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 14th, 2013 at 1:30 pm
Where: Room 307, Centre for Ability, 2805 Kingsway, Vancouver

Speaker: Dr. Gurjind Singh Rai, MD
Clinical Research Assistant at Prohealth Osteoporosis Clinic

Topic: Myasthenia Gravis and Osteoporosis
Osteoporosis is a health issue of great importance to all adults. Please invite anyone who wants to learn more about bone density, susceptibility to fractures and how to prevent them.

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 23rd. 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

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 Biotherapeutics
In February 2012, Linda, Barbara and I started to plan for our Annual General Meeting in April. The BC Association of Pharmacists was contacted and we were put in touch with Anissa Penneway, a registered pharmacist from Pharmasave in Yaletown, who wished to do more community outreach work. Anissa and I met and discussed topics for her presentation. We decided on “Pharmacist as Friend”, highlighting the fact that pharmacists are often the most accessible of the health care professionals. Who could, working as a team with you and your doctor, make sure you are getting the very best of medical care. For those of you who attended, I am sure you will agree with me, Anissa was a brilliant presenter, outlining the role of pharmacists today as well as clarifying current information on myasthenia gravis medications, herbal supplements and possible side effects of both. We came away with a new understanding of MG medications and the pharmacists position in the health care system.

The North Island Support Group in Parksville held a meeting in June which I attended. Dennis Shepeley, head of the Victoria MG group and a few of his members made the trip to join and support the meeting, I spoke about the MGABC’s responsibilities, our financial connection with Charitable Gaming, current MG research at UBC and elsewhere as well as the immediate future of the MG Association.

Later in June, the sun shone on us again, as we prepared for the Scotia Bank Charity Challenge. Half marathoners run out from UBC and the 5K runners and walkers journey around Lost Lagoon. Trevor Harris (by now you know he is our member, Jim Harris’s son, and his team is “The Spirit Runners”) took part as well as Jim’s daughter and grandchildren, our clerical support, Barb McDonald and member Tony Van Oort. Lorne Holyoak, David Sutherland, Jim Harris, Barbara and I helped out at the tent. The makeshift paper banner, “Ask me about the Snowflake Disease” prompted lots of questions from participants and supporters. We have had a permanent banner made. We want to thank all of you once again who fundraised, pledged on-line, as well as those of you who sent cheques to the office.

Running a non-profit medical support group requires a lot of administration. What makes it fun, interesting and challenging is our members, both new and “experienced”. Our members have always been our number one priority, and make running the MGABC worthwhile. My job is made so much easier with the help and encouragement of the MGABC Board of Directors, Linda Briggs (Treasurer Extraordinare), Barb McDonald, our clerical guru and newsletter czar, Dr. Gillian Gibson, my neurologist and Medical Advisor to MGABC. My sincere thanks to Angie Kwok, Executive Director of the Centre for Ability and her staff, who are always friendly and helpful. The MGABC is also grateful to the Province of British Columbia for declaring June - Myasthenia Gravis Awareness Month and for access to Charitable Gaming. A sincere thanks to you, our members, for your support, both financially and by attending meetings.

Respectively Submitted,

Brenda Kelsey
President
Dr. M.W. Nicolle’s PowerPoint presentation titled, Myasthenia Gravis: A Neurologist’s Perspective, is available for viewing directly on the MGCC website.

1. Simply log into MGCC website: www.mgcc-ccmg.org
2. Click to the Resource Material menu,
3. Move down to Visual Presentation, 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 affects antibodies in the body.

Double Vision in Myasthenics - Dr. Paul Donohue, Your Good Health

The eyes view objects form a slightly different position. To fuse the images they get into a single picture the six eye muscles of each eye and the three nerves that control them have to align the eyes in exact positions. If one or more muscles or one or more nerves are out of whack, people see two images. Diabetes, high blood pressure, small strokes, multiple sclerosis and myasthenia gravis are the major causes of double vision. A less-serious cause is a temporary disruption of blood supply to one of the eye nerves or eye muscles. In that instance, the visual disturbances clears in a matter of weeks or months.

Questions and Answers: John G. Quinlan MD University of Cincinnati

Thymectomy & Nutritional Therapy

**Question:** Is it true that nutritional therapy doesn’t work for patients who have done thymectomy? and is it okay to have nutritional therapy along with prednisone 3.5? 

**Answer:** We are unable to find any reliable study in the peer viewed scientific literature showing that nutritional therapy works in patients with Myasthenia Gravis. Mind you, it is important that patients who have difficulty swallowing maintain good nutrition, and there are a few reports on how to address this problem. Prednisone can cause problems in terms of a person’s overall nutritional status. There are a number of specific dietary steps that one would need to take when on prednisone. Chief among these is to take steps to avoid excessive weight gain which in turn leads to an increase in the risk for diabetes. You should discuss the specific – calorie counting, food selection and ways of monitoring your weight with your doctor. Depending on other medical conditions the advice may change from one patient to another – much like the symptoms of Myasthenia!
The Gods must love charity runs! Because again this year, we were blessed with blue skies and balmy weather. Trevor Harris and his Spirit Runners reminded us again about the value of commitment to a cause and we reaped the benefits. Jim Harris, Trevor’s dad, cheered his daughter and grandchildren through the 5k finish line as well as keeping the enthusiasm going for Tony Van Oort. It isn’t only the fund raising that we appreciate but also the personal time sacrificed to train for the run and then making that early, very early, morning trip to the start line.

Once again throughout June, we are celebrating MYASTHENIA GRAVIS AWARENESS MONTH. So set your alarms on Sunday, June 23rd, and come out to support our runners, walkers or volunteer! Join the fun and cheering section at the Finish Line in Stanley Park by the tennis courts.

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

Telus Answers Your Call!

TELUS recognizes and rewards the community volunteer work of team members and retirees through the Dollars for Doers program. Once an individual has recorded a minimum of 50 hours of volunteer service in a year they are able to direct a $200 grant to the registered Canadian charity or non-profit sports organization of their choice.

In 2012, TELUS team members, retirees and Community Ambassadors volunteered a total of 568,000 hours. In recognition of the team members and retirees who participated, TELUS donated $660,000 to Canadian charities. Since 2000, the TELUS team has volunteered over 4.8 million hours. For more information, please call 1-855-697-8183.
“WHERE DID THE WHOLE SNOWFLAKE THING COME FROM?” you might be wondering...well...

A number of years ago, 2002 to be exact, “Grammy Bev”, a long time member of a MG internet group, crafted snowflakes as get-well gifts for her MG friends. The idea spread and soon Snowflakes were being made and sent around the world to ill and hospitalized group members.

Why a snowflake? Because each snowflake is unique - as are the symptoms that differ from one MG patient to another. Each snowflake is fragile - fragility and weakness are classic MG symptoms. A group of snowflakes has the power of a blizzard, as each MG patient, support group and association has the combined strength of its members.

This is our new banner!

Ask us about the “Snowflake Disease”

Volunteers Needed for New BELIMUMAB Study at UBC with Dr. Oger

Dr. Oger is currently recruiting candidates for a trial on a potentially new drug for Myasthenia Gravis treatment. The study we are hoping to undertake is a randomized, placebo controlled, double blind study to evaluate the efficiency, safely, tolerability and pharmacodynamics of “BELIMUMAB” in subjects with generalized myasthenia gravis. If you are chosen to take part in this study, you will have to go to the Clinic at UBC Hospital for intravenous infusion one day a month for 6 months. If you are interested in participating, please contact the MG office. We can send you the study requirements by either mail or email or you may contact Sarah at Dr Ogers offices at 778-899-1983 directly.
SIMPLY CLEAR: You will feel better!

For those of us who suffer from terrible stomach cramps and/or diarrhea due to a Mestinon prescription, we have recently heard of a new product called “Simply Clear” made by Metamucil. “Simply Clear” is a sugar free, tasteless powder you add to any liquid to help with “what ails you”! The dosage is 1 tsp to 8 ounces or 1 cup of fluid - you can take it up to 4 times/day. Those who have tried “Simply Clear”, state that it has cut down on bowel difficulties dramatically. It is currently available at Walmart in Canada but may also be available at your local pharmacy and or healthfood store or chain. We have not found it available at either London Drugs, Shoppers Drug Mart or Costco. Many thanks to Dr. Otto Huhn and Mrs Jane Bryans for this great tip!

“BLACK BOX” Warning for Cipro (ciprofloxacin) and Avelox (moxifloxacin)

The Food & Drug Administration (FDA) has place the following boxed warning on the product labeling for the above mentioned drugs:

**Warning:** Fluoroquinolones, including AVELOX/CIPRO may exacerbate muscle weakness in persons with myasthenia gravis. Avoid AVELOX/CIPRO in patients with MG. The warning section in the product labeling within each package goes on to say: Exacerbation of Myasthenia Gravis: Fluoroquinolones, including CIPRO, have neuromuscular blocking activity and may exacerbate muscle weakness in persons with MG. Postmarketing serious adverse events, including death and requirements for ventilatory support, have been associated with fluoroquinolone use in persons with MG. Avoid CIPRO in patients with known history of MG.

Another antibiotic with a specific warning for MG is KETEK (telithromycin) which has also been associated with sometimes fatal worsening of MG.
Encouraged in part by drug marketing, more middle-aged people are getting bone-density tests and taking bone bolstering drugs for osteopenia - bone density that's somewhat low but not considered osteoporosis. Osteopenia is now referred to as low bone density and a calculator known as FRAX, developed by the World Health Organization, is available on-line to estimate fracture risk. It’s helpful in targeting treatment to those who will benefit from it, and away from those at lower risks.

WHO HAS IT?: A T-score (the result of a bone-density test) of minus 2.5 or worse indicates osteoporosis; a score ranging from minus 1 through minus 2.4 is now called low bone density. But the normal range in healthy 30-year-old women is from minus 2 to plus 2, so scores between minus 1 and minus 2 are technically normal.

HOW SERIOUS IS IT?: The risk of fracture depends on how close you are to the cutoff for osteoporosis and how rapidly you are losing bone. Bone loss accelerates during menopause and then slows down. But many factors speed bone loss, including smoking, heavy alcohol consumption, the use or oral steroids and rheumatoid arthritis. FRAX takes these and other risk factors into account.

HOW TO REDUCE YOUR RISK: Get plenty of calcium and vitamin D, do weight-bearing exercises such as walking and muscle strengthening exercises, don’t smoke, limit alcohol, sodium and caffeine and make your home fall proof.

HOW TO AVOID OVERTREATMENT: Women should have a bone-density test at age 65, men at age 70. You or your doctor can enter your information at www.shef.ac.uk/frax. Drug treatment is generally recommended for those with low bone density plus either a 3 percent or more risk of a hip fracture or a 20 percent or more risk of any major fracture in the next 10 years, as calculated by FRAX.

Nutrition for Healthy Bones (for adults with or at risk for Osteoporosis)

Literature containing information regarding how important calcium is as a mineral for the bones, how much calcium do you need, how do you make sure you are getting enough, as well as how much calcium is available in package foods etc, is readily available on the websites www: bc.womens.ca, or as a printout which can be sent from our office.

Topics covered include:

Vitamin D allows calcium to be taken to the bone.

How much Vitamin D do I need?

How do I make sure I am getting enough Vitamin D?

Foods and supplements Sources of Vitamin D.

Are other nutrients useful in treating osteoporosis?

Are there things I should do beyond getting adequate nutrients for my bones?
This article was originally published in Conquer, November 2008. At recent support group meetings and our educational meetings, MG patients have asked about muscle cramps, so we are publishing the article again with additional information about potassium and calcium. Muscle cramps seem to be a common problem among MG patients. Muscles require calcium, potassium and sodium to work properly. For relief of muscle cramps you might try the follow solutions, but check with your doctor first.

**Calcium**- Dictum dicalcium phosphate tablets crushed between your teeth before swallowing usually works in 10 to 15 minutes. Calcium carbonate aka Tums also helps prevent cramps. It is absorbed much slower than dicalcuim phosphate and is more useful as preventative. It is also a very good antacid and does not contain magnesium which many antacids contain. Potassium – It is important to have adequate potassium to prevent muscle problems. Too much can also cause muscles cramps. That is why most potassium tablets, capsules and liquids require a prescription. Potassium can also irritate the stomach. It is much better to get this mineral from potassium rich foods such as white beans, dark leafy greens, potatoes, dried apricots, acorn squash, yogurt (plain skim non-fat), fish, avocados, mushrooms and bananas.

**Salt** – An adequate amount of salt (sodium chloride) is needed to prevent muscle cramps as well. An MG patient shouldn’t go on a low-salt diet unless specifically recommended by his or her doctor. Of course, most canned and prepared foods have a high sodium content, so it is better to use the salt shaker sparingly. MG patients who are certain they do not have high blood pressure (or other prohibitive conditions) can usually relieve muscle cramps by eating a salty snack, such as pretzels. It is particularly important for MG patients to have the proper amount of calcium, potassium and sodium in their blood. Anytime you have a blood test done, ask your doctor for a copy of the lab report. It will show the amount of calcium, potassium and sodium as well as other things in your blood. It also shows the normal range for each.

Do not use over the counter preparations for muscle cramps, as these may contain quinine which can cause myasthenic muscles to stop working. Overuse of weak muscles will cause muscle cramps. Levels of activity you can tolerate reasonably will help keep your muscles in good condition.

*Note: In a Q&A article from the website, www.netwellness.org. Vitamin deficiency or hypothyroidism are also listed as possible causes of muscle cramps and should be considered if you have MG. Dehydration and low magnesium are also listed as possible causes of muscular cramping.*
Overcoming Exercise Hurdles

Our bodies are built for physical activity. Movement and regular exertion can trigger healthful changes in almost every cell type, tissue and organ system. Going without exercise contributes to a long list of health problems, especially during and after middle age. Yet most adults don’t get the minimum amount of aerobic exercise recommended by health and fitness experts and government guidelines. They suggest the equivalent of 30 minutes of moderate exercise, such as brisk walking or 15 minutes of more vigorous exercise, such as jogging or swimming, five days a week as well as two sessions of strength training to build muscle.

One reason we don’t exercise might be we feel it is a daunting task, especially if you are older or have chronic health conditions. Here are some easy steps to help get you started.

**Excuse # 1 - I NEVER HAVE ENOUGH TIME**

Slightly more than half of the unsuccessful exercisers surveyed blamed lack of time for preventing them from exercising. Successful exercisers, on the other hand, make exercise a priority.

An easy way to begin is by making everyday routines more physically challenging. For instance, try walking to work or the grocery store, even if it is part way. If that is too much, try moving your parking space farther away from your destination. How about one flight of stairs instead of an elevator to the top?

A few bouts of moderate exercise can be as beneficial as one LOOOOONG one! So without having to take out time for 30 minutes on the treadmill or exercise bike, you can get a similar benefit from walking 10 minutes before and after work, or to and from the grocery store. If want to join a gym for motivation, join one close to your home or workplace to minimize travel time. You can even try to set something up at home with a few light weights, therabands and DVDs.

**Excuse # 2 - I’M TOO OLD TO START NOW**

Really, if someone told you, you were too old to do something you wanted to do, they had probably better duck! (Hey, that’s called a right jab and guess what? It’s exercise!) It is never too late to start ANYTHING, including achieving aerobic fitness or gaining more muscle strength. Studies show that inactive men who started exercising as late as age 50 achieved survival rates comparable to men who had been active for much longer. No matter how old you are, or what gender, your muscles will respond quickly to training. Both men and women in their 80s and older who started resistance training in clinical studies gained strength as rapidly as younger adults.

Even for moderate physical activity, if you have been sedentary for awhile, you should consult your physician.

**Excuse # 3 - MY HEALTH ISN’T GOOD ENOUGH**

Now, that’s just crazy talk! Exercise is a proven treatment for diabetes, depression, high blood pressure, osteoporosis, peripheral vascular disease and other problems that may be common to aging. Many frail, chronically ill people and their caregivers assume incorrectly that exercise isn’t safe. But only a handful of health problems make exercise out of the question, such as retinal detachments, spinal instability, recent heart attack and extremely advanced heart failure.
Donations as of March 2013 and since last publication:

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In Memory of:

Jean Winslade and Norm Olenick - IMO Donald Robertson
Tammy Gerrior - IMO Jeannie Armitage
Stephen Olliver - IMO Janet Olliver
James Cogg - IMO a friend with Myasthenia Gravis

CORPORATE: Thompson Nicola Caribou UNITED WAY. The Provincial Employees CSF

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

Myasthenia Gravis Association of B.C - In Memory of Fred Taylor, Brenda Kelsey (monthly donation)

Donations are current as of March 12, 2013. We apologize for any errors or omissions. These do not include ScotiaCharity Challenge pledges due to space limitations.
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 (IVlg) 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.
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.

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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.