

MG NEWSLETTER

Spring
2018

[Myasthenia Gravis Association of British Columbia](#)

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E-mail: Myasthenia.Gravis@bc-cfa.org • Website: www.myastheniagravis.ca



The Myasthenia Gravis Association of BC

You are cordially invited to attend

The Annual General Meeting and Spring Support Group Meeting

When: **Sunday, April 15, 2018 @ 1:30 pm**

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



Special Guests

Dr. Michelle Mezei - *Clinical Assistant Professor,
Divison: Neurology UBC Department of Medicine*

and

Joel Oger



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

Two members for seats on the Board of Directors for the MGABC.

No previous experience necessary!

Commitment of two years for two afternoon meetings yearly.

Reply to: Brenda Kelsey or Linda Briggs

604-451-5511 Local 1284



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.

MG NEWSLETTER

Annual Report of MGABC for 2017



2017 was a year filled with highs and lows for the MGABC, the lows being the loss of three of our long time members; **Judy Bonny**, who worked with me in the MG office from 2001 to 2009 as accountant and newsletter editor, **Judy McDermid**, a faithful and loved member of the North Island MG group and **John Phillip**, a long time member of the Vancouver group. Our sincere sympathies go out to their families and friends.

Some of the highs were helping twenty one new myasthenic patients and their families with education and coping skills in living with myasthenia gravis. There were 14 males and 8 females, the youngest being 4 years old. We supplied over 1,000 pieces of literature to the MG clinic and over 130 pieces to members, care givers and physicians. There were approximately 55 calls and emails which Linda and I responded to in the office and at home.

Aside from supporting and educating our MG members, there is always administrative work to be done. The provincial government is changing the rules regarding non profit societies in B.C. and accordingly has asked that constitutions and by laws of these societies be updated and reported online. This daunting job was made easier with the help of **Ian Rose** and **Barbara McDonald**. Thank you both!

Due to poor turnout in participation and returns, the board of directors decided to drop the Scotia Bank Charity Challenge as a fund raiser and instead send a "letter of appeal" to our members and friends every second year. This has been successful and we are very grateful to those who supported this venture by paying membership dues and sending in donations.

As Lyle Brown of Culver and Co. had retired as MGABC auditor, it was voted at the last AGM to use **Manning Elliott** as our auditor for 2017. Linda and I met with them in their offices to introduce ourselves and discuss the financial requirements of the MG association.

In June, I received a call from a doctor at Memorial University Hospital in St. John's, NFLD. He had worked at the VGH neuromuscular unit for a month and wished to return to the unit to continue to study myasthenia gravis. He needed funding to pursue this fellowship and inquired whether the MGABC could be of any assistance. As there is a lengthy and detailed process to go through in order to be accepted as a fellow in the department, I asked **Dr. Oger** (ret.), who has experience in this process, to handle the request. This process took us until 2018 and I am pleased to say that, thanks to a very substantial donation from one of our members and some monies from the Myasthenia Gravis Trust Fund, we have been able to assist with funding. Dr. Aathi Pathmanathan will be starting at the NMDU in the fall of 2018.

I cannot thank **Linda Briggs** and **Barb McDonald** enough for all their help in the past year. They are absolutely necessary to this organization and both do an amazing job for us. It has been a year of significant changes and challenges for the MGABC and I am very grateful to the board of directors for their help and unfailing support.

Thanks, as always to **Angie Kwok**, director of the Centre for Ability and her very helpful and friendly staff.

In 2018 the MGABC will be celebrating its 60th year of incorporation as a non profit society. There will be celebratory meeting on October 14th, 2018, so mark your calendars and come and help us celebrate this amazing milestone.

Respectfully submitted,

Brenda Kelsey

A handwritten signature in black ink that reads "Brenda Kelsey". The signature is written in a cursive style with a large, prominent 'B'.

Spring 2018

Letter From Doctor Frykman
(Medical Director, UBC Diagnostic Services Laboratory)
To The MGABC

Dear Myasthenia Gravis Association of BC,

It has been a roller coaster ride in the UBC lab to say the least! Just a few months ago it was uncertain if we were to continue to exist!

At the same time: Our impact is larger than ever as we have successfully launched the MuSK Antibody test which has become an overnight success all over Canada.

Also, just last summer we were again saved economically by a generous donation by Mr. Eric Kong. Without this money we would not have been able to continue.

Since then the economy has stabilized and UBC has recognized the importance of our lab. Things have quieted down and we have been able to pass the rigorous CAP accreditation protocols in addition to DAP accreditation.

So, for the first time in two years life is now getting stable at the lab and we can again plan for the future. The staff is unchanged. Mr. Tariq Aziz was fired by UBC and rehired by me just recently. We are also welcoming Mrs. Anna Cruz back from maternity leave. Dr. Ebrima Gibbs continues with us.

In late 2018, I plan to launch two new MG tests: LRP4 and a high sensitivity Acetylcholine assay. Both will be licensed to us from Dr. Angela Vincent's lab in Oxford UK. The clinicians have asked for these tests and they will be meaningful in providing better care for all MG patients in Canada.

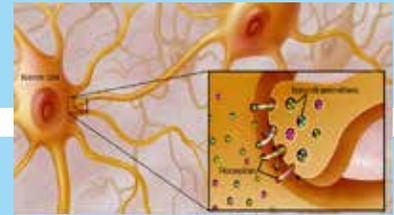
During 2019 the lab will be part of PHSA, the health authority and we will merge with VGH Pathology. This a good thing since the fit with UBC was not ideal.

I encourage you to consider future donations to this lab so that we can bring these new tests onboard to the benefit of all Canadian MG patients.

Best,

*Hans Frykman MD PhD FRCPC
Medical Director
UBC Diagnostic Services Laboratory
Clinical Assistant Professor of Medicine
University of British Columbia
Vancouver BC*





Myasthenia for GP's

The following article has been reprinted for our literature list (28) and is available for you to order and give to your GP or any health care professional you think might benefit from this information.

Myasthenia is an autoimmune disease whereby the nerve stimuli to voluntary muscles are blocked by antibodies. It can occur at any age and can be rapid or slow in its development.

It affects more females in children and younger age groups and males in the older age groups and the overall incidence is about 17/100,00 people – so it is not a common disease for a GP with a list size of up to 3,000 patients – yet, though not actually curable, it is a treatable condition and it can be dangerous to miss. There are various types of myasthenia gravis.

COMMON PRESENTING SYMPTOMS TO BE AWARE OF

Eyes: there may be double vision or a drooping of the eyelid caused by local muscle weakness.

Oral & Respiration: Difficulty in swallowing and sometimes difficulty in speech with the voice being much weaker. These symptoms should be addressed immediately with an emergency admission as it may lead to choking and/or a myasthenic crisis.

Limb weakness: The weakness tends to affect the proximal muscles of the limbs, such as the inability to lift the arms or legs making usual mobility difficult. The symptoms may be less obvious early in the day and may worsen at the end of the day or after exertion. Symptoms may also worsen in hot environments – including hot showers or sun bathing. Characteristically the limb muscles fatigue very quickly, especially when doing repetitive movements or exercises.

DIAGNOSIS

The first help in diagnosis is considering the disease as a possibility and becoming familiar with the variety of symptoms. Many presiding symptoms in older individuals are slow in developing and may be dismissed as just part of the aging process.

The drooping eyelid is a common presentation and should be an alert for follow up. Double vision also should bring the disease to mind as well as the increase in muscle weakness. A rarer variant may be in the ocular form but may develop into general myasthenia gravis. Being **immunosuppressed** makes it unwise to receive live vaccines.

Applying an ice-cold pad over a drooping eyelid can show a short-term relief. The presence of acetylcholine receptor antibodies in the blood is diagnostic though unfortunately not all cases show that. An Electromyography (EMG) test is usually requested by a neurologist and this will show a characteristic falling of muscle activity, when subjected to repeated stimulation.

TREATMENT

Due to the rareness of the disease and the initial difficulties in diagnosis, it is wise to refer the patient to a neurologist familiar with MG. The most important thing is to avoid a 'myasthenia crisis', in which case the patient has a very sudden and acute problem with breathing. This can come on very quickly for patients whose MG is not stable. Admission to hospital is necessary.

MEDICATION

This is usually begun in the hospital under supervision and may include the administering of Pyridostigmine (Mestinon) which provides short-term symptom relief but also need to be taken frequently. The aim of long-term treatment is to suppress the body's production of acetylcholine antibodies. Most patients require a steroid to induce and maintain remission. In severe cases, IVIG or plasma exchange may be used though the improvement may be short lived. In some, second-line immunosuppressant drugs are added to reduce the steroid requirement and long-term steroid use side-effects.

CAUTIONS

Some common medications, including antibiotics, used for other concurrent illnesses, can exacerbate MG. Check the following list of drugs cautioned or contraindicated.

VACCINATIONS

Being **immunosuppressed** makes it unwise to receive live vaccines.

LIVING WITH MG

Though the diagnosis may be difficult, once under control patients can live a reasonably normal life with normal life expectancy. The disease does affect individuals differently – so it is important to be aware of your activity level and schedule times to rest as well.



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Relatives of Myasthenics Be Aware...

It was recently brought our attention that the adult son of one of our members developed Myasthenia Gravis. This in itself is not unusual, as there is a predisposition to auto immune diseases in families.

*This man had a severe infection after abdominal surgery and was treated with **Ciproflaxin**. Soon after his recovery he was diagnosed with Myasthenia Gravis. No doubt the Ciproflaxin beat the infection and saved his life, but possibly another antibiotic could have worked as well.*

This is just a cautionary note for myasthenics and their close relatives to be aware of the possible reaction to Ciproflaxin.

Myasthenia Gravis & Drug Interactions

If you have myasthenia gravis, it's not unusual to be taking multiple medications. How do those drugs interact with drugs for infection, pain, or other illnesses, or with the over-the-counter (OTC) medications and supplements that can be found in most people's medicine chests.

The topic of "Myasthenia Gravis and Drug Interactions" was addressed at Conquer MG's October 2016 patient seminar in Oak Lawn, Illinois. The speaker was **Mitra Habibi**, PharmD, from the University of Illinois at Chicago College of Pharmacy. Doctor Habibi is a clinical pharmacist; she works with physicians to coordinate care and medications for patients in the hospital setting. She also teaches at the University.

Here are highlights from Dr. Habibi's presentation:

General Cautions

- Avoid combining your meds in an old pill bottle; the label will be inaccurate and confusing for others.
- Always keep an up-to-date list of your medications and doses in your wallet. That way you can share consistent and complete information with all of your health care providers.
- To avoid drug interaction problems, it's essential that each of your doctors has an accurate picture of all medications you're taking, including over-the-counter (OTC) meds and herbal supplements.
- OTC meds and supplements are drugs and can trigger interactions with other medications you take.
- As we age, our bodies – including the liver and kidneys – metabolize drugs differently. So doses need to change.

Medications that Can Worsen MG Weakness

- Antibiotics are the biggest classification of drugs that potentially cause problems in patients with MG. There are classes of antibiotics that can be used for MG patients and classes that should not be used. Key: your prescribing doctor should be aware that you have MG.
- Never use someone else's leftover antibiotics (even if you think you have the same illness), because you may be unaware of adverse effects with your MG or your other medications.
- Medications labeled with black box warnings related to myasthenia gravis should be avoided. The Food and Drug Administration (FDA) requires this strictest warning when there is significant risk of serious or life-threatening side effects. The warning is surrounded by a black outline on the prescription container and insert.

These antibiotics have black box warnings and should not be used for individuals with myasthenia gravis:

Fluoroquinolones (Ciprofloxacin (“Cipro”), levofloxacin, gatifloxacin, femifloxacin, norfloxacin, ofloxacin)
Ketek (telithromycin)

These antibiotics should also be avoided because they can cause neuromuscular weakness:

- Aminoglycosides (amikacin, gentamicin, kanamycin, neomycin, streptomycin, tobramycin)
- Tobramycin – probably the weakest neuromuscular blocking effect (least problematic)
- Macrolides (erythromycin, zithromycin or z-pack) – use cautiously, if at all
- Clindamycin – Likely to worsen MG

These antibiotics have not been shown to cause many problems for MG patients:

- Tetracycline (doxycycline, minocycline) – this may worsen MG
- Sulfonamides (Bactrim), Penicillin – causes rare cases, usually not a problem for majority of MG patients
- Voriconazole (antifungal) and peramivir (antiviral) reported to worsen MG
- Botulinum toxin (Botox) – avoid use.

Dr. Habibi also noted:

- Magnesium can interfere with neuromuscular transmission. The usual doses of medications containing magnesium (antacids, laxatives) are unlikely to cause problems – except in patients with kidney disease. The amount of magnesium in daily multivitamins is unlikely to cause problems. However, intravenous doses of magnesium sulfate can cause serious muscle weakness and should be avoided in MG patients.
- The effect of Beta blockers on myasthenia gravis depends on the dose and type of medication. Propranolol is the most likely offender to cause fatigue, while Atenolol is least likely.
- Steroids, commonly used to treat MG weakness, can have many adverse effects.
- With pain management, it’s important to consider the individual to minimize drug interactions. Your doctor should take into account the severity of your MG disease, other complicating illnesses, and other medications being used before recommending pain meds. In general, aspirin, non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and naproxen, and acetaminophen (Tylenol) are considered safe for MG, that is, they have not been shown to worsen MG or cause muscle weakness. However, each of these medications carry risks (for example, NSAIDs can increase the risk of stomach ulcers when taken with steroids), so it’s important to view the individual situation.



Dr.Mitra Habibi



Link to see a short clip from Dr. Habibi’s presentation that covers cautions for MG patients regarding antibiotics, including black box warnings. <https://www.youtube.com/watch?v=58b8Zb7-MJ0&feature=youtu.be>

Link to see Dr. Habibi’s full presentation covering black box warnings; the use of antibiotics, pain medication, magnesium, statins, over-the-counter medications, and quinine for MG patients; and steroid side effects. <https://www.youtube.com/watch?v=4eld79fg64A&feature=youtu.be>

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FDA News Release

FDA Updates Warnings for Fluoroquinolone Antibiotics

Limits use for acute bacterial sinusitis, acute bacterial exacerbation of chronic bronchitis and uncomplicated urinary tract infections

The U.S. Food and Drug Administration today approved safety labeling changes for a class of antibiotics, called fluoroquinolones, to enhance warnings about their association with disabling and potentially permanent side effects and to limit their use in patients with less serious bacterial infections.

“Fluoroquinolones have risks and benefits that should be considered very carefully,” said Edward Cox, M.D., director of the Office of Antimicrobial Products in the FDA’s Center for Drug Evaluation and Research. “It’s important that both health care providers and patients are aware of both the risks and benefits of fluoroquinolones and make an informed decision about their use.”

Fluoroquinolones are antibiotics that kill or stop the growth of bacteria. While these drugs are effective in treating serious bacterial infections, an FDA safety review found that both oral and injectable fluoroquinolones are associated with disabling side effects involving tendons, muscles, joints, nerves and the central nervous system. These side effects can occur hours to weeks after exposure to fluoroquinolones and may potentially be permanent.

Because the risk of these serious side effects generally outweighs the benefits for patients with acute bacterial sinusitis, acute exacerbation of chronic bronchitis and uncomplicated urinary tract infections, the FDA has determined that fluoroquinolones should be reserved for use in patients with these conditions who have no alternative treatment options. For some serious bacterial infections, including anthrax, plague and bacterial pneumonia among others, the benefits of fluoroquinolones outweigh the risks and it is appropriate for them to remain available as a therapeutic option.

FDA-approved fluoroquinolones include levofloxacin (Levaquin), ciprofloxacin (Cipro), ciprofloxacin extended-release tablets, moxifloxacin (Avelox), ofloxacin and gemifloxacin (Factive). The labeling changes include an updated Boxed Warning and revisions to the Warnings and Precautions section of the label about the risk of disabling and potentially irreversible adverse reactions that can occur together. The label also contains new limitation-of-use statements to reserve fluoroquinolones for patients who do not have other available treatment options for acute bacterial sinusitis, acute bacterial exacerbation of chronic bronchitis and uncomplicated urinary tract infections. The patient Medication Guide that is required to be given to the patient with each fluoroquinolone prescription describes the safety issues associated with these medicines.



The FDA first added a Boxed Warning to fluoroquinolones in July 2008 (ssLINK/UCM126085) for the increased risk of tendinitis and tendon rupture. In February 2011, the risk of worsening symptoms for those with myasthenia gravis was added to the Boxed Warning. In August 2013 (ssLINK/UCM365050), the agency required updates to the labels to describe the potential for irreversible peripheral neuropathy (serious nerve damage).



In November 2015, an FDA Advisory Committee (ssLINK/UCM424449) discussed the risks and benefits of fluoroquinolones for the treatment of acute bacterial sinusitis, acute bacterial exacerbation of chronic bronchitis and uncomplicated urinary tract infections based on new safety information. The new information focused on two or more side effects occurring at the same time and causing the potential for irreversible impairment. The advisory committee concluded that the serious risks associated with the use of fluoroquinolones for these types of uncomplicated infections generally outweighed the benefits for patients with other treatment options.

Today's action also follows a May 12, 2016, drug safety communication (/Drugs/DrugSafety/ucm500143.htm) advising that fluoroquinolones should be reserved for these conditions only when there are no other options available due to potentially permanent, disabling side effects occurring together. The drug safety communication also announced the required labeling updates to reflect this new safety information.

The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency is also responsible for the safety and security of our nation's food supply, cosmetics, dietary supplements, products that give off electronic radiation, and for regulating tobacco products.

<https://www.fda.gov/Drugs/DrugSafety/InformationbyDrugClass/ucm346750.htm>

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DONATIONS as of March 21, 2018...

S. Trujillo-Jenenez
Kelly Carson
Gayle Wilson
James Postnikoff
Thomas Barrett
Scott Didick
Andrew Dawes
Lorne Holyoak &
Muriel Carncross
Joel Oger
Edgar Lublow
Cliff Johnson
Mark Isaacs
Andrew Dawes

Nora Moore
Jerry Olynyk
Ellen Eby
Annie Mackinnon
Jantine Van Oort
Leslie Potter
Olive Worsfold
Dan Dube
Wendy Macfarlane
Michael Shirley
Peter Rogers
Yvonne Elliott
Ken Palmer

R. Douglas Reid
Margaret Ross
Jean Winslade
Ken Moore
Allan Thorp
Nancy Leuvekamp
Dorothy Symons
Sheila Gray-Moir
Marie Paterson
Eileen Maltinsky
Ken C Moore
May Morrison
Nancy Headley

Diane McLeod
Dawn Hogbin
Pauline Buckley
Rosa Tesler- Mabe
Wendy Robertson
Lily Forget
George Lopushinsky
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Jeanette Espinosa
The Benevity Communtiy Impact Fund

Robert Magri
Terry-Ann Callander
Bev Butler
Brenda Kelsey
Rose Pickard
Dennis Shpeley
Willike Van Linden Toi
Linda Beare
Ignacy Lipeic

Donations for Research at UBC...

Ruth Woodley
David Cumisky
Mary Gilholme
Al Craig
North Island Support Group

Donations In Memory of...



Stephen Olliver for Janet Olliver
Lois Otterbine for Norma "Jane" McLeod
Sandra Trimble for Stella Bumstead

Corporate Donations:

Canada Helps Org.

WE APOLOGIZE FOR ANY ERRORS OR OMISSIONS.

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 - NEW 2012
9. Thymectomy
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 **NEW**
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 or download forms at www.cra-arc.gc.ca/E/pbg/tf/t2201

BOOKS AVAILABLE:

- **You, Me and MG by Deborah Cavel-Greant, published 2005 (FREE)**
- **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)

***By mail: Myasthenia Gravis Research, UBC Annual Giving, 500-5950 University Blvd
Vancouver, BC V6T 1Z3***

***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

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 _____ E - MAIL _____

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.