The Myasthenia Gravis Association of BC

SUPPORT GROUP MEETING 2010

The Myasthenia Gravis Association of BC
cordially invites you to attend

THE Fall 2010 Support Group Meeting
When: Sunday, October 24th, 2010 @ 1:30 pm
Where: Legacy Room, Centre for Ability, 2805 Kingsway, Vancouver

Topic: MG Medication and More
Dr. Michelle Mezei MDCM FRCPC
Neuromuscular Disease Unit
UBC Division of Neurology

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

2011 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 bi-annual newsletter, free information pamphlets, notification of special programs of interest to Myasthenics, as well as support group meetings with speakers and staff members willing to support when called upon. Memberships renewed after September 30th, will be good for the coming year.

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

Articles contained in this newsletter are for information only. The MG Association of BC does not give medical advice. In matters of medical treatment, patients should consult their physicians.

*Newsletter and meeting supported by an unrestricted educational grant from Talecris Biotherapeutics
Two recent randomized, controlled trials failed to demonstrate a benefit of mycophenolate mofetil (MMF) over prednisone in the treatment of myasthenia gravis (MG). We reviewed our experience with MMF in MG to determine whether these trials may have been unsuccessful because of their short duration and the unpredicated benefit of prednisone. We reviewed outcomes and prednisone dosage for all our acetylcholine-receptor (AChR) antibody positive MG patients treated with MMF alone or with prednisone for at least three months. The percentage of patients with a desirable outcome (MG-specific Manual Muscle Muscle Test score <4 or Myasthenia Gravis Foundation of America post-invention status of minimal manifestations or better) began to increase after six months; 80% of those using MMG and followed for more than 24 months had a desirable outcome. For this group, prednisone dose decreased after 12 months; after 25 months, 54.5% of patients took no prednisone and 75% took less than 7.5 mg/day. This retrospective analysis provides class IV evidence that MMF begins to improve AChR-positive MG after six months, both with prednisone and as monotherapy.

Immunosuppression is the mainstay of treatment for myasthenia gravis (MG). In this paper, we review the mechanisms of action and clinical application of corticosteroids and different classes of immunosuppressive drugs that are currently used in MG patients, and presents the results of their use in more than 1000 patients with MG seen at our two center. Immunosuppressive treatment was considered along with, or as an alternative to thymectomy in MG patients with disabling weakness, not adequately controlled with anticholinesterase drugs. Overall 82% of our patients received immunosuppressants for at least 1 year, with frequencies varying according to disease severity, form 93 – 95% of those with thymoma or MUSk antibodies to 72% in ocular myasthenia. Prednisone was used in the great majority of patients, azathioprine was the first-choice immunosuppressant; mycophenolate mofetil and cyclosporine were used as second-choice agents. All clinical forms of Mg benefitted from immunosuppression: the rate of remission or minimal manifestations ranged from 85% in ocular myasthenia to 47% in thymoma-associated disease. Treatment was ultimately withdrawn in nearly 20% of anti-AChR positive early-onset patient, but in only 7 % of thymoma cases. The risk of complications appears to depend on drug dosage, treatment duration, and patient characteristics, the highest rate of serious side effects (20%) having been found in late-onset MG and the lowest (4%) in early-on-set disease. Although nonspecific, current immunosuppressive treatment is highly effective in most MG patients. Lack of randomized evidence, the need for prolonged administration, and unwanted effects are still relevant limitations to its use.
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Fall/Winter 2010

Remember!...

...if you would like to become a member of the Board,

contact Brenda Kelsey by phone at 778-329-0696 ext. 4
or e-mail to 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.
Myasthenia Gravis Foundation of America
PODCASTS Series

Podcasts are replacing CDs and DVDs in order to share information in a more time and cost effective way. A podcast is a program (music or talk) made available in digital format for automatic download over the internet to your home computer.

Dr. Ted Burns from the University of Virginia is producing a series of patient oriented podcasts for the MGFA with information on the diagnosis, treatment and management of MG through the MGFA website. You may listen to the podcasts at:

http://www.myastheniagravis.org/podcasts.cfm

1. What the patient and the caregiver should know about prescription drugs and MG

The participants discuss the use and management of drugs used for other conditions in the context of a diagnosis of MG. They discuss which drugs are best to avoid, if possible, and offer advice on how patients and families can work with clinicians to navigate through the list of potentially dangerous drugs.

2. A brief overview of Myasthenia Gravis, Part I - Clinical Manifestations and Diagnosis of MG

Dr Burn’s talks with Drs Saunders and Pascuzzi discussing the common presenting symptoms of MG, what symptoms should be of most concern to the patient and their family, how the diagnosis is made.

3. A brief overview of Myasthenia Gravis, Part II – Review of the cause of MG, the treatments and a discussion about MG and vaccines

The participants review the cause of MG (autoimmune) and briefly introduce the topic of treatments and the safety of vaccines for patients with MG. A later podcast will discuss this in more detail.

We encourage you to listen to these podcasts if you can, and to inform your primary care doctor, neurologist and nurse about them as well.

Influenza vaccination has been associated with adverse events including Guillain-Barre syndrome. Because the safety of influenza vaccination in patients with myasthenia gravis (MG) has not been established, some clinicians discourage vaccination for these patients. We explore whether the administration of influenza vaccine to patients with MG might increase the risk of myasthenic crisis. Using population-based healthcare data from Ontario, Canada from 1992 – 2007, we utilized the self-matched, case-series method of detecting events following vaccination. We studied patients with myasthenia who were hospitalized for MG within 42 weeks of influenza vaccination. We defined the primary risk interval as the 6 weeks following vaccination. Between January 1, 1992 and March 31, 2006, we identified 3667 hospital admission for MG. No seasonal trend in MG admissions was evident. In 513 instances, hospitalization occurred within 42 weeks following vaccination in patients previously diagnosed with MG. Among these patients 266 (52%) were men. The median age was 74 years and 86 (17%) had previously undergone thymectomy. The estimated relative incidence of admission for MG in the primary risk interval compared with the control interval was 90.84 (95% confidence interval 0>65 – 1.09). We found similar results in stratified analyses according to gender, age and thymectomy status. Vaccination of patients with MG against influenza was not found to be associated with exacerbations of the disease.

Our findings do not support the practice of withholding influenza vaccination in patients with MG.

MG RESEARCH - * These items are summaries (or abstracts) of professional research studies relating to Myasthenia Gravis. They are for your information only and the intention is to keep patients and provides up to date with current MG research*
How to Best Prepare for IVIG Treatment OR “What the Doctors and Nurses won’t tell you but you need to know about Immune Globulin”

By Jen Walsh*

I have a love/hate relationship with IVIG. I love that it has keep me out of the hospital, preserved my muscles that allow me to breathe, and those that I use to swallow. I hate that it takes six hours to infuse every two weeks and that it doesn’t always work consistently to manage my other symptoms. I also hate the cost, but love the donors who makes it possible for me to receive this saving treatment.

I have an autoimmune neuromuscular disorder called Myasthenia Gravis which takes away my ability to open my eyes, walk or grip things at it’s mildest and can literally cause my diaphragm to stop working at it’s worst. Fortunately there are treatments, but there is no cure. And so, my physician team decided that I would be a good candidate for IVIG. Some other diseases that IVIG treats include, but are limited to, Multiple Sclerosis, Kawasaki Syndrome, Primary and Secondary Immunodeficiency Syndromes.

This is my guide for new patients undergoing IVIG Treatment – or those who don’t feel their treatment is going so well. I have been receiving IVIG since December 2009 and my current protocol is every two weeks.

• Hydrate, Hydrate, Hydrate – I don’t care if you don’t drink water, this is a MUST! You must start hydrating at least 48 hours prior to infusion and for the following 48 hours, not to mention during the procedure. If you are not well hydrated you are increasing your risk for blood clots, aseptic meningitis (aka the world’s most excruciatingly painful headache) and an extreme feeling of flu.

• Take Benadryl and Tylenol – Most doctors will order this in what they call “pre-meds’. Ask your nurse first so you don’t double dose. If you aren’t getting it in your IV, make sure to take it by mouth. The Benadryl gives you a better chance of not having an allergic reaction which can set off the immune response thus rendering the whole treatment useless. The Tylenol will reduce the achy, flu like feeling as your body processes the high volume of healthy donor immune cells.

• Get a good night’s sleep before and after - Anyone with an autoimmune disorder knows a poor night’s sleep can worsen their symptoms. Well, I have found that my IVIG works better if I get a good night’s sleep the night before and the night of the treatment.

• Prepare many snacks to eat during treatment – I tend to crave protein based foods but anything healthy is good. It will help to stave off a head or stomach ache. My recommendations include: cheese and crackers, nuts, bananas, clementines, or an everything bagel with cream cheese and tomatoes slices. Prepare whatever you like the night before so you don’t have to worry about it the day of the treatment.

• Avoid Stress at all costs – Stress sets off the immune response and will render the treatment less effective because your faulty immune system wins the fight, so to speak. I have found when there is high stress, my treatments do not work so well.

So, that about wraps it up. While I am sorry to hear you have to have IVIG, I truly hope this helps.

*Jen Walsh is a Great Lakes Chapter Member from Grand Rapids, Michigan who has published multiple articles and blogs on her experience with Myasthenia Gravis.
Update to SCOTIABANK Charity Challenge and Your Fund Raising Efforts

Myasthenics Extraordinaire and their generous friends and family!

A very big Thank You to all of you who sent in donations and collected pledges for our runners this June, in the ScotiaBank Charity Challenge. Your efforts raised almost $ 8000.00 in donations for our Association.

Special thanks go out to those members and their friends and families who also collected donations. They are Jeanette Espinosa, Christopher Hum, Lara-Rose Duong, Justin Philcox, Nicholas Duong, Sara Rabey, Frances Sokalski, Lily Forget, and our two top fund raisers Trevor Harris and his sister, Valerie Fair - the son and daughter of MG member Jim Harris, who together brought in over $ 5000.00.

Congratulations to all!

Due to space constraints, we are unable to list the individual names of those who so generously donated to the ScotiaBank Charity Challenge. We apologize for these omissions.

MG Logo Contest

When you see the Golden Arches, you think of McDonalds, KFC and it's the Colonel and his chickens, a tied ribbon - AIDs or Breast Cancer. Recognizable logos continually place the company, corporation or charity in your mind. We need you to help us find that special logo for Myasthenia Gravis Association of BC, so we are sponsoring a LOGO CONTEST. The lucky winner and three friends will enjoy a cruise and a lovely gourmet lunch aboard the MV MENOKEN, skippered by Brenda and Len Kelsey!.

As you may remember from this years ScotiaChallenge Fund Raising letter, new MG patient Jim Harris has initiated the process for our Association to be considered as a registered charity for the 2011 race. If we are chosen, Jim has agreed to contribute the 'substantial' registration fee. Runners and spectators alike will become aware of the Myasthenia Gravis Association of British Columbia! Put on your thinking caps, let the creative juices flow and let’s see what we can come up with.

You may enter as many times as you like. Please submit entries to the MGABC office either by email or post. Entries will not be returned. All entries must be in by December 1, 2010. The winning entry will be chosen by the Board of Directors.
Genome Study (GWAS) Update

From Dr Oger in collaboration with the laboratory of Neurogenetics at the National Institute of Health.

Earlier in the year, Dr. Oger asked us to send out information forms and applications to our members who might be interested and eligible to participate in a research study – the purpose of which was to recognize genetic characteristics at the DNA level of Myasthenia Gravis. In order to be eligible for the study, one must be Caucasian and currently be on medication for Myasthenia Gravis.

Attached is an excerpt from an e-mail from Dr. Oger to the Myasthenia Gravis Association of B.C. on the progress of the study.

“Our research group has distinguished itself at the International level: In the thymectomy trial we have enrolled 9 patients which is the second best site IN THE WORLD out of 52 groups of researchers. The GWAS (Genome wide advanced screening) project is progressing rapidly and there will soon be 1,000 MG patients having volunteered. Over 100 of them come from Vancouver. Thanks to your help.”

19 positions still remain available, so if anyone is interested in volunteering, please contact our office and we would be happy to send you the application form.

IN MEMORIAM

It is with great regret and sadness that we mark the sudden death of Ron Grisdale on August 19th. Ron suffered a severe heart attack and died in Lions Gate Hospital emergency. You may remember Ron from our meetings, as he always wore shorts whatever the season! Ron was a member of the Myasthenia Gravis Association of B.C. for several years as well as a board member for 5 years. He was a stalwart and loyal member, always ready to help out and contribute to the meetings.

Ron was a devoted member of the West Vancouver Baptist church and very active in their family programs. He was predeceased by his wife Daphne and is lovingly remembered by his son Don, daughter Deborah and their families. We would like to extend our sincere condolences to the entire family.

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.
MGABC member, Jack Munro is honoured by The Board of Governors of the British Columbia Institute of Technology. BCIT was pleased to announce the recipients of the degree of Honorary Doctors of Technology. The outstanding individuals have been recognized for their contributions in the fields of publishing, health, natural and renewable resources and sport. Throughout their distinguished careers, the honourees continued their commitment to community and philanthropy.

Myasthenia Gravis Association board member, Jack Munro was recognized as one of this year’s six recipients and joins 45 other outstanding and honored British Columbians. Jack has also been honoured with the Order of Canada, and with a Jubilee Medal from Queen Elizabeth II.

All of us at the Myasthenia Gravis Association of BC congratulate Jack!

**Milestones**

**SOAP OPERA ALERT!**

*Days of Our Lives* to Bring Back Maggie’s MG

According to a February 9th 2010, article posted on the TV Guide Website, Suzanne Rogers' character Maggie Horton, on the popular daytime soap “Days of Our Lives” will see her storyline include a reoccurrence of her Myasthenia Gravis. Rogers was diagnosed with MG in the mind-80’s with symptoms affecting her from the neck up. At the time, Days also gave the disease to Maggie to explain the sudden and shocking change in her appearance. Ms. Rogers had gained considerable weight and had facial bloating due to her medications. Though she has been in remission for several years, the storyline will include more generalized MG symptoms for ‘Maggie’, such as weakness in her arms and legs. The episodes which started airing in March of this year, hopes to bring more awareness to a disease that is relatively obscurity.

(Source: MG Manitoba, March 2010)
Ismail Abbadi
William Churchill
Edith Lublow
Ken Palmer
Joan Buttal
Mary Gilholme
Harry Gray
Katherine Cashmore in honour of Judy Bonny
Oliver Worsfold
Johanna Nadiger
Judy Bonny in honour of Brenda Kelsey
Bruce Davis
Leslie Allen
M. Frances Speakman
William Davenport
Berta Smith
Velma Cotton
Guenther Kradepohl
Angie Apostolides
Jane Bryans
Jean Winslade
Dr Otto Huhn
Annie MacKinnon
Jantine Van Oort
Allan Thorp
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Jerry Olynyk
Frank M. Lines
Ian Bennett
Ray Humphries
Lyne Garner
Les Crosby
James Clogg
Henry Aben
Jack Munro
Yvonne Elliott
David Sutherland
William and Margaret Esson
Joan Salmon
Ray & Liane Humphries
Allan Thorp
Susan Drummond
Betty Bisschop
Dorothy Symons
Brenda Kelsey in honor of Judy & Gene Bonny’s 50th
Edward Zatorski
Al Craig
William Godden

Barbara Hovland
Marion Garbutt
Barbara Thomas
Mark Revell
Jeanette Espinosa
Mary Simmer
Sheila Gray-Moir
Lavinia Lo
Carol McBryde
Scott Didick
Les Crosby
Maybelle Morrison
Rod Osborne
Joan Prokopchuk
Marsha Tillman
Kathy Geremia
Robin Burwash
Rose Jones
Nadia Anderson
Sandra Trimble
Beverley Butler
Rose Pickard
Lorna J Andrews
Betty Kinaschuk
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United Way, Alberta
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WE APOLOGIZE FOR ANY ERRORS OR OMISSIONS.
PLEASE NOTE THAT INDIVIDUAL DONORS TO THE SCOTIABANK CHARITY CHALLENGE
ARE NOT LISTED DUE TO SPACE CONSTRAINTS. WE THANK YOU!
LITERATURE ORDER

Name_______________________________________________________________________

Address_____________________________________________________________________

LITERATURE AVAILABLE:

- 1. Myasthenia Gravis Facts
- 2. Successful Coping with Chronic Illness
- 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 Myastheia Gravis
- 13. Fresnel Prism to correct double vision
- 14. Aids for Droopy eyelids - Lundie Loop for Glasses and Calvin Eye Lift Tapes
- 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 the office.
MG NEWSLETTER

MEMBERSHIP DONATIONS
MGABC’S membership year is January 1st to December 31st. 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 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!
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*If you are donating directly to UBC, please make your cheque payable to UBC Myasthenia Account, and mail directly to: Dr. Oger. Be sure to 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

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Phone_________________________________ MG Patient □ Yes □ No
Membership ($10.00) $___________________ (no tax receipt will be issued)
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TOTAL AMOUNT ENCLOSED $___________________

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