MYASTHENIA GRAVIS ASSOCIATION of B.C.

Spring 2025

Spring Newsletter

Spring AGM & Support Meeting

Sunday, April 27th at 1:00 pm

AGM: 1:00 - 1:30

2805 Kingsway, Vancouver, B.C.

- Sandwiches and Healthy Food will be available for your enjoyment.
- Special Guest Speaker: Dr. Kristen Attwell-Pope from Victoria General Hospital.
- Our Medical Advisor will be presenting and holding a Q & A.
- Future Plans.

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 WEB SITE: 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. 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

WE'RE ON facebook

OUR BOARD

- **Kelly Carson**
- **Linda Briggs**
- **Joel Oger**
- **Kayo Devicic**
- **James Postnikoff**
- **3 Open Positions**

A Word From Our President

Spring has Sprung! I hope Spring 2025 finds you well! Can you believe that it is 2025? First of all, I need to apologize to those who did not receive their Fall Newsletter. We had set up a new email system and it failed us, or I failed us. Let's hope we are all reading this right now from the newsletter.

It wasn't a bad winter here in the Pemberton Valley, so I feel grateful. I hope you all survived your winter where ever you are from. I'm hoping for a fun Spring meeting on April 27th, 2025. We have invited a few speakers, and of course our very own Dr. Joel Oger will be there to enlighten us on what's going on in the scientific world of Myasthenia Gravis. Dr. Oger Spoke at the Conference in Saudi Arabia in February this year, and I spoke at the Camino 101 workshop in Vancouver in February.

During the Spring AGM, which should only take up 30 minutes of your time, we will be electing new Board members and renewing old ones. If you would like to let your name stand for a 2, or 3-year term, please let me know and I can direct you on how you can do this. Of course we will take names from the floor as well.

You may, or may not know that at the UBC lab is where all Myasthenia Blood tests are sent. With that, they send out the results to the Doctors who sent them in. Our organization's contact information is now added to the bottom of all positive test results, so that Doctors can direct patients to us, so that they are not alone in their MG Journey. A huge thank you to Dr. Oger for making this happen. Recently, the UBC lab is in the process of organizing a demographic of MG patients by age, and related information, all made possible by means of research donations by our organization. Stay tuned for results.

[Cont. p.4]

From Our Scientific Advisor

-By Joel Oger

Reflections on the new medications available for MG

To compare the effectiveness of new medication, one now uses the measures of NNT *(Number Needed to Treat),* and to measure the risk we use NNA *(Number Needed to Arm)*. Further to compare cost, one uses CPIO, or Cost Improvement Outcome.

A comparison of the NeoNatal FcReceptor Inhibitors *(Ravulizumab or Ultomiris®, and Efgartigimod or Vyvgart ®)* to the Complement Inhibitors zilucoplan or Zilbrysk® has been done.

Efgartigimod had the best efficacy as it had the lowest NNT to improve MG functions. They all had the same level of risk, which was similar across all comparisons. Among all new treatments compared, Efgartigimod (Vyvgart®) IV had the lowest CPIO.

What has really scared me in reviewing these publications is the following:

CPIO Cost to show improvement were staggering, and I would say Shocking:

For efgartigimod was $645,406/ year;
For rozanolixizumab was $1,839,110/year;
For Zilucoplan was $1,936,905/year;

Only Vyvgar is available in Canada today, but It is obvious that no Health Care system will be able to afford to make all of these medications available to all its MG patients.

After all, how many new MG patients in Canada every year?

Joel Oger MD FRCPC FAAN FANA
Professor Emeritus in Medicine UBC
Chevalier d el'Ordre du Mérite (Fr)

RESOURCES

BC Neuroimmunology
bcneuro.ca

VANCOUVER Centre for NEUROMUSCULAR Disease
vancouverneuromuscular.ca

mg™
MYASTHENIA GRAVIS FOUNDATION OF AMERICA

MG EMS Considerations & Triage

CanadaHelps.org

United Way
British Columbia

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

You may ask what we do with funds such as membership dues, and research monies. When you donate to the General Account, some of the money goes toward sustaining the office, paying for rent, and office supplies. Other money is allotted to fund Medical Professionals who have decided to work in the area of Myasthenia Gravis. Over the last few years, we have granted research money to a Neurologist wishing to specialize in the area of MG.

Currently, we are in the process of offering funds towards the New NeuroMuscular Disease Unit at Victoria General Hospital, so they can have a full-time Nurse. We are also waiting to hear about the cost of a piece of Equipment that they are in need of! This would not be the first time we funded equipment. Years ago we purchased a couple of freezers for the UBC lab, so they can keep all of the blood samples to test for MG. So Please do as many others have done, and consider the Myasthenia Gravis Association of BC for your donations, and wills. I assure you we do great work with your dollars.

So, what you may ask are my plans for Spring? Well as you know I walked 800 km in Spain last year from SJPP *(Saint Jean Pied de Port)* France, to Santiago de Compostela, Spain. This is what they call the Camino de Santiago. This year after our Spring meeting I plan to fly to Portugal, and walk the Camino Portuguese, which is a mere 260 km. I feel blessed that I am still in remission, and able to do these things. I like to tell you about them, because I want you to know there is life after an MG diagnosis.

We are always looking for happy MG stories that you may like to share in our Newsletter. So please, if you have a story that you would like to share don't hesitate to let me know.

Kelly Marie Carson
MGABC President

[Read Kelly's Camino story from Pique Magazine]

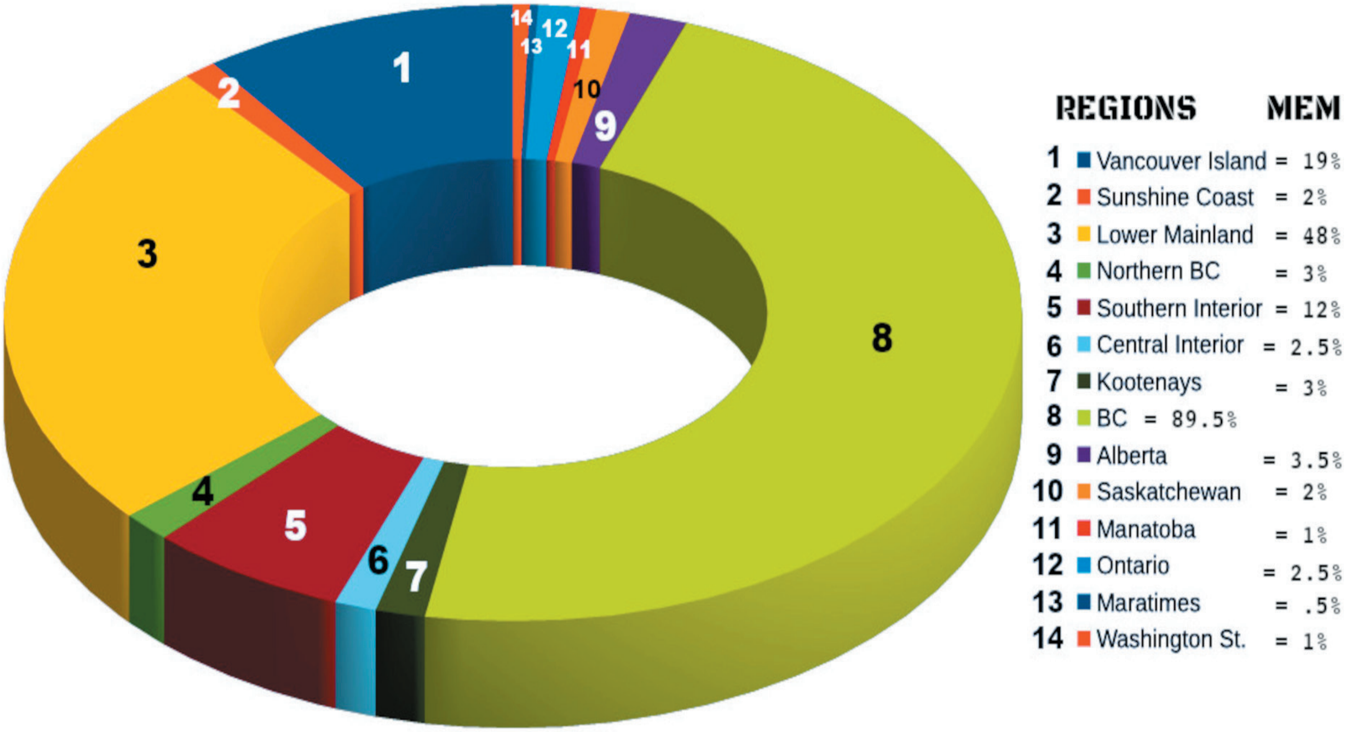
Our Membership

by Kelly Carson

When managing the membership of an organization, it is important to know who that membership is. This involves knowing where people are located, and how may people are located in a given region. From those numbers, data can be derived. First of all, we developed the chart below, calculating the numbers in percentage values to make it easier to work with. So, for example of the total, 89.5% of the membership are in B.C. That means that the other 10.5% are in other provinces, with 1% being in Washington State.

Let's have a look inside B.C. 48% of the membership reside on the lower mainland. 2% reside a 40 minute ferry ride away on the Sunshine Coast. Does that mean we need to promote ourselves more in that area to provide support, and increase membership? At this point in time we know we have a relatively low number of people there connected to MG, but for all we know there are possibly double, to triple that number. The same question and reasoning could be applied to Northern B.C., and the Kootenays, both large regions at 3%.

In those regions with higher numbers, like the lower mainland at 48%, and Vancouver Island at 19%, tells us that there is higher demand for our services, but may also indicate that the numbers we have may just be scratching the surface. There may be more people there with MG that don't even know about the MGABC. On top of that, there could be people out there that don't realize they have MG, because there is not enough promotion of the symptoms. This is why it is important to analyze membership numbers, so we know what, and where to promote ourselves in order to increase membership income, so that we can provide support where it is needed.



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!

Subcutaneous Immune Globulin (SCIg) Therapy

By Stephen Baker

Unfortunately, many of the conventional treatments for MG haven't worked for me, or have caused dreadful side effects. As a result, I was reliant on IVIg every two weeks. While it was highly effective and significantly improved my quality of life, it also became restrictive, forcing me to structure my life around treatment rather than my family. IVIg became the priority, when in reality, my family should have come first, with treatment and MG in the background.

After my thymectomy, I was determined to shift MG out of the center of my life. I no longer wanted my world to revolve around it. That's when I learned about subcutaneous immunoglobulin therapy (SCIg). A potential replacement for my IVIg treatment.

I spoke with my neurologist, who agreed it was worth trying, and he referred me to the Subcutaneous Immune Globulin Clinic at St. Paul's Hospital. From there, I was connected to the corresponding clinic within Fraser Health, where I live. After two training sessions at the clinic, I was ready to manage the infusions on my own. The necessary equipment is couriered to my home from Ontario, and I pick up my SCIg from my local blood bank. Thanks to B.C.'s Fair PharmaCare program, there is no cost to me for this treatment.

To store my supply, I purchased a bar fridge, which holds three months worth of SCIg. The real magic of the SCIg infusions is the flexibility it gives me, and I can do my infusions at a time that suits me from the comfort of my home, while watching TV. This newfound freedom has been a game-changer for both me and my family.

One of the biggest benefits was being able to take a four-week road trip to California last summer. My wife Tina, and our two children had an unforgettable time making memories this time with MG in the background, rather than at the forefront. I no longer had to plan vacations around hospital-based IVIg appointments, or cut trips short to return for treatment. I simply packed a cooler with my SCIg and ice packs, brought along a bag of medical supplies, carried a letter for the border, and off we went.

For those interested in B.C., St. Paul's Hospital SCIg Clinic can be contacted via email at **SCIGClinicSPH@providencehealth.bc.ca**

They will be able to link you to a clinic in your health authority.

Recently, I have started rituximab therapy and hope that over time, I will be able to reduce and eventually discontinue SCIg, as I now receive rituximab infusions every six months.

We are looking for personal stories of life with MG. From diagnosis through the experience, and into remission. A one to two page overview of your experience as a story for the Newsletter. If you are a patient, or a Caregiver of someone with MG, and would like to share your story, please contact President Kelly Carson @:

mgabc@myasthenia-gravis.ca

(604) 451-5511
[Ext. 1284]

MGABC SPRING NEWSLETTER
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Editor: G.Skidmore!
Front page banner:
-Turtles in Trout Lake, Beaver Island, B.C.

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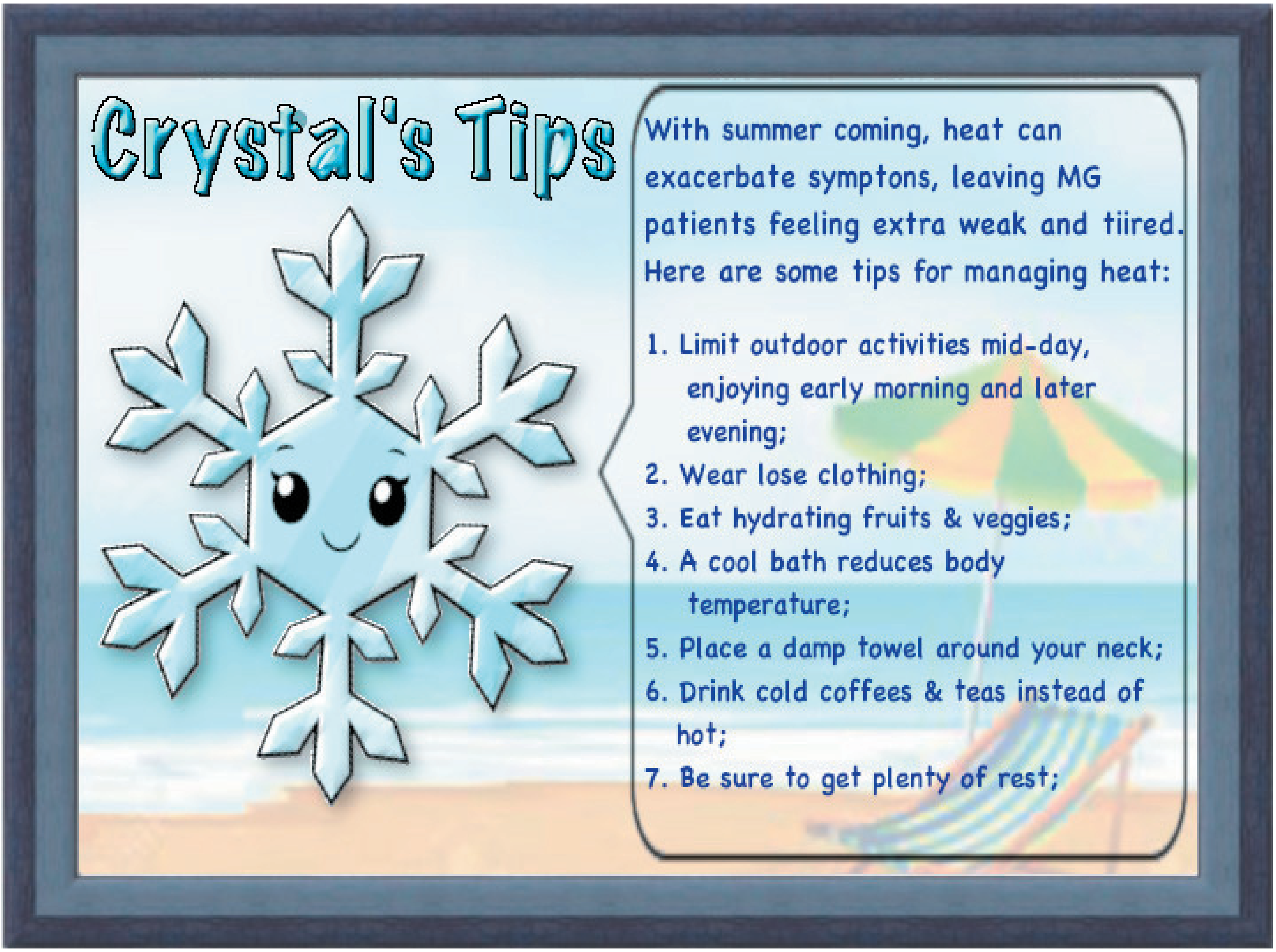
Turn Awareness into ACTION JUNE IS MG AWARENESS MONTH



Crystal's Tips

With summer coming, heat can exacerbate symptons, leaving MG patients feeling extra weak and tiired. Here are some tips for managing heat:

1. Limit outdoor activities mid-day, enjoying early morning and later evening;
2. Wear lose clothing;
3. Eat hydrating fruits & veggies;
4. A cool bath reduces body temperature;
5. Place a damp towel around your neck;
6. Drink cold coffees & teas instead of hot;
7. Be sure to get plenty of rest;

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

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Last Name______________________ First Name ______________________

Address______________________________ Prov.__________

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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)** $__________

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Last Name______________________First Name ______________________

Address______________________________ City________________

Prov.______________ Postal Code____________

Phone__________________ E - MAIL______________________