

# MG NEWSLETTER

[Myasthenia Gravis Association of British Columbia](#)

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The Myasthenia Gravis Association of BC  
cordially invites you to attend

## THE ANNUAL GENERAL MEETING and

### *Retirement Celebration for Doctor Joel Oger*

Invited guests will include Dr Kristen Jack - who will be taking over Dr Oger's patients - and meet Dr Hans Frykman, who will be replacing Dr Oger at the immunobiology lab at UBC as well as continuing to do MG research and diagnostics.

Come in to say your goodbyes to our "go to MG doctor", support his election to the MGABC Board of Directors and help all of us express our profound thanks and gratitude for his years of service

When: **Sunday, April 12th at 1:30 pm**

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

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 (1284)  
or email: [mgabc@centreforability.bc.ca](mailto:mgabc@centreforability.bc.ca)

#### **AGM: Elections for Board of Directors.**

If you are interested in becoming a Board Member,  
please call either Brenda or Linda.

### **June is MG Awareness Month AGAIN!**

And in celebration, the Myasthenia Gravis Association is asking patients, friends and family to participate in the **Scotiabank Group Charity Challenge**, June 28th.

There are opportunities to pledge on-line as well as mail in pledge sheets. We have included a pledge sheet for your convenience.

**For additional race information, please visit [www.canadarunningseries.com/svhmCHARITY.html](http://www.canadarunningseries.com/svhmCHARITY.html)**



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 their physicians.

\*Newsletter and meeting supported by an unrestricted educational grant from **Grifols Canada Inc.**

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## ANNUAL REPORT of the MYASTHENIA GRAVIS ASSOCIATION of British Columbia, 2014

Support groups allow those with a common diagnosis to come together and share ideas, coping skills, medical experiences and, most importantly, exchange emotional support. The primary goal of a support group is to ensure no one living with a disease or condition ever feel alone. The Myasthenia Gravis Association of BC certainly works to achieve this goal - this year and every year. In 2014 the MGABC counselled 19 new patients and/or their caregivers. This doesn't mean just 19 phone calls or emails. We actively chat with the patient, find out what medications they are taking, their individual needs, make referrals and mail out literature. We do follow up calls and encourage people to let us know how they are doing. Linda (Briggs) and I also advise current patients regarding health care issues, upcoming medical treatments, doctor referrals and general support in dealing with Myasthenia. The MGABC receives requests and information from other agencies and other MG support groups.

In spite of an excellent speaker, The Annual General Meeting last April was very poorly attended. In order to maintain our standing as a worthwhile support group, we need better attendance at our meetings.

The ScotiaBank Charity Challenge, the MGABC's main fund raiser, also did not meet expectations in 2014. We hope that the Charity Challenge in June of this year, 2015, will have a better outcome.

Dr Kristin Jack, the new neurologist at the Myasthenia Gravis Clinic has put together an information folder to hand out to new MG patients. The MGABC is proud to have provided the literature for these folders. At the request of the MGABC, Dr Jack and Dr Gibson wrote an article for the BC Journal of Medicine: "A Review of Myasthenia Gravis: Classifications, Common Diagnostic Tests and Therapeutic Strategies". We hope that this article will make family practitioners more aware of MG and think of it when faced with a patient with potentially difficult neurological problems.

The MG support groups on Vancouver Island are both going strong and doing their part for the Vancouver Island members. Thanks to Dennis Shpeley and his wife as well as John and Lise Skalos for such dedicated work.

On behalf of the board of directors and the members of the Myasthenia Gravis Association, I would like to acknowledge Angie Kwok, CFA director, and her staff at the Centre for Ability for their cheerful and efficient support and advice. A final big thank you to Linda Briggs and Barb McDonald, my office sidekicks - and pals - with whom I could not do without. Ladies, I could not do this job without you ! Thank you again.

Respectfully submitted,



Brenda Kelsey  
President

## From the MG Network...

### 8 Good Reasons for Attending a Support Group Meeting

It seems everyone these days has a reason 'not' to attend a Support Group Meeting. Here are a few reasons why you might want to reconsider 'your reason' and come...

***If you are a newly diagnosed Myasthenis:***

You should go because you will meet people who have gone through the very same thing as you - the same diagnosis, the same frustration, the same very steep learning curve. These people understand! You can learn about your choices for medical treatment, learn what others have done to cope, and how they cope. Doctors are wonderful, but there is nothing like hearing it straight "from the horse's mouth"

***If you have had MG for years think you know all there is to know about MG:***

This is great ! Just think of all the information you are able to give to new patients. Patients who would otherwise not have the opportunity to benefit from your experience, your wisdom and your fortitude.

***If you aren't feeling well despite your medications:***

You are likely to meet someone at the meeting you has had the same or a similar experience. They may be able to give you suggestions on how to make things easier. At the very least you will find a room full of people who are truly interested and understand.

***If you feel great:***

Once again this is terrific! How about sharing some of those great feelings with others? Knowing that others who are also suffering with the day to day sometimes debilitating effects of MG are now leading 'normal' lives can be encouraging. Negative stress can play a detrimental part in MG, we all need encouragement.

***If you are not sure about your treatment or have questions about your symptoms:***

At a support meeting you can compare notes with others in the same boat. What you may not think is a result of MG, may very well be experienced by others.

***If you think a meeting might be depressing:***

You will meet people who, although they may be worse off than you, continue to remain upbeat and positive. Having a disease like MG can be depressing - that's why we offer these meetings!

***If you think it is too far to travel:***

Okay. You have a good excuse. What about contacting your local office and asking if there are other patients in your area and starting a group of your own ?

***If you think the meeting are boring:***

We serve food ! And it is good to meet new friends and reconnect with old ones.



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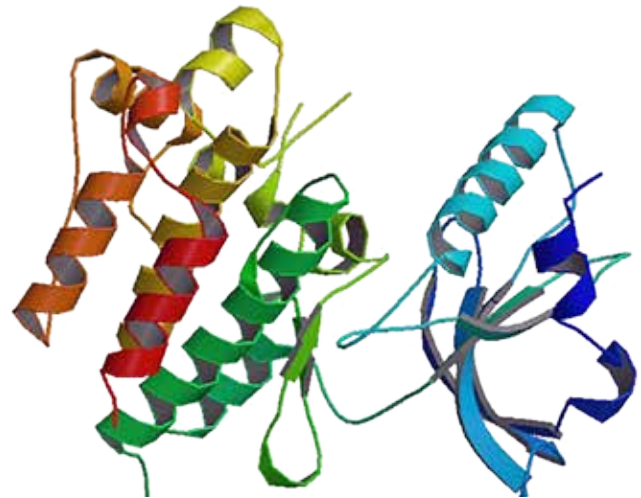
## **Anti-MuSK Antibody Myasthenia Gravis: clinical findings and response to treatment in two large cohorts.**

**INTRODUCTION:** Myasthenia gravis (MG) patients with autoantibodies to muscle-specific tyrosine kinase (MuSK) represent a distinct subset of those with this disease. Treatment and outcome data in these patients are limited and conflicting.

**METHODS:** We reviewed 110 MuSK-MG patients from two large clinics in Italy and the USA.

**RESULTS:** Thirty-nine to 49% of patients with generalized, acetylcholine receptor antibody (AChR-Ab)-negative MG had MuSK-MG. Eighty-five percent were female, with disease onset typically in the fourth decade. Ocular and/or bulbar symptoms were present at onset in 79% of those studied. Eighty-five percent were MGFA class III or greater, and crisis occurred in 28%. Plasma exchange (PLEX) produced improvement in 93%, whereas only 61% improved after intravenous immunoglobulin. Long-term outcomes were comparable to those of patients with AChR-AB-positive MG.

**CONCLUSIONS:** MuSK-MG has a marked female predominance with frequent oculobulbar weakness and crises. Many patients deteriorate rapidly early in the disease, and PLEX is usually the preferred treatment. Long-term outcomes are similar to those of patients with AChR-Ab(+) MG.



*receptor tyrosine kinase*

*Wiley Periodicals, Inc.*

## ATTITUDE

ATTITUDE to me in more important than facts.

It is more important than appearances, giftedness, or skill. It will make or break a company...a church..a home.

The remarkable thing is we have a choice everyday regarding the attitude we will embrace for that day.

We cannot change our past...we cannot change the fact that people will act in a certain way.

We cannot change the inevitable. The only thing we can do is play on the one thing we have, and that is our attitude.

I am convinced that life is 10% what happens to me and 90% how I react to it. And so it is with you... we are in charge of our ATTITUDE.

## 12 STEPS TO BETTER HEALTH

1. **Educate yourself after your diagnosis.** Knowledge is power. Know more than your doctor does. Learn about treatments, medicines and research that is being conducted. Visit websites and join SUPPORT GROUPS.
2. **Practice the four basic tenets of a “healthy lifestyle”.** These rules will improve your chances of living a product life despite your chronic health problems.
  - A) Don't smoke. If you do – give it up
  - B) Maintain a health body weight
  - C) Eat a balanced diet. Eat your fruits and vegetables and drink lots of water.
  - D) Try to exercise daily – at least 30 minutes.
3. **Practise mental exercises.** Continue to study and learn.
4. **Balance rest with activity.** Adjust your schedule to accommodate brief naps if needed. But remain active. Be as involved with life and other people as possible.
5. **Interact productively with your doctor as an active partner in the management of your disease.** Ask questions, express yourself, be your own advocate. And most importantly, be honest about how you are feeling. Be neither a victim nor a saint.
6. **Maintain a positive attitude.** We all face changes in our lives, some good some not. It's not so much what happens as how we chose to deal with it. Stay focused on staying grounded and looking forward, hard as it may sometimes be.
7. **Minimize and manage the stress(es) in your life.** Avoid getting yourself overly worked up. Take control of stressful situations rather than letting them take control of you. If you need to, ask for help.
8. **Don't focus on chronological AGE!** Try to focus instead on ways to take care of yourself, now, today. Try to stay healthy and active. Start new hobbies or activities. Enjoy family and friends as much as possible. Stay involved and informed.
9. **Don't isolate yourself.** Remember no man is an island. Resist hiding away. Cherish communication with others, conversations and laughter.
10. **Don't stop looking for solutions to the problems you face in living with a chronic disease.** This really is of the utmost importance – always stay aware of what is out there for you in the form of treatments, management and support for you. Take charge, ask questions and engage in a support group to share your discoveries.
11. **Accept your chronic disease as part of your life now, rather than focusing on how it used to be.** Acceptance is a big part of regaining control of your life and improving health status. This disease is only one facet of your life, of who you are, and should not be your primary or only focus.
12. **Attempt to find mental, emotional and spiritual comfort in whatever way suits you.** Meditation, gentle yoga classes, reading, listening to music or prayer. Engage others by discussing your needs openly – be kind to yourself and gentle with those you love. They can be and most likely are as affected by your illness as you are.



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## MYASTHENIA GRAVIS AND INSECTICIDES

Myasthenia gravis patients may be at risk when coming into contact with insecticides. Some of the commonly used insecticides are intended to disrupt the nervous system of an insect by attacking enzymes. These same enzymes are also found in the neuromuscular junction of humans.



Recent studies show that other insecticides may cause damage to the brain, other parts of the nervous system, and testes when combine with medicines frequently prescribed to myasthenics.

The popular insecticides in use today are **organophosphates**. This class of chemical is designed to kill insects by disrupting their brains and nervous systems. Specifically, they inhibit the function of a key enzyme in the nervous system called cholinesterase.

**Carbamates** are another insecticides which inhibits cholinesterase, which is found in humans as well as insects. Both of these insecticides work similarly to Mestinon, the brand name for pyridostigmine bromide. As medication, they are all cholinesterase inhibitors.

Why should a myasthenic be wary of a chemical that work like the medicine they take to control their disease? Simply, **overdose**. ***Mestinon works for a myasthenic when taken in the correct dosage. Too much Mestinon may cause exacerbation of MG and send a myasthenic into a crisis.***

Donald A Barone DO an MDA Clinic Director, was asked what insecticides a myasthenic should avoid. He said, 'Organophosphorous pesticides have potent anticholinesterase properties and may produce a cholinergic crisis in anyone excessively exposed. Myasthenic patients, especially those on anticholinesterase medication, are likely to be more susceptible to the toxic effects.'

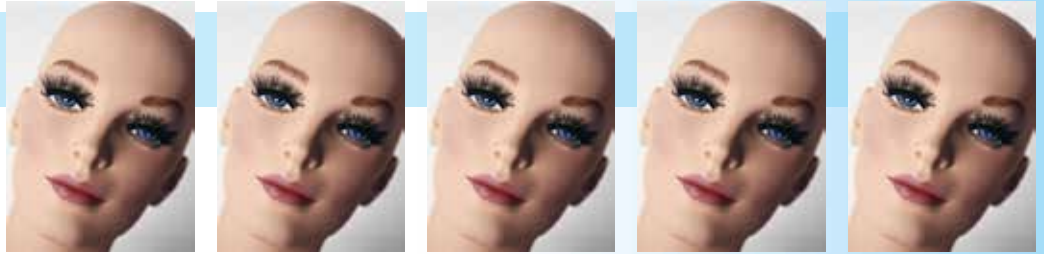
A myasthenic experiencing severe difficulty breathing or swallowing defines a myasthenic crisis. A cholinergic crisis is a chemically induced overdose of medication or overexposure to an anticholinesterase agent. The symptoms of a cholinergic crisis can include muscle weakness, muscle twitching, sweating, excessive salivation, and constricted pupils. It is frequently difficult to tell the difference between these two crises, but treatment for the first is to **increase** cholinesterase inhibitors, and treatment for the latter is to **decrease** cholinesterase inhibitors. A Tensilon test can be used to help differentiate between the two.

There are two other popular insecticides myasthenics need to know about. These are N, N-diethyl-m-toluamide, now called diethyl-3-methylbenzamide (DEET) and permethrin.

Studies at Duke Medical Centre in 1996, showed that pyridostigmine bromide alone caused no long-term effects, but when combined with either of the insecticides there were definite problems. DEET products are applied directly to the skin and permethrin products are sprayed about to repel insects. These studies of insecticides are not conducted directly for or with MG patients, and so there is no information on what levels insecticides can be considered safe or unsafe for a person taking pyrodostigmine bromide.

DEET is one of the few pesticides that can be applied to the skin. It is often found in sprays, liquids, lotions, moist towelettes, wristbands and even tablecloths. According to the National Information Centre, scientists do not completely understand how it works on insects and believe it may effect receptors in a mosquito antennae. With more than 30 years of research on the effects of pesticides' on the brain clearly indicate the need for caution among the general public. Health Canada has subsequently banned all products with more than a 30% concentration of DEET.

## Botox and MG



Botox is a commercially available prescription medication primarily used for the removal of facial

lines and wrinkles, as well as for neurological conditions such as hemifacial spasm and blepharospasm. It is a purified form of botulinum toxin, and extremely potent neuromuscular blocker of release of acetylcholine at the neuromuscular junction. While it is usually only locally absorbed, there is the potential for it to spread to other tissues. Or even rarely cause systemic symptoms.

There is at least one reported case of an individual who received serial injections for hemifacial spasm who develop flagrant Myasthenia Gravis which swallowing difficulties, and weakness of the neck muscles. She was found to have had positive antibodies to acetylcholine receptors. The myasthenia was unmasked in this unusual case. For that reason, botox should be considered a contraindicated for individuals with either ocular or systemic myasthenia gravis.

*AMPS PACIFIC NORTHWEST CHAPTER*

## EYELID SURGERY

With MG you must be very cautious about having surgery to correct droopiness of the eyelid. This is a "Ptosis" caused by MG, and two factors must be considered. The first is that muscle strength tends to vary considerably when MG is the cause of the weakness. As such, it can be difficult to know how much surgery is necessary. A surgical correction that proves acceptable today may not be acceptable if muscular strength improves at a later date.



The second factor is that MG often causes limitation of eye movement. With natural blinking of an eye or during sleep, the eyes roll upward under the upper lid. This provides protection to the front window of the eye (the cornea), which is very susceptible to becoming dry if it is exposed to the air without sufficient wetting. Persistent drying of the cornea can cause a permanent scar that might limit vision. As such, with MG, it is often true that the muscle weakness limits the upward movement of the eyes, thus placing them at risk for excessive drying. Surgical correction of a droopy eyelid is performed by tightening the eyelid, which may make it less able to move up and down to provide necessary protection. The combination of eyelid surgery and limited eyelid movement can lead to cornea damage and visual loss. It should be remembered that a patient who may present with drooping of the eyelids will be tempted to seek out surgical treatment, only to have the eyes become unable to turn upward months later and have their vision at risk.

Generally myasthenics should avoid eyelid surgery as the risks outweigh the cosmetic benefits.

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## A GENOME-WIDE STUDY OF MYASTHENIA GRAVIS

THANK YOU TO ALL OF OUR MEMBERS WHO VOLUNTEERED TO TAKE PART IN THIS STUDY. THE STUDY WAS PUBLISHED IN THE JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, FEBRUARY, 2015.

**IMPORTANCE:** Myasthenia gravis is a chronic, autoimmune, neuromuscular disease characterized by fluctuating weakness of the voluntary muscle groups. Although genetic factors are known to play a role in this neuroimmunological condition, the genetic etiology underlying myasthenia gravis is not well understood.

**OBJECTIVE:** To identify genetic variants that alter susceptibility to myasthenia gravis, we performed a genome wide study.

**CONCLUSIONS:** The GWAS identified susceptibility loci for Acetylcholinesterase antibody positive myasthenia gravis and it showed distinct, but overlapping genetic risk factors underlying early and late onset disease. Although future studies involving deep resequencing of these loci will be required to identify the functional variants underlying these association signals, our data suggest that clinical trials of immunomodulatory therapies could be considered in patients with myasthenia gravis with refractory disease failing to respond to standard therapies.



...Stay tuned for the results of the Thymectomy trial in January, 2016, in Oxford, England.



## HILLBILLY BOB'S MEDICAL TERMS

**DILATE: TO LIVE LONG**

**MORBID: A HIGHER OFFER THAN I BID**

**PELVIS: ELVIS'S SECOND COUSIN**

**VARICOSE: NEAR BY**

**TUMOUR: MORE THAN ONE**

**TABLET: A SMALL TABLE.**



# Spring 2015

## “THE JACK MUNRO MEMORIAL FUND” DONATIONS

Mark Anderson  
Linda Briggs  
Lorna Andrews  
Brenda and Len Kelsey

Wayne and Judy DeRose  
Adrian Wall  
Joel Oger  
Nora Moore

Frank Szeto  
Gord Voth  
Yvonne Lyle

*Donations made to  
**The Jack Munro Memorial Fund** will fund  
Myasthenia Gravis Research at UBC  
and should be sent to the  
Myasthenia Gravis office.*



## More Sun for the RUN - Sunday, June 28, 2015

Our presence at the **Scotia Charity Challenge** last June was very disappointing, as was the amount of money raised. This event and our involvement are essential for bringing much need awareness to Myasthenia Gravis. The provincial government has consistently recognized June as Myasthenia Gravis Awareness month. Let's increase our commitment by not only fund raising but by also participating and support those who walk and run for in support of MG. Help us help all of you by donating on-line at the race website or by mailing in your pledge form which is enclosed.



***For additional race  
information and to make donations online,  
please visit  
[www.canadarunningseries.com/svhmCHARITY.html](http://www.canadarunningseries.com/svhmCHARITY.html)***

## DONATIONS AS OF MARCH 2014 and since last publication

Barb Thomas	Bev Butler	J. Espinosa
Al Craig	Lynn&Jerry Duncan	Al Friesen
Dr Otto Huhn	Maybelle Morrison	W. van Linden Tol
Micheal Shirley	Carol Klassen	Doreene Kerr
Ian Bennett	Alice Hay	Diane Rouleau
Ed Zatorski	K.C. Moore	G. Lopushinsky
Dominic Leung	Karren Shimonek	Elisabeth Sephton
Terry Raymond	Don Osterhout	Bobbi Gordon
Bill Davenport	Velma Cotton	Jane Bryans
Clifford Johnson	Rose Pickard	David Palmer
John&Pat Chesterman	Pauline Buckley	Olive Worsfold
Jean Winslade	Tim March	Dorothy Symons
Jantine Van Oort	R.Doug Reid	Annie MacKinnon
Ken Porterfield	Doreene Kerr	N Leuvekamp
Doug Boyd	Linda Beare	P Saunders
Muriel Morrison	Helen Martin	Tom Callander
Nancy Headley	Victoria Chou	Olive Worsfold
Tim March	Yvonne Elliott	T Stirling
T&N Tronsgard	James Clogg	K W Moore
Rose Jones	M Gilholme	R Magri
Marilou Paterson	Frank Murdoch	Margo Csontos
Al Botteselle	W Macfarlane	S McFayden
Allan Thorp	Rose Jones	J Mirabelli
Betty Bisschop	Mark Revell	Terry Miller
Grace DeRoche	J&M Phillips	J Olynyk
Richard Douglas	P.Sanders	Tom Noiles
Bart McGuire	James Postnikoff	Yvonne Lyle
Betty Bisschop	E&E Lublow	Thelma Aba
Joan Salmon	Lois Ngai	Gayle Wilson
Mary Gilholme	Dawn Hogbin	

### *In Memory of*

**Stephen and Susan Olliver for Janet Olliver**

**Linda Briggs for Jack Elliott**

**Bob and Cathy Lefeaux for Jack Elliott**

**CORPORATE : UNITED WAY: Thompson Nicola Caribou  
CHIMP - The Charitable Impact Foundation  
HYDRO ONE**

**Myasthenia Gravis Association of B.C - Brenda Kelsey (monthly donation) for research @ U.B.C.**

## 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
- 18. School Package for Children with Myasthenia Gravis
- 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
- 29. Tips on applying for CCP Disability Benefits
- 30. Advocacy Help Sheet
- 31. Disability Tax Credit - Form T2201 or download forms at [www.cra-arc.gc.ca/E/pbg/tf/t2201](http://www.cra-arc.gc.ca/E/pbg/tf/t2201)

### BOOKS AVAILABLE:

- **You, Me and MG by Deborah Cavel-Greant, published 2005 (\$20.00 from MGABC)**
- **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, French and Spanish. If you would like a copy, please contact our offices.

## MEMBERSHIP and DONATIONS

MGABC's **\$20** membership is valid Jan. 1st to Dec. 31st. Any membership received after Oct. 1st will be good for the following year. To make a donation, complete the form below and return it with your cheque or money order (we cannot accept credit card payments). Please do not send cash in the mail.

Your donation and membership fees help defray operating costs, and entitles you to the following:

**Newsletters bi-annually...MG literature and pamphlets...  
Notice of meetings...Up-to-date information on MG**

### ***You Can Help!***

***Your support can make a vital difference. Please donate to Myasthenia Gravis Research at UBC.***

***Online:*** [www.supporting.ubc.ca/mg](http://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.**

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Make Cheque payable to: MYASTHENIA GRAVIS ASSOCIATION of BC  
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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 [mgabc@centreforability.bc.ca](mailto:mgabc@centreforability.bc.ca) with the words **"E-mail request"** in the subject line. Thank you.