

MG NEWSLETTER

Fall 2015

[Myasthenia Gravis Association of British Columbia](#)

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The Myasthenia Gravis Association of BC SUPPORT GROUP MEETING 2015



The Myasthenia Gravis Association of BC

cordially invites you to attend

The Fall 2015 Support Group Meeting



When: **Sunday, October 25th, 2015 @ 1:30 pm**

Where: **Room 307, Centre for Ability, 2805 Kingsway, Vancouver**

Special Guest Speaker

Dr Zaeem Siddiqi - Associate Professor, Division of Neurology in the
Department of Medicine at the University of Alberta
and **Dr Joel Oger**.

**Come and learn about the latest information and research
available for MG**

**This is an excellent opportunity for MG patients in remission or new patients to
share stories and receive support from other
people with Myasthenia Gravis.**

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

2016 Membership Drive and Fundraising Begins!

Every October we ask MGABC members to renew their memberships. The annual cost is \$20.00 per 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 support you. Memberships renewed after September 30th will be good for the coming year. If this fee, for any reason, poses a hardship to you financially, please let us know and we will extend your membership free of charge.

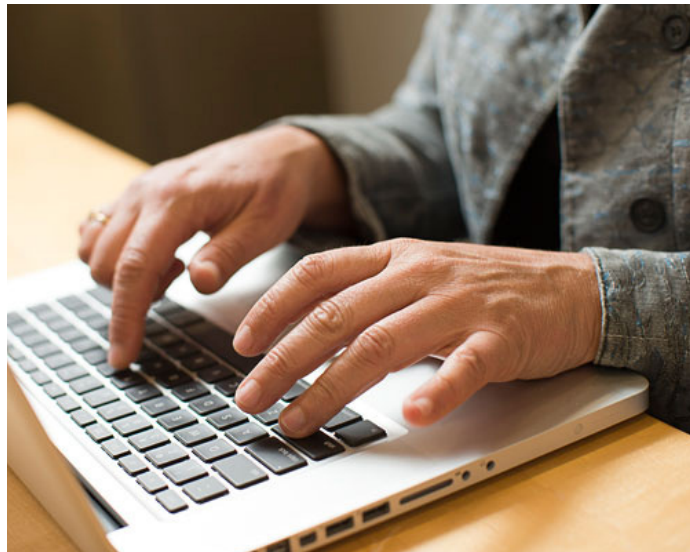
Articles contained in this newsletter are for information only. The MG Association of BC does not give medical advice. In matters of medical treatment, patients should consult with their physicians.
The MGABC is grateful to the province of BC for their charitable gaming grants.

MG NEWSLETTER

FROM THE WORLD WIDE WEB: Online Support

The Internet can be a great tool for information about Myasthenia Gravis and to find support from the comfort of your home.

There are many on-line forums such as DailyStrength.org, MDJunction.com, Neuro Talk Support Groups. Also Yahoo Groups has several groups related to MG such as MG_Moms and MGelders, as well as mgfriendsandfamily group. Also, remember other social media groups such as Facebook, Twitter and even Pinterest. These are great places to connect with people living with MG who are also experiencing many of the same things as you are. Facebook has general support groups as well as more specific groups such as Women with Myasthenia Gravis.



The MG Foundation of America <http://myastheniagravis.org/> has podcasts that you can listen to which are patient oriented with information on the diagnosis, treatment and management of MG. Just do a general search for online support groups for Myasthneia Gravis and find a group with similar interests as your own.

MuSK Testing at UBC

It has been pointed out to the MGABC that a number of neurologists in Canada do not know that the test to measure MuSK antibodies AchRAB negative MG has been done at UBC since 2013. Prior to that time, the suspected MuSK samples had to be forwarded to the Mayo Clinic in the US and/or to Oxford University in the UK at a large cost. It also meant the results of these tests took a long time to be received, processed and returned. The MuSK tests at the University of BC have been developed with the financial support of the Myasthenia Gravis Association of BC and the University of BC and will be submitted for approval to the Medical Services Commission of BC. Since the Canadian agreement on service transfers (parallel to the Meech Lake Accord of 1987), it is now federal policy that if one province approves a certain medical service, then all provinces can benefit from this same service.



The Myasthenia Gravis Association of BC is very proud that through our grants to the Neuroimmunology Laboratory at the Centre for Brain Health on the UBC campus, we have been able to support and facilitate MuSK testing faster and at less expense to British Columbians and to all

Fall 2015

Better treatment could be on the horizon for Myasthenia Gravis

Published on September 14, 2015

Myasthenia Gravis (MG) is a debilitating and potentially deadly disease that can afflict anyone, characterized by severe muscle weakness, affecting control of facial expressions, arm and leg movements, chewing, swallowing, coughing and breathing. There is no cure, only treatment.

The diagnosis of MG can be difficult and many diagnostic tools require specialized training and equipment that is not widely available, and many patients are misdiagnosed and inappropriately managed. To treat weakness and avoid potentially fatal respiratory failure, patients with MG usually require long-term immunosuppression with oral drugs, which can cause adverse effects on the immune system. In addition, there is a long delay between onset of therapy and response with many oral immunosuppressive drugs and no clinical or laboratory methods predict response.



A better and more targeted treatment could be on the horizon, with a grant provided to Dr. Jeffrey T. Guptill, MD, MA, MHS, Assistant Professor, Department of Neurology, Duke University, by the Myasthenia Gravis Foundation of America, allowing Dr. Guptill and his team to use innovative immunologic techniques to identify biomarkers in patients with MG that will improve diagnosis and predict therapeutic responses.

The key primary goals of the grant are to investigate immune system pathways and cells that show evidence of MG. This is important because there are existing drugs that target these pathways, so if it can be determined that they are useful, it would pave the way for clinical trials for certain drug therapies. Most of the therapies available now are not very targeted. The goal is that these would allow targeted therapies, with less negative impact on the immune system, fewer unnecessary side effects and infections.

Because this disease is considered rare—approximately 20 out of 100,000 individuals in the U.S. have been diagnosed with MG, most research in this area has been done in small collaborations. As part of the grant, Dr. Guptill will also create a multi-center research network of MG centers to develop a repository of MG blood samples for use in future studies.

This network of repositories will not only benefit the MG community, but could be used for studying other autoimmune diseases, creating a ripple effect to improving treatments in other areas.

Source: Kellen Company





WHAT'S YOUR POISON?

The debt Myasthenics owe to herbalists and poisoners

Dr. Maria Elena Farrugia. Dr. Ian Spreadbury and
Professor Nick Willcox.
The MGA/ MDC Centre, Oxford

In a recent article, we saw how researchers have taken advantage of venoms from creepy crawlies to help us in diagnosis and even treatment. Now it is the turn of the plants. As before, poisons have provided vital starting points for investigating how nerve --> muscle triggering works normally, and some have proved even more crucial friends in treating myasthenia.

A brief reminder (see diagram below)

The *ignition system* of our '**voluntary muscles**' depends on the chemical transmitter ACh (the '*ignition keys*') which is released when the nerve endings are switched on by impulses from the brain. The ACh then latches into special receptors ('AChR' = '*ignition locks*') on the muscle surface - and that triggers the muscle to contract. The spare ACh

is broken down by ACh esterase (AChE). The muscle AChR is called '**nicotinic**' because it is targetted by nicotine from the tobacco plant (*Nicotiana Affinis*). In most myasthenics, *the numbers of these AChRs are too low* - whether because of an immune attack or an inherited fault.

Licensed to kill...

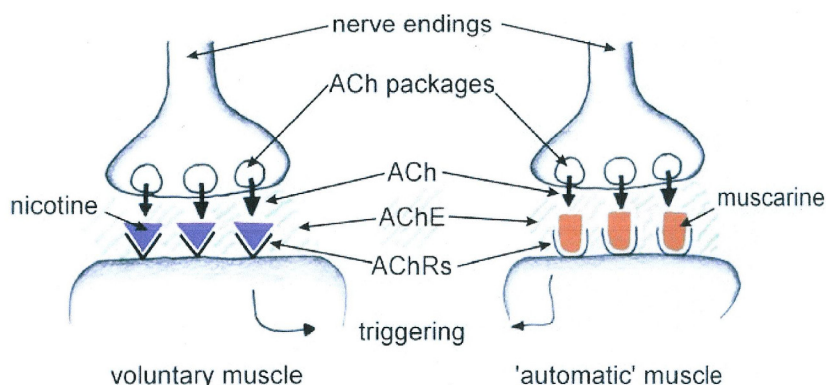
How poisoned darts helped to explain the defects in MG ...

Many poisons belong to the large family of 'alkaloids'. One key player is '**curare**' (it rhymes with Harare in Zimbabwe). It has long been used as an arrow poison by South American Indians (eg in Ecuador and Peru); its name means a venomous decoction, and it is boiled down from the barks of various trees. Sir Walter Raleigh and others mentioned it, but its preparation was first described by the versatile Alexander von Humboldt, in 1807. He was one of the last universal scholars in the natural sciences - not only a geographer but also a naturalist, botanist, author, artist and sociologist. Derived from the trees *Strychnos toxifera* or *Strychnos guianensis* and *Chondrodendron tomentosum*, curare was used so much by warring tribes and hunters that it was very valuable. Using arrows and silent blow- pipes, they could kill birds in only two minutes, small mammals in 10, and larger ones in 20 minutes.

The famous French researcher, Claude Bernard, discovered in 1855 that curare paralyzes voluntary muscles but not the heart, and kills by stopping breathing. He concluded that it affected nerve --> muscle triggering. We now know that it simply blocks nicotinic AChRs, and so makes muscles floppy - exactly as in MG when the AChR numbers are too low.

... and to save lives...

Now we come back to our heroine, **Dr. Mary Walker**, who was discussing a new myasthenic with the Neurologist, Dr. Denny Brown. They came to the conclusion that myasthenia seemed like poisoning with curare - to which myasthenics are super-sensitive. Desperate for some treatment - because MG was then often fatal - she injected another plant drug, physostigmine, because it had been the best known curare-antidote since 1900 (as shown by the Viennese Dr. J. Pal). When she tried it, the patient improved dramatically, a breakthrough she published in the Lancet in 1934. That drug is very similar to 'Tensilon', and is a short-acting version of the myasthenics' dear friend **Mestinon** (properly called **pyridostigmine**); this relative of physostigmine was first used in 1954. Mary Walker quickly realized that these drugs worked by blocking AChE, so delaying the breakdown of the ACh and boosting its chances of triggering the muscles - rather like using more choke when the car is cold.



Physostigmine comes from the West African Calabar bean (*Physostigma venenosum*), and was used there for trial by ordeal, rather like ducking suspected witches under water in this country. In Edinburgh in 1855, it had been shown to constrict the pupils (by enhancing the effects of ACh, as we now know).

In 1927, an American myasthenic, Harriet Edgeworth, tested another herbal drug on herself called **ephedrine**; for the next few years, it was the best hope for myasthenics. It soups up the muscle ignition slightly because it mimics the effects of adrenalin - the 'fight, fright, flight response' that you all know so well (pounding heart, sweating, hair standing on end...). It also helped Harriet to tolerate heat much better. (continued next page)

Ephedrine is derived from various *Ephedra* species, especially *E. sinica*. Also known as *Ma huang*, it has been used in Chinese medicine, probably as far back as 2800 BC, to treat colds and asthma; its cousins are still used as decongestants for 'bunged-up' noses and asthma. Ephedra was used by the Zen monks to encourage calm concentration during meditation and by Gengis Khan's bodyguards to keep them alert on sentry duty. Other alkaloids have less desirable side-effects; some are dangerous in MG, eg muscle relaxants or pain-killers such as Acetaminophen and Oxycodone, and also some herbal remedies.

Understanding the side-effects of mestinon...

Many 'automatic functions' also depend on ACh as transmitter; they include pupil contraction (in the eye), slowing of the heart and stimulating gut and bladder movements. They are not affected by the MG, because these '**muscarinic**' AChRs are completely different from the nicotinic AChRs in muscle; unlike them, they are stimulated by the toadstool poison, *muscarine*. Its effects include diarrhoea, gut cramps and sweating - rather like a mestinon overdose. It is one of several poisons in a toadstool you know well - the one with the red cap and white spots beloved of garden gnomes - the Fly Agaric (*Amanita muscaria*). The diagram shows the nicotinic and muscarinic Acetylcholine receptors.



...and treating them too...

Two lovely big eyes? The 'automatic' effects of ACh are normally stopped when it is destroyed by AChE. But they can get out of hand if the AChE is blocked too much by overdosing with Mestinon, which can cause gut over activity and diarrhoea - rather like muscarine poisoning - as many of you know only too well. Luckily, we can reduce that with yet another plant poison, **atropine** or its cousin **probanthine**. These drugs block the 'automatic' (muscarinic) AChRs without affecting the (nicotinic) AChRs in the muscles, (see diagram) and therefore block these Mestinon side-effects selectively. They also help to speed up the heart and dilate the pupils.

Atropine comes from a plant you probably know, Deadly Nightshade; it was called *Atropa belladonna* because the wide pupils enhance the beauty of a comely girl. It is now used as a 'premed' before anaesthetics/surgery because it dries up the juices in the mouth and lungs, and so prevents blockages and infections in the airways.

In conclusion, no matter how lethal such poisons may be, they may well have their uses in diagnosis and treatment. What is more, we should all be grateful to all the herbalists collectors and researchers for investigating them. **How many further valuable drugs are now at risk because of extinctions?**

Mycophenolate, otherwise known as CellCept is derived from the fungus *Penicillium stoloniferum*. The discovery of Mycophenolate was developed by Dr. Tony Allison who in 1954 first showed that the sickle cell gene protects against malaria!

We thank the authors, Drs Maria Elena Farrugia, Ian Spreadbury and Professor Nick Wilcox of The MGA/MDC Centre, Oxford and MGAUK for their kind permission to reprint this article.

A man was telling his neighbour, "I just bought a new hearing aid. It cost me \$ 4000.00, and it is state of the art!"

"Really?", replied the neighbour, "What kind is it?"

"Twelve-thirty."

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How Herbs and Natural Remedies Interfere with Drugs We May Need as Myasthenics

New MG patients are often surprised to learn that some of the herbs they may have been taking to make themselves feel better are doing the opposite. The following list summarizes how some herbs interact adversely with drugs you may be taking for your MG symptoms, as well as other illnesses.

Echinacea: is used for strengthening the immune system and preventing colds and flu	Interferes with action of immunosuppressant drugs such as prednisone, imuran and cyclosporine. It also can interfere with other drugs such as Valium, calcium channel blockers, HIV drugs and antifungals such as Nizoral. WARNING Echinacea may elevate the levels of some drugs, causing increased drug toxicity.
Melatonin: is used for insomnia and jet lag	Possible interference with immunosuppressants, antidepressants and heart medication such as Adalat. Melatonin use can interfere as well with the action of immunosuppressants, and can cause excessive sleepiness when taken with an antidepressant. It may also increase the heart rate and blood pressure.
Garlic: is used for cold and flu prevention and to check high cholesterol	Garlic can reduce the levels of immunosuppressants and HIV protease inhibitors thus lessening their efficacy and may also cause excessive and spontaneous bleeding in those who use aspirin and/or blood thinners.
Coenzyme Q-10: is used with the hope it will prevent or help cure heart disease	Coenzyme Q-10 has been known to interfere with blood thinners used in treating heart disease as it may increase blood clotting. It may also interfere with cancer chemotherapy, reducing its effectiveness.
Ginkgo Biloba: may be taken for memory loss as well as poor circulation	Ginkgo may interfere with aspirin, blood thinners and anticonvulsants such as Dilantin. It may cause spontaneous and excessive bleeding for those who use aspirin and blood thinners, as well as reduce the effectiveness of anticonvulsants.
St John's Wort: is often taken for depression	St. John's Wort is known to interfere with medications used for depression, HIV protease inhibitors, asthma, blood thinning, heart problems, oral contraception and antibiotic Tetracycline. It can cause severe headaches, stomach upset and restlessness, while significantly increasing the elimination of these drugs, thereby making them noticeably less effective. Sun sensitivity also increases when using St. John's Wort.

Myasthenia Gravis, Herbs and Other Supplements

by Stephen TePastte M.D.

Those of us with Myasthenia Gravis possess an antibody directing destructive forces towards our own healthy muscle tissue. The focus of the attack is specifically the post-synaptic junction, which receives nerve impulses at the neuromuscular junction. Anything that increases immune activity can worsen our MG. That is why stress and infection can wipe us out and sometimes even provoke a full relapse. We must be very careful about exposing ourselves to any immune stimulation.

Prior to my diagnosis of MG in late 1998, I unfortunately took Echinacea, which for myasthenics is bad, as it is a potent non-specific stimulator of the immune system. Later, in doing research on vitamins, minerals and herbs, I found some that do actually benefit us in some circumstances. Mostly though, what I found was these products are, at best, only mildly effective and, at worst, potentially risky.



In general it is appropriate for adults who have MG to take certain vitamins and minerals for the promotion of general good health. It is probably especially important that we take calcium supplements, as many of us are prescribed Prednisone. Most likely long term use of this drug will necessitate taking not only calcium but also prescriptive drugs to prevent Osteoporosis.

Ephedrine, an old drug that was used as a treatment for MG many years ago was reintroduced as a herbal product called "Ma Huang" and targeted for weight loss and increased energy. However, in MG it can help muscle function as it reacts directly at the neuromuscular junction. Ma Huang may be difficult to obtain. Be sure you get it from a reliable source as there have been reports of inadvertent toxic levels in some products leading to deaths in the US. Ephedrine and/or Ma Huang has not been shown as effective for weight loss or increase energy however. Do not use products with this ingredient without first discussing

with your doctor.

Coenzyme Q10 and Creatine are two supplements that have been used in muscle disease but are not considered effective in the treatment of MG. They are usually used by healthy individuals looking to augment or enhance their physical performance and are very expensive. They may be fairly safe but not worth the risk of unknown ill effects.

We myasthenics are fortunate to have a great deal of scientific knowledge about the nature of our disease. This allows us in most cases to have our disease managed satisfactorily and to live near normal lives. We owe this to advances in conventional medicine. Although we must always keep an open mind, we must not allow ourselves to be duped by quick fixes and overt advertising.

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UNCONVENTIONAL THERAPIES

Daily, the media is filled with news of alternative forms of medical treatment. People with chronic illnesses sometimes resort to these alternative treatments when they are dissatisfied with their conventional medical treatments.

Alternative medicine has many names – *homeopathic, natural, holistic, New Age* even *unconventional*. Practitioners of these types of medicine are often considered “Healers” but may include a variety of types, some not as ethical or educated as others and some ill-trained and unlicensed.

Many alternative practitioners are however educated, licensed and regulated (e.g. acupuncturists, chiropractors). Additionally, some physicians and nurses often use alternative medical methods in their conventional practices.

Patients with myasthenia gravis may be tempted to try alternative forms of therapy for a number of reasons. Myasthenics occasionally experience variations in the course of their illness when weakness may be more pronounced. It may be advisable during those times for physicians to make adjustments in the patient’s treatment plan and sometimes these changes require patience and perseverance to find the most acceptable form of treatment. You may become discouraged especially if you are experiencing unpleasant reactions. Sometimes patients feel the doctor does not understand or empathize. Family members or friends who do not understand the complexities of the disease may try to help by suggesting unconventional therapies. Highly visible advertising in the media may be persuasive and enticing as well.



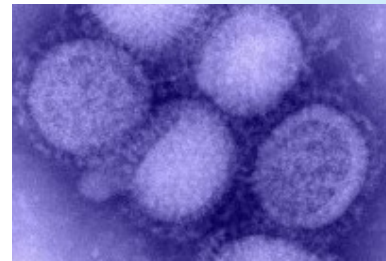
While some forms of alternative medicine may be harmless in nature, it is important to remember that there is no scientific basis for many of these therapies. Medical treatments are not considered standard unless they can be scientifically demonstrated to be safe and effective. This may not be the case with unconventional treatments, many of which are often expensive and can be dangerous to your health. If you are considering an unconventional therapy, special diet, or nutritional supplement, please speak with your doctor first.

Know the Difference between a Cold and H1N1 Flu Symptoms



A **COLD** and its symptoms tend to develop over a few days.

- Headache
- Sneezing
- Coughing: either hacking or mucus-producing
- Stuffy Nose
- Sore Throat
- Mild fatigue and/or body aches



The **H1N1 FLU** has a rapid onset within 3-6 hours. It hits hard and includes sudden symptoms.

- High Fever in 80% of cases > 100°F
- Severe aches and pains
- Cough: Dry Hacking/no mucus
- Headache
- Chills

Vaccinations and MG

“Will getting a vaccine, such as a flu shot worsen my myasthenia gravis?”

It is generally believed that vaccinations (e.g. influenza) are safe in patients with MG. The evidence suggests that vaccine-related worsening of MG is rare. Thus most MG specialists believe the benefits of immunization outweigh any small risk related to any possible transient worsening of MG symptoms. If you have any concern about this, please discuss this topic with your doctors.

“If I am on immunosuppression for my myasthenia gravis, is it safe to get a vaccine?”

If you are taking immunosuppressive medication, such as Prednisone, Azathioprine or Mycophenolate, it is still okay to get a flu shot or other inactivated, dead vaccines such as the pneumonia shot. However if you are taking immunosuppression, it is usually recommended you avoid **live, attenuated** vaccines, such as shingles vaccine and the nasal spray form of the influenza vaccine. The more common influenza injection or the flu shot is inactivated and thus not alive, so it is much safer in immunosuppressed patients. If you are considering getting a vaccine, and are unsure, ask your doctor if any of the drugs you are taking are immunosuppressive and, if so, is the vaccine safe for you. It is worth noting again that most vaccines are inactivated but because there are a ‘few’ that are not, MG patients should be careful. These activated vaccines carry a higher risk for those patients who are immunosuppressed.



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Although it was another beautiful day for the SCOTIABANK Charity Challenge we had a very poor turnout. We are especially grateful to Dr and Mrs Oger and their grandson who walked the 5k and to Katherine McGillivray (nee Kelsey) and her friends, Cathy Snow and Alicia de Leo, who ran the 1/2 marathon. We thank them for all of their pledges and for giving us a participating presence. THANK YOU, ALL!!

Joan Nuttall
Lorne Kastrukoff
Michelle Eisner
Nancy Bogle
Taria Aziz
Ruby Ma
Ebrina Gibbs
Theresa Jiwa
George Kimura
Margo Csontos

Ian Folkers
Willowbrook Collision
Brenda Laidlaw
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Ken and Hanna Hyland
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Donations In Memory Of:

Sheryle Johnson and Barbara Ball In Memory of Paula Horning

Corporate Donations:

Telus for Telus Cares

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. Advocacy Help Sheet
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 (\$20.00 from MGABC)**
- **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)**

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

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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 Myasthenia.Gravis@bc-cfa.org with the words "**E-mail request**" in the subject line. Thank you.