The Myasthenia Gravis Association of BC cordially invites you to attend

THE Fall 2011 Support Group Meeting

When: Sunday, October 30th, 2011 @ 1:30 pm

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

Topic: New and On-going Studies in Myasthenia Gravis

Dr. Joel Oger
Professor of Neurology
University of British Columbia

Question Period to follow. 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 locals 1284/1347 or email: mgabc@centreforability.bc.ca

* Please note, the Legacy Room (307) has moved to the 3rd floor of 2805 Kingsway. Please be sure to enter from the front door on Kingsway.

2012 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 and allow us to staff and maintain a clerical person. Contributions for research are always needed as Dr. Oger is able to continue 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 with their physicians.

The MGABC is grateful to the province of BC for their charitable gaming grants.
Browsing the tangled Web

The Internet has no equal as an information storehouse. The trick is to know how to get right to a source of useful information and not waste time on websites that are biased, trying to sell you something, or just plain wrong. Two patients I saw one recent morning illustrate the hazards and promise of online health research.

“Doc, I know what I’ve got and it’s not good,” the 54-year-old high school math teacher fearfully admitted. He had midback pain for the past month, and after a Google search netted him a mere 6.5 million results, somehow settled on an abdominal aortic aneurysm (a worrisome bulge in the body’s main blood vessel) as the logical explanation. No reassuring words on my part served to ease his apprehension. It took a sonogram to convince him that he wasn’t at death’s door.

The second patient, a 60-year-old librarian, was referred to me after her primary-care physician told her she had Graves’ disease (an overactive thyroid). She arrived for her appointment armed with computer printouts of useful, accurate information, and was fully prepared to discuss the pros and cons of treatment options for her problem.

In my professional memory, nothing has changed the doctor-patient relationship as radically as the Internet. As recently as 1995, about one of 10 American adults had online access; today, about three of four adults and just shy of 100 percent of teenagers use it to get information and communicate with others, according to the Pew Research Center. The one-way flow of health information from doctor to patient is now a dialogue, or even, at times, a debate.

CAVEATEMPTOR.COM

Google and Yahoo are among the most used search engines. But almost anyone can pay these websites to display advertisements—called “-sponsored links.” And anyone with something to sell can set up a website with few, if any, checks and balances on what it says.

While information sites like AOL sometimes post paid links, many links are nothing more than ads for individual products. Just the other day I searched Google for “flu symptoms” and up popped ads for Kleenex, Tylenol, and the homeopathic preparation called Oscillococcinum.

The top “natural” (i.e. unpaid) search results might also include some sites marketing a specific product. For instance, a recent Google search I did on “enlarged prostate” yielded information from the Mayo Clinic and the National Institutes of Health, but also the website for an unproven herbal product.

To complete the confusion, major sites like WebMD.com provide reliable noncommercial content as well as content sponsored by commercial interests, such as drug companies.

THE OTHER DOTS

What’s left are the generally commercial-free government websites (with addresses that end in “.gov”) and academic ones (“.edu”).

Some not-for-profit organizations run websites (“.org”) that are ad-free (including our own ConsumerReportsHealth.org, which charges for some of its information) and some take advertising. Others are littered with advertising, and some are fronts for industries or manufacturers with a commercial agenda.

Consumers visiting an unfamiliar website should always check the “About Us” section for clues about who is funding the content.

Figuring out the pecking order among websites requires narrowing the choices to those few that provide up-to-date, reliable, and understandable information. Many qualify. No doubt your doctors can recommend personal favorites. This is my own current Top 5 list:

- www.cdc.gov for information about infectious diseases, travel medicine, and epidemiology.
- www.fda.gov for information about drugs.
- www.medlineplus.gov for information about diseases.

Marvin M. Lipman, M.D., has been Consumers Union’s chief medical adviser since 1967. He is a diplomate of the American Board of Internal Medicine (certified in endocrinology and metabolism) and is clinical professor emeritus of medicine at New York Medical College.
A new study for Myasthenics overseen by Dr. Oger and his team at UBC.

If you meet the following criteria, please contact Anne 604-822-7696. Trials will be very intensive with 12 visits to UBC of one day each over a period of 40 weeks.

Subjects eligible for enrollment in the study must meet all of the following criteria:

1. Subjects aged 18 years and older, with life expectancy of greater than 1 year.
2. MG of class II to IVa inclusive. (more than ocular but not on a respirator)
3. Acetylcholine receptor (AChR) antibody positive.
4. Stable dose (defined as no dose changes) not exceeding the maximum doses of the following therapy(ies) prior to screening: for Mestinon 2 weeks prior to screening, for Prednisone (up to 40mg/day) for at least 1 month prior to screening for azathioprine for at least 6 months prior to screening, mycophenolate for at least 6 months prior to screening, or cyclosporine for at least 3 months prior to screening.
5. Quantitative Myasthenia Gravis (QMG) score of 8 or greater, with at least 4 points derived from signs other than ocular
6. A female subject not planning or able to become pregnant.
7. Capable of giving written informed consent, which includes compliance with the requirements and restrictions listed in the consent form.
8. Normal ECG and Liver function

Exclusion Criteria:

Subjects meeting any of the following criteria must not be enrolled in the study:
1. The subject has participated in a clinical trial and has received an investigational product within 30 days, 5 half-lives or twice the duration of the biological effect of the investigational product (whichever is longer) prior to screening or planning to take any investigational drug for the planned duration of study participation (6 months after the last dose of study drug).
2. Thymoma.
3. Thymectomy within 12 month.
4. May require (in the opinion of investigator) treatment with IVIg and/or plasmapheresis during the 24 week treatment period.
5. Have received IVIg and/or plasmapheresis within 90 days prior to screening.
6. Have received a live vaccine within 30 days of study Day 0 (baseline).
7. Have received cyclophosphamide or any other immunosuppressive agent apart from the ones allowed by the inclusion criteria #4, within the past 6 months.
8. Have another medical condition that requires treatment with steroids or immunosuppressive agents.
9. Have a history of cancer
10. Have HIV-1, hepatitis B surface antigen or hepatitis C antibody.
11. Have an IgG Grade 3 or greater deficiency (≤400mg/dL) or IgA deficiency (IgA<10mg/dL).
12. Subjects who have evidence of serious suicide risk including any history of suicidal behavior in the last 6 months and/or any suicidal ideation of type 4 or 5 on the C-SSRS (Appendix 4) in the last 2 months or who in the investigator’s judgment, pose a significant suicide risk.
Congratulations to all who participated in the run on Sunday, June 26, 2011. It was a beautiful, warm, sunny day and with the help of our tireless volunteers, Jim Harris, Dave Sutherland, Virginia Angus and Lorne Holyoak, we set up the Myasthenia Gravis tent and spent the day cheering on the runners and answering questions of those who stopped by our tent. Trevor Harris added to his successful fund raising efforts of last year by including his running group in fund raising endeavours. Another group, who have a co-worker with MG, also donned MG running jerseys and raised money for our cause. We were very grateful for the lovely weather - after a precarious start to summer - but even more grateful to all of you who contributed on-line and the runners and their families who so proudly represented the Myasthenia Gravis Association of BC. Due to Scotiabank’s involvement, and on-line donations, we are at the time of this mailing unable to list all the individual names of those who so generously donated to this very worthwhile event. In the Spring newsletter we will give a whole page to the event with updates and pictures! A conservative estimate of the monies raised is over $8,000.00!!

MG tee shirts available for sale - $20.00 A picture will be posted on the MG website

MG Logo Contest WINNERS - The Van Oort Family!

In the Spring newsletter we let you know of the winners of our logo contest and the wonderful prize that awaited them! On August 13th, the Van Oort family boarded the MV Menoken skippered by Len and Brenda Kelsey. It was a beautiful day which included swimming and swing rope dives into the water, as well as a gourmet lunch on the dock. Everyone had a wonderful day. In the accompanying picture are: Tony and Jantine and their children, Braedan, Rubin, Riannon and Eric.
The GWAS is proceeding virtually exactly as we had anticipated.

1) As of the beginning of July, we had obtained the entire set of 1,100 DNA samples (saliva) and coded patient information. The information is in spreadsheet form in both Microsoft Excel and Access. The actual processing of the material is proceeding in the laboratory of Neurogenetics at the National Institutes of Health, in collaboration with Dr. Bryan Traymor, Chief of the Neuromuscular Division.

2) DNA has been extracted from all the samples. Measurement of the DNA in every sample has been carried out, and they all have sufficient DNA for the study purposes. About 100 of the samples were concentrated before the next step.

3) The DNA has been “plated” - that is, the correct amount of DNA has been placed in each microwell and is ready for the next step.

4) To evaluate the “quality” of the DNA, a couple of the plates have been tested by PCR (polymerase chain reaction) which results in amplification of the DNA and thereby confirms its quality. They all amplified successfully.

5) The material is now ready for genotyping. That is, it will be run on the “chips” to evaluate 700,000 genes (actually ‘single nucleotide polymorphisms’). This step will allow us to compare the 1100 MG samples with the nearly 4,000 normal controls for which we have comparable control data. The large number of MG samples will run in a single batch beginning in a few weeks.

We will keep you all informed as we continue to make progress. Dr. Traynor and I are very pleased with the pace at which the project is going.

Daniel B. Drachman
Professor of Neurology&Neuroscience
WW Smith Charitable Trust Professor of Neuroimmunology.

How is it, one careless match can start a forest fire and it takes a whole box to start a campfire?
Milestones

Stewardship Award

Dr. Otto Huhn - is the consulting Pathologist at Banff Mineral Springs Hospital, an MGABC member and a Myasthenic.

“There’s so much misery, misfortune and disease in the world, if I can contribute just a tiny bit that will be a big achievement” - Dr. Otto Huhn

Dr. Otto Huhn has had a rich and lengthy career with Covenant Health’s Banff Mineral Springs Hospital. He came to Banff at the request of the College of Physicians and Surgeons to provide leadership and direction for laboratory services.

“When I arrived at the Mineral Springs Hospital laboratory, one technologist worked with nine chemistries to do CBCs manually and urine analysis for a global population that grew to 20-30,000 people in the summertime,” remembered Dr. Huhn. “At that time, I made a commitment to make sure the people in the Bow Corridor had proper lab services within our limited resources.”

Dr. Huhn has exceeded that commitment and has been a strong advocate for the hospital when funding for lab services has been very difficult to build and sustain lab services. After careful analysis, he matched program activity in Emergency and Acute Care to lab services, and two lab test options grew to over 200 diagnostic options because “we needed it,” said Dr. Huhn.

Dr. Huhn has used Covenant Health resources wisely, and over the years has offered his own personal resources to acquire needed equipment. “It started with just some simple instrumentation, and early on I gave them my own microscope,” said Dr. Huhn.

Now he uses his gentle nature to negotiate prices and payment options for the latest technologies that will have the most benefit for this vital community hospital.

“Dr. Huhn’s savvy and careful deliberations helped with the purchase and fundraising for the new Gem 4000,” said Susan Blonski. This equipment makes a big difference in health services, as it has reduced the number of call backs after hours by having RNs use it as a point of care device, and it has the potential to reduce operation costs in the lab.

Dr. Huhn has achieved four honourary life memberships for his work by esteemed medical associations across the country. The commitment he made to his profession over forty years ago is even stronger today, as Dr. Huhn acknowledges that the older he gets, “I feel a deeper sense of social responsibility and a sense of duty toward our fellow man.”

“It fills me with so much gratitude,” he concluded.
Fall/Winter 2011

DONATIONS AS OF MARCH 1, 2011, we have received with much gratitude and thanks!

Sandra Trimble
Jo - Ann Caldwell
Shirley McFadyen
Joan Prokopchuk
Janette Van Oort
Catherine Lefeaux
Yvonne Elliott
David Sutherland
Dorothy Symons
Gord Voth
Dagmar Pribil
Dr Otto Huhn
Lynn Walters
Debbie Jackson

Ed Gore
Frank Lines
Diane Mar-Nicolle
Wendy McFarlane
Gordon Voth
Elizabeth Lewis
Keith Milton
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Ian&Opal Folkers
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Corporate: The Hydrecs/John Mausser, Telus/Norm&Doris Taylor, Telus/Rose Hare, Telus/Norm Taylor, Telus/Anonymous, United Way, The Hydrecs Fund (BC Hydro), Costco Wholesale/ED

In Memory of:

Rod Osborne: Marlene Hanna, Mr & Mrs J Wish, Bob and Sharon Henderson Marie and Eric Renholm, Joan Honeyman, Earl and Deloris Mac Rae, Neil Green, Agnes Carlson, Randy Ickringill, Edie &Tim Kernighan, Sonia &Ed Martin, Donna Osborne, Connie Osborne and Family, Mr & Mrs Peter Qualizza, Ernest& Edvige Weingand, Paul & Diane Wolnyiec, Trudy Zonneveld, PRL Pacific Construction Ltd., Henry & Rosa Marie Locken, Murray and Shirley Brooks, Marlene Hanna, Grace Krovac, Brad Wish, Audrey Mackin.
Jim Kirwen: Brenda Kelsey, Mary & Bob Gilholme.
Genevieve Carter - Ken & Jean Winslade.

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!

IN MEMORIAM

It is with great sadness that we relay the news of the passing of one of our Honorary Board Members, Jim Kirwen on April 9, 2011, at the age of 97. Jim was born in Glasgow, Scotland on November 11, 1913. He was preceded in death by his siblings: Mary, Bessie, Alan, Willie and Jenny as well by his wife Sheila (Hellewell) and is survived by his four daughters, Jill, Jean (Glezos), Jaisri Margaret (Lambert) and Alice (McSherry). He is also survived by his six grandchildren and many nieces and nephews, both here and in Australia and England. He worked as a Structural Engineer in Malaya, Hong Kong and Glasgow before moving to Vancouver with his family in 1950. He was Chief Engineer at Western Bridge for many years before forming Kirwen Engineering Inc. As well, he was a founding member of the Myasthenia Gravis Association and a life member of the Association of Professional Engineers.

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.
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 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.

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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.