

MG NEWSLETTER



[Myasthenia Gravis Association of British Columbia](#)

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E-mail: mgabc@centreforability.bc.ca • Web site: www.myastheniagravis.ca

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 10th 2011 at 1:30 pm**

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

AGM: Elections for Board of Directors.

If you are interested in becoming a Board Member, please call either Brenda or Linda
at 778-329-0696 Ext. 4

Speaker: Professor Chloe G. K. Atkins

Chloe Atkins is an Associate Professor in the Department of Commuciation and Culture, Law and Society Program at the University of Calgary and a Myasthenic. She is also the author of *My Imaginary Illness - A Journey into Uncertainty and Prejudice in Medical Diagnosis*.

Topic: "A Patient's Perspective on Professional (Physician) Peer Pressure and the Psychologizing of Disease".

Prof Atkins will have copies of her book available for sale at the meeting. See page 5 for Brenda Kelsey's review.

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 778-329-0696 Ext. 4
or email: mgabc@centreforability.bc.ca

June is MG Awareness Month AGAIN!

To celebrate **MG Awareness Month**, the Myasthenia Gravis Association is again asking patients, friends and family to participate in the **Scotia Bank Group Charity Challenge**. Myasthenia Gravis is a designated charity this year, with a new logo and the opportunity to collect pledges on-line. We have also 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 Talecris Biotherapeutics

MG NEWSLETTER

ANNUAL REPORT of the MYASTHENIA GRAVIS ASSOCIATION of British Columbia 2011

*“Mya...what? “
“Myasthenia Gravis!”
“I’ve never heard of it. What is it?”*

How many times have we heard this comment when we tell people about the rare and interesting disease we all share? The Myasthenia Gravis Association of BC is working very hard to make health professionals and the general public more aware of Myasthenia Gravis.

In 2010, the Provincial Government declared June would be Myasthenia Gravis Awareness month. To highlight this proclamation, we encouraged members and their friends and family to take part in the Scotia Bank Group Charity Challenge on June 27th raising pledge dollars and bringing additional awareness to our association. Lara Rose Duong and many of her friends raised money and walked and ran in Kamloops. Jim Harris, his son Trevor and Trevor’s running group, as well as Jim’s daughter Valerie Fair raised over \$ 8000.00!! These included pledges from the running teams as well as pledge solicitation from family and friends. We are very grateful to all for their efforts.

There were two very successful support group meetings in 2010. In the spring, Len Kelsey spoke at our AGM addressing the need for not only myasthenics but everyone to be prepared for a medical emergency at home and when travelling abroad. Many important topics were covered and everyone felt they learned valuable tips. At our fall meeting, Dr Michelle Mezei from the Neuromuscular Disease Clinic at VGH presented a lecture on “Myasthenia Gravis – Medication and More”. Both meetings stimulated a lively discussion and many questions.

The MGABC was sorry to hear that Judy Wilson, the clinical nurse at the Neuromuscular Disease Unit was leaving in order to work full time at the Heart and Stroke Clinic at St. Paul’s Hospital. We all appreciated Judy’s dedication to our cause and her hard work and wish her well in her new position. The clinical nurse position has since been filled by Cate Tadey, RN. We look forward to working with Cate and continuing our excellent relationships with the doctors of the NMD Unit.

We must also note the very sad passing of Ron Grisdale, a long standing active MG member and member of our Board of Directors. We miss him.

We were proud this year to be able to continue to support Dr. Oger in his research projects, both financially and in the Genome Study at UBC in which many of us participated as research subjects. Dr. Oger’s MG research projects are part of an international group and we are happy to not only support him but also to be aiding MG researchers all over the world.

The Myasthenia Gravis Association of BC is very grateful to Dr Benjamin Patchell and Talecris Biotherapeutics for their unrestricted education grants for our meetings and newsletter publication. We are also grateful to the Province of BC for their ongoing support for access to charitable gaming. Angie Kwok director of CFA and her staff have been unfailing in their cheerful assistance throughout the year.

On a personal note, I could not do this job without the assistance of Linda Briggs and Barb McDonald. Both are amazing fun in the office and are dedicated to the MGABC! Thanks Ladies!! Also your Board of Directors are a great group of people and equally dedicated to the association, and I appreciate all of them for their time and support.

Thanks also to Dr. Gillian Gibson's team at the Neuromuscular Disease Unit. They are there for all of us whenever we need them. We look forward to another year of growth within the organization, the furthering of our cause publicly, and continued support from all of our members and their families by their membership fees, their generous donations and their attendance at bi-annual meetings.

Respectfully submitted,

Brenda Kelsey

Brenda Kelsey
President



The SEGWAYE Program



Are you 18 - 25 years old with a neurological diagnosis?

Do you want to:

- ✓ Discover the right job for you?
- ✓ Learn the skills you need?



Contact us for:

- ✓ Information and Resources
- ✓ Referrals
- ✓ Services at no cost



604-630-3034
www.centreforability.bc.ca

Remember!...

...if you would like to become a member of the Board, please contact **Brenda Kelsey** by phone at **778-329-0696** ext. 4 or by e-mail at **mgabc@centreforability.bc.ca** Brenda will be happy to tell you of the duties of members, how often they meet, and the duration of their tenure.

MG NEWSLETTER

From the MG Network...The World Wide Web and all it offers.

Course and treatment of Myasthenia Gravis during pregnancy

Pregnancy and family planning issues are frequent concerns in the medical care of patients with myasthenia gravis since disease onset often coincides with the life period which is decisive in this respect. Although pregnancy, delivery and breast feeding represent special circumstances in these patients, they are not associated with higher risks of complications compared to normal pregnancy, delivery and postpartum period. Frequently asked questions regarding the course of pregnancy as well as the impact of the disease and particularly medical treatment on pregnancy and the fetus or neonate. Great significance is attached to the mode of delivery since it is still widely accepted that patients with myasthenia gravis have to deliver per elective caesarean section. This paper gives an overview and provides a basis for the medical care and individual counseling of patients with myasthenia gravis who want to start a family or are already pregnant.



Pregnancy and Childbirth with Neuromuscular Diseases

In the summer edition of Quest Magazine, Summer July-August 2010, Margaret Whal, Amy Labbe and Miriam Davidson wrote an article examining the subject of pregnancy and childbirth with neuromuscular diseases from a medical point of view. Personal stories from women with varying types of neuromuscular diseases, a chart of disease-specific complications and advice were included. Here is an excerpt:

“ Having a baby can be the most thrilling and rewarding experience of a woman’s life, yet it can also be fraught with fear and uncertainty. This is especially true for women with Neuromuscular Diseases. This special report takes a look at the issues that arise for expectant mothers with muscle disease and find that, with proper care and planning, these women are usually - although not always - able to have successful pregnancies and give birth to healthy children”

The article in its totality may be read online at quest.mda.org. There is also a printable PDF version available. If you do not have access to a computer, you may call the MDA offices at (218) 727-3466 or (952) 832-5517 and request a copy to be mailed to you.

MASELLI RECEIVES 1.6 MILLION GRANT TO STUDY COMPLEX NEUROMUSCULAR DISORDER

(SACRAMENTO, CA) – UC Davis School of Medicine Professor of Neurology Ricardo Maselli has received a five year, \$1.6 million grant from the National Institute of Neurological Disorder and Stroke to study congenital myasthenic syndromes (CMS). These inherited disorders, which result from impaired transmission of electrical signals through the neuromuscular junction, can cause profound and sometimes life-threatening muscle weakness. Maselli will study the molecular basis of the various forms of CMS to develop targeted treatments for these conditions. In contrast with acquired myasthenia gravis, autoimmunity is not involved in the pathogenesis of CMS, therefore immunosuppressive therapy plays no role in its treatments. Maselli's laboratory is using high-throughput techniques of DNA sequencing based on microchip technology and is focusing on fundamental signal-transduction pathways actively in the development and maintenance of the neuromuscular junction. His laboratory for the first time recently identified a linkage between CMS and a rare genetic disorder causing renal dysfunction. He also is testing the in-vitro effects of a new type of medication for congenital myasthenia.

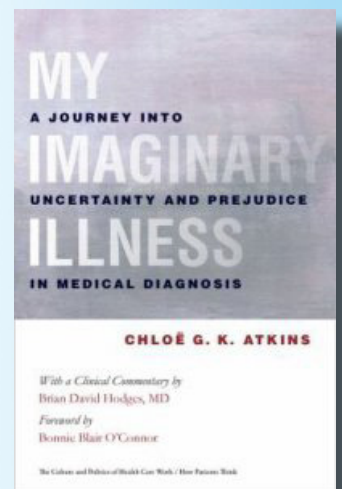
The UC Davis School of Medicine is among the nation's leading medical schools, recognized for its research and primary-care programs. The school offers fully accredited master's degree programs in public health and in informatics, and its combined MD – PhD program is training the next generation of physician-scientist to conduct high impact research and translate discoveries into better clinical care. Along with being a recognized leader in medical research, the school is committed to serving underserved communities and advancing rural health.

Reprinted with permission: MG Ontario Newsletter, August 2010

BOOK REVIEW by Brenda Kelsey

***My Imaginary Illness - A Journey into Uncertainty and Prejudice in Medical Diagnosis* by Chloe G.K. Atkins**

When she was 21, Chloe Atkins began displaying symptoms of a mysterious illness. Certain treatments were tried and when none worked, she was told her illness was psychosomatic. This book is about a 10 year journey of emotional and physical patient mismanagement prior to her diagnosis of Myasthenia Gravis. Dr Atkins investigates how the medical establishment applies psychological stereotypes to illnesses it is yet unable to explain. I highly recommend this book for MG patients and health professionals, especially medical students and resident doctors and nurses. It is extremely well written with many insights into Myasthenia Gravis.



See the Literature list on page 11 to order your copy.

* You may also listen to Chloe's interview on CBC's *The Current* at [CBC_The_Current_Chloe_Atkins_Oct_5_2010.mp3](#)

MG NEWSLETTER

Questions about the Shingles Vaccine



Is there a vaccine to prevent shingles?

Yes. The Center for Disease Control recommends Zostavax for use in people 60 years and older to prevent shingles. This is a one-time vaccination. Zostavax does not treat shingles or post-herpetic neuralgia (pain after the rash is gone) once it develops.

Is the vaccine safe?

The FDA has licensed the vaccine as safe. The vaccine has been tested in about 20,000 people aged 60 years and older. The most common side effects in people who got the vaccine were redness, soreness, swelling or itching at the shot site and headaches. The Center for Disease Control, working with the FDA, will continue to monitor the safety of the vaccine after it is in general use.

The shingles vaccine is made of a weakened form of the chickenpox virus. Can a person who has received the vaccine infect others with this virus?

No. It is safe to be around infants and young children, pregnant women, or people with weakened immune systems after you get the shingles vaccine. Transmission of the chickenpox virus from a person who has received the shingles vaccine has never been documented.

Some people who get the shingles vaccine will develop a chickenpox like rash near the place where they were vaccinated. As a precaution, this rash should be covered until it disappears. How effective is the shingles vaccine?

In a clinical trial involving thousands of adults 60 years and older, Zostavax reduced the risk of shingles by about half (51%) and the risk of post-herpetic neuralgia by 67%. While the vaccine was most effective in people 60-90 years old it also provided some protection for other groups.

How long does the vaccine last?

Researchers suggest that the shingles vaccine is effective for at least six years, but may last much longer. Ongoing studies are being conducted to determine exactly how long the vaccine protects against shingles.

Who should NOT get the vaccine?

- ✓ People who have had life-threatening allergic reaction to gelatin or the antibiotic neomycin.
- ✓ People who have a severe allergy to any component of the vaccine.
- ✓ People with a weakened immune system as a result of leukemia, lymphoma or any other blood or bone cancer.
- ✓ People with HIV/AIDS who have T-cell counts below 200.
- ✓ People being treated with drugs that affect the immune system, including high-dose steroids.

Decisions about vaccines or any medications should be discussed with your health care provider, who is well informed about your MG.

How we got involved with the ScotiaBank Group Charity Challenge

In the last two years you have received pledge requests for MG patient Kathy Geremia as she ran in support of and to bring awareness to Myasthenia Gravis. Kathy's goals were small at first, running in 2002 in a local race she organized herself in Port Moody. Many of you were there cheering her on. Local celebrityism wasn't enough for Kathy though, and she set her sites on conquering the Big City and running in the 2008 ScotiaBank Group Charity Challenge. Kathy came to us for help and again members and friends pledged their dollars and support! In 2010, Kathy was not feeling well enough to run but the baton was passed and Trevor Harris, son of patient Jim Harris in Vancouver, and Lara Rose Duong, in Kamloops both ran.

In Kamloops, Lara Rose and her friends and family started a running group and collected pledges for MG. Jim's son Trevor and his running group in Vancouver, who were already registered for the race, also made fund raising for the event their ultimate goal. Jim's daughter Valerie Fair also garnered support for the cause by fundraising. In total the family raised over \$8,000.00, while Lara Rose's group raised over \$ 800.00.

MGABC was not however a recognized charity for the event and we were unable to raise funds on-line on the run web site or advertise. This year, thanks to the generosity of Jim Harris, the Myasthenia Gravis Association of B.C. is a registered charity for the event. The registration fee of \$ 600.00 which Jim paid himself (thank you again Jim!) comes with more benefits than just on-line fund raising capabilities and visibility; we also have available 10 registration packages free of charge. If there are any other runners out there who would like to raise funds and run on our behalf, please let us know.



While Jim was busy emailing and meeting with the run organizers, we had a logo contest to come up with an image that would be associated with myasthenia gravis.

The winning logo featured, is by Tony Van Oort, husband of MG patient, Jantine. Their winning entry earns them a day on the water aboard the MV Menoken, guests of Len and Brenda Kelsey.

It goes without saying, we all owe Jim a great debt for his commitment, time and financial assistance. I hope you will all respond in kind, with pledges – either mailed to the office with the enclosed form or on-line at <http://www.canadarunningseries.com/svhm/svhmCHARITY.htm>, where you are able to use credit cards.

Thank you again for all of your ongoing support and to those who are 'hitting the pavement' on June 26th Good Luck!!



Best wishes to you and your family during the Easter Season!

MG NEWSLETTER

Good News about Chocolate

Finally there is a good excuse to indulge in a much-loved treat! The “chocolate cure” for emotional stress is now getting new support from a clinical trial published online in ACS’ Journal of Proteome Research. It found that eating about an ounce and a half of dark chocolate a day for two weeks reduced levels of stress hormones in the bodies of people feeling highly stressed. This favorite treat also partially corrected other stress related biochemical imbalances.



In the study scientists identified reductions in stress hormones and other stress-related biochemical agents in volunteers who rated themselves as highly stressed and ate 1.4 oz of dark chocolate for two weeks. “The study provides strong evidence that a daily consumption of 40 grams [1.4 ounces] during a period of 2 weeks is sufficient to modify the metabolism of healthy human volunteers.” the scientists say.

in dark chocolate may reduce risk factors for heart disease and other physical conditions. Studies also suggest that dark chocolate may ease emotional stress. Until now, however, there was little evidence from research in humans on exactly how it might have those stress-busting effects.

Sunil Kochhar and colleagues note growing scientific evidence that antioxidants and other beneficial substances

Medical News Today

Article URL:<http://www.medicalnewstoday.com/articles/176940.php>

We remember with fondness and are saddened by their passing.
Rod Osborne and Dr. E.A. (Ted) Trites
in February, 2011.



Autoimmune Disease Defined

We know that MG is an autoimmune disease or disorder, Following is a brief explanation of autoimmunity and theories about its causes.

AUTOIMMUNE DISORDERS

An autoimmune disorder is a condition that occurs when the immune system mistakenly attacks and destroys healthy body tissue. There are more than 80 different types of autoimmune disorders.

CAUSES

Normally the immune system's army of white blood cells helps protect the body from harmful substances called antigens. Examples of antigens include bacteria, viruses, toxins, cancer cells and blood or tissues from another person or species. The immune system produces antibodies that destroy these harmful substances.

But in patients with an autoimmune disorder, the immune system can't tell the difference between healthy body tissue and antigens. The result is an immune response that attacks normal body tissues. This response is a hypersensitive reaction similar to the response in allergies. In allergies, the immune system reacts to an external substance that it normally would ignore. With autoimmune disorders, the immune system reacts to normal body tissues. What causes the immune system to no longer tell the difference between healthy body tissue and antigens is unknown. One theory is that some microorganisms (such as bacteria) and drugs may trigger some of these changes, especially in people who have genes that make them more likely to get autoimmune disorders.

Source: Medline Plus - A Service of the U.S. National Library of Health and NIH

Does having One Autoimmune Disease Lead to Another ?

Disorders of an autoimmune nature are known to occur with increased frequency in patients with another autoimmune disease. About 25 percent of patients with autoimmune diseases have a tendency to develop additional autoimmune disorders.

Source: http://autoimmunedisease.suite101.com/article.cfm/multiple_autoimmune_syndrome

Suite 101.com Media Inc is a private Canadian company based in Vancouver, BC with offices in Berlin and an international staff of 30.

To you, insane world, I have but one reply: I refuse.

Marina Tsvetaeva

Mary Gilholme	Jack & Debbie Munro	Rod Osborne
Jantine Van Oort	Shoki Shamasdin	Yvonne Elliott
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Gayle Wilson	Lois Nagai	Ray Humphries
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Ellie Yang	Maybelle Morrison	Olive Worsfold
Klaus Irmiler	Thelma Abma	Edward Gore
Barbara Thomas	Marsha Tillman	Nancy Luevekamp
The Brown Family	Dawn Hogbin	Michael Shirley
Rikkert Vos	Fred& Irene Taylor	Linda Stafford
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George Lopushinsky	Doug Boyd	Laurie Templeton
Marsha Tillman	John Skalos	John Gianoli
Ken Moore	Marie L Paterson	Wilikee Van Linden Tol
RC Douglas		

In Memory Of

Heather Windrum: Catherine Ireland, Triana Newton, Herman & Hulda Klassen, Ed & Betty Wilson, Wendy Aguire

Janet Olliver: Stephen Olliver

Jeannie Armitage: Tammy Gerrior

The Estate of Dorothy Siira

Joyce Robertson: Jean Winslade

CORPORATE

Thompson Nicola Cariboo United Way

TELUS Cares: Dollars for Donors

Norm & Doris Taylor, Rose Hare

RESEARCH Donations

Brenda Kelsey – monthly auto debit plan.

Nicole Tessier, The Regina MG Support Group/Theresa Persson

The Myasthenia Gravis Association of BC.

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.)
- **My Imaginary Illness - A Journey into Uncertainty and Prejudice in Medical Diagnosis** by Dr Chloe G.K. Atkins

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 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 ***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.