

Fall 2026



Fall Newsletter



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Fall Support Group Meeting Sunday, October 25th, 1:00pm - 4:00pm

2805 Kingsway, Vancouver, B.C.

- 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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President: Kelly Carson
@ext.1284



www.myasthenia-gravis.ca



WE'RE ON
facebook

A Word from our President

Fall is here, as I write this on the last day of Summer. Be sure to start thinking about taking care of you. Drink plenty of fluids, get lots of rest, enjoy the beauty of Autumn with the changing colors and beautiful sunsets. Take the time to get outside for some fresh air and spend quality time with family and friends.

For those of you who attended our Spring meeting you know that I and our treasurer Linda Briggs have been re-elected to our positions. Yay, thank you for having faith in us and in my opinion supporting the direction we have been going. We also added a new Board member! Thank you so much Willeke van Linden Tol for letting your name stand and for giving your time to our board, Willeke is from Victoria BC. For those wondering, our board meets two times a year and we have two Membership Meetings a year. We are still on the lookout for a working Neurologist to sit on our board.

On October 10th I will again be setting up a table at the Myasthenia Gravis Foundation of America Health Fair in Seattle. They usually have a couple of interesting speakers, and I get to learn things from the drug companies and others attending the Health Fair. This year I have heard that one of our members are attending and one of our Board members will be joining me at our table. FYI, we have a Board member from the USA LuAnn is a huge asset to our Board and we are so lucky to have her.

[continued on page 3]



OUR BOARD

Kelly Carson – President

Linda Briggs – Treasurer

James Postnikoff

Kayo Devicic

LuAnn Burgmuller

Willeke van Linden

I reported in the last newsletter that the Board was thinking about again donating to the Victoria Neurological Clinic to top up the wage of the RN working there. I am happy to report that **they** managed to secure all the funding themselves, which is great news. So, we are instead funding a Vitalograph Micro Spirometer for them. You may be familiar with this piece of equipment if you ever went to the ER or clinic with breathing issues. This tests the volume of your lung capacity. The Board has also agreed to donate more of these pieces of equipment to places who need them. Mostly clinics who may be sharing just one with a hospital. As I came from small town of Pemberton when I was first sick, I feel that it would be another place where this piece of equipment could be beneficial. We shall keep you posted.

We have not yet secured our first support group meeting in Victoria. It is important to the Board that these meetings are meaningful and that our members' information be protected. We will start in the new year by having these meetings, maybe at the Victoria General Hospital, but we could only secure a room during the weekday, if we want to meet on the weekend, we will have to look for a different space. If you have any ideas or if you have any contacts to a community space, please let me know. If you are interested in attending, please also let me know. If you would like to be involved in helping to get these meetings started, please don't hesitate to contact me. You can text me at 778- 888 – 9649 or leave a message or you can email mgabc@myasthenia-gravis.ca

A little about me. I was diagnosed with MG after a long time of the Dr's thinking it was something else, from a bug picked up in Mexico to a sexual assault as an infant reoccurring memory (hence the inability speak). It wasn't until I moved to a smaller town on Vancouver Island where there was a visiting Dr from South Africa who figured it out and gave me the tensilon test. But then came the list of treatments, many that caused more harm than relief from the disease. After a thymectomy and finding treatments that worked for me, I gratefully went into remission. I have been in remission for many years, but I know that there is no cure for MG, so I try to live a healthy lifestyle, try to keep away from stress (which is easier said than done) and practice gratitude daily. I am retired now from my day job and doing some acting whenever I am lucky enough to get a gig. But stay involved with MGABC because I am a great example of being able to live a long life with MG

I know our newsletter goes out to all our members, and you can't all make it to our Fall 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 October 25th, 2026.

Fun Fact our meeting in October is our first meeting where you can attend by Zoom great for those who live too far away to attend. But please if you can attend do, just being in the room with others with MG is so delightful and we can learn so much from each other... and the food...YUM

ZOOM INFORMATION

Myasthenia Gravis Association of BC Fall Support Group Meeting
Oct 25, 2026, 01:00 PM Vancouver
Meeting ID 882 4912 6231

Kelly Carson

RESOURCES



MG EMS Considerations & Triage



United Way
British Columbia



Spot Lite

Vyvgart

I posted this because I have been informed that this is a great treatment for MG and it is approved across Canada by Pharmacare except for BC.

I know of one of our members who has moved to another Province in hopes of getting this treatment.

MG is a snowflake disease meaning that not all patients are the same, so because symptoms are not the same nor are the treatments. What works for some does not work for others... So, we have members waiting for this treatment.

When I was first sick IVIG was not available in Canada for MG. Well, it is now.... I can tell you that I had a lot to do with that... We CAN be the squeaky wheel; we CAN make a difference.

Are you still suffering? Are you waiting for this treatment option? Please let us know and lets

Vyvgart (efgartigimod alfa) is an innovative neonatal Fc receptor (FcRn) blocker authorized by Health Canada to treat generalized myasthenia gravis

- **Approval:** Health Canada approved Vyvgart (IV)
- **Coverage:** BC PharmaCare has historically restricted or not listed standard public reimbursement for certain indications like gMG pending ongoing economic reviews and cost-effectiveness evaluations.



“ I believe that the greatest gift
you can give your family and
the world is a healthy you. ”

— Joyce Meyer

MGABC FALL NEWSLETTER

2026 Myasthenia Gravis Association of BC

Front Page Banner:
K. Carson photo
Steveston, Richmond BC

Editor: Kelly M Carson

Contributor: G. Skidmore

Grandview Printing

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

“ You only live once,
but if you do it right,
once is enough. ”

—Mae West



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!



Thymectomy benefits older gMG patients without a thymus tumor

Written by Marganda Maia, PhD September 2026

Surgery to remove gland also helps reduce corticosteroid doses

- Thymectomy Surgery effectively manages generalized myasthenia gravis in both younger and older patients, a study found.
- The study included patients who did not have a thymus tumor.
- The surgery to remove the thymus gland also reduced reliance on immunosuppressive medications.

Thymectomy – a surgery to remove the thymus gland – can help keep generalized myasthenia gravis (gMG) under control while decreasing the need for immunosuppressive medication in both younger and older patients without a thymus tumor, a study found.

Earlier study found thymectomy benefitted younger patients

In MG, self-reactive antibodies mistakenly attack proteins involved in nerve-muscle communication, causing symptoms such as muscle weakness and fatigue. In many MG patients, this autoimmune response is linked to abnormalities in the thymus, including a thymoma, which is a tumor that grows from the cells of that small gland.

A thymectomy is often recommended for treating NG in patients who have a thymoma because it can reduce the production of antibodies, including self-reactive ones. An earlier clinical trial, called MGTX (NCT00294658), showed that this type of surgery can also benefit patients with non-thymomatous MG, that is, MG without a thymoma. However, data came mainly from patients younger than 50.

To understand whether benefits also apply to older patients, the researchers looked at whether a thymectomy is as effective and safe in adults age 50 or older as it is in younger adults with non-thymomatous gMG. This common form of the disease is marked by weakness affecting muscle groups throughout the body.

The researchers retrospectively reviewed the medical records of 79 adults with non-thymomatous gMG who underwent a thymectomy at Cleveland Clinic Foundation between 1999 and 2022.

A total of 34 patients (43%) were 50 or older, and 45 (57%) were younger than 50. Most (78.5%) had self-reactive antibodies against the acetylcholine protein the most common type of MG-driving antibody.

Compared with younger patients, older patients were significantly older at diagnoses (mean of 60.3 years vs 31.7 years) and were significantly less likely to be women (38.2% vs. 82.2%).

The older group also showed significantly higher rates of minimally invasive thymectomy (82.4% vs 60% and significantly lower rates of thymic enlargement (26.5% vs. 73.3%).

[continued on page 8]

Practical tips for people with MG

- **Pace your energy:** Break daily tasks into small steps and rest before you feel completely exhausted. Schedule your hardest activities during your strongest times of day, which is usually the morning.
- **Learn and track triggers:** Keep a daily symptom diary to identify what makes your fatigue worse. Common flare-up triggers include emotional stress, hot temperatures, infections, and lack of sleep.
- **Be cautious with medications:** Always tell your doctors and pharmacists you have MG. Certain drugs—including specific antibiotics, beta-blockers, and magnesium products—can worsen MG weakness and must be used with extreme caution or avoided.
- **Modify meals for swallowing fatigue:** Eat smaller, more frequent meals if chewing or swallowing becomes tiring by the end of a meal. Choose softer foods when tired, sit completely upright while eating, and avoid talking between bites.
- **Take medications strictly on time:** If you take prescription medications like pyridostigmine (Mestinon), stick rigidly to your prescribed schedule to keep your muscle strength stable.
- **Monitor your breathing:** Watch for early warning signs of respiratory muscle weakness, such as shortness of breath or trouble speaking a full sentence without pausing. Seek emergency medical care immediately.

Donations

General Donations:

Jan Clark
Doris Nicholson
Victor Barwin
Willeke van Linden Tol
Anonymous
Janet Benoit
Doris Nicholson
Charlene Dawson
Joan & Trevor Heaver
Jeanette Espinosa
Ken C Moore
Laura Anderson
Kathy Chatten
Lyle Bolton
Public Service Pension Plan
Nora Moore
Linda Scanlan
Mark Revell
Benda Kelsey
Dorothy Watters
Joe Frisbe
Sharon Phillips
Tom Tronsgard
Sandra Trimble
Jean Winslade
Patrick Dean
David Caldwell
Kenneth W Moore
Burt McGuire
Betty Wong
Carrie Anne Van Veen
Victor Barwin
Blake Forest
Gayle Wilson
M Maxwell

Monthly Donations:

Kelly M Carson
Eileen Maltinsky
Fiona McQuarrie



Donations In Memory of:

Tom Barrett – Fiona McQuarrie
Lorne Holyoak – Frances Lawson
Henre Leslie Jensen – Gail Jensen
Polly Tan & Julian Tan – Jane Finlayson

Donations in Honour of:

LuAnn Burgmuller – Janet Benoit
Joanne Mirabekki – The Stean Family

Distribution from Wills, Estates

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

Thymectomy benefits older gMG patients without a thymus tumor

[continued from page 6]

Younger, older patients showed improvement in symptoms severity

After the thymectomy, both groups showed improvement in the Myasthenia Gravis Foundation of America classification, which grades how severe symptoms are and how much the disease affects different body functions. The proportion of people experiencing improvement was similar between the two age groups at six, 12, and 24 months and at the final follow-up.

The number of post-surgery exacerbations, which are episodes of sudden symptom worsening, was also similar between the two age groups. The need for rescue treatment, such as intravenous immunoglobulin (IVIG), which provides healthy antibodies through a vein, or plasmapheresis, which removes disease-causing antibodies from the blood, was also not significantly different between the groups.

People in both groups also had similar scores on the mg Activities of Daily Living scale, which assesses the disease's impact on everyday activities such as eating, speaking, breathing, and walking. A similar percentage of older and younger patients achieved minimal symptom expression, meaning they had very few or no symptoms (55.9% vs. 44.4%, respectfully).

The percentage of patients who reduced their daily of corticosteroids by at least 10% was also similar between the groups of all time point evaluated. Corticosteroids work by suppressing the immune system but can cause serious side effects when used at high doses or for too long.

At the final follow-up, about half of patients (44% in the older group vs. 49% in the younger group) were taking 5 mg or less of the corticosteroid prednisone daily without additional immunosuppressive therapies.

The safety and efficacy of thymectomy in those aged 50 or older with non-thymomatous MG appear comparable to that of their younger counterparts.

For the whole story you can click this link
<https://myastheniagravisnews.com/news/thymectomy-benefits-older-gmg-patients-without-thymus-tumor/>



Canadian and BC Disability Benefits for Myasthenia Gravis

Drooping eyelids, muscle fatigue, and severe weakness from myasthenia gravis can qualify you for financial and tax assistance in British Columbia.

Disability Tax Credit (DTC)

- **What it is:** A non-refundable federal tax credit reducing income tax.
- **How MG qualifies:** Impairments lasting over 12 months in categories like walking, feeding, or cumulative daily restrictions.

Action: Have a medical practitioner sign Form T2201

Canadian Disability Benefit (CDB)

- **What it is:** A monthly federal benefit for low income working age adults (18 – 64)
- **How MG qualifies:** You must first be approved for the Disability Tax Credit (DTC)

Action: File your annual tax return to maintain eligibility.

BC Persons with Disabilities (PWD)

- **What is it:** Provincial monthly financial assistance and health supplements.
- **MG qualifies:** Severe, prolonged impairment significantly restricting daily living activities.

Action: Apply through the BC Ministry of Social Development with your doctor.

The BC Employment and Assistance Program for Persons with Disabilities provides disability assistance and supplements to support greater independence
www.canadadisabilitybenefit www.bcdisability.com



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

Vancouver, BC V5R 5H9



<https://www.canadahelps.org/>

Membership ☐

OR

Search:

Donations ☐

Myasthenia Gravis of BC

Research ☐

Last Name _____ First Name _____

Address _____ Prov. _____

Postal Code _____ EMAIL _____ Phone _____

MG Patient: **Yes No**

Membership \$20.00

Donation:

TOTAL AMOUNT ENCLOSED

\$ _____ (no tax receipt will be issued) \$ _____ (a tax receipt will be issued for donations) \$ _____

Have you moved? Please send in the information as soon as possible!

Last Name _____ First Name _____

Address _____ City _____

Prov. _____ Postal Code _____

Phone _____ E - MAIL _____



Myasthenia Gravis Association of British Columbia
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