

MG NEWSLETTER

[Myasthenia Gravis Association of British Columbia](#)

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The Myasthenia Gravis Association of BC

You are cordially invited to attend

The Annual General Meeting and Spring Support Group Meeting

When: **Sunday, April 14, 2019 @ 1:30 pm**

Where: **Room 307, Centre for Ability, 2805 Kingsway, Vancouver**



Special Guest Speaker Dr. Aathi Pathmanathan

Dr Pathmanathan will answer questions and discuss experiences at VGH Neuromuscular Diseases Unit regarding MG Studies and Research Projects.

Refreshments will be served.

Friends, relatives, health professionals and other interested parties are welcome to attend.

For further information, please contact
Brenda Kelsey or Linda Briggs at 604-451-5511 local 1284 or
email: Myasthenia.Gravis@bc-cfa.org

2019 Membership Drive and Fundraising Begins!

Every October we ask MGABC members to renew their memberships. The annual cost is \$20.00 per member. This fee includes a bi-annual newsletter, free information pamphlets, notification of special programs of interest to Myasthenics, support group meetings with speakers, as well as staff willing to support you. Memberships renewed after September 30th will be good for the coming year. ***Look inside for the exciting fundraising event for March, 2019!***

PLEASE HELP US REDUCE PRINTING AND POSTAL COSTS BY READING THE NEWSLETTER ONLINE ON OUR WEBSITE - Myastheniagravis.ca.

Send us an email with *Newsletter* in the subject line and we will be sure to inform you when it has been posted.

Articles contained in this newsletter are for information only. The MG Association of BC does not give medical advice. In matters of medical treatment, patients should consult with their physicians.

Annual Report of MGABC for 2018

What a “wow” year for the MGABC! We have been incorporated as a nonprofit society for 60 years. This makes us the second oldest in North America after the MGAFA.

To celebrate, we had a fundraising luncheon and a silent auction. This was a fun social event as well as a financial success. Many thanks to all who participated by attending, donating items, and buying them. A list of sponsors is on page 3.

You will remember that last year we sponsored a neurologist to come to VGH to learn about myasthenia gravis. Dr. Pathamanan started at the MG clinic in the fall of 2018 and is now working at the Neuromuscular Diseases Unit learning about MG and also taking part in MG research projects.

During 2018, we counseled, educated and supported 20 new MG patients and their families. There were 7 men and 13 women, all of various ages. We also mailed out 115 pieces of literature to our members.

I would like to thank the board of directors of the MGABC. They have been such a great help and support this past year. Special recognition goes to Linda Briggs, David Sutherland, and Joel Oger.

A huge thank you to Barb McDonald for doing such a great job with the newsletter, clerical duties, and organizing and helping during the silent auction.

I would also like to recognize Tariq Assiz, who helped so much with the lunch and auction. Tariq works at the Immuno-Biology lab at UBC with Dr. Frykman doing MG research and diagnostics.

We appreciate and thank the staff of the Centre for Ability. They are always friendly and generous with their advice and help.

Respectfully submitted,



Brenda Kelsey

Spring 2019



October 14th, 2018 was a beautiful sunny Sunday in Vancouver, and a dedicated group of Myasthenia Gravis patients, friends and family met at the Centre for Ability in Vancouver. Their purpose was to celebrate the 60th Anniversary of incorporation of MGABC, enjoy a catered luncheon and bid on a variety of items that had been donated to the Association for a Silent Auction. The goal was to help raise money for the Myasthenia Gravis Association of British Columbia.

Up for auction were baked goods, paintings, ceramic wear, gift baskets donated by local businesses, catered dinners, opera tickets, gourmet chocolates and wine, and a boat trip with lunch. I am sure all of the attendees will agree it was a great afternoon made even more so by the amount of money raised...close to \$3,000!

60!

We are most grateful to the following:

VanCity Pinetree Community Branch - David's Teas, Coquitlam Centre
Moody Ales, Port Moody - Twin Sails, Port Moody - Parkside Ales, Port Moody
The Boathouse, Port Moody - Rocky Point Ice Cream Parlor - Cockney Kings, Burnaby
Las Margarita's Restaurant - Oxygen Yoga, Port Moody
Fostering Debate Talent FDT - Save-on-Foods, Market Crossing - TD Bank, Market Crossing White Spot, Market Crossing - London Drugs, Market Crossing
Conte Foods in the Big Bend area - Starbucks Coffee at Kingsway and Tyne - Safeway - Caulfeild Village
Esso Coffee Machine (ECM), 1st & Boundary
The Keg - The Granville Island Hotel.





**MYASTHENIA GRAVIS
ASSOCIATION OF BC PRESENTS:**

Mozart for Myasthenia

A BENEFIT CONCERT

MARCH 30, 2019 | 7:30PM

KOERNER RECITAL HALL AT VANCOUVER ACADEMY OF MUSIC
1270 CHESTNUT ST, VANCOUVER



Myasthenia Gravis (MG) is a rare chronic auto-immune neuromuscular disease which can strike anyone at any age. The symptoms are severe fatigue and muscle weakness in eyes, throat, limbs, and chest which can compromise breathing, leading to a crisis situation.

As these symptoms are fluctuating and present differently in each patient, MG is very difficult to diagnose and to treat. If diagnosed and treated early, there is hope for a nearly normal life with and sometimes without medication. More research is needed into the cause and treatment of Myasthenia Gravis and for more doctors to recognise this rare orphan disease.

Proceeds from Mozart For Myasthenia will go towards supporting a young doctors fellowship in neurology focused on Myasthenia Gravis.

FEATURING WORKS OF MOZART PERFORMED BY:

Andrew Dawes, violin | Isabel Vila, violin
Jason Ho, viola | Eric Wilson, cello | Jane Coop, piano

TICKETS: MGABC.EVENTBRITE.CA

\$25 general | \$40 couple | \$18 Students

Includes a glass of white wine or a pop.

SPONSORED BY:



*We thank all patrons for ticket proceeds that, together with individual donations, will help fund this cause that advances the mission of MGABC. **Please also consider making a gift** through Canada Helps by visiting myastheniagravis.ca.*

Hard to Swallow!

It appears that commonly used clinical scales used to measure symptoms of severity in myasthenic patients who exhibit problems in swallowing and risk of aspiration are insufficient. Patients who have difficulty swallowing (dysphagia) and have disease severity classified as IIb/IIIb (MGFA clinical classification) need appropriate therapeutic management regardless of how they score on the clinical scales. Neurological exams should be accompanied by swallowing-specific exams such as endoscopy.

Certain conditions, such as MG, can weaken a person's throat muscles, making it difficult to swallow food. The severity varies among patients. Both oral and pharyngeal phases of swallowing are frequently disturbed in MG patients. This is one of the most serious symptoms of MG, as it may lead to the silent aspiration of food or fluids into airways, as well as introducing bacteria into the lungs. However, the best way to avoid this is still unclear.

Swallowing studies reveal the symptom is more severe in patients who also have more severe neurological symptoms as measured by MGFA classification. These results should alert neurologist to the risk of silent aspiration, even in patients diagnosed with clinically and neurologically mild MG. In the future, prospective studies that include more patients, age-matched controls and assessment of the diversity of these 'dysphagia' patterns are needed.



Soliris (Eculizumab) for Myasthenia Gravis

Soliris was developed by Alexion Pharmaceuticals, and approved by both the U.S. FDA and the European Commission in 2017, to treat certain adults with generalized Myasthenia Gravis. It is given as an intravenous (IV) infusion once weekly, followed by a fifth dose one week later and then with ongoing infusions once every two weeks. Soliris is also FDA-approved for treatment of paroxysmal nocturnal hemoglobinuria and atypical hemolytic uremic syndrome.

How it works...

Soliris is designed to block part of the immune system called the terminal complement cascade, consisting of a series of reactions that trigger the damaging immune response seen in MG. Soliris binds to and inhibits the cleavage of a protein called C5, an essential step at the start of a cascade.

In clinical trials, prior to its approval for first treatment for generalized myasthenia gravis, it showed a clinically meaningful reduction in the disease severity in treated patients as compared to those on a placebo. Substantial improvements were observed in myasthenia gravis composite (MGC) scores and the 15-item myasthenia gravis quality of life (MG-QOL15) score. It did not however achieve significance in its primary goal which was a change in myasthenia gravis activities of daily living (MG-ADL).

This FDA approved Phase 3 clinical trial, (NCT01997229) was called **REGAIN**. A Phase 3 open-label extension study (NCT02301624) was initiated to assess Soliris' long-term safety and efficacy in those patients who had taken part in **REGAIN**. An interim analysis indicated sustained benefits after 52 weeks of additional treatment and safety findings were also consistent. This Phase 3 extension is expected to conclude in January of 2019.

Side effects associated with Soliris use include headache, dizziness, fever, nausea, infections, fatigue, bladder pain and common cold symptoms.

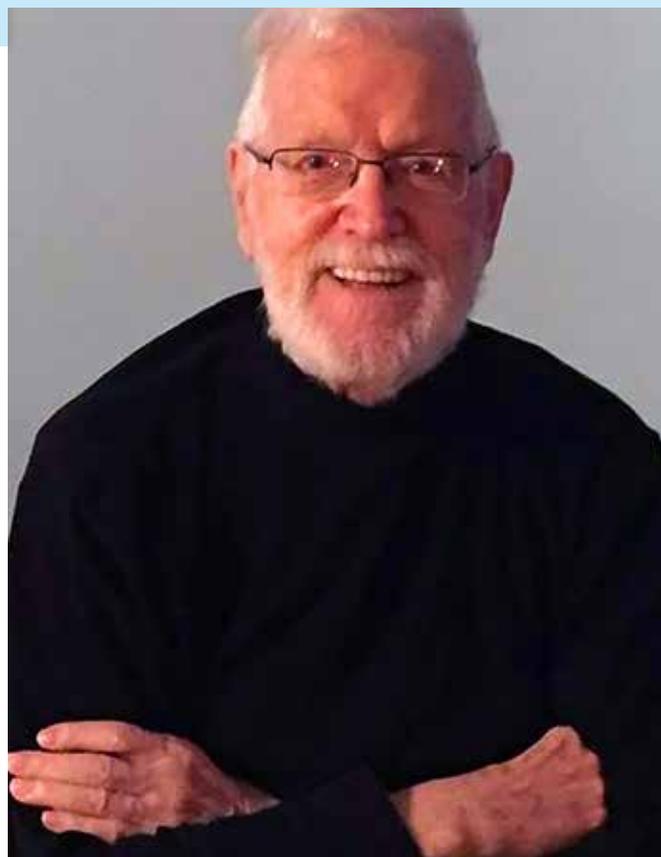


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In Memoriam: **TOM STIRLING**

Some of you may remember Tom as one of the driving forces behind starting the the North Island Myasthenia Gravis Support group. Tom was born in Scotland and emigrated to Canada in 1960 to marry his Scottish sweetheart who had emigrated with her family a few years before.

Tom lived a full and healthy life until he was stricken with Myasthenia Gravis in 1993. He was living in the Parksville area at the time and was dismayed to find there was no local support group. Tom teamed up with Ken Butler, another myasthenic patient and came to Vancouver MG office to see how they could start a support group in the Parksville area. With some funding and a little advice they started the North Island Support Group which is still active today.



When Tom moved to live near his daughter in Port McNeil in 2008 he had to give up an active role in the group. Tom was in good health until last spring when he was diagnosed with angina, had a bad fall and had to have a leg amputated. With his health failing Tom was determined to live to see his great grandchild, which he managed to do.

Tom will be remembered for his dedication to his family and for furthering the cause of Myasthenia Gravis on Vancouver Island. His last words were "Love to all".

Why Am I Not Just Tired?

as published as a column by Retha De Wet, A Good Life with Bad Muscles

I would sleep 18 hours a day. I'd wake up and take a shower ...only to fall asleep again from exhaustion directly after. I would become tired when preparing a meal and then again after eating the same meal. With muscles that are always weak, making every activity strenuous, it makes sense that myasthenics are always tired and never fully rested.

Sleeping does make the fatigue feel less intense, though, which is why I take frequent naps. I struggle to function without them. A telltale sign of myasthenia gravis is that there seems to be a slight improvement in muscle function with rest, and what epitomizes rest as well as sleep? Sleep is as important to my treatment plan as Mestinon (pyridostigmine bromide) or my immunosuppressive medications.

Others often say, "I'm tired, too. Just push through it." That greatly frustrates me. I am not the same kind of tired as my healthy peers. They might never know the critical levels of exhaustion I experience. They won't have to, and for that, I believe they should be grateful.

One of the perks of being eternally tired is that I have developed the unique skill of being able to fall asleep anywhere and in most positions. During my current travels through Europe, I have learned that sleeping in any position is a beneficial skill, though it can leave me with a very sore body and stiff muscles. So, my advice is to always make sure you have a pillow or something similar to support your weak neck when you think you might be sleeping in some odd positions, like when using public transport.

Never think that you are too weak for admitting you are tired and need to rest. You are strong for taking responsibility for your health. Our muscles might be tired but our souls need not be. Life is beautiful. Never stop fighting.



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7 Small Changes That Can Improve Life With Myasthenia Gravis

Pallavi Rao Narvekar

We are the “privileged” few. The chosen ones.

You know, the ones diagnosed and living with myasthenia gravis.

Myasthenia gravis affects 20 out of 100,000 people in the United States.

Aaah, now that we have the official stats in place, let us get on with the art of living a fruitful life with myasthenia gravis.

I believe acceptance is the first step towards managing neuromuscular disorders in general –myasthenia gravis in particular.

So easy to write. So difficult to imbibe and implement. No wonder I decided to write and speak about it only when I completely accepted that MG is a reality of my life.

I learned and accepted that it is OK to change my life and day-to-day living as per my health condition and muscle strength to make it easier for myself and indirectly easier for my family.

These are simple adjustments that go a long way in easing the discomfort from the fact that one is unable to do things all by oneself. See if you would like to incorporate the same into your life or that of your loved ones having neuromuscular issues.

1. Wake Me Up Before You Go Go...

...should actually be don't wake me up before you go. Let me sleep till whatever time. It is OK to sleep till 8:00 or 9:00 a.m. I don't have to jog or go for a marathon practice session. My body is asking me to rest a little more and I shall do exactly that.

2. Mugged

Yes, the mug in the bathroom. It weighs as much as the five-kilogram (about 11 pounds) dumbbells I used to effortlessly pick up at the gym 15 years ago. They are heavy to pick up as is – add water to that and I am doomed. So I found an alternate. There are smaller mugs available, a little bigger than your coffee mug! It suddenly eases the effort, both physically and mentally. It is OK to buy one.

3. Help

A magic word. Help. Take help. From whoever is close by and/or is close to you. There are things you might not be able to do all by yourself today so it is OK to ask for help.

Bath: Oh, this is one is tough on those “bad” days. One has to psychologically prepare oneself for the event of the day! Ask someone to scrub your back. It is better than gasping for breath and being totally exhausted the rest of the day.

Changing clothes: Do you know how difficult it is to put your hands in the sleeves and pull a shirt over your neck and shoulders? It's a task as difficult as climbing up the EBC (Everest Base Camp), except we do it each day. Take help from a family member, for God's sake. Feel like a kid. Get pampered.

Hair wash: Hair wash day is the one of the most grueling days of the week. However, we now need to adjust the days and frequency according to our energy levels and muscle power. Each hair wash is generally accompanied by red, swollen, watery eyes because I am unable to keep them shut as tightly as before.

Solution? Lessen the number of washes if possible. Change your hairstyle as per each passing day. Day one: Ooo...blow dried hair. Day two: ponytailed hair. Day three: plaited hair. Day four: the gelled and bun look. Day five: Good Lord... hair wash day – but this time ask someone to wash it for you. And it is OK to ask.



4. Baby Food

Mish mash your favorite foods and eat. It's better to have overcooked rice and millets than to struggle with it and overwork the poor facial muscles. No one is going to judge you on what you are eating and if someone does, you know what to do. Accept help from someone.

5. No Means No

I never learned this in my life, but now is the time to say it. Say no to...

Parties and weddings: Please tell me if you remember who did not come to your wedding or party from the long guest list that you missed terribly that day. No one misses the absence of a guest in a big party or marriage ceremony. It is fine to be cuddled in bed, conserving energy for the next day rather than being at an open air wedding, putting your lungs at risk and rushing to the ICU.

Movies: It is OK to say no to a movie plan by friends and family. Thank God we live in the digital age and have options galore: Netflix, Amazon Prime and 200 channels on TV. Eventually we shall get back to it but presently, chances are we might catch an infection from going to a movie.

Visiting guests: Say no if you are not up to it. If they understand, keep them in your friend list but if they get upset, chuck them right away. Also, unashamedly ask and ensure that they are not getting a cold or a cough as a gift for you.



6. Footsie

Silly me discovered this just recently. When bending down leads to breathlessness (like you just did 20 minutes on the treadmill at a high speed), you need to change the tactic. Use your foot instead. Of course, it is to be done only by those who have leg and calf muscle strength. But yes, you could use your foot to switch the floor buttons on and off, pick things from the floor or clear the bed with one leg swoosh (when no one is around to see or help).

7. Rest, Rest, Rest

It is OK to have a mid-morning, afternoon and a mid-evening power nap. That is like an energy drink for us.

These small changes can be incorporated when the going is tough. Once my medication went into effect, my symptoms subsided and I could see remission at the end of the (till now) dark, never-ending tunnel. Now I can get back to a more action-oriented life.

Till then my friend, the key word is OK.

It's OK to take it easy and it's OK to accept help.

Meanwhile, as always, a small, little prayer that the medical fraternity finds a cure for myasthenia gravis soon. Very soon.

This post originally appeared on [Pallavi Rao's blog](#).

Pallavi Rao Narvekar: A Radio Jockey by profession, I was struck with MG 10 years ago. 3 times thymoma survivor, a Myasthenia crisis, a near respiratory failure and a number of pneumonia attacks, I have been there done that.

It's OK

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DONATIONS as of February 1, 2019...

S. Trujillo Jiminez
Rosa Tessler
Gayle Wilson
James Postnikoff
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Cliff Johnson
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Donations In Memory of...



Stephen Olliver for Janet Olliver
Joseph Tatangelo for Pat Tatangelo
Heather Bernier, Fiona Stirling and
Brenda Kelsey for Tom Stirling
Winsome Rauch, Michael Wispinski and
Roy Kendall for Ed Haaf

Corporate Donations:

TELUS CARES
David Sutherland and Rose Hare



CanadaHelps.org.
Eric Kong
Dr. M. Mezei
Dr. C. Krieger
Karen Alexander - Myasthenia Gravis Research



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
7. Drug pamphlets:
(a)Mestinon (b)Imuran (c)Prednisone (d)Cyclosporine (e)Cellcept
(f) Tacrolimus
8. Drugs that aggravate MG - **2012**
10. Plasmapheresis
11. IVIG - Intravenous Gamma Globulin
12. Ocular MG
13. Nutrition for Healthy Bones
15. Dentistry and the Myasthenic
16. Pregnancy and Myasthenia Gravis
17. Myasthenia Gravis in Children and Adolescents - **NEW**
19. Congenital Myasthenia Gravis
20. Emergency Care of Myasthenia Patient
21. Mestinon - A possible emergency measure
22. Assessment & Management of Speech & Swallowing in Myasthenia Gravis
23. Hospital Package: Nursing Care of the Myasthenic; Hospitals Can be Dangerous;
Anesthesiology Drugs
24. Practical Guide to MG
25. Dr Oger's book for Family Physicians - free to MG members
26. MG ID Emergency Alert Card
27. Providing Emotional Support for patients with MG
28. Myasthenia Gravis Information for GPs **NEW**
29. Tips on applying for CCP Disability Benefits
31. 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 book stores)**

Please note: General Myasthenia Gravis information is now available in Mandarin. If you would like a copy, please contact our offices.

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MEMBERSHIP and 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
Notice of meetings...Up-to-date information on MG**

You Can Help!

Your support can make a vital difference in the fight against Myasthenia Gravis at UBC.

Online: www.supporting.ubc.ca/MG Phone: 1-877-717-GIVE (4483)

We can now also receive donations online through CanadaHelps.org

****If you are donating directly to UBC, please let us know so we may include your name in the RESEARCH DONOR list.***

Make Cheque payable to: MYASTHENIA GRAVIS ASSOCIATION of BC
Mail your cheque to: Myasthenia Gravis Association of BC
2805 Kingsway, Vancouver, BC V5R 5H9

Last Name _____ First Name _____

Address _____

City _____ Prov. _____ Postal Code _____

Phone _____ MG Patient Yes No

Email _____

Membership (\$20.00) \$ _____ (no tax receipt will be issued)

Donation \$ _____ (a tax receipt will be issued for donations)

TOTAL AMOUNT ENCLOSED \$ _____

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

Last Name _____ First Name _____

Address _____

City _____ Prov. _____ Postal Code _____

Phone _____ EMAIL _____

If you are no longer interested in receiving our mailings, or would like to receive them by e-mail, please send your request to us at Myasthenia.Gravis@bc-cfa.org with the words "**E-mail request**" in the subject line. Thank you.