September 2017 MG Canada

President’s memo:


MG chronic patients will find the new University Health Network study now in progress on “trigger factors for relapses in Myasthenia Gravis” particularly interesting. It seems to me that mental attitude is a major factor in personal well being. See brief overview article (on Page 14-15) on how you can participate.

From my modest experience as President now for a few years, we chronic MG patients seem at our best when we’re thinking positive. Bonnie Prentice, Margaret Gartner and Karly Quinn, who keep our MG Canada Facebook Support group running and totally current, are brilliant examples. If you haven’t joined the conversation you should consider it. Check out the ‘Mindful Cup of Tea’ article Bonnie referred and ‘Mindful’ Magazine gave us permission to run. “Mindfulness” will be a feature our next MG Support meeting. You can participate

Continued on Page 2
President’s Message Cont. from Page 1

with a Mindfulness speaker. If you can’t make it because you’re too far away, etc., then check out our ‘Livestream’ of the meeting while in progress or after on Video at MG YouTube Channel TV. Find the link on our base web site www.MGCanada.org

Other features in this issue include:

- Reminder on MG Fit national fundraising campaign
- National Healthcare Data Base project report from Tara Buonpensiero
- Criteria for “trigger factors for relapses in Myasthenia Gravis” UHN study looking for volunteers

Wrapping it up….. what can be more relaxing than the great outdoors fishing.

Take care everyone.
Love hearing from you anytime.
CapCowan@MGCanada.org 905 642 2545

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Upcoming Events

**Saturday, September 30, 2017. Edmonton Myasthenia Gravis Patient Education Day** at Executive Royal Hotel, Edmonton., Alberta. For inquiries contact Aimee Soloway at 780-407-8388 or mgday@ahs.ca

**Sunday, October 1, 2017, Myasthenia Gravis Society of Canada Support Meeting.** Loblaws Community Meeting Room, Bayview Village Mall, 2877 Bayview Village Mall, North York, M2K 2S3. 6-8 p.m.
Info 905 642 2545.

**Thursday, September 21, 2017. Myasthenia Gravis Manitoba** is holding a support meeting at 7:00 pm at St. Boniface Hospital, 409 Tache Avenue, Winnipeg, Basement South Entrance. Room AG001 & 2. Info 204 444 7802

**Vancouver Island Support Groups:** Contact information for Parksville is John Skalos, North Island MG Association 250-754-9636. email: lisaandjohn@shaw.ca. For Victoria Dennis Shpeley, MG Victoria Support Group, 250-478-0131. email: shpeleys@shaw.ca.
Myasthenia Gravis Society of Canada

MG Support Meeting

Sunday, October 1, 2017  6 - 8 pm.

Living With Myasthenia Gravis

Support Meeting for those living with Myasthenia Gravis, caregivers, family, friends & interested others to meet.

Loblaws Community Meeting Room, Bayview Village Mall, 2877 Bayview Avenue, North York, M2K 2S3.
(The Meeting Room is located upstairs, S/W corner of the store, Elevator access.) Public Transit Access, subway access at Bayview Station on the Sheppard Subway. Free Parking in Bayview

For this meeting, we request those members who are able, with last name starting M-Z bring a food item to share. Loblaws has asked that any food served come from their store.

Info at 905 642 2545  www.MGCanada.org

Anagrams

A DECIMAL POINT: When you rearrange the letters: A DOT IN PLACE
THE EYES: When you rearrange the letters: THEY SEE
ELEVEN PLUS TWO: When you rearrange the letters: TWELVE PLUS ONE
Progress on the Medical Professional Database

Why the Medical Professional Database?
How many times have you told a medical professional that you have Myasthenia Gravis and in return you get a blank stare? My family doctor has prescribed me antibiotics that are on the list of medications MG patients shouldn’t take twice now. Thank goodness I researched the medications before I took them.

One of the objectives of the Myasthenia Gravis Society of Canada is to advance education about MG by providing seminars, literature and other means of multi-media communication, to diagnosed MG patients, their families, friends, caregivers and the medical profession. By raising awareness of MG we hope to reduce the time it takes for new patients to be diagnosed and to get the treatments and special accommodations needed in our day to day lives.  (Editor’s Note: See pledge form Page 3)

To advance this objective, we are continuing to make progress on a database of medical professionals. This database will be used to share critical information about MG with medical professionals across the Country.

The first priority in preparing the database has been on identifying Canadian medical associations. The database includes the full range of medical professions from the fields of neurology, dentistry, massage therapy, physicians, naturopaths, nurses etc.

By reaching out to the Canadian medical associations, we have the ability to reach 225,000 (and counting) medical professionals and raise awareness of MG Canada. Some initial work has been undertaken to include Provincial associations which increases the number to about 430,000. This number will only increase as more Provincial associations are added to the database.

This is just the start. The next priority will be to reach out to colleges and universities to raise awareness of MG to the next generation of medical professionals.

How Can You Help?

While a lot of work has already been done, there is a lot more to do. If you have time to volunteer to help with this initiative, please get in touch with me at buonpensiero@yahoo.com.

Tara Buonpensiero, Director, MG Canada
May 2017 Support Meeting Introduced

MG Fit Fundraising Campaign

See Pages 6 & 7 for more information.

MG Meetings Offer Opportunities to Share With Others
What is MG Fit?  

MG Fit is the First National Fundraising Campaign by Myasthenia Gravis Society of Canada.

MG Fit intends to assist in the costs of improving awareness and support of MG patients, caregivers, health care professionals and MG researchers.

The MG Fit campaign fulfills the mission of MG Canada to promote the health of MG patients by providing access to information and support group programs; to advance MG education through seminars, literature and other multi-media communications; and to receive and maintain funds for qualified MG research, or researches for MG cure. See Donor Form on Page 7.

Moreover, MG Fit intends to be a sustainable platform for MG patients to achieve wholeness in view of the changed dynamics of their bodies, minds and spirits. Those living with MG eventually realize that they have a “new normal” which limits their capabilities. MG Fit promotes the acceptance of MG chronic realities which will allow patients to pursue stability through treatment, and attain growth through the determination to live within their “new normal.” Thus, more than just an awareness and fundraising campaign, MG Fit gives patients the opportunity to achieve personal well being, and reach new levels of fulfillment and wholeness given the realities of the chronic disease.

Myasthenia Gravis (MG) is a rare neurological autoimmune disease that causes muscle weakness. There are several treatment options for MG patients, and no singular treatment works for everyone. As of today, no cure has been found for MG but it can be stabilized with treatment by a neurologist specializing in MG.

MG Canada, a registered not-for-profit organization with Charitable # 81155 1431 RR0001, estimates that about 30,000 Canadians may have MG, but many have never been diagnosed, or worse, have been misdiagnosed with other conditions which can become life-threatening if they suffocate due to severe weakness of the respiratory muscles.

Continued on Page 7
Donor Form

“I am Stepping Up for MG Fit!”

Name:_____________________________________________________
Address:__________________________________________________
City____________________ Prov._______ P.C. ________________
Phone ____________________________________
Email: ________________________________________________

I support MG Fit by donating:
(Please select one)
___1,000 steps = $10
___2,000 steps = $20
___5,000 steps = $50
___10,000 steps = $100 Silver
___50,000 steps = $500 Gold
___100,000 steps = $1,000 Platinum

Please indicate:
___Online donation
___Cheque donation

For online donations please go to
www.MGCanada.org & www.MGFit.org

For cheque donations please write cheque and mail to:
Myasthenia Gravis Society of Canada
247 Harold Avenue, Stouffville, On., L4A 1C1
Further information Email Give@MGCanada.org
Or call 905 642 2545 or www.MGCanada.org/donate

Myasthenia Gravis Society of Canada
is registered charity #81155 1431 RR0001.
Tax Receipts for donations of $10 and over
are issued unless otherwise specified.
I noticed that Cap Cowan mentioned how the Mindfulness Course would/could help us. I took this course several years ago and YES, it has been most helpful. I ran across this link this afternoon and it not only is a pretty good explanation of how mindfulness can help us, but it's cool way to calm yourself. Please give it a try!!

The following article, “Mindful Cup of Tea” was referred by Bonnie and ‘Mindful’ Magazine gave us permission to run.

How to Be Mindful With a Cup of Tea

When it’s difficult to meditate, you can build moments of mindfulness into the day through simple activities like brewing and enjoying a cup of tea.

By Ed Halliwell | November 16, 2016,
Published with permission of Mindful Magazine.

Bringing mindfulness to simple activities like drinking tea trains us to direct attention consciously. We might think we choose what we’re paying attention to in life, but in reality most of us are driven by habit and impulse. By deliberately choosing to attend to an activity, we slow things down and let ourselves become aware of the process.
of attending and perhaps how little control we usually have over it. We might notice the repeated wandering of the mind as we attempt to stay with what’s happening right now.

We are learning to see what’s often obscured by distraction. By coming back repeatedly to the various aspects of tea-drinking, we are cultivating the capacity to focus. And because we’re practicing this with gentleness, without judging ourselves or striving to reach some goal (even the goal of becoming better at paying attention), we are simultaneously training in acceptance and compassion.

Mindfulness means paying attention with the senses, in the body—feeling, touching, seeing, hearing, and tasting. Sensing always happens within the body and in the present moment (you can’t feel something in your thoughts, or in the past or future), so this tuning in to sensing helps to bring us into the reality of here and now. Sensing mindfully thus creates a space where we can experience what is happening, rather than what we think should happen or what has already happened. It’s a chance to practice resting the analytical mind that habitually searches for solutions, even when none is available.

We are also practicing conscious choice. By watching how we make simple decisions—pouring water, disposing of a teabag, swallowing—we are bringing a deliberate awareness to activities that are often performed half-asleep. (Have you ever found yourself putting milk in a friend’s preferred black tea just because that’s how you take it yourself?) If we are unaware of how we get caught up, it’s impossible to become free. But if we can start to practice seeing when we are acting on autopilot, through force of habit, or on impulse, we have already created the possibility of something different. We are starting to know what we are doing as we are doing it. This knowledge can begin with tea-drinking, and can then expand to every aspect of life.

Continued on Page 10
Mindful Tea-Drinking Practice

If you are feeling very depressed or anxious, even short periods of meditation can seem overwhelming at first. So bringing mindfulness to everyday activities such as drinking a cup of tea, cleaning your teeth, or going for a walk is a gentle way to begin. It’s also a helpful way to develop your practice. Below are a few suggestions on how to practice mindful tea-drinking. Obviously, you can make and drink the tea in any way you like, or you can replace it with another regular activity. The important thing is to let go into seeing, feeling, tasting, touching, and hearing, and to return gently to the senses whenever you notice the mind straying into thought.

1. **Pay attention to the sound of the water heating and boiling in the kettle. Hear its bubbling and gurgling.** Can you see wisps of steam coming from the spout? Does the kettle subtly shake from the movement of the water inside? Be open to your senses, rather than try to analyze what’s happening.

2. Notice the feeling of being in your environment: your bottom’s contact with the chair or the floor, if you’re sitting down; the weight of your feet on the ground, if you’re standing.

3. **Pouring the tea, watch the colour of the water change as it meets the teabag.** Be interested in the transformation from clear water to tea, and the tinkling of liquid as it fills the cup. When your mind wanders into thought, as it probably will, gently return your attention to sensing.

4. **Lifting the teabag out with a spoon, feel the touch of the handle against your fingers, and the weight of the bag dropping away as you tip it into the bin.** Let yourself hear any related sounds, such as the opening and closing of the bin lid. Notice any tendency to do this on autopilot, and come back to present-moment sensing when you find you’ve drifted to distraction.

Continued on Page 11

Be open to your senses, rather than try to analyze what’s happening.
5. **If you take milk and sugar, be interested in how you feel as you reach for and add these ingredients to the brew.** Do you really want them? How do you know?

6. **Notice the warming of the cup that contains the hot liquid.** How do your hands feel as you hold it?

7. **Now, bring the cup to your lips.** Be interested in how your hand and arm know how to move in this direction without you having to tell them consciously what to do.

8. **Take a sip of tea.** Rather than gulping it down, see if you can let the taste tickle your tongue. Perhaps gently move the liquid around your mouth. Savor the taste—is it pleasant? Or perhaps you’d prefer it stronger or weaker? You don’t have to do anything about it (unless you choose to). Just be aware of your sensations and the liking or disliking of them. If there are thoughts, let them enter into and then pass through your mind without following them. Try to stay with the tasting. Notice without judgement any desire to rush the drinking, and any impatience that comes.

**If there are thoughts, let them enter into and then pass through your mind without following them. Try to stay with the tasting. Notice without judgement any desire to rush the drinking, and any impatience that comes.**

9. **When you decide to swallow the tea, notice how that decision is made.** Is it a conscious choice, or does it happen automatically? Stay present to the swallowing, the reflex movements in the back of the mouth and the throat, the trickle of liquid down into the stomach. How does it feel to be swallowing?

10. **Notice how the liquid seems to disappear.** Is there a point when the tea stops being separate from you? When and how do you recognize that moment?

11. **Pause now, noticing any feelings of irritation, or thoughts such as: Hurry up, I’ve got better things to do.** Or perhaps a sense of peace or stillness enters you. If so, where do you feel it? Is it changing from moment to moment, or staying the same? Maybe there’s something else going on in your mind and body, perhaps unrelated to the tea-drinking, pulling you into thoughts of the past or the future. If so, just notice it. Whatever comes up in your experience is okay from the perspective of meditation—there’s no right or wrong thing to notice.
Bring gentle awareness to whatever emerges. Becoming conscious of how much the mind wanders is a sign of growing awareness.

12. **Take a look around you, opening your eyes to your surroundings without buying into evaluations about them.** Just be aware of any thoughts or feelings that come up.

13. Now, return your attention to the cup of tea in your hand. (Has the temperature dropped?) Watch as you decide when to begin the process of taking another sip. Return to step seven, and continue drinking the tea until the cup is empty, or you decide to stop drinking. If the latter, be curious about what is prompting that decision. Has the tea gone cold, has the taste changed, is there an impulse to get on with your next activity? (If the latter, what does that feel like? Is there a place in your body where you feel it most strongly?) Whatever you choose to do in each moment, try to watch the experience from an engaged observer’s perspective.

You don’t have to follow these steps like a strict to-do list. The key is to open yourself to the spirit of the practice, sensing with gentle precision what’s happening, moment by moment, and coming back to sensing whenever you notice you’ve drifted into thought.

*This blogpost is an extract from Into The Heart of Mindfulness by Ed Halliwell Mindful Magazine reproduced by permission*

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**Another Facebook Post on “Mindfulness”**

Laura Pinto 8:11 May 23

Is the Society certain that it wishes to promote mindfulness? Apart from the critiques of it as superficially appropriating Buddhist principles, it is scientifically sketchy. While it might be shown to have therapeutic benefits in the future, the evidence is scant and a lot of thinkers do not support it. A few "popular" things you can read include these links (focus is more on work-paced programs, but more broadly applicable; there are more interesting academic things I’ve seen with more complex arguments against its usefulness since it pathologizes the individual to a large extent). Anyway, for those interested: https://www.spectator.co.uk/2014/11/whats-wrong-with-mindfulness-more-than-you-might-think/, http://www.salon.com/2014/12/06/mindfulness-truthiness_problem_sam_harris_science_and_the_truth_about_buddhist_tradition/, http://www.telegraph.co.uk/women/womens-life/11331034/Mindfulness-the-saddest-trend-of-2015.html, http://www.huffingtonpost.com/ron-purser/cutting-through-the-corporate-mindfulness-hype_b_9512998.html
2017 Myasthenia Gravis Patient Education Day in Edmonton, Alberta

Please join us for the 8th Annual Myasthenia Gravis (MG) education day. Attend presentations by MG experts on new developments and treatments, participate in discussions about enhancing your quality of life, and learn about techniques for coping with MG.

Date: Saturday, September 30, 2017, 8:30 am

See detailed schedule below or download PDF

Location: Executive Royal Hotel - Edmonton Airport
Address: 8450 Sparrow Dr., Leduc AB

Registration Open!
Complete your registration online.

Download the 2017 MG Patient Education Day Invitation
For inquiries please contact Aimee Soloway at 780-407-8388 or email mgday@ahs.ca

Plum Tree?
September
2017

MG Canada’s Newsletter “Contact” is published by

Myasthenia Gravis Society of Canada

c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2
Phone 905 642 2545 www.MGCanada.org

Do you have an MG article of interest to “Contact”?
Please forward to CapCowan@MGCanada.org

Articles in the Myasthenia Gravis Society of Canada Newsletter express the views of the author and are for information only, not medical advice. Patients should consult with their physicians for medical treatment.
A new Patient Participant Research project by UHN (University Health Network) called “Prospective study of trigger factors for relapses in Myasthenia Gravis” is looking for 250 MG patient volunteers.

Excerpts from Background/Purpose …“Physical and psychological stress has been implicated in the development of autoimmune disease. Some well-recognized factors that may trigger or worsen MG are surgery, immunization, emotional stress, intercurrent illness (example – viral infection), some medication, menstruation, hot or cold weather, etc. Of course not only does stress cause disease, but the disease itself also causes significant stress in the patients, creating a vicious cycle.

The study goal is to explore whether stress, depression and/or anxiety, or certain personality traits are associated with a higher rate of MG relapses. There will be four types of questionnaires: Beck’s Depression Inventory, Trier Inventory for assessment of Chronic Stress (TICS), the Homes & Rahe Stress Scale and NEO PI-R Personality type scale.”

Study Design: “There will be a prospective 12-month study of patients attending the Prosserman Family Neuromuscular clinic or admitted or UHN – Toronto General Hospital for management of MG. We will assess if psychological stress factors such as depression or different life events (divorce, family death, move, job loss, etc.) or personality type predispose to an MG relapse. We will start to enroll patients in 2017. This study will compare stable patients with those having MG relapses or worsening with respect to the presence of chronic stress, depression or a certain stressful life event which may lead to an MG relapse. Also, we hypothesize that we will discover a relationship between specific personality types and the likelihood of suffering a relapse. We plan to enroll 250 participants.”
Continued from Page 14

Complete consent form is 5 pages of details including other reassurances & methods of confidentiality, personal assessments with study team, personal contributions to benefit others, deeply personal aspects of 4 questionnaires, possibility of remote answers if necessary.

All 5 pages of the study consent form will be published online at www.MGCanada.org for personal, individual MG patient follow-up directly with UHN. MG Canada member readers who wish a hard copy without access to email will be offered a copy by postal mail on request from MG Canada or preferably emailed the complete version on request.

This writer and MG Canada strongly endorses and encourages the research initiative and highly recommends MG patient participation in this “triggers” study, a unique medical study patient participant approach to better understand MG patient causes and effects on mental health and well being.

CJC

A Big “Thank You” to all for your memberships, donations, and “Celebration of Life” gifts received to assist our charitable purposes to: “Promote health by providing individuals with Myasthenia Gravis with access to information or group support programs; To advance education by providing seminars on Myasthenia Gravis diagnosed patients, families, friends, caregivers, the medical profession; and to support research.”

Donations can be mailed to Myasthenia Gravis Society of Canada, 247 Harold Avenue, Stouffville, Ontario, L4A 1C2. 905 642 2545

Or online at www.MGCanada.org/donate

Registered Charity# 81155 1431 RR0001
Need to Talk? Here are Some MG Friends:

**BY PHONE: The Peer Support Group.** Whether you have recently received the news that you have Myasthenia Gravis, or you have been living with MG and want to share your experience, these members have offered their support. Please feel free to contact them to discuss your experience.

**Ages under 40**
- *Tiina Elder*, Mississauga. (905)-565-5875  email: tiina.stuart@gmail.com
- *Jill Thomson*, Calgary, AB. T2J 0V6  403-286-0056

**Ages 41 – 60**
- *Phillip Sanderson*, Harriston, ON, N0G 1Z0. (519) 338-3356

**Ages Over 61**
- *Florence Pye*, Carleton Place, ON, K7C 1P8. (613) 257-1847
- *Vikki LeDez*, Sunderland, ON, L0C 1H0  (705)-357-0377  email: vledez@yahoo.ca
- *Fernanda Nascimento*, St. Catherines, ON. 905-937-9762

**ONLINE: Myasthenia Gravis Support Canada**

On Facebook, you can connect with others affected by Myasthenia Gravis through the Myasthenia Gravis Support Canada Facebook page, another way to learn more through discussion, posting and comments. Use this URL:  
https://www.facebook.com/groups/1380379838949713/ and link text is Myasthenia Gravis Support Canada.

“Start by doing what’s necessary; then do what’s possible; and suddenly you are doing the impossible.” Francis of Assisi
MEMBERSHIP APPLICATION

Date ___________________________ New Member _____ Renewal _____

Last Name _____________________________________ Male _____ Female _____

First Name ___________________________ Date of Birth ____________________

Address __________________________________ Apt. or Unit No. ________

City _____________________________________ Postal Code ________________

Phone ______ - _______ - ________ Cell Phone ______ - _______ - ________

Name of Spouse, Partner or Significant Other (Optional)

____________________________________________________________________

E-mail Address ___________________________ @___________________________

In order to reduce postage costs I would like to receive the quarterly newsletter “Contact” via e-mail, rather than by regular mail: Yes ______ No ______

Would you like us to call you? Yes ______ No ______

For “Myasthenics Only” and for statistical purposes (held in strictest confidence):

My Neurologist is Dr. __________________________

Neurologist’s Telephone No. _______ - _______ - _______

ANNUAL MEMBERSHIP FEE

$ 20.00 + $2.60 HST = $ 22.60 $ ________ (12 months – Individual or Family)

or $ 50.00 + $ 6.50 HST = $ 56.50 $ ________ (36 months – Individual or Family)

Donation $ ________ (optional)

Total $ ________

Please complete as much of the form as possible.
All information will be kept in the strictest confidence.

It is important to keep your membership and record of information up to date and accurate each year. Please advise any changes during your renewal period.

Questions or Changes? Call 905 642 2545 or e-mail to membership@MGCanada.org

Mail completed form and payment to:

Membership Coordinator – Myasthenia Gravis Society of Canada
c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2.

Please make cheque payable to: Myasthenia Gravis Society of Canada

Tax Receipt issued for Donations of $10 or more. Registered Charity#81155 1431 RR0001
Quotes from Online: “Hi Everyone! I’m reporting good news this morning! After a long haul with Myasthenia, Thymoma removal, chemotherapy and tests and scan beyond measure, my MRI yesterday has shown no cancer. The remaining area they were concerned about is consistent with post operative tissue. My Myasthenia symptoms seem to be in remission as well. My next scan is in 3 months. God willing no tests, scans, pills or doctors until then. We are in a happy place today!”

“So I had my first Pre thymectomy consult with (my doctor) in London. It went well. He explained why MG patients need to get their chests cracked open. I guess all of the Thymus must be removed and that’s the only way. It was a lot to digest and to be quite honest a little scary. My biggest fear is I will get worse.”

“Hi everyone! I’ve been feeling bloated and full for the last couple months and was wondering if this could be a side effect of prednisone? Has anyone else experienced this? What about with pred withdrawal? Thanks!”

“I know some days it’s hard to be grateful when you have this diagnosis... but I believe positivity is a necessity in dealing with difficult situations. I’ve seen this 30 Days of Gratitude on other FB pages, and we thought this might be something that we could share and maybe get a little more insight into what makes us all tick.

There will be a new post each day. September 1—What smell are you grateful for today?”