

# MG NEWSLETTER

Fall 2013



[Myasthenia Gravis Association of British Columbia](http://www.myastheniagravis.ca)  
2805 Kingsway, Vancouver BC V5R 5H9 · Tel 604-451-5511 local 1284 · Fax 604-451-5651  
E-mail: [mgabc@centreforability.bc.ca](mailto:mgabc@centreforability.bc.ca) • Web site: [www.myastheniagravis.ca](http://www.myastheniagravis.ca)



## The Myasthenia Gravis Association of BC

cordially invites you to attend

### THE Fall 2013 Support Group Meeting

When: **Sunday, October 27th, 2013 @ 1:30 pm**

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

### Special Guest Speaker: Dr. Joel Oger MD, FRCPC

Professor department of Medicine (Neurology), Pathology, Psychiatry (Neurosciences) and Brain Research Centre, University of British Columbia, Vancouver, B.C. Canada

Prepare questions for Dr. Oger to answer - if you are out of town, you may send questions to us by email prior to Friday, Oct.25th and we will ask them on your behalf.

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

## 2014 Membership Drive & Fundraising Begins!

Every October we ask MGABC members to renew their memberships. The annual cost remains \$10.00 per member. Your fee includes a bi-annual newsletter, free information pamphlets, notification of special programs of interest to Myasthenics, as well as support group meetings with speakers and staff members willing to support when called upon. Memberships renewed after September 30th, will be good for the coming year.

October is also the time when we ask for donations to keep our programs going, allow us to staff and maintain a clerical office. Research contributions are always an on-going request. Dr. Oger continues his MG research at the University of British Columbia with your help.

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.  
The MGABC is grateful to the province of BC for their charitable gaming grants

# MG NEWSLETTER

## From the World Wide Web... MG Awareness Educational Videos

From Iris Biteen, President of the Myasthenia Gravis Coalition of Canada

### **Myasthenia Gravis - Are You Experiencing Symptoms ?** (2min 53sec)

<https://vimeo.com/user18866730/review/68629454/c8d63cbb61> -  
please cut and paste into your browser

### **Myasthenia Gravis - Early Onset Ocular Symptoms** (60sec)

<http://vimeo.com/user18866730/review/68828892/a8fd3a5433>

HUTV will be running the long version in more than 200 medical waiting areas throughout Alberta and we are hopeful other similar medical place base networks across Canada will include one of the versions in their programming schedule. The links have also been forwarded to the Alberta Association of Optometrists.

Special Recognition to all of those who gave of their time and talents:

Grifols Canada

Dr. Michael Nicolle

Dr. Zaeem Siddiqi

Dr. M W Nicolle's PowerPoint presentation, **MYASTHENIA GRAVIS: A Neurologist's Perspective**, is available for viewing directly on the MGCC website!

- 1) Simply log on to the MGCC website: [www.mgcc-ccmg.org](http://www.mgcc-ccmg.org)
- 2) Click to the Resource Material menu
- 3) Move down to Visual Presentation marker and
- 4) Proceed to page 1

This 55 slide presentation offers a full overview of myasthenia gravis – symptoms, treatments, etc and is an excellent visual presentation on how MG antibodies act in the body.

*Drop the question of what tomorrow may bring, and count as profit every day that fate allows you.*

*Horace*

## KNOW THE DIFFERENCE BETWEEN A COLD AND FLU SYMPTOMS THIS FALL

### Symptoms

**Fever** is rare with a cold but is usually present with the flu in up to 80% of all cases. A temperature of 100 F or higher (98.6 is our norm) for 3 to 4 days is also associated with the flu.

**Coughing** a hacking (mucus-producing) cough is present with a cold, whereas a non-productive or dry cough is with the flu.

**Aches** - Slight body aches and pains can be part of both the flu and a cold. Severe aches and pains are more common with the flu.

**Stuffy nose** - Stuffy nose is commonly present with a cold and typically resolves itself within a week. There is usually no stuffy nose with the flu.

**Chills** - Chills are uncommon with a cold. 60% of people who have the flu will experience chills.

**Tiredness** - Tiredness is fairly mild with a cold whereas it is moderate to severe with the flu.



**Sneezing** - Sneezing is commonly present with a cold. Sneezing is not common with the flu.

**Sudden Symptoms** - Cold symptoms tend to develop over a few days. The flu usually has a rapid onset within 3-6 hours and hits HARD. It includes sudden symptoms like high fever, aches and pains.

**Headache** - A headache is fairly uncommon with a cold as well as the flu.

**Sore Throat** - Commonly present with a cold, not as evident with the flu.

**Chest discomfort** is usually mild or moderate with a cold. With the flu, chest discomfort is usually severe.



### Can corticosteroids affect one's memory?

Yes, according to several studies. Both short and long-term use of oral steroids – for arthritis, autoimmune disorders, and other conditions – has been found to impede learning and memory, possibly by altering the brain's hippocampus region. Corticosteroids can also cause mood changes and sleep problems, which in turn could hinder memory. A small study in 2007 found the effect is usually strongest right after starting treatment and tapers over time. It might be reversed if you stop taking the drug, lower the dose or take it later in the day, according to an analysis of 16 studies. For people on long-term corticosteroid therapy, there's limited evidence that the neurologic drugs Lamotrigine (Lamictal and generic) or Memantine (Namenda and generic) can help counter memory decline.



# MG NEWSLETTER

## Emails from our members

We were sorry to hear from the spouse of one of our members of her passing. But what was touching and very thoughtful in the face of his loss was his email to us – and request, that we share with you information he received as a result of the autopsy. It appears without telling anyone, “R” stopped taking her Prednisone and other prescription drugs, afraid they were harmful to her liver and other organs, months before her passing. As a result, she died of ‘asphyxia caused by untreated myasthenia gravis’. In layman’s terms, her lungs just quit working. The coroner’s report indicated she died in her sleep with no deterioration of her internal organs and no signs of cancer or any other indication that the medications were affecting her adversely.

“R” husband sends this message to all of us “..if this information can be passed on to other patients and it saves a life...then “R” didn’t die in vain. I thank you for the support the MG society has provided us in the last 15 years. .”

**One of our new members also shared an email with us regarding his inquiry about the origins of his plasma replacement. He sent an email to the exchange at UBC asking “...why my new blood comes from US donors, via Switzerland?”**

Here is the answer he received from Dr. Dana Devine, VP Medical, Scientific and Research Affairs at the Canadian Blood Services.

“ ... therapeutic plasmapheresis is the treatment in which we remove a patient’s plasma and replace it with donor plasma. Because repeated use of this procedure often triggers eventual allergic reactions in recipients to single donor plasma products (reasons unknown) and involves the exposure of the patient to a large number of different donors, Canada has recently begun to offer a kind of commercial plasma (trade name – Octapharma) that is treated to reduce the chances of carrying contaminants and also has a lower reaction rate. It is prepared by pooling plasma from dozens of donors and putting it through a pathogen inactivation process called ‘solvent/detergent treatment’. The product is made in Europe and not in Canada, because the company does not have facilities here. At the moment Octapharma (the company) is the only company currently making this product. The plasma used comes from US donors who do not have the VCJD ( Variant Creutzfeldt-Jakob disease ) risk that European donors do”.

FYI : The combined annual plasma fractionation capacity of Octapharma’s plant exceeds 4.25 million litres of plasma annually.

And yes, Ian, we’d rather it was chocolate too!



## WHAT WE CAN LEARN FROM A GOOSE

...maybe not as silly as we thought!

In the fall when you see geese heading south for the winter (already a brilliant idea!) and flying along in formation, you might consider what science has discovered about why they fly the way they do. Research has showed, as each bird flaps its wings, it creates an uplift for the bird immediately following. By flying in V formation the whole flock adds at least 71% greater flying range than if the birds flew on their own.

*People who share a common direction and sense of community can get where they are going more quickly and easily as well, because they are travelling on the thrust of one another.*

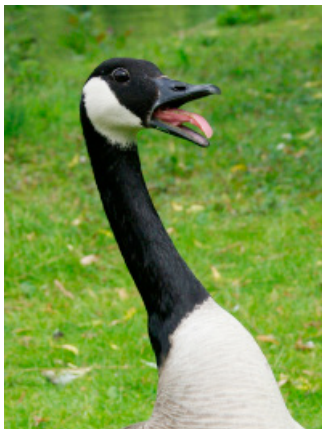
When a goose falls out of formation it suddenly feels the drag and resistance of trying to go it alone..and quickly gets back into formation to again take the advantage of the “lifting power” of the bird in front.

*We have as much sense as a goose, when we will stay in formation with those who are headed in the same direction as we are.*

When the head goose gets tired, it rotates back in wing and another goose flies to the point. It is sensible to take turns doing demanding jobs.

Geese honking behind the lead geese, are encouraging those up front to keep up their speed.

*What are we saying when we are honking from behind ?*



Finally, when a goose gets sick or wounded by gun shots, and falls from formation, two other geese will fall out with as well and follow it down to lend help and protection. They stay with the fallen goose until it is either able to fly or dies. Only then do they launch out on their own, or try to catch up to their original formation.

***And so, maybe, if we have the sense of the geese, we will stand by each other more often.***

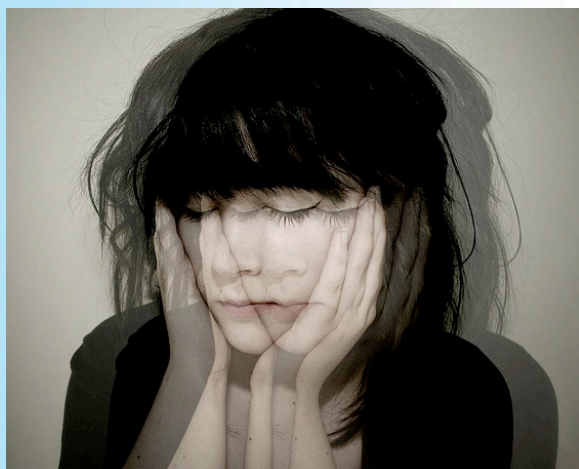


# MG NEWSLETTER

## Ocular MG - A Prism Solution

- from article by Gary Nelsen, Springfield Support Group Leader and Dr. Shaun Hill, Optometrist

Double vision is often the first sign to appear for those of us who have been diagnosed with myasthenia gravis. For some, like me, that continues to be the primary symptom. I was diagnosed in 2006 and struggled with double vision, even after having tried Mestinon, Imuran, Predisone and Cellcept, and found little help.



Two years ago my ophthalmologist recommended that we try prisms in my eye glasses. I was not enthused because we had tried temporary prisms which can be stuck on the lenses and they had not helped at all. But my ophthalmologist wanted to have my optometrist perform the eye exam late in the morning when my symptoms were less severe.

The new glasses were amazing almost totally relieving me of the double vision. When my eyes were checked a year later the optometrist made an additional adjustment. The result - no double vision at all, tired or not. It is a WOW !

I asked my optometrist to explain what he did, in the hope that relaying this information might help someone else, as we all know about the 'snowflake' aspect of MG and how different symptoms can be from one person to another.

Here is his response:

"Myasthenia gravis is an unpredictable disease in which the muscles and nerves innervating the muscles seem randomly disconnected from patient's perspective. Myasthenia gravis is known to cause ptosis (drooping) of the eyelid, diplopia (double vision) and tumors of the thymus gland, as well as muscle weakness including difficulties swallowing and breathing."

"My patient has experienced ocular difficulties due to having myasthenia gravis for over six years. He began having vertical double vision. The difficulty was that the amount of vertical prism necessary would change from one visit to the next. Every four to five months the amount of prism kept changing. With some patients this can change hourly or even after a few minutes. After approximately four years, the vertical prism stabilized and with a slight horizontal prism included, his diplopia has stabilized for the last ten months."

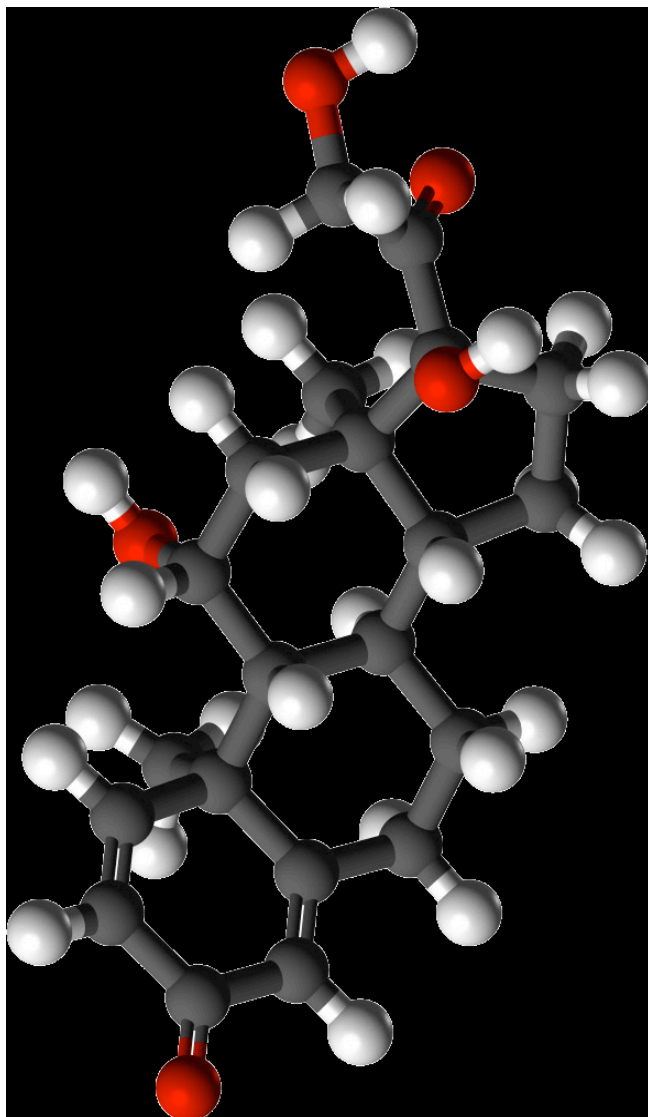
"The hidden pearl is that the patient's best visual acuity (clearness and sharpness of vision) should be maximized and expect fluctuation. Cataract surgery could improve the overall quality of vision".

We thank the *MGF of Illinois - Conquer, September 2013* and Gary Nelsen for this article.



## UPDATE ON PRODUCT AVAILABILITY - "SIMPLY CLEAR" at London Drugs - beside the regular line of Metamucil products

### Study of Prednisone and Ocular MG



A study to determine the effectiveness of prednisone for treating ocular myasthenia is underway. Spearheaded by Dr. Michael Benatar of the University of Miami, the study is recruiting participants in a number of locations including Florida, Kansas City, New York and North Carolina (no Illinois or Indiana sites are included.) According to [www.clinicaltrials.gov](http://www.clinicaltrials.gov), the study "aims to learn whether or not prednisone is effective in improving the symptoms of double vision and drooping eyes that are experienced by patients with ocular myasthenia." The study also aims to "find a dose of prednisone that is well tolerated and safe" that also is "effective in improving the symptoms of ocular myasthenia."

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**Brenda Kelsey**, 3rd from left, **Andrew Dawes**, and **Linda Briggs**, President and Board members of MGABC presenting a cheque to **Dr. Oger**, far left, and **Tariq Aziz**. **Dr. Ebrima Gibbs**, 2nd from right and **Zahra Pakzad** were also in attendance. These monies will help support the use of the immunobiosensor platform for rapid detection of MUSK antibodies. This piece of equipment will do in half a day a procedure which would otherwise may have taken 4-6 weeks to complete.

## Kudos to Board Member **Andrew Dawes** for his recent recognition - a 2013 Lifetime Artistic Achievement (Classical Music) Award



### **ANDREW DAWES**

Lifetime Artistic  
Achievement Award  
(Classical Music)

Andy has won many other awards of distinction – including the Chalmers National Music Award, The Canada Council’s Molson Prize and 3 Juno Awards. In 2000, the Canadian Broadcasting Corporation named the Orford String Quartet as one of “The Great Canadian Performers of the Twentieth Century”. In 2002 he was the recipient of the Dorothy Somerset Award for Excellence in Performance and Development awarded by the University of British Columbia and also the Jubilee Medal awarded by Queen Elizabeth II for exceptional qualities and service to Canada.



## Donations after March 2013 to date:



The lengthy list of donors is a direct result of your donations and the efforts of those members and their friends and family who participated in the Scotiabank Charity Challenge on June 23rd, 2013. We owe a HUGE debt of thanks to : Mary Rose, Team Jo, Trevor Harris, Kelly Carson, Jeanette Espinosa , Lily Forget and Valerie, Trevor and Spencer Fair whose combine efforts with yours, raised almost \$ 20,000.00!

Leslie Potter  
Suzanne Patterson  
Chriss Stearne  
Anne Marsh  
Linda Beare  
Fred Ashworth  
Michael Kemble  
Patricia MacKenzie  
Nicole Tessier  
Wendy Macfarlane  
Sheila McWilliams  
Yvonne Elliott  
David Sutherland  
Edgar and Edith Lublow  
Lorne Holyoak  
Allan Thorp  
Lois Ngai  
Thelma Abma  
Joan Salmon  
Gayle Wilson  
Otto Huhn  
Joanne Mirabelli

John Rubin  
Doreene Kerr  
Jim Harris  
Daniel Moric  
Roger Bayley  
Barbara Ann Reid  
Ian Morgan Medical Services Inc  
Linda Stafford  
Dorine Uridge  
Gabrielle Joule  
Lily Forget  
Keith Goddard  
West Vancouver Rotary Sunrise Ass  
Mrs. J. Krogseth  
Lois Redman  
Bruce Potter  
Lynne Hards  
Katherine Coutts  
Linda Mary Pedersen  
Rosalind McLeod  
Maggie Sander/Moore  
Georgina Rivers

C.Gordon Cooling  
Alistair Martin  
Albert B. Somody  
Desmond Bell  
Sam Chan  
Angus Simpson  
Nancy Buckham  
Dawn Hogbin  
Stephen C. Heming  
Klaus Rudert  
Rick Oswald  
Daisy's Ladies Consignment  
Douglas Husband  
Roland Embree  
Elizabeth Estabrook  
Karen&Bill Holden  
Derek Oswald  
Cathy Gray  
Winnie Choi  
Thomas Milton  
Carl&Su Dorozio  
John L. Young  
David Motion  
Jacqueline McTavish  
Bill Hayes

# MG NEWSLETTER

James Postnikoff  
Timothy March  
Emily Strange  
Marsha Tillmann  
Alfred Craig  
Tony Lipiec  
Nicholas & Marlis Rowe  
Andrew Dawes  
Jose Hosking  
Louis & Jani Guzy  
Heidi Peters  
Cecilia Joan McIntyre  
Elizabeth MacDonald  
Earle Newton  
Margaret Barbour  
Clara Hartree  
James Cruickshank  
Iain Hume  
Patricia Davis  
Michael & Maureen Byrne  
Cathy Thompson  
Di Hill  
Rhonda Lott  
Bonnie Curl  
Lois Diczki  
Jose Espinosa  
Linda Finch  
Brenda Kelsey  
Leslie Potter  
Sean Buhl  
Junk Car Towing  
Isabelle Neill  
Laurel Hadfield  
John McIntosh  
Peter Grant  
Marie Revve  
Kenny Kyan  
Reid Point Marina  
Jason Harris  
Pacific Potato Corporation  
Roy Gordon  
Walsh King

Mary-Ann Booth  
Mary Laudien  
Elaine Voci Skills Coaching  
Robert Murdock  
Larry Hill  
David Keir  
Angela Walsh  
Judith Ray  
Victoria Nelson  
Glenda Treleaven  
Reid Pauley  
Michele Maguire  
Pat Gerein  
Raymundita Torrenueva  
Darlene Nowland  
Kelly Carson  
Lynne Walters  
Leslie Wade  
John Gould  
Paulo Arreaga  
Marie Payette-Falls  
Barbara Wuhrer  
Robert Michieli  
Kent & Gary Bubbs  
Bill Witte  
Claire Stone  
Brian Hart  
Michael Carter  
Ellen Nakashima  
John Richardson  
M. Hall  
Cal Johnson  
Gary Morrison  
Murray Joymore  
Esther Delvicario  
Sandra Garnham  
Ken Wilson  
Norma Gauld  
Helen Hardisty  
Christiane Ahpin  
Robert (Barry) Childs  
Mary Hall

Fred Wuhrer  
William Weir  
David Torrance  
Angela Gregory  
Al Hasley  
Anne Brown  
Graham McIsaac  
Patrick McAuley  
Melville Barracliffe  
Roger Woodhead  
D. Hall  
Peter Jarvis  
Ross Hedley  
Kathleen Jarvis  
Paul Morantz  
Maggie McKenzie  
Janis Bosley  
Margaret Kolodziej  
Hans Gray  
Lynn Oary  
Jack Pruski  
Gordon Janzen  
Patricia Okin  
Willy Schulz  
Deborah Davidson  
Robert McGill  
Karen Sharp  
Robert Martin  
David Hall  
David Fitzgerald  
Padraig Gooderham  
Blair MacLean  
Stacey Easton  
Susan Jeffery  
Philip Davidson  
Jeremy Haile  
Donald Baker

**CORPORATE: Grifols Canada, The Hydrecs Fund, United Way of Alberta Capital, The United Way of Burlington and Greater Hamilton**

**MG Research Donations to Dr Oger at the University of B.C.**  
(picture on page 8)

We have not yet received all of the name of those who contributed on-line directly. We apologize for these omission and/or errors.

## LITERATURE ORDER

Name \_\_\_\_\_

Address \_\_\_\_\_

### LITERATURE AVAILABLE:

- 1. Myasthenia Gravis Facts
- 2. MG Glossary: Definitions of medical terms used in M.G.
- 3. Myasthenia Gravis Survival Guide
- 7. Drug pamphlets:  
 \_\_\_(a)Mestinon; \_\_\_(b)Imuran; \_\_\_(c)Prednisone; \_\_\_(d)Cyclosporine; \_\_\_(e)Cellcept  
 \_\_\_(f) Tacrolimus
- 8. Drugs to Avoid with Myasthenia Gravis (Updated 2004)
- 9. Thymectomy
- 10. Plasmapheresis
- 11. Intravenous Gamma Globulin (IVIg) for the treatment of Myasthenia Gravis
- 12. Ocular Myasthenia Gravis
- 13. Healthy Nutrition for Healthy Bones
- 15. Dentistry and the Myasthenic
- 16. Pregnancy and Myasthenia Gravis
- 17. Myasthenia Gravis in Children
- 18. School Package for Children with Myasthenia Gravis
- 19. Congenital Myasthenia Gravis
- 20. Emergency Care of Myasthenia Gravis
- 21. Mestinon Under the Tongue - 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. Alternate Therapies
- 26. Myasthenia Gravis Identification Card
- 27. Applying for CCP Disability Benefits
- 27 A. Advocacy Access Help Sheet
- 28. 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)
- 29. A Practical Guide to Myasthenia Gravis by Keesey & Sonshine **Excellent Booklet**
- 30. Providing Emotional Support for a Relative with MG

### BOOKS AVAILABLE:

- **You, Me and MG by Deborah Cavel-Greant, published 2005 (\$20.00 from MGABC)**
- **A Guide to the Diagnosis and Management of Myasthenia Gravis by Dr. Joel Oger, published 2008 - FREE OF CHARGE TO FAMILY PHYSICIANS of MG members**
- **My Imaginary Illness - Dr. Chloe Atkins A Journey into uncertainty and prejudice in medical diagnosis (For short term loan. You may also purchase through local book stores)**

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

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## MEMBERSHIP DONATIONS

MGABC'S membership year is January 1st to December 31st. Any membership received after October 1st will be good for the following year. To make a donation, please complete the form below and return it with your check or money order (we cannot accept credit card payments and we ask that you 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](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.**

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 (\$10.00) \$ \_\_\_\_\_ (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.