Fall 2024

MGABC
MYASTHENIA GRAVIS ASSOCIATION of B.C.

Fall Newsletter

INSIDE

Fall MG Support Meeting

Sunday, October 20th at 1:00 pm

2805 Kingsway, Vancouver, B.C.

- Sandwiches and Healthy Food will be available for your enjoyment.
- President Kelly Carson will talk about Camino de Santiago.
- 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

Myasthenia Gravis Association of B.C

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

(604) 451-5511

President Kelly Carson
@ ext. 1284

MGABC

myasthenia-gravis.ca

MGABC
MYASTHENIA GRAVIS ASSOCIATION of B.C.

WE'RE ON facebook

OUR BOARD

- Kelly Carson - President
- Open Position - Vice President
- Linda Briggs - Treasurer
- Joel - Oger - Scientific Advisor

Board Members at Large:

- Kayo Devicic
- James Postnikoff

A Word From Our President

It's so hard to believe that I am already writing my Fall 2024 Report. Personally, it was an amazing year for me. During the April AGM I announced that I was going to walk 800 km in France and Spain. Walking this distance is called the Camino de Santiago. The reason I told our membership that I was doing this, is because I want you to know that there is life after being diagnosed with Myasthenia Gravis. I was diagnosed 30 years ago. During my weakest moment I was in a wheelchair, which was a real low point in my life.

Thymectomy; trying different treatments; IVIG; changing my personal habits, like no alcohol, arid ridding my life of stresses as best I can. So very hard to do, but I believe it contributed to my remission.

I want to be clear I would not have walked the Camino de Santiago if I was not in remission. I feel that trying such a feat while on medication, and having symptoms would not be a smart thing to do. I hope you enjoy some of my trip on our FB page, or out web site through the video slide shows *"Kelly's Journey - Part 1 & 2".*

Speaking of communication, I am so grateful for our amazing volunteer IT guys, Euan and Glen! I am just amazed that they give their time to update our web site, and newly created Facebook Page. We want to get to as many people: those who are newly diagnosed, long time Myasthenics, and those not yet confirmed. We want you to know that we are here for you.

I want to thank our current Board, as well as those who have left for personal reasons, and those who resigned, because it is time to let others step up and take a role on our Board. A huge thank you to Nancy for her endless contributions on our board for the past 25 years. Enjoy your retirement from the MGABC Board, and know that you will be missed.

Kelly Carson
[President MGABC]

From Our Scientific Advisor

-By Joel Oger

NOVETLTREATMENTS FOR MG RECEIVING APPROVAL IN US

Quoted from MG NEWS The Myasthenia Gravis Foundation of America. August 2024 Newsletter. (https://myasthenia.org/Treatments/Treatment-Overview)

Neonatal Fc receptor (FcRn) blockers

The U.S. Food and Drug Administration (FDA) has approved argenx's VYVGART® (efgartigimod alfa-fcab) for the treatment of generalized myasthenia gravis (gMG) in adult patients who are anti-acetylcholine receptor (AChR) antibody positive. RYSTIGGO® (rozanolixizumab-noli) has also been approved by the U.S. FDA for the treatment of generalized myasthenia gravis (gMG) in adult patients who are anti-acetylcholine receptor (AchR) or anti-muscle-specific tyrosine kinase (MuSK) antibody positive. These patients represent approximately 85% of the total gMG population.

VYVGART is a prescription medication and the first FDA-approved treatment that uses a fragment of an IgG antibody to treat adults with anti-AChR antibody positive generalized myasthenia Gravis. It is given in treatment cycles with a break between each cycle. A treatment cycle consists of a 1-hour infusion each week for 4 weeks (4 infusions total). The treatment is specifically designed to attach to and block the neonatal Fc receptor (FcRn), resulting in the reduction of IgG antibodies, including the harmful AChR antibodies that cause gMG symptoms. Receptors called "FcRn" extend the life of IgG antibodies. In gMG, this allows harmful AChR antibodies to continue causing gMG symptoms. But IgG antibodies, including harmful AChR antibodies, that cannot attach to an FcRn are removed by the body. When harmful AChR antibodies that cause gMG symptoms are removed, they can no longer disrupt nerve-muscle communication. There is also a subcutaneous injection treatment called VYVGART® Hytrulo (efgartigimod alfa and hyaluronidase-qvfc). These treatments are offered by argenx and you can learn more by visiting https://vyvgart.com/

[Cont Next Page]

General Donations:

*Anonymous

*Lorna Andrews

*Jane Bryans

*Patrick Dean

*Jeanette Espinosa

*Don Holmes

*Lorna Holypak

*Lavina Lo

*Reina McAfee

*Tania Moore

*Kenneth C. Moore

*Kenneth W. Moore

*James Postnikoff

*Mark Revell

*Elizabeth Richards

*Wendy Robertson

*Maria do Santos

*Michael Shirley

*Allan Thorp

*Sandra Trimble

*Jean Tronsgard

*United Way of Lower Mainland

*Gail Wilson

*Eric Wong

*Katherine Wood

United Way British Columbia

[Cont. from page 3 - NOVETLTREATMENTS]

C5 Protein Inhibitors

AstraZeneca, and its Alexion rare disease group, announced that the United States Food & Drug Administration (FDA) has officially approved the Ultomiris® (ravulizumab-cwvz) treatment for adult patients with generalized myasthenia gravis (gMG) who are anti-acetylcholine receptor (AChR) antibody-positive, which represents 80% of people living with the disease.This FDA action marks the first and only approval for a long-acting C5 complement inhibitor for the treatment of gMG. According to Alexion, the medication works by inhibiting the C5 protein in the terminal complement cascade, a part of the body's immune system. When activated in an uncontrolled manner, the complement cascade over-responds, leading the body to attack its own healthy cells. Ultomiris is administered intravenously every eight weeks in adult patients, following a loading dose. Ultomiris showed early effect and lasting improvement in activities of daily living and has potential to reduce treatment burden with dosing every 8 weeks.

You can read more about this treatment at the ollowing website:

https://www.astrazeneca.com/media-centre/press-releases/2022/ultomiris-approved-in-the-us-for-adults-with-generalised-myasthenia-gravis.html

Complement Inhibitors including Soliris

Soliris® or its generic name eculizumab, is the newest classification of infusible drugs to be FDA-approved for the treatment of gMG in adult patients who are anti-acetylcholine receptor antibody positive. This drug works to reduce immune system attacks that may contribute to gMG symptoms. You and your doctor will decide if this approach is best for you.

Myasthenia Gravis - Patient Treatment Preferences

UHN
Toronto General
Toronto Western
Princess Margaret
Toronto Rehab
Michener Institute

Primary Investigator: Carolina Barnett-Tapia, MD, PhD
Contact Phone: 416-340-4800 Ext 3957
Contact Email: c.barnetttapia@utoronto.ca

SURVEY: https://barnettoutcomesresearch.hostedincanadasurveys.ca/117429?lang=en

Research Donations:

*J.Oger

Monthly Donations:

*Anonymous

*Tom Barret

*Kelly Carson

*Eileen Maltinsky

Donations in Memory of:

***Mark Anderson:**
Judy Adkins
Janis Clark

***Ken Butler:**
Beverly Butler.

***Stewart Gibson:**
Katherine Chatten.

***David Sutherland:**
Kelly Carson.

CanadaHelps.org

MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT

2024 Seattle Community Health Fair

By Kelly Carson

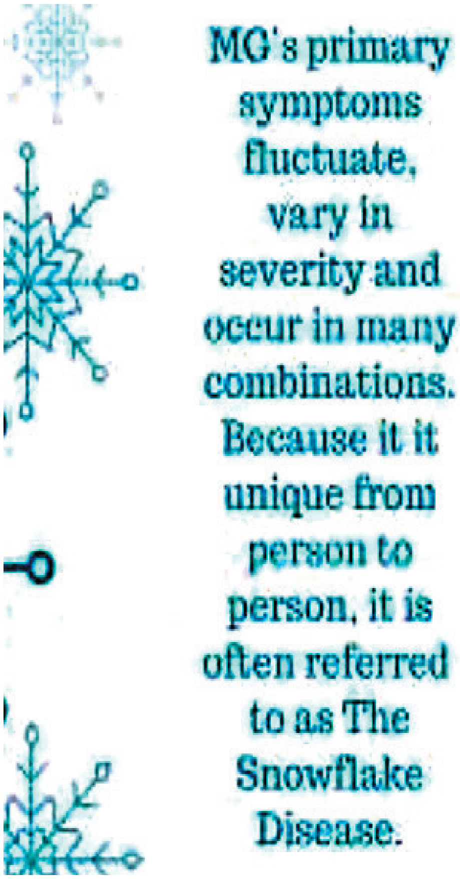
G.Skidmore! - Interviewer

Kelly Carson President of MGABC says *“It was an honor to be invited to attend for the 2nd year in a row at the Seattle Community Health Fair, put on by the Myasthenia Gravis Foundation of America. Meeting people who live so close to our border, and who are very interested in attending our support meetings is just a bonus*. *Supporting patients with Myasthenia Gravis is what both organizations are interested in, and I feel we both do a pretty great job. There really are no Boarders when it comes to MG. It was a pleasure to chat with two of our members while in Seattle at the Health Fair too!”*

Something different that the MGFA did at this Health Fair was to include speakers. I hope that they continue to do this. Both Christyn Edmundson, MD – Swedish Health - *“MG Symptoms and Improving Quality of Life”*, and Barbara J. Distad, MD – UW Medicine - *“Taking Care of Yourself When You Have MG”* were the featured speakers, and their topics.

Dr. Edmundson was easy to follow. She spoke in a way that a new patient with MG could understand. Here is a little about her. Dr. Edmundson is a board-certified neurologist specializing in neuromuscular medicine, and electrodiagnostics *(electromyography and nerve conduction studies)*. Her clinical practice focuses on the diagnosis, and treatment of disorders of the peripheral nervous system. She offers particular interest, and expertise in both autoimmune and inherited neuromuscular disorders. She believes in partnering with patients and families to help them understand their symptoms and diseases, enabling informed and collaborative decision-making regarding diagnostics, and goals of care and medical treatment. Clinical interests include Neuromuscular Medicine; Inherited and acquired disorders of the muscle; neuromuscular junction; and peripheral nerves and motor neurons.

[Cont. on page 6]



MG's primary symptoms fluctuate, vary in severity and occur in many combinations. Because it it unique from person to person, it is often referred to as The Snowflake Disease.

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!

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]

[Cont. from p.5 - Community Health Fairs]

Barbara Jane Distad, M.D. was refreshing and talked about ways and ideas to keep active with MG and some ideas of how to fit exercise into your life even with the difficulties of MG. She is board certified in Neurology by the American Board of Electrodiagnostic Medicine. She is working at Neurology Rehabilitation Medicine Clinic Montlake, and Electrodiagnostic Lab at UW Medical Center. Dr. Distad participates in clinical research trails and strives to provide excellent, individualized care by emphasizing education and ensuring patients understand their treatment options. Dr. Distad earned her M.D. at the Medical College of Ohio. Her clinical focus is neuromuscular disease. She is also a Professor of Neurology at UW Medicine.

In closing, Kelly says *“I appreciate the relationship that the Myasthenia Gravis Association has with the Myasthenia Gravis Foundation of America, and look forward to a fabulous future attending their events”.*

RESOURCES

mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

mgc
Myasthenia
Gravis
Coalition
of Canada
mgcc-ccmg.org

BC Neuroimmunology
bcneuro.ca

VANCOUVER Centre for
NEUROMUSCULAR Disease
vancouverneuromuscular.ca

MGABC FALL NEWSLETTER

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Editor: G.Skidmore!

Front page banner:

-Aspens in Banff National Park (2014)

VOLUNTEERING – FOUNDATION OF SUCCESS.

Hello MGABC, my name is Glen, and I'm the Editor of your Newsletter. The Prez has asked me to write a short article about the important role of the volunteer. Volunteers are the grass roots, and front line of numerous organizations, and events. Without them, many couldn't exist. Take service clubs for example. Groups like the Lions Club, and Kin Canada whose members volunteer their time to assist communities in a variety of ways. Fund raising for specific causes *(many of them health related)*, through hands-on efforts like construction, or by staging events with proceeds going to the given cause.

Community coalitions are another important part of a community. Typically, an alliance of volunteer members working toward defending, and/or preserving a part of the community. Senior's rights, and protection of designated park lands are just a couple of examples of the important role they play. Countless volunteer hours are spent raising awareness, and lobbying governments. Often achieving success by raising a community's awareness to actions that may otherwise go unnoticed until it's too late to rectify the situation!

So, these are just a couple of examples of how volunteering in a community can make a positive difference. Over the years I have been involved as a volunteer in two Community Coalitions, both Senior's Advocacy groups *(Communications & web work)*; a Labour Council *(Communications & web work)*; as well as Kin Canada *(Hall Manager & web work)*. I find two things come from volunteering:

1) Through each endeavor, I learn about a given topic, and gain specific skill sets. So for example, in the case of Senior's Advocacy, through the organization I learned about the long-term care needs of seniors on the coast. Through the work of the organization's volunteers, we raised the public's awareness for the need for a quality senior's public health care centre, vs. the private-for-profit facility under construction at the time. In doing this, I gained knowledge in assembling public forums, and preparing petitions for presentation at the legislature.

2) I believe that one benefits from the community in which they live, in one way or another. So, I like to dedicate a certain percentage of my time to give back to the community, and help to continue to make it a great place to live.

Today, I find myself as Editor of the MGABC newsletter. Myasthenia Gravis is a condition I never knew existed prior to this endeavor. So, my objective is to help provide the latest information and resources for the membership, and to help raise public awareness of Myasthenia Gravis. I'm Thankful for the opportunity, and I look forward to working with the Myasthenia Gravis Association of B.C.

There's plenty of room to volunteer. So if you have some time you can give, it can be time well spent helping to support and sustain the MGABC. If you have an interest, or past experience in administration, help in the office would be an asset. From stuffing envelopes, to filling the role of Board Member are areas where help is needed. Working, and developing fund raising campaigns is also needed. Meeting room preparation & clean-up helps lighten the workload all round. For more information about volunteering with the MGABC, talk to, or contact President Kelly Carson @:

(604) 451-5511 [ext. 1284] or mgabc@myasthenia-gravis.ca

G.Skidmore!
[Editor – MGABC Newsletter]

EVENT MANAGEMENT & COMMUNICATIONS

The time has come to upgrade our communications at public events. Banners are the first place to start, so we have three new items on order. The first one is illustrated to the left. It is a retractable vertical banner showcasing our branding. It stands 5 feet tall by 2 feet wide, and will be easily seen across rooms or outdoor areas, which will make it easy for people to find us.

The second item will be a horizontal banner, which is still under development at this time, but will be in the neighborhood of about 6 feet long by 2 feet wide, with our name, branding, and web address loud & proud. It will be great to have, and can be set up behind the table; used on its own, and even represent us somewhere if we're not there.

Finally, the third item is a branded tablecloth that will clearly mark our table, and can be used in combination with banners, or be used on its own. Branding is an important part of communications as it gives us a consistent, recognizable look.

Crystal's Tips

If you're planning to do any winter travelling, here are a few things to keep in mind:

1. Check prescriptions, and plan ahead for necessary refills;
2. Keep your medical history with you, or consider wearing a Medical Alert ID;
3. Consider sending luggage to your destination ahead of time to minimize stress during travel;
4. Dress for weather - It's wise to have a hood, hat, gloves and ear-muffs when in cold places.

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 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 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________________________