Spring Newsletter

Spring 2024

INSIDE

Spring MG AGM & Support Meeting

Sunday, April 21st at 1:00 pm

AGM: 1:00 – 1:30

2805 Kingsway, Vancouver, B.C.

- Sandwiches and healthy food will be available for your enjoyment.
- Our new President will talk about upcoming trip to Europe, a healthy future is capable with MG.
- Our Medical Advisor will be presenting and taking questions.
- Discussion about June being Myasthenia Gravis Awareness Month.
- Questions to our presenters.
- 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://myastheniagravis.ca

Myasthenia Gravis Association of B.C.

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

(604) 451-5511

President Kelly Carson at ext. 1284

OUR BOARD

- Kelly Carson – President
- Steven Baker – Vice President
- Linda Briggs - Treasurer
- Joel Oger - Scientific Advisor

Board Members at Large:

- Nancy Headley
- James Postnikoff

A Word from our President – Trip to Europe!

Myasthenia Gravis is no longer a death sentence, and I am living proof! If you have attended one of our support group meetings, then you've heard my story right from the horse's mouth. Well, I have news! On May 11th I will be flying to France, and seeing the sites for 2 days. Then taking the train to Saint Jean Pied de Port in France, and walking 800 km to Santiago Spain. I would have never believed that I could do this back in the mid 90's when I was not able to walk at all, dress myself, or speak without sounding like a drunken sailor. I am so grateful for my remission, and that I am able to make this amazing once in a life time trip.

As June is Myasthenia Gravis month I am excited that I will be walking the Camino to celebrate.

https://followthecamino.com/

-Kelly Carson, President MGABC.

From Our Scientific Advisor

– *By Joel Oger*

Dear members of the Myasthenia Gravis Foundation of British Columbia, My name is Joel Oger, I am a retired neurologist with a special interest in MG. The Board of MGABC has offered me to be the Scientific Advisor for the group. I already sit as a Scientific Advisor of the MGF of Canada. These are volunteer positions, and I am honored to have been offered them. I will try to be a translator/interpret between Scientists and Members.

Here is a short and sweet paper that represents the best educated medical opinions for treatment of MG. This comes from the Nordic countries of Europe and generally Canadian physicians have very similar therapeutic positions.

This is the work of the Specialists in MG from those countries: Sweden, Norway, Denmark, Iceland and Finland. As your scientific, I consider that it summarizes what I consider the best way to treat Myasthenia Gravis. Notice that it describes new treatments, however those are presently very difficult *(or awfully expensive)*. For those of you who would like to read the whole paper here is the reference:

Generalized myasthenia gravis with acetylcholine receptor antibodies: A guidance for treatment European J. of Neurology 2024 Feb 6:e16229. (doi: 10.1111/ene.16229.).

ABSTRACT

Background: Generalized Myasthenia Gravis (MG) with antibodies against the acetylcho-line receptor is a chronic disease causing muscle weakness. Access to novel treatments warrants authoritative treatment recommendations. The Nordic countries have similar, comprehensive health systems, mandatory health registers, and extensive MG research.

Methods: MG experts and patient representatives from the five Nordic countries formed a working group to prepare treatment guidance for MG based on a systematic literature search and consensus meetings.

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Donor list from October 1, 2023 – January 31, 2024

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In Memory of David Sutherland

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Results: Pyridostigmine represents the first-line symptomatic treatment, while ambeno-nium and beta adrenergic agonists are second-line options. Early thymectomy should be undertaken if a thymoma, and in non-thymoma patients up to the age of 50–65 years if not obtaining remission on symptomatic treatment. Most patients need immunosuppressive drug treatment. Combining corticosteroids at the lowest possible dose with azathioprine is recommended, rituximab being an alternative first-line option. Mycophenolate, metho-trexate, and tacrolimus represent second-line immunosuppression. Plasma exchange andintravenous immunoglobulin are used for myasthenic crises and acute exacerbations. Novel complement inhibitors and FcRn blockers are effective and fast-acting treatments with promising safety profiles. Their use depends on local availability, refunding policies, and cost–benefit analyses. Adapted physical training is recommended. Planning of pregnancies with optimal treatment, information, and awareness of neonatal MG is necessary. Social support and adaptation of work and daily life activities are recommended.

Conclusions: Successful treatment of MG rests on timely combination of different interventions. Due to spontaneous disease fluctuations, comorbidities, and changes in life conditions, regular long-term specialized follow-up is needed. Most patients do reason-ably well but there is room for further improvement. Novel treatments are promising,though subject to restricted access due to costs.

Joel Oger D. en M., FRCPC, FAAN, FANA.
Recruitment of patients to the Myasthenia Gravis Association of BC.

Patient Stories by Shelby Emanuels

I was diagnosed with general Myasthenia Gravis in October 2019, mere months before the pandemic began. Being in my early 30's, and the mom of 2 little girls aged almost 2 and 5 ½, this was a very unwelcome diagnosis. However, at least I got the answers as to why my body was behaving strangely. Thus starting the rollercoaster of doctors, tests, failed and successful treatments, and huge changes to my life.

In the span of one year, I went from being an active hiker, Army Cadet officer, and lover of camping and the outdoors, to using a walker or scooter to get around. Other life changes included having to order my groceries and my kids clothes, because I no longer had the strength to drive to, or walk around a store. I could no longer read my children stories, or take them to the playground, or even pick them up. It was quite difficult to have to try to explain to my 2 & 5 year old that mommy's muscles were not strong anymore.

When I was first diagnosed I began the usual treatments of Mestinon and Prednisone. I was sent for CT scan to check my thymus. I was told at the time that it was normal for my age. Unfortunately, I was about to discover that I happen to have quite a refractory case of MG. This meant I don't respond to most treatments. Within the month of my diagnosis, I started Prednisone. While increasing my dose, I proceeded to get worse, and my neurologist at the time ordered a round of IVIG, which I did not respond to. Just before Christmas 2019, I was admitted to VGH with my symptoms worsening. VGH was wonderful, and they started me on a round of Plasmapheresis ***[cont. next page]***

In Honor of Brenda Kelsey

Linda Briggs

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ARE YOU INTERESTED IN VOLUNTEERING?

**** Are you an IT person?***

**** Have Communications Skills?***

****Board Member Interest or Experience?***

**** Newsletter Editor?***

**** Interested in Fundraising?***

**** Stuffing envelopes?***

**** Help with meeting setups/ takedowns?***

**** Start a local MG support group?***

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

(*plasma exchange or PLEX treatments),* which thankfully I did respond to.

My first neurologist was a resident, and felt I had exceeded her capacity to care for me. I was then referred to another neurologist. When I met this neurologist, it was during the initial lockdowns of the pandemic, and consequently a number of my appointments were on the phone, not in person, which in hindsight I feel negatively affected my care.

During the pandemic I didn't feel that the public school board had a safe option for my family based on my being immunocompromised, and at high risk of covid complications. I ended up pulling my older daughter out of public school, and I started homeschooling her. So here I was trying to figure out how best to teach my daughter, all while trying to work out my MG treatments. I was not only trying to figure out the *"new normal"* of the pandemic, but also my *"new normal"* of living with MG.

My second neurologist started me on Cellcept *(Mycophenelate Mofetil),* and wanted me to stay on that for a year, along with the Prednisone. Benefits of treatment for MG take a lot of time. I didn't gain any benefit from these treatments, and only dealt with the horrible side effects of these drugs. I gained a lot of weight, and became quite puffy in my face, and body from the lengthy, high dose of Prednisone. I was eager to get off that medication.

When the first round of Covid vaccinations became available, I wanted to get something that would help me feel more able to fight off Covid, should I ever get it. I was about to learn just how much anything that compromised my immune system would exacerbate my MG. About ten days after my 1st Covid vaccine I was steadily getting worse. One morning I woke up, and I was having a progressively harder time breathing. I took extra Mestinon, and was driven to the local hospital. Luckily the mestinon kicked in by the time I got there, and I could breath enough to talk. I still had to use a wheelchair, and help to get into the ER as I was still very weak. The ER Doctors at the hospital didn't know what to do with me, and ended up sending me home to follow up with my Neurologist. My follow up ended up being a phone call, where I could not be assessed properly. That Neurologist told me she would be ordering Rituximab for me, and it should take about two weeks. SIX weeks later, after multiple phone calls to my Neurologist's office, I finally heard back from her. I had not been doing well this whole time, and she was very difficult to get ahold of. At this point in time she admitted me to VGH for 5 days, wherethey did another round of PLEX treatment. Thankfully, this hospitalization was the key to start my regular PLEX treatments that really helped to improve my overall quality of life. I came home feeling better, but very much still recovering. When I spoke with the Neurologist at a later date, she told me I was too stoic, and didn't know how badly I was doing. I feel this would have been better mitigated had I been seen in person. I did finally get my first round of Rituximab 4 ½ months after my hospitalization.

Early the following year, I ended up asking for a referral to see Dr. Jack at the VGH MG Clinic. She was amazing! She ordered another CT scan of my thymus. As it turns out, my initial scan did show some thymic

Shelby & Family

Editor:

G.Skidmore!

tissue, and the new scan showed I had more than I should for my age.

She encouraged me to stick with Rituximab, and that she often sees greater improvement after two to three rounds of treatment. She was right! Two years after starting Rituximab I was doing well enough that I was able to start driving again, running some of my own errands, and I was able to read short stories to my kids.

Fast forward to December 2023, I was finally stable enough to handle surgery. I had my thymus removed by what they call Bilateral VATS *(Video Assisted Thoracic Surgery)* Thymectomy. The surgery did exacerbate my MG, leaving me in need of extra PLEX treatments during recovery. At the end of the day, the surgery went very well as did my recovery. VGH was the best place for me to be.

When I got the pathology report at my follow up appointment with my surgeon, it showed that not only was my thymus enlarged, it stated that I had "*True Thymic Hyperplasia*". In other words, my thymus was HUGE. Normal Thymus glands in adults are 2-3 cm long, and weigh about 15 grams. Mine was 16.5 cm long, and weighed 40 grams.

I'm am so glad I went ahead with the surgery. Once I recovered physically, I found that I was able to lower my dose of Mestinin by half, and at what should have been my weakest time *(as I was in-between doses of Rituximab)*, I was doing a lot better than expected. Now just 2 ½ months after surgery, I was able to take my kids to the Vancouver Aquarium! Not only was I able to drive from Surrey to Stanley Park, but I was also able to get around without a walker! Now, I'm not back to 100% normal *(pre-mg "normal")*, but I have hope that with continued treatment I may be able to reach clinical remission.

Some final thoughts:

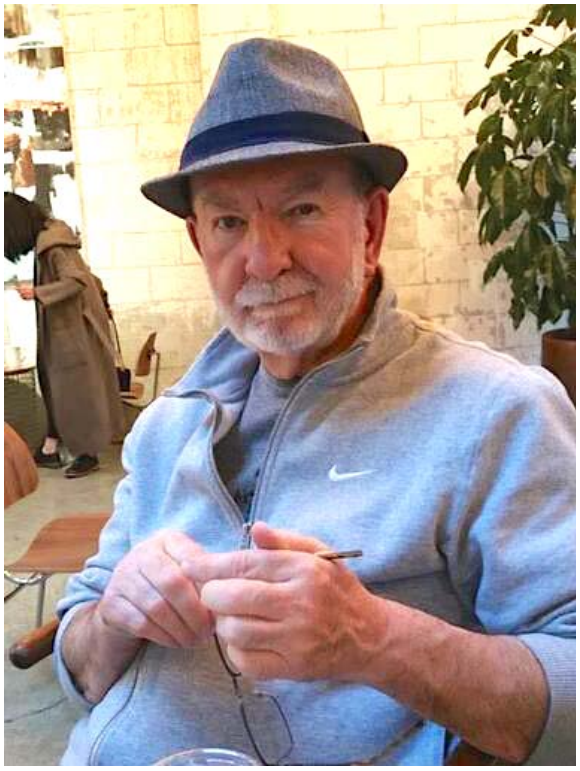
- When going through the really hard times, do whatever you can to make your life easier, Buy shredded cheese; pre-cut food; an electric can opener, etc.
- Use mobility aids that can help preserve energy. There's no shame in it!
- Use technology. I got an app for kids that had *"Read-To-Me"* books. It helped make up for not being able to read to my kids.
- Advocate for yourself!! If your not happy with your care, say something, or ask for a referral to a different Doctor.
- Seek out others with mg to talk to. It helps not feeling so alone in your diagnosis.

-Shelby Emanuels

BIG THANKS!

A special thank you to our Treasurer Linda Briggs working hard for us even though she had a fall in November (not related to MG) and broke her wrist. What a trooper !

In memory of David Sutherland



David Sutherland November 11, 1948 – October 9, 2023

On October 9th 2023 we lost one of our most active volunteers. Not only was David a Board member for many years, he was also the voice you heard on the phone reminding you of a membership meeting coming up. David was always the first one to arrive to help set up meetings and always stayed to put away chairs and to take any food left over to the recovery center behind our building.

David was also a signing authority for our organization and was always readily available when called upon for anything asked of him. If you would like to donate money honoring David Sutherland just please write his name on your donation check and mail it to:

MGABC 2805 Kingsway, Vancouver, BC V5R 5H9

or through Van-city:

https://www.vancitycommunityfoundation.ca/give/donor-advised-funds/myasthenia-gravis-association-bc-fund

or Canada Helps:

https://www.canadahelps.org/en/dn/41531

BE PREPARED! - Emergency Protocol for MG Patients

We are all uniquely different, and react differently. So your emergency protocol may be different than any other MG patient. What c
informed.

Talk to your neurologist and be sure both of you are aware of what mechanisms need to go into place should you “go into crisis” The two of you should have an understanding of the protocol and come up with a plan together.

Write up a brief explanation of your illness and all of your medications and dosages. Your doctor’s name and contact numbers, MSP number, next-of-kin and advocate information. Make several copies – be sure to update this information, whenever there is any change. Keep a copy in a medical folder or on a file card. Put a copy on the fridge, in your glove compartment, your purse, wallet, briefcase, lap top bag, anything you might carry with you. Get a MEDIC ALERT bracelet or medallion.

It is a good idea to get in the habit of keeping a medication ‘diary’, listing what medications you’ve taken each day, in what strengths, and at what times. This is invaluable to any caregiver or emergency response person, should you not be able to speak for yourself.

If you are feeling ‘off’ one day, make note of it. When it started, how it manifested? Do you have a fever, slow healing sore, nausea or vomiting? If you are having problems swallowing, placing your MESTINON under your tongue helps it absorb quickly and may bring relief. If you sit down and try to relax, do you feel better?

When does it become serious? When nothing helps and you still feel lousy!

If you are not able to swallow your medication or enough liquids to stay adequately hydrated this is a serious situation and requires you to go to Emergency.

●Call your neurologist (or have someone do it for you) – as per your plan.

●Relate the information from the medical diary.

●If you and your doctor feel you should go to Emergency, ask him or her to call ahead and let them know you are coming.

●Take the Medical File and Medical Diary with you as you may not be able to answer questions easily.

●If possible take your meds and whatever you need to swallow them, yoghurt, pudding etc. You won't want to have to wait for the hospital to order them from the hospital pharmacy. Do not take any medications until you are seen by the ER doctor, in case it is the medication level itself that is the problem.

● Be sure the attending nurse and physician understand your condition. If you are unable to talk to them, be sure they read the paper. Be sure someone is aware of your present condition and watches to be sure are not getting worse as you may have to wait to be seen by ER staff.

And while all of this is going on, DO NOT PANIC. It sounds simplistic but panic will only make your symptoms worse and could cloud the underlying MG issue that needs to be addressed.

Source: Foundation Focus, MGFA, Spring 2006
https://myastheniagravis.ca/articles/be-prepared-emergency-protocol-for-mg-patients/

REBRANDING THE MGABC ❄

MGABC
MYASTHENIA GRAVIS ASSOCIATION of B.C.

A logo should tell the story of the organization. Our Board has decided that MGABC needs a facelift, and a website upgrade to remind ourselves of *"Who we are"* and *"What we represent"* or *"What we are and Who we represent."*

Each Myasthenic, like each snowflake are not alike. We are each individual when it comes to diagnosis, and treatment. From symptoms to remission, not one of us is the same, hence the *"Snowflake Disease".* The change started last year with our thank you cards. This led to our Newsletter Editor helping to re-create the logo for us, which is now on our stationary, our website, and of course our Newsletter.

We are so blessed to have the help of Glen Skidmore who gives of his time to edit our newsletter, and more recently rebranding. Thank You Glen! Our other fabulous volunteer creator is Euan Bowman, and we would like to Thank him for taking care of our website, and helping us with the upgrade.

Kelly Carson, President, MGABC

LITERATURE ORDER

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 offices.

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

OR

https://www.canadahelps.org/

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Myasthenia Gravis of BC

Membership ☐

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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_____