The Myasthenia Gravis Association of BC  
SUPPORT GROUP MEETING 2012

The Myasthenia Gravis Association of BC  
cordially invites you to attend  
THE Fall 2012 Support Group Meeting  
When: Sunday, October 14th, 2012 @ 1:30 pm  
Where: Legacy Room - #307, Centre for Ability, 2805 Kingsway, Vancouver  

Topic: “Challenges and Solutions of Living with MG”

This is an excellent opportunity for MG patients in remission or new patients to share stories and receive support from other people with Myasthenia Gravis.

Dr. Michelle Mezei MDCD FRCPC will be on hand to answer question. Dr. Mezei works with Dr. Gibson at the MG Clinic at Vancouver General Hospital.

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: mgabc@centreforability.bc.ca

Attendance at the MGABC meetings has been falling off, we urge everyone to attend. It would be very sad for all mg patients, past and future, if support meetings have to be cancelled due to lack of attendance. Remember, this is a great way for all of us to stay connected, though our primary goal is to ensure everyone living with Myasthenia Gravis never feels alone again. We want to educate and also provide a safety net between yourselves and the medical system. Those of us who share a common diagnosis come together to share ideas, coping tips and the many ups and downs of MG but most importantly provide emotional support. Please join us on the 14th.

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. The MGABC is grateful to the province of BC for their charitable gaming grants.
Living with MG – Helpful Tools

We know many people don’t have access to the Internet, so periodically we will post web-sourced information. This is from Living with MG - Healthy Living with MG section of the MGF of Illinois website, [www.myastheniagravis.org](http://www.myastheniagravis.org).

When your MG is active, these ideas might be helpful:

**Getting Around**
- A lightweight cane can offer support
- Use a city shopping cart or wheeled luggage cart, either on the street or to bring things from the car inside
- A handicapped parking sticker or decal can make walks shorter when doing errands in the car.
- Use shopping scooters if available
- Consider a chair lift in your home if necessary

**In the Kitchen**
- Invest in new electric appliances ie, can openers, hand blenders
- Put things you use regularly within easy reach. Avoid getting down to the floor or going up on a chair or stool when possible.
- Choose smaller containers for storing food items
- Try to use lighterweight pot and pans as well as dishes

**In the Bathroom**
- Install hand rails and grab bars if your can.
- Use a plastic shower chair.
- Try a flexible hose attachment on your shower head, so you can sit while bathing

**For Yourself**
- A properly-fitted cervical collar can help support your neck, while writing, reading or using a computer
- Tape up your eye lids when necessary. Your eye doctor may have light adhesive tape that temporarily keeps eyelids from drooping. Or you may try silk tape that is used in hospitals
- If your breathing is weak, your doctor may prescribe the use of a C-PAP (or Bi-PAP) machine. While you wear a mask, the machine forces regulated puffs of air into your lung, giving your breathing muscles a well needed break. You may even be able to sleep with the C-PAP.

“MOST OF US HAVE FAR MORE COURAGE THAN WE EVER DREAMED WE POSSESSED.”

Dale Carnegie
HEALTH TIP: Caregivers, Don’t Ignore Your Own Health

Caring for someone else during a serious illness can take a lot out of you. The American Academy of Family Physicians says it’s important to take care of yourself as you care for someone else. The academy offers these suggestions:

- Get a regular checkup with your own doctor
- Take some time for yourself
- Eat a healthy, nutritious and balanced diet
- Schedule time for fun and exercise
- Help manage stress with techniques such as meditation and yoga.
- Find time for plenty of sleep

For additional tips, go to: http://www.alm.nih.gov/medlineplus/caregivers.html

Hospitals Can Be Dangerous For Myasthenics

Myasthenia Gravis is a rare disorder in the eyes of most of the world. In fact, few workers in the health-care system will come into contact with MG patients during their careers. As a result, patients with MG who must make use of the health care system, for any reason, are wise to adopt a cautious approach when they are admitted to hospital. It is natural to assume people operating a hospital would be educated in the appropriate handling of a patient with MG. The truth is often far from that assumption.

During a recent hospital stay, an MG patient became keenly aware of the importance of staying on guard in order to protect his best interests as a myasthenic. He found that many of the nurses, aides and medical technicians welcomed his input.

To remain passively trusting, however can be dangerous, so this article was written with the hope his experience help raise the consciousness of other myasthenics in how to approach contact within the healthcare system.

The doctor told this patient one day, he was wanted in the hospital to perform a series of tests for a gastrointestinal problem of unknown cause. He needed to be hydrated intravenously since he had lost a lot of fluids. As hospitals are not unknown to him, he thought he knew what was coming. He learned however that a myasthenic needs to be pro-active at the very on-set – admission. With a suppressed immune systems, many myasthenics take Imuran - and without knowledge they may be asked to share a room with someone who has an illness that could be potentially dangerous for a myasthenic.

Myasthenia Gravis itself, rarely causes death. But serious illnesses such as pneumonia and tuberculosis can be extremely dangerous to myasthenics with a compromised immune system. After several days in the hospital, the patient made a comment to his doctor that he felt, he was not getting enough sleep and this was affecting his overall health. The doctor responded in what is considered a typical response by some medical personal, and prescribed a sleeping pill rather than speaking to him directly. Convinced that most doctors have never been admitted into the hospital the patient felt what he really needed was to be left alone at night for a time to relax, rather than a sleeping pill, knowing as well, that some sleeping medication is not recommended for myasthenics. Similarly other drugs were prescribed without first checking their safety for myasthenics. One day, the patient was scheduled for a procedure which required anesthesia. The patient again assumed the skilled technicians would be alert to any special considerations for a patient with myasthenia. In questioning the nurse administering the drug, the patient realized she had no knowledge whether the drugs were or were not safe for myasthenic.
Though the patient appreciated her honesty the fact that the information regarding his MG had gone unnoticed, he decided it was up to him to ensure his own safety. He asked the attending nurse to call a neurologist before they continued any further and to inquire about the safety of the anesthesia. This is a situation many myasthenics can find themselves even though there are many people who work in the system and who are by and large an educated and caring group of individuals, though they may not be completely knowledgeable about MG.

We want to emphasize that the only protection a myasthenic can expect to have is their own personal education and an “on-guard” attitude. Be sure to ask lots of questions about the treatment and medications you are being given and be sure all of your caregivers know of your condition. If you are unable to advocate on your own behalf – be sure you have an informed family member, friend or colleague to act for you.

Editors Note: The MGABC office in Vancouver has copies of Dr Ogers’ book and hospital packages available for our members who may have to be or need to be admitted to hospital.

Again this year, we want to thank all of those who participated in the Scotiabank Charity Challenge on June 24, 2012 - runners, walkers, fund raisers and volunteers! The weather gods smiled on this event once again, providing one of the warmest and loveliest of June days. Dave Sutherland, Lorne Holyoak, Jim Harris, Barb McDonald and Brenda Kelsey were all on site cheering the runners on, as well as managing the Myasthenia Gravis booth. A last minute suggestion by Lorne Holyoak had Barbara racing to produce a banner that read “Ask me about the Snowflake Disease”. It was a brilliant idea as many people stopped by to ask about its meaning and were engaged in conversation and amazed they had not heard about MG. We are having a permanent banner made for all future MG events!
### Drugs that may Cause or Worsen Symptoms of Myasthenia Gravis

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<tr>
<th>Drug Uses</th>
<th>Drug Names/Class</th>
<th>Common Names (when available)</th>
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<tr>
<td>Drugs used to Treat Immune Conditions</td>
<td>Interferon Alpha</td>
<td>Roferon/Infergen/Intron A</td>
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<td>Steroids</td>
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<td>Drugs used in Surgery</td>
<td>Atracurium</td>
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<td>Rocuronium</td>
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<td>Succinylcholine</td>
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<td>Isofluurane</td>
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<td>Drugs used as Local Anaesthetics</td>
<td>Lidocaine</td>
<td>Xylocaine</td>
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<td>Procaine</td>
<td>Novocaine</td>
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<td>Drugs used to Treat Infections (taken orally or by injection)</td>
<td>Ciprofloxacin</td>
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<td>Gentamicin</td>
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<td>Neomycin</td>
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<td>Sulfonamides</td>
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<td>Clarithromycin</td>
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<td>Pyrantel Pamoate</td>
<td>Combantrin</td>
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<td>Imipenem-Cilastatin</td>
<td>Primaxin</td>
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<td>Drugs used in Cardiovascular Conditions</td>
<td>Verapamil</td>
<td>Isoptin</td>
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<td></td>
<td>Procainamide</td>
<td>Procan</td>
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<td>Bretylium</td>
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More Drugs to Avoid – many thanks to our members for keeping us informed.

We hope anyone who has drug or treatment issues will let us know.

WARNING ABOUT AN ANTIBIOTIC GIVEN FOR PNEUMONIA

DOXYCYLINE

This drug can cause an upset stomach and weakness in the throat muscles. As well as a danger for Myasthenics of coughing or vomiting. It should be used with extreme care and/or ask your caregiver for another antibiotic.

LEVAQUIN and ZITROMAX

MIDAZOLAM and FENTANYL

Both of these drugs can cause major breathing problems

Personal pats on the back

When was the last time you gave yourself a pat on the back? Can you even remember? Perhaps it was for job you did well or a difficulty you managed to overcome or we able to cope with. The list of these types of situations can go on and on ... Many of us, often forget to give ourselves the self-applause for the accomplishments we make, however small or seemingly insignificant.

Each one that’s been achieved means it’s a goal that has been reached, a challenge that has been met, another step taken - actions instead of dreams or wishes. Sometimes, too, it’s the small steps we take which will make the difference between reaching that last mile to even getting there at all.

Why don’t we do it?

Perhaps it’s a sense of guilt or not wanting to be over-proud. It may just mean we don’t feel deserving enough to accept self-praise or rewards.

Let us all remember that the next time we succeed - however small - or better yet, the next time we try, we will stop to give ourselves a gentle pat on the back. Each of us deserves the small effort it takes and it can result in having a healthier self-esteem and a greater sense of self worth.
When I asked a few patients, “Is there anything what bothers you most having MG?” the answers were so consistent that I knew this was worth the time. “Having to take prednisone” was almost universal. Understanding the use of corticosteroids is a critical aspect of treating MG and one for which every patient should have a clear sense.

Immunosuppressant therapy of some kind will be necessary in the majority of patients with many MG. Since the disease tends to be chronic, many MG patients also need to anticipate taking therapy for a long time. It can be argued that without immunosuppression, the immune system has an unopposed attack against the neuromuscular junction since Mestinon, when taken alone, treats only symptoms but does nothing to deter the autoimmunity.

Among the immune agents, corticosteroids and, in particular, prednisone, are arguably the most effective treatments. While there are few studies demonstrating effectiveness, years of experience have clearly taught us that this is a beneficial drug. Improvement usually begins within weeks of when high dose therapy is initiated, (Prednisone 60mg a day) and it may even work within a few days in some. The vast majority will respond by several months. Note that no other drug has the profile of allowing patients to maintain a predictable and sustained recovery over the first few months after onset.

Despite being so effective, corticosteroids have an obvious downside in the variety of adverse effects associated with both short and long term use. Thus, the best medicine we have, by far, has significant limitations. This is a tough dilemma for the clinician which makes us all think hard about other options. It follows that whenever someone begins Prednisone, the long term goal is to achieve stable recovery while avoiding steroid related adverse effects. This requires eventually determining the minimal clinically effective dose and considering the use of second Prednisone-sparing drug if that dose is too high. The idea is to gradually replace prednisone with something that has fewer side effects and similar efficacy. While this cannot be done in the short run, there are several medications that can decrease the chances of being on prednisone in the long term. Medications in this category primarily include Azathioprine (Imuran), IV1G, Cyclosporine A, Cytoxan and Mycophenylate, Mofetil. The reader needs to be familiar with what we actually know.
Imuran is actually the best studied prednisone-sparing agent. In contrast and somewhat surprisingly, Imuran is not good at treating Myasthenia Gravis if used by itself as a first line agent. Moreover, the benefit as a prednisone-sparing agent does not accrue until the third year after beginning the medication. That means, even if a new Myasthenic goes on a combination of Imuran and Prednisone, it might take about three years to really increase the odds of getting off steroids. That means staying the course for a long time. It follows that there is a waiting period for Imuran to work, and it is possible that a patient has a few exacerbations (worsening) during this time. During these exacerbations, the clinician might temporarily increase Prednisone and then taper it off when the exacerbation resolves. This approach differs from switching from Imuran to something else, in the hope of having fewer exacerbations with time.

One other agent, CellCept, seems to have a reputation for being better than Imuran. While this impression is cautiously hopeful, the truth of the matter is we don’t actually know how to compare the agents, since there is only anecdotal information from a few uncontrolled studies. Knowledge of three key issues are lacking: how long it takes to start working, how well it works, and whether it can be used.

2013 Membership Drive & Fundraising Begins!

Every October we ask MGABC members to renew their memberships. The annual cost remains $10.00 per member. Your fee include a biannual newsletter, free information pamphlets, notification of special programs of interest to Myasthenics, as well as support group meetings with speakers and staff members. Memberships renewed after September 30th are valid for 2013.

October is also the time when we ask for donations to keep our programs going and allow us to staff and maintain a clerical person. Contributions for research are always needed in order for Dr. Oger to continue his fine work into Myasthenia Gravis research at the University of British Columbia.
DONATIONS AS OF MARCH 16, 2012

Received with much gratitude and thanks! Includes donations directed to research

Roger Cooper   Ruth Brill   Lavinia Lo
Roberta Gordon  Marsha Tillman  Emily Strange
Joan Prokopchak  Reina McAfee  Allan Thorp
Lois Ngai  David Sutherland  Ken Porterfield
Peter Sanders  Gayle Wilson  Yvonne Elliott
Edgar& Edith Lublow  Paula Horning  Jane Bryans
Mary Ann Leach  Pamela Yorke-Hardy  Wendy MacFarlane
Joanne Mirabelli  Maybelle Morrison  Gord Voth
Glen Challenger  Helen Martin  Richard Douglas
Susanne Kavanagh  Elbertha Bisschop  Sonia Lightfoot
Roger&Maureen Cooper  Doreene Kerr  Carol McBryde
Terry-Ann Callander  Linda Stafford  Chriss Steane
North Island Support Group  HYDRECS
Brenda Kelsey/monthly donation

Donations made directly to the ScotiaBank Charity Challenge are unable to be listed here due to space issues. Those donors who sent donations to the MG office are listed below:

Reg Vidmar  Samantha Perry  Kim Wheeler
Sara Underwood  Margriet Neels  Danica Anderson
Gillian Elsey  Tony van Oort  Will van Oort
Judy Royal  Lily Forget  Brenda Kelsey
Gabrielle Joule  Dorine Ūridge  Ken Porterfield
Jeanette Espinosa  Michele Maguire  Reid Pauley
Raymundita Torrenveva  Glenda Trelevaven  Martin&Judy Roy
Al&Pat Gerein  Bill Higgins  Michael Shirley
Lynda Rose  Beverly Butler  Debbie Jackson
Jim Kloot  Linda Briggs

In Memory of:
Jeannie Armitage - Tammi Gerrior

Memorial gifts are a wonderful way of recognizing the importance of MGABC to the person being named. You may also recognize those with MG by sending a donation in their name for occasions such as birthdays, anniversaries, recognized holidays and/or Mothers and Fathers Day. We will notify the honoree by letter of your memorial donation and all donors will receive a tax receipt.
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
- 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.
MG NEWSLETTER

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 You may donate:
Online: www.supporting.ubc.ca/mg OR by calling: 1-877-717-GIVE (4483)
By mail: Myasthenia Gravis Research, UBC Annual Giving, 500-5950 University Blvd, Vancouver, BC V6T 1Z3

If you would like to donate to Dr Oger directly, please make your cheque payable to UBC Myasthenia Account, and mail c/o Dr Oger - S159 MG RESEARCH
2211 Westbrook Mall, Vancouver, BC V6T 2BS

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.