emotional resilience.

Eating and drinking

You may find that myasthenia gravis causes you to experience swallowing issues. To address this challenge, diet adjustments may be necessary, in addition to taking medication.

Some tips may help to make eating easier:

- If chewing is tiring, eat softer foods and have smaller meals throughout the day.
- Puree, mash, and chop foods to make them easier to eat.
- Avoid hot foods or warm liquids, which can relax the throat muscles.
- Drink thicker liquids, which may be safer to swallow than thinner drinks.
- Alternate small bites of solid food with small sips of a liquid.
- Have your largest meal earlier in the day, when you have more energy.
- Rest before eating.

Speech and communication

Muscles for breathing and those in the mouth, throat, and neck are often affected in people who have MG, which can lead to difficulties in speaking.

Medications for MG symptoms typically address this problem, but you may want to consider seeing a speech and language pathologist. These therapists can show you how to do muscle-strengthening exercises and offer new approaches or devices for communicating.

Problems with speech and communication may pose unique challenges at work. One solution is to schedule meetings for the times when you usually feel more rested.



[continued from page 6]

Emotional stress, good and bad

Emotional stress is another trigger that doesn't get enough of the right attention. It's not the emotions themselves, in my opinion, but rather the cascade of hormones that follows them. Strong feelings release cortisol and adrenaline, and those hormones change how muscles function and how quickly they fatigue. I've had days when a difficult conversation left my legs shaking hours later. I've had mornings when waking up anxious meant my jaw felt heavy before I even got out of bed. Stress doesn't stay in mind when you have MG. It settles into the breath, the muscles, the small movements you usually take for granted.

Then there's the strange category of "good stress," called eustress, like the excitement of seeing someone you love, the anticipation of an event, the joy of a celebration. These moments should feel light, but my body doesn't always know the difference between good and bad adrenaline. I've had days when happiness left me just as weak as fear.

It's a confusing kind of betrayal, one that makes you rethink how you pace even the joyful parts of your life. One of the most surprising triggers is a prolonged elevated heart rate. It took years of trial and error to figure out that once my heart rate climbs past a certain point, my diaphragm starts to fatigue and my breathing gets shallow. For me, that threshold is around 110 beats per minute, a number I only discovered because I wear a smartwatch and kept noticing the same pattern, regardless of the activity. It makes exercise more complicated, and it means even intimate moments with my husband sometimes require pacing and awareness. But once I understood

the pattern, I learned to work with it rather than being blindsided by it.

Illness, even mild illness, is a trigger that hides in plain sight. A simple cold can turn into days of weakness. A night of poor sleep can make my symptoms louder before I even realize what's happening. Hormonal shifts, too, can send everything off balance. These internal triggers are some of the hardest to predict because they don't announce themselves. They just show up all willy-nilly. It's rather rude when you think about it. And when there's a five-minute crash, the moment when everything changes without warning. I can go from functioning to barely standing in the span of a few breaths. It's one of the most bewildering parts of MG, and it's often tied to triggers I didn't see coming or a perfect storm of multiple triggers that add up to an avalanche of chaos. These crashes reminded me that MG doesn't always give you time to prepare.

Learning these hidden triggers hasn't made MG predictable, but it has made it more understandable. I've learned to pay attention to the small cues like my breathing, my tongue and jaw, and the heaviness in my limbs. I've learned to step away from noise, to pause during conflict, to pace even the joyful moments. I've learned that, managing MG isn't just about avoiding the obvious triggers. It's about honoring the quiet ones, the ones that whisper before they roar.

These triggers no one warns you about. But once you learn them, you start to navigate your days with a little more clarity, a little more compassion, and a little more steadiness in a body that doesn't always offer it.

Myasthenia Gravis News Mar. 2026 written by Shawna Barns

“ “ *Our greatest weakness lies in giving up. The most certain way to succeed is always to try just one more time.* ” ”

– Thomas A. Edison



Crystal's Tips



Turn Awareness into
ACTION
JUNE IS MG
AWARENESS MONTH

Awareness month serves as an opportunity to educate the public and support those affected by MG. How? You ask. Here are some ideas:

***Start a conversation on the topic with friends, or on workplace breaks;**

***Get permission at work to have posters and handouts;**

***If you know people who have MG, ask them what could be done to make their life a little bit easier.**



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LITERATURE ORDER

MYASTHENIA GRAVIS ASSOCIATION of BC
MGABC

2805 Kingsway
Vancouver, BC V5R 5H9

Name _____

Address _____

LITERATURE AVAILABLE:

1. Myasthenia Gravis Facts
2. MG Glossary: Definitions of medical terms used in M.G.
3. MG Survival Guide
4. Drug pamphlets: (a) Mestinon (b) Imuran (c) Prednisone (d) Cyclosporine (e) Cellcept
5. Drugs that aggravate MG - 2012
6. Tacrolimus* - New drug for immunosuppressive medication
7. Plasmapheresis
8. IVIG - Intravenous Gamma Globulin
9. Ocular MG
10. Nutrition for Healthy Bones
11. Dentistry and the Myasthenic
12. Pregnancy and Myasthenia Gravis
13. Myasthenia Gravis in Children and Adolescents - **NEW**
14. Congenital Myasthenia Gravis
15. Emergency Care of Myasthenia Patient
16. Mestinon - A possible emergency measure
17. Assessment & Management of Speech & Swallowing in Myasthenia Gravis
18. Hospital Package: Nursing Care of the Myasthenic; Hospitals Can be Dangerous; Anesthesiology Drugs
19. Practical Guide to MG
20. Dr Oger's book for Family Physicians - free to MG members
21. MG ID Emergency Alert Card
22. Providing Emotional Support for patients with MG
23. Myasthenia Gravis Information for GPs **NEW**
24. Tips on applying for CPP Disability Benefits
25. Disability Tax Credit - Form T2201 **must be** downloaded at www.cra-arc.gc.ca/E/pbg/tf/t2201

BOOKS AVAILABLE:

My Imaginary Illness - Dr. Chloe Atkins, A Journey into uncertainty and prejudice in medical diagnosis. (for short term loan or purchase through your local bookstores)

Please note: General Myasthenia Gravis information is now available in Mandarin. If you would like a copy, please contact our office.



MEMBERSHIP & DONATIONS

MGABC'S membership year is January 1st to December 31st. Membership received after October 1st will be good for the following year. To donate, please complete the form below and return it with your cheque or money order (we cannot accept credit card payments and we ask that you do not send cash in the mail).

Your donation and membership fees help defray operating costs, and entitles you to the following; Newsletters biannually..., MG literature and pamphlets, and Notice of meetings...Up-to-date information on MG.

You can Help find a Cure !

Your support can make a vital difference in the research for a cure for Myasthenia Gravis.

Please make your donation by cheque or money order payable to, or online through Canada Helps:

MYASTHENIA GRAVIS ASSOCIATION of BC
MGABC
2805 Kingsway
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<https://www.canadahelps.org/>

Membership

OR

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Donations

Myasthenia Gravis of BC

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MG Patient: **Yes No**

Membership \$20.00

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