MGABC
MYASTHENIA GRAVIS ASSOCIATION of B.C.

Fall 2025

Fall Newsletter

INSIDE

Fall Support Meeting

Sunday, October 19th at 1:00 pm
2805 Kingsway, Vancouver, B.C.

- Sandwiches and Healthy Food will be available for your enjoyment.
- Special Guest Speaker: Kayla Holliston (RN) Victoria General Hospital Neuro-muscular Disease Unit.
- President Kelly Carson Walking her second Camino from Portugal to Santiago Spain.
- Sharing stories from Members.
- It is with great sadness that announce the passing of one of our members, Tom Barrett. *(See obituary on p.8).*

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

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. Patients should consult with their physicians.

Myasthenia Gravis Association of B.C

2805 Kingsway,
Vancouver, B.C.
V5R 5H9

(604) 451-5511

President Kelly Carson
@ 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

Well, fall is upon us, but as I write this report it is so sunny outside and the temperature is 25 degrees. Let's hope for a mild winter!

We did something a little different this year with our funds. We put a call out to partially fund a Fellow (post-residency training period for physicians) which we have done in the past. We received no response, but what we did learn about was a Neuro-Muscular Clinic at Victoria General Hospital over seen by Dr. Kristen Attwell-Pope. The Board agreed to fund the last 20% of the wage of an RN for the clinic in order for the Clinic to have a full-time RN.

At the Spring Meeting we had the pleasure of meeting Dr. Attwell-Pope and gave her a check for $20,000.00, and we set aside $5,000.00 for education specific to MG for the RN. The Kayla Holliston RN was able to go to Ottawa this summer and learn from some of the best. You can read parts of her report in this newsletter. But, even better Kayla will be joining us at our Fall meeting, you can meet her yourself and hear about how our funding has given her the opportunity to learn more about MG which will help her to be a better RN for our members on Vancouver Island.

From Kayla:

"I am very appreciative to have the opportunity to go to the CNSF conference in Ottawa this year thanks to the Myasthenia Gravis Association of British Columbia (MGABC). This opportunity allowed me to expand my knowledge of Myasthenia Gravis and other neuromuscular diseases/disorders in my new role as a neuromuscular nurse"

[Continued on p.4]

Spot Lite

Kayla Holliston (RN) Victoria General Hospital Neuromuscular Clinic
(Article taken from her Canadian Neurological Science Federation 2025 Congress Conference Report)

My main goal of attending his conference was to get in as many sessions as I could that involved MG, and if none was available at that time, then a session that involved neuromuscular disorders/diseases.

I am still new to my role as a neuromuscular nurse, so I am very grateful to have this opportunity to educate myself about the various neuromuscular diseases/disorders, including MG. In addition to educating myself, another goal of mine was to network with the other neurologists and pharmaceutical companies to help increase our resources in our new clinic.

<u>Sessions attended</u>:

- Approaches to Mitochondrial Neurologic Disorders.
- Poster Moderated Sessions (EMG/Neuromuscular).
- Neurogenetics.
- Neuromuscular Discussion.
- Therapeutic Advance in Neuromuscular Medicine.
  Among other presentations and working lunches.

One takeaway from this conference is learning more about Myasthenia Gravis (MG) while I worked with MG patient on the acute neurosciences floor of Victoria General Hospital, I never fully understood the diagnosis as we were so focused on the immediate symptoms. Listening to the different case studies and different medications really helped to get a better understanding of how MG presents and is treated. Learning about all the treatment options such as IVIG, ScIG, cholinesterase inhibitors, completement inhibitors, etc. was also helpful. I can now say that I have a better understanding of MG and can now help to educate our MG patients that come into the clinic.

[Continued on p.5]

RESOURCES

BC Neuroimmunology
bcneuro.ca

VANCOUVER Centre for NEUROMUSCULAR Disease
vancouverneuromuscular.ca

mg™
MYASTHENIA GRAVIS FOUNDATION OF AMERICA

MG EMS Considerations & Triage

United Way British Columbia

[A Word from our President, cont. from p.2]

We have changed a heading in our Newsletter to “About Our Members” it was called “Patient Stories”. But since not all of our members have MG, and some of our members have done some great things for MG, we thought we should include them in our Newsletter. This is important to know that there can be a great exciting life after an MG diagnosis and also how you can support your family member or friend with MG.

You may be aware of some of the exciting trips I have taken lately, last year walking the Camino de Santiago from France across the Pyrenees Mountains to Santiago Spain. And you will read about my trip this year from Porto, Portugal to Santiago Spain. And in fact, we have another member in Spain as I am writing this walking his own Camino de Santiago. Let’s hope we see him at the Fall meeting... No pressure!

We have had a board members term expire and a Board Member resign and of course our new Board member who was voted in during our Spring meeting. As our Board ages I am always looking for fresh ideas and fresh members to our Board. Could that be you? We only have two Board meetings a year and two Membership meetings. It’s not a lot to ask, but you could make a big difference to our Association.

We are lucky enough to welcome LuAnn Burgmuller from Ferndale Washington. I met LuAnn on one of my trips to Seattle at the Myasthenia Gravis Foundation of America Health Fair of which we have been setting up a booth for the last 3 years. I find these Health Fairs to not only be interesting to attend, but it is also encouraging to have people enjoy our newsletters and join our membership.

In closing, I would like to thank our membership for their generous donations that enable us to carry on supporting those newly diagnosed and those who like myself have had MG for a very long time.

Please enjoy this Newsletter!

I hope to see you at the Fall meeting October 19th 2025 in Vancouver.

MGABC Webmeister Euan Bowman on the Camino de Santiage, September 2025

[Spot Light - Kayla Holliston (RN) cont. from p.2]

Another take away from this conference regarding MG is all the new medications there are for it. It felt like on the theme for the whole conference was how there are now FcRn inhibitor medications for MG, and how the treatment options for MG are continuing to grow.

A very interesting topic that came up a few times during the conference is the discrepancies between Provinces regarding medication coverage. A neurologist brought up how a patient could get an education covered in one province, but to move to another and it is not covered. The of these drugs is Vyvgart, which is approved for all Provinces accept for BC. Vyvgart was one of the new FcRn inhibitors and there was quite a few case studies discussed showing how effective it can be for certain MG Patients, so it was quite sad to hear that BC was a Province that does not currently fund it.

Kayla's full report will be on hand at the Fall meeting. You can pick up a copy there. And also Kayla will be attending the meeting, and be available to answer questions.

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, which 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 Fall Meeting or by mail or through Canada Helps, will be valid until December 31 2026 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
[MGABC Treasurer]

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!

CanadaHelps.org

ABOUT OUR MEMBERS

A trip to Seattle to the Myasthenia Gravis Foundation of America Community Health Fair September 13th 2025

By Kelly Carson

This was our third year of setting up a booth at the MGFA Health Fair. If you haven't been it can be a worthwhile experience. Again, this year they had two speakers:

Dr. Christyn Edmundson, from Swedish Health Services – she spoke about treatment Options for MG, what was most interesting was when one of the members of the audience asked a question about MG being hereditary, I found her response to make the most sense that I have heard in years. I'm not going to repeat what she said, what I will do is try to have her come and speak at one of our meetings.

Riana Giust, MS, CN Integrative & Functional Medicine Nutritionist, from Starkel Nutrition – Nourishing Resilience: How Nutrition can Support Your MG Journey. I spoke with Riana after the meeting and am hoping to have a Canadian Colleague of her speak at our Fall or Spring 2026 meeting.

Our Newsletters are always well received, and a few of our membership applications were picked up. We currently have 3 new members from the United States who live closer to our meetings than to their own, and we are so grateful to have them. We also have a new Board Member who was voted in at the Spring meeting who is a resident of the United States.

Practical Sleep Tips for People with MG

- 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: 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:

  * Ask your doctor about timing your medications so they don't interfere with sleep;

  * Avoid 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 from Myasthenia Gravis News is not meant to replace instruction from your physician

MGABC FALL NEWSLETTER

Editor: G.Skidmore!
Front page banner:
-Marsh scape, preceding Ruby Lake, B.C.

Donations

General Donations:

Stephen Baker

Al and Diana Botteselle

Lisa Brink

Judith Codrington

Barbara Crichton

Maria Debbane

Hilary Dube

Tyler Harding

Mark Issacs

Fabiola Lamb

Provincial Employees
Community Services Fund

Mark Revell

Ian Rise

Doris and Michael Shirley

Allan Thorp

Tom Tronsgard

Wilhelmina Van Lindental

Kenneth Winslade

Gayle Wilson

Monthly Donations:

Kelly Carson,

Eileen Maitinsky.

Donations in Memory of:

Mark Anderson - Janice Clark,

Tom Barrett - Fiona McQuarrie
(Monthly Donor)

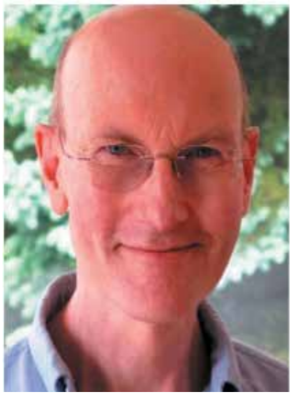
Gordon Regar - Charyl Bradley

Donations in Honor of:

Lloyd Charnely,
Paul and Penelope Dunas

If we have missed anyone our deepest apologies.

Donation List as of Sept 18, 2025



Tom Barrett
January 20, 1954 - September 15, 2025

Tom passed away peacefully at Royal Columbian Hospital in New Westminster, B.C., with his beloved wife Fiona McQuarrie holding his hand.

Thomas Edward Barrett was born in Victoria, B.C., the only child of his loving parents Ted *(also Thomas Edward)* and Joan *(nee White)*. In 1959, the Barretts moved to Vancouver, where Tom attended Captain Cook Elementary and Killarney Secondary School. At Killarney, he played tuba in the school band, and played league hockey at Killarney Community Centre. After graduating from high school, he headed for Toronto, where he eventually decided that he wanted to do something other than working on an assembly line in an antifreeze factory. He had seen the movie The Front Page in Grade 10, and that made him think that journalism might be interesting.

He signed up for the journalism program at Humber College, where, he recalled, in one of his courses he was the only student still enrolled at the end of the term. After two semesters at Humber, Tom returned to Vancouver and completed his journalism diploma at Langara College. In 1974, he was hired as a reporter at The Vancouver Sun. During his nearly three decades at the Sun, Tom specialized in political reporting, spending several years in the press gallery at the BC Legislature. He covered numerous federal, provincial and municipal elections, following candidates on the campaign trail, doing election night coverage on deadline, and writing insightful analyses. Tom was also a feature writer and a television, film, and culture writer at the Sun. His newsroom nickname was *“The Doctor”* because of his alleged resemblance to Steven *(Doc)* Kupka of the band Tower of Power.

Although Tom was always modest about his work, he was highly respected by his colleagues at the Sun and in the media for his ability to find and follow a story, his outstanding writing skills, his kindness and gentle spirit, and his dry but always on the mark sense of humour. He was serious about the craft of journalism, but he also had a lot of fun doing it.

He met Fiona while they both worked at the Sun, and they were married in 1987. They commuted between Edmonton and Vancouver during her doctoral studies, and then lived in Prince Edward Island for three years. When Fiona accepted a job in the Fraser Valley and they returned to the Lower Mainland, they were faced with the question of where to live when their workplaces were nearly 80 kilometers apart. With his usual careful attention to detail, Tom sat down with a map, stretched a piece of string between the locations of their respective workplaces, and stuck a pin in the middle of the string. That was how they ended up in the Maillardville neighbourhood of Coquitlam.

Tom took a buyout from the Sun in 2002. He became one of the first contributors to the online news site The Tyee and taught in the journalism program at Kwantlen Polytechnic University. He also completed a Bachelor of Professional Arts in Communication Studies at Athabasca University, graduating *“with Great Distinction”* in 2007.

In the last ten years he experienced physical challenges that restricted his mobility and his opportunities to socialize. Frustratingly, these limitations also made it difficult for him to do the kind of research and writing he loved. But he remained positive and had made significant progress toward better health.

Tom was a thoughtful and affectionate man. He loved comics, movies, baseball, history, art, architecture, and music. He had an endless sense of curiosity. He was an enthusiastic reader, and never stopped trying to improve his own writing. He always had a notebook by his side to write down quotes that he particularly liked, or words that intrigued him. He was a loyal friend. He was, and is, deeply loved.

Tom leaves his wife Fiona, his mother-in-law Carol McQuarrie, his brother-in-law Michael McQuarrie, his cousins Grace Garrison and Marg and Don Jacobson, and friends all around the world.

Many thanks to the BC Ambulance Service and the dedicated staff of the cardiac surgery ICU unit at Royal Columbian Hospital, for their compassionate and respectful care of Tom.

Memorial donations may be made to the Myasthenia Gravis Association of BC (https://myasthenia-gravis.ca).

“It’s a beautiful world, P.K. Purvis.” - P.G. Wodehouse

Published on September 27, 2025 in The Vancouver Sun & The Province

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.

MGABC
MYASTHENIA GRAVIS ASSOCIATION of B.C.

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 biannuall

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 Hel

MYASTHENIA GRAVIS ASSOCIATION of BC
MGABC
2805 Kingsway
Vancouver, BC V5R 5H9

OR

CanadaHelps
https://www.canadahelps.org/

Search:

`Myasthenia Gravis of BC`

Membership ☐

Donations ☐

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____________________________________