

MG NEWSLETTER

[Myasthenia Gravis Association of British Columbia](#)

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Spring
2012

Wellness

The Myasthenia Gravis Association of BC ANNUAL GENERAL MEETING

The Myasthenia Gravis Association of BC
cordially invites you to attend

THE ANNUAL GENERAL MEETING

When: **Sunday, April 15th, 2012 at 1:30 pm**

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

Speaker: Anissa Penneway, RPh
Graduate of UBC Pharmaceutical Sciences

Topic: Pharmacist as “Friend”

Pharmacists are often the most accessible of health care professionals. Working as a team with you and your doctor, pharmacists can help make sure you get the best possible care.

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

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 24th.

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



**MYASTHENIA GRAVIS
ASSOCIATION OF BC**

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 Talecris Biotherapeutics*

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ANNUAL REPORT of the MYASTHENIA GRAVIS ASSOCIATION of British Columbia, 2011

The year 2011 was an eventful one for the Myasthenia Gravis Association. It began with news that we were to move offices back to 2805 Kingsway. Linda and I started clearing out old files and out of date medical information. The packing cases arrived in April and we moved in May. Thanks to the well organized staff at the Centre for Ability, the move went very smoothly and we were settled in our bright new office by the end of the month. During this time, Barbara McDonald was working on our spring newsletter in order to get it to our members before the Annual General Meeting on the 10th of April. The guest speaker at the AGM was Professor Chloe Atkins, an associate professor in the faculty of Communications, Culture and Law at the University of Calgary.

Professor Atkins had written a book called "My Imaginary Illness" A journey into uncertainty and prejudice in Medical Diagnosis. Professor Atkins had suffered for 15 years, most of the time, confined to a wheelchair, being told her symptoms were psychological. It was not until she received a diagnosis and treatment for Myasthenia Gravis did she begin to feel well. She now lives a full and active life. Professor Atkins spoke candidly about how physicians can easily put a psychological label on a patient who cannot advocate for themselves.

During the busy spring, Linda, Barbara and I were meeting with Jim Harris, an MGA member regarding the association's participation in the Scotiabank Charity Challenge. Jim and his family were instrumental in our gaining registration as a charitable recipient in the annual run. This year Barbara will be handling the race particulars. Last year, she handled the administration of our registration and then with a team of volunteers, set up a Myasthenia Gravis booth at the finish line and handed out refreshments to our runners and Myasthenia Gravis Facts brochures. Not only did we receive donations and pledges by mail in the form of cheques, we were also able to receive donations on-line through a variety of credit cards. Jim's family, the other runners, members and friends and family helped the Myasthenia Gravis Association raise over \$8,000.00 for this event. The Association is so very grateful to Jim Harris and his equally generous children and grandchildren and to Barbara and the team of volunteers for their hard work.

Summers are usually pretty quiet around the MG office but Linda, Barbara and I keep coming in to check the mail, emails and phone messages. Myasthenia Gravis does not stop in the summer and Barbara and I started planning the Fall 2012 newsletter.

At the fall support group meeting, Dr Oger gave an overview of all the Myasthenia Gravis research studies he is involved in. Internationally, there is a Thymectomy Study and the MG Genome (DNA) study. Locally he published a study on "The Increasing Incidence of Elderly Onset Seropositive Myasthenia Gravis in BC." The MGABC was proud to sponsor the study and see its publication in the "Neurology" journal. The MGABC continues to support Dr Ogers research at UBC, and in 2011, we donated \$ 6,000.00.

We should all be very grateful to Dr Oger for his efforts on our behalf.

I am so proud of the MGABC as we have a very dedicated Board of Directors, and active volunteer pool and members who support us both financially and by attending meetings. I am also very grateful to Linda Briggs and Barb McDonald, David Sutherland, and our Board of Directors, for their help and support throughout the year. Angie Kwok and the CFA staff are always cheerful with their "advice" and help. And a big "thank you" to Dr Gillian Gibson for being our medical advisor.

Respectively Submitted:



Brenda Kelsey
President

From the MG Network...Mark your calendars

**The 2012 MG Foundation of America National Conference will be held April 25-27
in Las Vegas, NV at the Bally Hotel.**

The National Conference combines the Foundation's annual business meeting with the opportunity for patients and their families to learn more about the disease and its treatment, current research, and tips to learn 'how to live' with MG from experienced medical professionals and patients.

Source: National MGFA Website www.myasthenia.org

3rd Annual Myasthenia Gravis Education Day, Sept. 29, 2012

Dr Siddiqi, neurologist at the University of Edmonton will be hosting a meeting for patients and their families. The time and place are yet to be confirmed. If you live in the Edmonton area and would like to attend, please send the MGABC office an email or give us a call, and we will forward the information.

Scotiabank Group Charity Challenge 2012 June 24, 2012

Come support our runners and walkers, volunteer or just join the cheering section at the finish line in Stanley Park at the field by the tennis courts

Managing Your Health Care

"Your MG is very active"

It's a funny way of describing the illness that may leave you anything but active. With active MG, one of your biggest challenges is keeping track. You track symptoms. You track medications. You track appointments and bills and insurance benefits. Feeling overwhelmed? There is a website that can help: <http://www.pugetsoundhealthalliance.org/resources/GenericToolstoManageYourHealthandHealthCare.html>.

This website offers many practical tools for managing your health care information. "My Health Record: A Workbook" gives you space to list contact information for all specialists and insurance providers. There is a page for symptoms, a page for medications (with room for useful details like dose and start date and special instructions), lab numbers and more.

The site offers printable wallet cards for emergency information and medical lists, questions to ask your doctors, and tips for evaluating hospitals. There's even a section that describes which websites offer the most reliable medical information.



*Use what talents you
possess, the woods would
be very silent if no birds
sang but those that sang
the best.*

Henry Van Dyke

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A Day to Remember - Sunday, June 26, 2011

Though the sun shines brightly over the city, there is still an early morning mist. Thousands of people huddle together in and around the arena at UBC anticipating the next few minutes and, for some, hours. A murmur begins to move through the crowd and the nervous laughter and camaraderie lessens. People hug, cross and pat themselves looking anxiously for the quickest escape route. Arms swing, knees bend, heads bow, and then....the gun goes off...and the first wave of Half Marathon runners in the Scotiabank Group Charity Challenge 2011 attack the roadways!



At the finish line in Stanley Park, we are milling around the table, pulling over chairs to stand on so we can secure the banner to our tent. Boxes and bags spill over on the warm grass, there is no urgency in our movements, we are just happy to be outside in the sun, sipping coffees and talking with each other. And then we wait, we listen, and in the distance cheers and claps, shouts of encouragement – our runners are arriving. And as they do one by one, by twos, by groups and clusters, the excitement mounts. For the next two hours it does not lessen as each and every dedicated runner and walker make their way through the finish radiating relief and pride.



Trevor Harris(L) and his dedicated team, THE SPIRIT RUNNERS

For additional race information and in order to make donations online, please visit www.canadarunningseries.com/svhmCHARITY.html



**MYASTHENIA GRAVIS
ASSOCIATION OF BC**

We give very special thanks to all who ran, walked, and volunteered. And for those who so generously donated, we thank:

Jim Harris	Kenny Kyan	Donald Fair
Grove Crest Farms	Reed Point Marina	Anne-Marie Filgas
Cynthia Fransico	Kimberley Hughes	Kenny Kyan
Dorine Jane Uridge	Rick Oswald	T.Greg/Lynne Schnell
Lily Forget	D Hamilton	Richmond Cowboys
The Pacific Potato Corp	Terri Haggerty	Jerry Gill
Nancy Wells	Maddy/Ella Teasell	Jim/Loretta Teasell
Andy Teasell	Gabrielle Joule	Tracie Berg
Don Buxton	Diane Martin	Joey Browne
Michelle Kates	Navdeep Hundal	Dan Matwichyn
John/Mary Kormend	Gwen/Rob Myles	Fraserland Farms
Naomi/Marc Broudo	Eleanor Brown	Winnie Choi
Merrilee Crofton	AGPower Sale Inc	Elizabeth Eastbrook
Peter Grant	Lori Hadfield	Carol/Mike Harper
Dave Harris	Jason Harris	Quinn Harris
Trevor Harris	Boss Hogg	Bruce Kennedy
Arlene Kyan	DJ Husband	Rita Reeves
John/Joan Young	Michael Shirley	Viv/John Keel
Janet Nieckarz	Dense Wiley	Donna McLennan
The Bougeois	Joey Howard	Kenzi Markling
Ivor Palmer	Madeline Palmer	Dayna Glerean
Annee Baker	Paula Bedford	Cal Buxton
Nicole Emery	Dana Gibson	Stephanie Goodwin
Brenda Kelsey	Karen Lau	Nicole Maas
Trina Simonson	Hollie Williams	Rob Wilson
Sharon Wilson	Jane Brown	Laura Graveling
Randall Schaefer	Don Abrahamson	
Alison/Joanne Kerford	In Memory of - P. Harris	

Our dedicated volunteers:

Virginia Angus	Lorne Holyoak	Jim Harris
David Sutherland	Barb McDonald	

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Yoga's Spiritual Balance May Boost Health

Yoga may be becoming more of a mainstream approach to health woes. A growing body of scientific evidence is building the case that the spiritual balance created by yoga provides proven health benefits.

Research has found that yoga can help people who are dealing with health problems as wide-ranging as back pain, chronic headaches, sleeplessness, obesity, neck aches, upset stomach, anxiety, depression, and high blood pressure, said Bat Bir Singh Khalsa, an assistant professor of medicine at Harvard Medical School and an associate neuroscientist in the Division of Sleep Medicine at Brigham and Women's Hospital in Boston. Yoga may also help bolster the immune system by lowering stress. "When you reduce stress, you make the body healthier" he said. "When the body is healthy, it is able to use its own defenses better."

The health benefits mainly stem from yoga's focus on the connection between the mind and body, Khalsa said. "The evidence really shows that yoga is good at reducing stress and helping people cope with the stress they have. It improves management of stress both psychologically and physiologically."

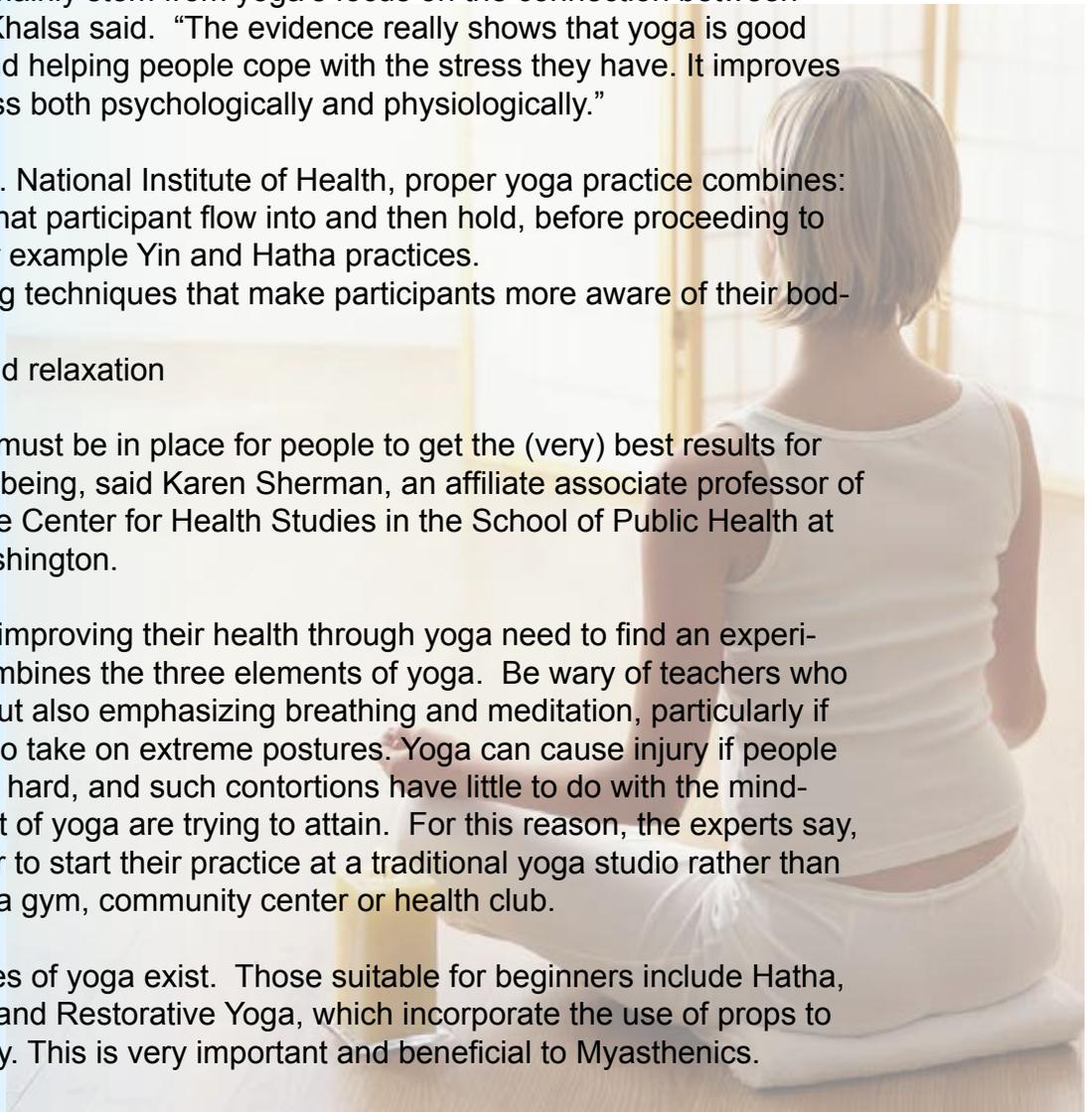
According to the U.S. National Institute of Health, proper yoga practice combines:

- Physical postures that participant flow into and then hold, before proceeding to the next posture. For example Yin and Hatha practices.
- A focus on breathing techniques that make participants more aware of their bodies
- Deep meditation and relaxation

All of those elements must be in place for people to get the (very) best results for their health and well-being, said Karen Sherman, an affiliate associate professor of epidemiology with the Center for Health Studies in the School of Public Health at the University of Washington.

People interested in improving their health through yoga need to find an experienced teacher who combines the three elements of yoga. Be wary of teachers who focus on postures without also emphasizing breathing and meditation, particularly if they press students to take on extreme postures. Yoga can cause injury if people push themselves too hard, and such contortions have little to do with the mind-body link that students of yoga are trying to attain. For this reason, the experts say, people may do better to start their practice at a traditional yoga studio rather than taking yoga through a gym, community center or health club.

Many different styles of yoga exist. Those suitable for beginners include Hatha, Kundalini, Viniyoga, and Restorative Yoga, which incorporate the use of props to help support the body. This is very important and beneficial to Myasthenics.



Green Tea Helps Fight Autoimmune Disease

Researchers at the Linus Pauling Institute at Oregon State University have discovered that one of the beneficial compounds found in green tea has a powerful ability to fight autoimmune disease. They found that the compound increases the number of 'regulatory T cells' that play a key role in immune function.

This may be one of the underlying mechanisms for the health benefits of green tea, which has attracted wide interest for its ability to help control inflammation, improve immune function and prevent cancer.

Though pharmaceutical drugs are available that perform similar roles and have been the subject of much research, they have problems with toxicity. A natural food product might provide a long-term, sustainable way to accomplish this same goal without toxicity, said the researchers.

This appears to be a natural, plant-driven compound that can affect the number of regulatory T cells and in the process improve immune function. When fully understood this could provide an easy and safe way to help control autoimmune problems and address various diseases.

In this study, OSU scientists did experiments with a compound in green tea, a polyphenol called EGCG, which is believed to be responsible for much of its health benefits and both anti-inflammatory and anti-cancer characteristics. They found it could cause a higher production of regulatory T cells. Its effects were not as potent as some of those produced by prescription drugs, but it also raised few concerns about long-term use or toxicity.

EGCG may have health benefits through an epigenetic mechanism, meaning we aren't changing the underlying DNA codes, but just influencing what gets expressed, what cells get turned on. And we may be able to do this with a simple, whole-food approach.

The findings have been published in *Immunology Letters*, a division of ScienceDirect. ScienceDirect is a leading full-text scientific database offering journal articles and chapters from more than 2,500 peer-reviewed journals and more than 11,000 books.

Editor's note: The Myasthenia Gravis Association has some concerns about this rather ambiguous article. As Myasthenics, taking the drugs Presnison, Imuran and Cellcept, we are attempting to suppress our immune systems to slow down the production of antibodies and especially T cells. If the compound in green tea is said to increase the number of T cells, this may exacerbate an autoimmune disease. Beware of any "Natural" product that advocates boosting the immune system.



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Cheap Towels

By: Willeke van Linden Tol
Member MGABC

Over the last 20 months I have learned to “manage” my daily activities around my MG and I wanted to share some of them. They are true for me, but, it could be different for you. I just hope it creates some awareness in your own daily life.

- 1.How dirty are you? Unless you have been wallowing in mud, a sitting bath for all the strategic places should be sufficient.
- 2.Or, if you have slightly more energy; the WW2 ration of a 5 inch bath is enough to splash yourself to get clean.
- 3.If you do take a real bath, do not use hot, and do not stay too long. A little oil will save you body lotion application. Just be safe getting out of the slippery bath.
- 4.Forget expensive 300-thread towels, they are too heavy. Cheap thin towels save your muscles. At bath - and laundry time. Also, do not go for the heavy luxurious bathrobe either, it will weigh you down.
- 5.Rest after washing, otherwise you are behind the eight ball from the start.
- 6.Eat a hearty breakfast; it might be the only meal you can swallow that day. Eat little portions during the day.
- 7.Do not waste energy getting to places. Use a car to get to your destination. Wheelchairs are also for Myasthenics, as are Handicap stickers.
- 8.Most valued tools on weak days & in hospital: Eye bag & iPod! My eyes are the first to get tired, making reading, computer or TV impossible. I lay down with a good book on my iPod & get lost in the story with an eye bag to still my eyes. Sometimes it only takes ½ hour to recover,. If I would have tried to push myself I end up in bed full time.
- 9.Light & noise are a huge issue for me. I carry earplugs & sunglasses for noisy places and restaurants.
- 10.When having a conversation, ask people to sit down. Ensure you're on same height or place them lower. “Looking up” is a sure way to get tired eyes & a fallen face with drooping mouth. As soon as I start to feel like I am looking from under a baseball cap; I know I have to rest. Do not apologize. Go and retreat. Friends do understand.
- 11.I avoid big dinner parties with multiple conversations. A group of 4 at the dinner table is more manageable. I often ask to have one conversation at the time. Big lesson with MG is to learn to be assertive.
- 12.Do not look up to television. You're wasting energy. Slightly downward gaze with your eyes is more comfortable.
- 13.Reinvent yourself! Due to medication (prednisone) I was swollen to twice my size, a nice round moon face with a good red flush. Nothing fit, and dressing was an ordeal. I re- arranged my closet and went out to buy or borrow clothing without zippers or buttons. I choose new colours to suit my new face . Changed my hair colour & make up to suit my new complexion. Beautiful scarves hide my buffalo neck. These are ideas to turn something negative into positive; you can embrace the change.
- 14.Ask for help. You do need a good advocate who can speak on your behalf on bad days and in hospital. Also, friends & family will be happy to actually be able to do something for you. I have re- organized my pantry, closet & kitchen for easier access. I wipe but do not scrub, and sweep but do not vacuum. I have friends & family (thank you, Kees & kids) who do the heavy cleaning. *(continued next page)*

15. Be your own Advocate. Be aware of your triggers. Keep a journal for medications, treatments & symptoms of a weak day. It took a long time for me to connect the dots, to realize the consequences of my actions. I thought I would save you some time so to have some extra muscle for the fun things in life. A journal is a good place to get the bad thoughts off your chest! It might help with difficult days.

SHOULD YOU EXERCISE IF YOU HAVE MG? Well.....

Should MG patients undertake an exercise program? Different sources provide different answers to this question. The very general answer is –exercise is helpful for people with MG, but patients should not embark on an exercise program that requires maximum output and produce weakness. Exercise should be done in a way that stops short of muscle fatigue, and this will vary from person to person, depending on age, overall fitness level, MG symptoms and other factors.

From Caremark Health Resources: Physical and emotional stress can worsen MG. Exercise can help relieve stress, but it is important not to over exert yourself. People with MG often need to rest more frequently than other people, but a supervised program that includes aerobic exercise and moderate strength-training may be possible. Ask your doctor and a physical therapist experienced with MG patients to tailor an exercise program to your specific needs.

From Livingstrong.com: One of the frustrating components of myasthenia gravis is the tendency of symptoms to come and go. Some days you may feel capable of exercising, while on others a simple walk to the mailbox may leave you extremely fatigued. For this reason only your doctor can advise you on how and when to exercise. Together, you can set up guidelines on how much exercise is healthy for you and under what circumstances you should attempt it.

If your doctor approves, the elliptical machine may be a good way to build an exercise regimen. First, look for non-skid foot panels. You won't need to lift your feet off the panels to use the elliptical, so there's less danger of falling than there is with a treadmill. Many ellipticals offer two sets of grab bars – one set that moves and that is stationary. Be sure you use the stationary set for extra support.

There is even a current clinical trial to examine how active and fit 30 individuals are with chronic, generalized myasthenia. This study will also determine whether a three month home exercise program with aerobic, resistive and pulmonary training can improve physical activity, strength, fitness, lung function and reduce cardiovascular disease risk.



So, exercise is a good thing. Be sure to talk to your doctor before you begin any exercise program and ask for some guidelines. If he is vague about specifics, ask him if he can recommend a physical therapist who has worked with MG patients. Keep in mind that slow progress is fine and very worthwhile.

DONATIONS AS OF OCTOBER 1, 2011

Henry Aben	James Boyd	Dr Otto Huhn
George Lopushinsky	Eldon Whitecotton	Olive Worsfold
Allan Thorp	Marsha Tillman	Elizabeth Sephton
Timothy March	Edward Gore	Ismail Abbadi
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Michael Shirley	Ed Zatorski	Richard Douglas
Helen Martin	James Postnikoff	Linda Beare

In Memory of

Jim Kirwen - Jerry Olynyk

Janet Olliver - Stephen Olliver

CORPORATE : TELUS CARES - "Dollars for Do'ers": Eileen Davenport, David Sutherland and Rose Hare, Dawn Hogbin and Doris Taylor

MG RESEARCH DONATIONS to Dr OGER at the University of B.C.

Myasthenia Gravis Ass. of B.C, Nicole Tessier and as a monthly donor, Brenda Kelsey

Donations are current as of March 1, 2012. We apologize for any errors or omissions.

LITERATURE ORDER

Name _____

Address _____

LITERATURE AVAILABLE:

- 1. Myasthenia Gravis Facts
- 3. Survival Guide
- 6. M.G. 101 - Comprehensive information on MG from history to up-to-date treatment
- 7. Drug pamphlets:
 ___(a)Mestinon; ___(b)Imuran; ___(c)Prednisone; ___(d)Cyclosporine; ___(e)Cellcept
- 8. Drugs to Avoid with Myasthenia Gravis (Updated 2004)
- 9. Thymectomy pamphlet
- 10. Plasmapheresis pamphlet
- 11. Intravenous Gamma Globulin (IVIg) for the treatment of Myasthenia Gravis
- 12. Ocular Myasthenia Gravis
- 13. Fresnel Prism to correct double vision
- 15. Dentistry and the Myasthenic
- 16. Pregnancy and Myasthenia Gravis
- 17. Myasthenia Gravis in Children & Adolescents
- 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 - Vitamins, minerals, herbs, & other supplements; MG & mercury amalgam
- 25. Medic Alert Application
- 26. Myasthenia Gravis Identification Card
- 27. Tips on Applying for CCP Disability Benefits
- 27 A. Advocacy Access Help Sheet
- 28. A Practical Guide to Myasthenia Gravis by Keesey & Sonshine **Excellent Booklet**
- 29. Providing Emotional Support for a Relative with MG
- 30. 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 (\$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
- **Commitment to Health** by Jerry Olynyk (Loan only. Not available for purchase.)

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

MEMBERSHIP and DONATIONS

MGABC's **\$10** 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 ***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 with the words **"E-mail request"** in the subject line. Thank you.