The Myasthenia Gravis Association of BC

cordially invites you to attend

The Fall 2017 Support Group Meeting

When: Sunday, October 29th, 2017 @ 1:30 pm
Where: Room 307, Centre for Ability, 2805 Kingsway, Vancouver

We will not have a set topic for the meeting but would like to invite MG patients to share and discuss their symptoms, challenges and recent treatments.

Kelly Carson, a board member and MG patient will also share her ‘personal’ take on living with MG. Kelly proves to be an inspiring comedic speaker whose ultimate goal is to give others hope for their future living with MG.

Dr. Kristin Jack will join us to answer questions.

Refreshments will be served.
Friends, relatives, health professionals and other interested parties are welcome to attend.

For further information, please contact Brenda Kelsey or Linda Briggs at 604-451-5511 local 1284 or email: Myasthenia.Gravis@bc-cfa.org

2018 Membership Drive and Fundraising Begins!
Every October we ask MGABC members to renew their memberships. The annual cost is $20/member. This fee includes a bi-annual newsletter, free information pamphlets, notification of special programs of interest to Myasthenics, support group meetings with speakers as well as staff willing to help and support you. Memberships renewed after September 30th will be good for the coming year. If for any reason, this fee poses a financial hardship, please let us know and we will extend your membership free of charge.

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.
FROM THE WORLD WIDE WEB

Fantastic Things   Elyse Bruce

We recently received a letter from an Elyse Bruce from Sevierville, IN who told us of the first ever children’s book to explain Myasthenia Gravis in accurate and positive terms for both children and adults.

Missy Barrett is our 9 year-old fictional heroine who has been delighting her readers since 2012 with her insights and interpretation of the world around her. Her older brother, Josh, has Myasthenia Gravis.

In this particular book, “Fantastic Things”, Missy learns from Josh what having MG means to him. You may Google the Canadian Amazon site with the title and view the book for purchase. It is affordably priced. For those of you who may be Kindle Unlimited subscribers, the eBook is free.

A word about Miss Bruce: Elyse Bruce is a woman of many talents. She is an award winning professional musician, singer-songwriter, composer, illustrator, playwright and the author of more than 20 books.

Over the years and between what seems like a myriad of projects, Miss Bruce devotes her time to raising a son with multiple health issues, one of which is Myasthenia Gravis. It is through his eyes and her talent that Missy Barrett speaks to us about this rare, incurable and often life threatening condition that strikes 2 in 1 million minors.

Parents’ Program – When Your Child has MG

On the Myasthenia Gravis Foundation Website – www.myasthenia.org, there is a section devoted to helping parents of children with MG to support their children more successfully. The website will be updated from time to time adding new content and resources. Please be sure to check back periodically for new material. And remember, your child can lead a full, happy and useful life with a little extra help.

Resources:

Understanding Your Child’s Myasthenia Gravis – learn about what MG is, how it is diagnosed, medications and therapies, what to expect with MG and managing MG.

Your Child and Exercise – learn about the benefits of exercise and how important it is to your child’s life and health, find out how to fit it into your lives even with the challenges of MG.

A Parent’s Guide – Steering Your Child with MG to School Success - This section deals with how to help your child have a quality school experience, working with teachers, tips on classroom accommodations for children with disabilities.

Resources for Parents – List of Helpful Websites – Find listings and links to a wide scope of potential resources.

Tracking Chart – a handy chart where you are able to record your child’s ups and downs daily and/or hourly in order to track patterns that may help you and your child manage their days and outings.
Wilma J Koopman, RN (EC), MScN NP of the MGFA Nurses Advisory Board conducted a study to explore the relationship between hope, coping and the quality of life experienced by adult patients with MG.

The initial diagnosis of MG is fraught with questions, primarily because it takes so long for a ‘true’ diagnosis to be achieved. Many patients are stopped in their tracks and “What now? And Why me?” The shock and lack of knowledge of this elusive disease add to heightened levels of anxiety. Often multiple medications are required and their frequency and potency change until personal equilibrium is achieved.

The study, which selected it’s 100 participants from the London Health Centre in London, Ontario MG Database. All MuSK AB positive patients were invited to participate as they are low in number. 57 were male and 43 were female: the average age was 61, 78% had generalized MG, 24% ocular. 83% were AChR positive, 8% were MuSK positive and 9% were sero-negative. Among the group the following medications were taken: Mestinon 92%, Prednisone 78%, Azathioprine 57% and Cellcept 21%.

Questionnaires given to the participants included demographic information, measure of their ability to perform activities of daily living (MG-ADL), a score on Hope (Hope Herth Index), main strategies of coping (Jalowiec Coping Scale) and their quality of life scores (MGQOL< SE36v2)

The mean scores indicated a high level of hope with positive readiness and expectancy as the most frequently used ‘coping mechanism’. The other three most effective were being optimistic, confrontive – relating to facing the problem and working to solve it, and self-reliance. So like many areas of life, trying to think positively, keeping a sense of humour, focusing on the good things and keeping your life as normal as possible are reliable coping mechanisms.

It is important to notice this group had mild disease and few symptoms of active disease. Most identified with a ‘good tolerability of their MG symptoms.’ Participants in this survey were hopeful and wished more healthcare professionals understood the need to promote strategies to inspire and thereby improve the quality of life for their MG patients.

The full study and charts may be viewed at: [http://cann.caissues/?IID=volume38-issue1-2016e](http://cann.caissues/?IID=volume38-issue1-2016e) Canadian Journal of Neuroscience Nurses.
A Short History of Myasthenia Gravis

The first described case – which was likely Myasthenia Gravis – is that of a Native American tribal chief of the Powhatan Confederacy, Chief Opechancanough (1554-1646). Virginian chroniclers reported: *The excessive fatigue he encountered wrecked his constitution; his flesh was macerated; his sinews lost their tone and elasticity. His eyelids became so heavy he could not see unless they were lifted by his attendants and he was unable to walk at the end.*

In 1658, an unpublished Latin letter was written by Dr. John Maplet, a physician working in Bath. The letter noted that he was in charge of a little boy of seven who could not speak and was so weak his limbs and joints were unable to support him. He could neither stand nor walk.

Later in 1672, Thomas Willis, an English physician, described a female patient with “fatiguable weakness” describing she “temporarily lost her power of speech and became ‘mute as a fish.’” However, this account written also in Latin was not largely noticed until 1903. Though other physicians were also treating patients with the same symptoms, there was no treatment available and death resulted in the majority of cases. The first modern description of MG was made in 1877 by Samuel Wilks, a London physician. Towards the end of the 19th century, primary muscle diseases and diseases due to denervation of muscles were studied by English, French, and German physicians.

The name Myasthenia Gravis was suggested by Friedrich Jolly, a German neurologist who conducted repetitive nerve stimulation studies to assess neuromuscular junction disorders, now known as the Jolly Test. The name was accepted at a meeting of the Berlin Society of Psychiatry and Neurology in November, 1899. The name is derived from the Greek and Latin, Myasthenia meaning *muscle* and Gravis meaning *heavy or severe*. For the next decade, MG was treated primarily with “organotherapy” (organic extracts suprarenal, thyroid, pituitary, and ovarian glands) on the supposition the disease might be an endocrine function these other glands are counteracting with.

Attempts at rational treatments for MG began in the 1930’s. It was suggested by Dr. Mary Broadfoot Walker that MG symptoms were similar to those of curare poisoning, which was treated with physostigmine, a cholinesterase inhibitor. In clinical trials, she showed that administering physostigmine promptly improved MG symptoms. She postulated that “*It may be significant that physostigmine inhibits the action of the esterase that destroys acetylcholine.*”
In 1936 further work showed acetylcholine was liberated at motor nerve endings (now termed ligand-gated ion channels) to produce the same effect in ordinary muscles and that its action was limited by the ferment, cholinesterase.

Because thymus pathology is common in MG, as early as 1937 it was reported that MG patients who underwent a thymectomy improved postoperatively, thus establishing thymectomy as a treatment for MG.

In 1944 and 1945, examination of the thymus gland showed a curare-like substance. In 1945, a phyridostigmine bromide (PB) – a reversible cholinesterase (ChE), is synthesized by Hoffman-LaRoche Laboratories in Basle, Switzerland and is available for sale under the tradename MESTINON. Ten years after the synthesis of Mestinon, the FDA approved it as a safe treatment for MG.

Research continued and in 1959-1960 two doctors, Simpson and Nastuck, proposed independently that MG has an autoimmune etiology.

Since the 1970’s new medications have been developed to help control MG symptoms. Prednisone and azathioprine (Imuran) have both become established treatments and plasma exchange was introduced as an effective acuter treatment for severe cases. Studies of immunization with AChR – showed the development of MG-like symptoms prompting the use of immunosuppressants in treating MG: Plamapheresis (1977), Globulin (1984), and Cellcept (1998).

Perseverance is not only a quality of the doctors and researchers who study the cases and develop the drugs and strategies for the treatment of Myasthenia Gravis. It is also the quality of those who are afflicted with the disease, as they continue to assist in studies such as volunteering DNA to determine which genes are associated with Myasthenia Gravis.

INDIVIDUAL COMMITMENT TO A GROUP EFFORT... THAT IS WHAT MAKES A TEAM WORK, A COMPANY WORK, A SOCIETY WORK, A CIVILIZATION WORK. 

Vince Lombardi (1913-1970)
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Donations and In Memory Of:

Happy Birthday, Dianne Botteselli from Lynn Third, Mary Coote and Tom Clarke.

In Memory of Beth Bowden from Maria Luisa MaCrae, Grace Bereton, Mona Jean Dando and Eleanor Haywood.

Ruth Woodley for David Cumiky.

Lois Otterbine for Norma ‘Jane’ McLeod.

Jack Munro Memorial Fund:

Adrian Wall, Chrissie Steane, Joel and Marie-Louise Oger, Nora Moore

Corporate Donations:

Vancity Foundation
Provincial Employees Community Service United Way

WE APOLOGIZE FOR ANY ERRORS OR OMISSIONS.
LITERATURE ORDER

Name_______________________________________________________________________
Address_____________________________________________________________________

LITERATURE AVAILABLE:

- 1. Myasthenia Gravis Facts
- 2. MG Glossary: Definitions of medical terms used in M.G.
- 3. MG Survival Guide
- 7. Drug pamphlets:
  - (a) Mestinon
  - (b) Imuran
  - (c) Prednisone
  - (d) Cyclosporine
  - (e) Cellcept
  - (f) Tacrolimus
- 8. Drugs That Aggravate MG - NEW 2012
- 9. Thymectomy
- 10. Plasmapheresis
- 11. IVIG - Intravenous Gamma Globulin
- 12. Ocular MG
- 13. Nutrition for Healthy Bones
- 15. Dentistry and the Myasthenic
- 16. Pregnancy and Myasthenia Gravis
- 17. Myasthenia Gravis in Children and Adolescents - NEW
- 18. School Package for Children with Myasthenia Gravis
- 19. Congenital Myasthenia Gravis
- 20. Emergency Care of Myasthenia Patient
- 21. Mestinon - 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. Practical Guide to MG
- 25. Dr Oger’s book for Family Physicians - free to MG members
- 26. MG ID Emergency Alert Card NEW
- 27. Providing Emotional Support for patients with MG
- 29. Tips on applying for CCP Disability Benefits
- 30.
- 31. 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 (at no cost)
- My Imaginary Illness - Dr. Chloe Atkins A Journey into uncertainty and prejudice in medical diagnosis (For short term loan or purchase through your local book stores)
- Dr. Oger’s Book: A Guide to the Diagnosis and Management of Myasthenia Gravis - free to MG patients and their physicians.

Please note: General Myasthenia Gravis information is now available in Mandarin. If you would like a copy, please contact our offices.
MG NEWSLETTER

MEMBERSHIP and DONATIONS

MGABC’s membership year is January 1st to December 31st. Membership received after October 1st will be good for the following year. To donate, please complete the form below and return it with your cheque or money order (we cannot accept credit card payments and we ask that you do not send cash in the mail). Your donation and membership fees help defray operating costs, and entitles you to the following:

Newsletters biannually...MG literature and pamphlets
Notice of meetings...Up-to-date information on MG

You Can Help!

Your support can make a vital difference in the fight against Myasthenia Gravis 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 $20.00 $___________________ (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.