Please be sure to call ahead and RSVP! We will need to confirm our catering order. $20/adult and $10/children under 12. Payment can be accepted at the door, but it is preferable for cheques to be mailed to the office ahead of time.
If you are donating items for the Silent Auction, please drop them off at our office and/or make arrangements for pick up. We will do our best to accommodate you. If you were planning to bring something for the auction with you, be sure to let us know what it is and send a digital image. We need to prepare the space and the bid sheets.

PROPOSED AGENDA
12:00 – 12:45: Welcome and viewing of auction items
12:45 – 1:45: Luncheon
1:45 to 2:30: Last chance to bid on items, cake, tea and coffee
2:30: Bidding ends, a few words from the fund raising committee and introduction of Dr Aathi Pathmananthan.
Payment (cash or cheques) and pick up of auction items.
Hope, Coping, and Quality of Life in Adults with Myasthenia Gravis – Results of a Study.

Wilma J. Koopman, RN (EC), MScN NP, MGFA Nurse Advisory Board

The diagnosis of myasthenia gravis causes patients to stop in their tracks and consider “WOW, why me and what is going to happen now?” The shock and lack of knowledge or awareness about this rare disease adds an added level of anxiety. The multiple medications we use to treat the disease, including prednisone (“oh, no I have heard so many bad things about this drug, so I will never go on it”) does not make anyone feel in control. But be calm, you may be surprised at the results of this study.

The aim of the study was to explore the relationship between hope, coping, and quality of life in adults with myasthenia gravis. Two research questions guided this study: What is the relationship between hope, well-being, coping and quality of life in adults with MG? Do well-being and quality of life mediate the relationship between hope and coping in adults with MG? Patients were selected from the London Health Science Center, London, CANADA, MG Database by random sampling and stratifications to match the proportion of these patients in the MG population. All MuSK AB-positive patients were invited to participate as they are low in number. We asked 100 patients with MG to complete six questionnaires that included demographic information, measures of their ability to perform activities of daily living (MG-ADL), a score on Hope (Hope Herth Index), their main strategies and methods of coping (Jalowiec Coping Scale), and their quality of life scores (MGQOL, SF36v2). See the key results of the study below.

Demographics: Of the 100 patients, 57 were male and 43 were female. The mean age was 62 years with an average of age 51 at the onset. Seventy-six percent had generalized MG with 24% had ocular. Eighty-three percent were AChR positive, while eight percent were MuSK positive and another 9% were sero-negative. The group took the following medications: Mestinon - 92%; Prednisone – 78%; Azathioprine – 57%; Cellcept – 21%.

In patients, the mean hope scores indicated a high level of hope with positive readiness and expectancy (“I have a sense of direction”) as the most frequently used coping style. The three most frequently and effectively used coping strategies were being were being optimistic (maintaining positive attitudes about the problem), confrontive (constructive problem-solving, facing up to and confronting the problem or situation) and self-reliant (depending on yourself to deal with the problem, rather than on others). Emotive (worrying) was the least used and least effective coping strategy. The highest ranked scores reported using a particular coping method either sometimes or often and included: trying to think positively (96%), trying to keep a sense of humor (93%), thinking about the good things in your life (92%) and trying to keep your life as normal as possible and not to let problems interfere (91%).

It is important to note that this group of patients had mild disease and few symptoms of active disease. Patients identified quality of life as “good tolerability of their MG symptoms”. Age and length of illness were not significant factors. However, females age and their ability to perform daily activities showed a significant relationship with improved quality of life. There was a moderate correlation found for hope and QOL and hope and mental well-being.

Participants in this study were hopeful. Healthcare professionals need to understand and promote strategies to inspire hope and thereby improve quality of life in MG patients. The following could be used to inspire hope: patient education, stories of successful MG patient experiences and affirming “there is a light at the end of the tunnel”.

The full study results are published by Wilma J.Koopman, RN (EC), MScN NP, Nicole LeBlanc, RN MScN, Sue Fowler, RN, Ph.D., Michael W. Nicolle, MD, Denise Hulley, CCRP, London Health Sciences Center, London, Canada; http://cann.caissues/?ilD=volume 38-issue1-2016e Canadian Journal of Neuroscience Nurses
In late 2017, the MGABC offices received a request from a young neurologist in training, requesting financial support in order to do a one year fellowship in the Neuro-Muscular Diseases Unit at Vancouver General Hospital. The ultimate goal was to obtain specialized training in Electromyography and the treatment of Myasthenia Gravis. As a result of the laboratory work of Dr. Oger and the clinical work of Doctors Gibson and Mezei, Vancouver is recognized as a reputed centre in Canada specializing in the research and treatment of MG.

The MGABC was not in a position to provide monetary support, but discussions began with the unit at Vancouver General, the UBC Foundation and the Kong Family Fund for MG. As fate would have it, at this same time a very generous $10,000 donation was received at MGABC from a long-time member, and suddenly the proposal became a possibility. With the funding coming together and Doctor Aathi Pathmananathan’s excellent credentials, he arrived from St. John, NFLD to begin his fellowship.

Dr. Pathmananathan – Aathi, was born in Sri-Lanka but moved with his family to Toronto when he was 5 years old. He did all his schooling in Toronto, completing a Bachelor in Science then applying to medical school at Trinity College in Dublin, Ireland. After completing his medical degree, Aathi returned to Canada where he started his neurology residency in St. John, NFLD. Having completed the 4 year residency, he successfully passed his Neurology specialty examinations at the Royal College of Physicians. Following his move to Vancouver, Dr. Pathmanathan began work at the NMDU under the guidance of Drs. Jack, Chapman, Mezei and Briemberg, learning how to manage MG. During this time, he will also be acquiring a diploma in Electromyography.

Dr. Pathmananathan is a slim young man, smiling easily and very personable. His contact is direct and his voice calm. He will be at our Fund Raising Event on October 14th. Please come and welcome Aathi to our family, here at the Myasthenia Gravis Association of BC.
The most important aspect of life is to keep breathing. That may be glaringly obvious, but I hadn’t really thought about it until I couldn’t breathe.

When your breathing capacity starts to decline, each breath gets incrementally more shallow. You begin to panic. Yet, panic makes it worse. You’re told to stay calm, so you can keep breathing. But you can’t breathe, so is it possible to stay calm?

Last fall, at the age of 29, I spent the better part of four weeks as an inpatient at Toronto General Hospital with this task – trying to keep breathing on my own.

“How long will this last?” I anxiously asked my neurology resident when I had been transferred to the ICU. I had been transferred because my breathing capacity had diminished such that I needed frequent monitoring, in case I needed to be intubated – when a tube is inserted through the mouth into the airway to help you breathe.

I had lost the ability to swallow or talk, and communicated through text message with the doctors and my family. A feeding tube had to be inserted so I could take the medications I needed. I felt like I was choking on my own throat secretions; it was excruciating and I could not quell my anxiety, despite my family’s best efforts to calm me. The doctors said we had to wait for the new medications to kick in. Thus far, they had not.

I see myself as an independent, competent woman. But in this moment, I felt as if I had lost everything. I was in a constant state of panic, the adrenaline pumping through my veins. I couldn’t concentrate on anything other than the fear and confusion. I couldn’t sleep and I dreaded being alone, even momentarily.
I had been admitted to the hospital because I had a rare neuromuscular disorder called myasthenia gravis. You have probably never heard of it – neither had I, prior to diagnosis. I was diagnosed a few years ago, at 28, when I was having difficulty moving my face to chew or smile. I felt like I had run a marathon every day, despite just doing regular tasks around the house. By the time of my hospital admission one year later, I had descended into a myasthenic crisis. I slowly lost the ability to chew and swallow, and my breathing capacity steadily declined.

Before my myasthenia symptoms began, I was carefree and able-bodied. The extent of my interaction with our health-care system prior to my diagnosis was restricted to one incident when I managed to lodge a fishbone in my throat in my early 20s. A trip to urgent care and a really long pair of tweezers swiftly solved this problem.

Myasthenia gravis is an autoimmune disease. Women are significantly more likely than men to be diagnosed with autoimmune diseases and women are likely to be diagnosed in their child-rearing years. So I was incredibly typical, with my rare disease.

The disease, being highly treatable and not degenerative, felt manageable for my type-A self, when I was first diagnosed. I’d start taking some medications, regularly receive a blood product (IVIG) and continue on with my everyday life. But I didn’t know how bad it could get, having never had a crisis at that point. I didn’t know that losing the ability to swallow, a reduced breathing capacity and feeling as though you are choking on yourself, could put you on the brink of hysteria, let alone death, if untreated.

Thankfully, a few days into my stay in the ICU last year, the medications began to work. On my final day in the ICU, I was strong enough to get out of bed and I took a short walk around the hall. I read a poster in the hallway outside my room that said the goal of this particular ICU was to provide excellent health care to the sickest patients in Canada. This was equally distressing and motivating to me. I spent 28 years in near-perfect health. It seemed impossible to consider myself one of the sickest patients in Canada. I was suddenly adamant that I needed to get better, and fast. A week later I was discharged.

I now regularly have flashbacks to the crisis, knowing that it could happen again at any time by a spike in my immune system caused by the flu, or another respiratory infection.

Health is precarious, yet we don’t think about it that way when we are healthy, especially when we are young and healthy. Young people often see themselves as immune from the ailments that plague the elderly. My 27-year-old self would have told you that rare disorders and diseases only affect a select few. Now I know this is naïve. Good health can be ephemeral and just beyond reach.

Knowing that being in good health is precarious sometimes manifests itself as gratitude. I am incredibly lucky for my quick diagnosis, our public health-care system and the care I received (and continue to receive).

Other times, it manifests itself as utter fear. Will today be the day I have a crisis? A myasthenia crisis can occur over weeks, days or hours. I could be fine today and in an ICU tomorrow. This is a reality that I will live with for the rest of my life. Myasthenia Gravis is a highly treatable but not (currently) curable illness.

I’m working on limiting the fear and anxiety that goes along with this truth, but it’s a journey. Some days the gratitude prevails over the fear, and other days the fear triumphs the gratitude.

My main goals now are to stay calm and keep breathing. It may seem simple, but if you can’t do that, what else matters?

Liz Witiuk Lives in Toronto.
Donations To Date:

Jerry Olynyk  Stewart Roberts  Opal Brown-Folkers  Jason Harris
George Kimura  Velma Cotton  Gayle Wilson  James Harris
Mark Revell  Lorne Holyoak  Jean Carncross  Nina Chand
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Rosanna Bremmer  Deb Salizar  Edgar Lublow  Wendy Robertson
Kenny Kan  Allan Thorp  Dominic Leung  Brenda Kelsey
Jillian Harris – Reed Point Marina

Corporate Donations:

Provincial Employees Community Serv. Fund
United Way Greater Toronto

New Donation Options!...

We are pleased to offer you an even more convenient way to make your donations to MGABC.

Using the VanCity Community Foundation, you may log on to: https://www.vancitycommunityfoundation.ca/give/donor-advised-funds/myasthenia-gravis-association-bc-fund. This direct link will allow you to make a donation and have the tax receipt issued to you electronically. Membership dues cannot be used here in conjunction with a donation, so you will still have to issue a cheque to the office for your annual membership, due in October.

CanadaHelps.org is also able to receive donations for MGABC and will issue tax receipts. Log on to: https://www.canadahelps.org/en/ Search for charity – myasthenia gravis and it will open to a page showing our logo and press ‘Learn more’ and you will be directed to our page and the option to Donate.

2019 Membership Drive

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.
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.