Billion $steps Goal All Over Myasthenia Gravis

MG Canada’s slogan “$tep up for MG Fit” launches an ambitious national campaign for Myasthenia Gravis Society of Canada – 1 step at a time - specifically at least 1 billion steps starting May 28, 2017 at our MG Canada Support meetings across Canada.

“It’s time all Canadians know what Myasthenia Gravis (MG) is, who gets MG and how and where to get professional health care MG treatment,” said Cap Cowan, president, Myasthenia Gravis Society of Canada.

Canadians everywhere should know the signs of MG crisis, what to do and where to get help. MG Canada estimates over 30,000 Canadians could have MG but many don’t know it so they are often misdiagnosed with other conditions, putting them in mortal danger of suffocation or worse.

MG Canada’s first national fundraising campaign aims to assist in dramatically improving awareness and support of Myasthenia Gravis for Canadian MG patients and caregivers, MG health care professionals and MG researchers, one step at a time valued at a penny per step.

For more information, sponsorships and donations please visit www.MGFit.org contact Cap Cowan at 905 642 2545 or email BillionSteps4MG@MGCanada.org.
Give online at www.MGCanada.org

See Page 3 for details
President’s Message

Spring at last. The promise of great things to come. New growth. New ideas. New hope. Not often but occasionally I get a pearl of insight from a church sermon – but I’ve been very lucky recently. Two very appropriate ideas should benefit our MG Canada visions. The concept of Mindfulness and how it can be applied for MG patients

Mindfulness

ˈmɪn(d)ɪnəs noun
A mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations, used as a therapeutic technique – especially developed for chronic health issue patients.

“We are a People”

The fact is as MG Canada or Myasthenia Gravis Society of Canada, we've become our own unique entity. A National family of common interest people with a common purpose as advocates of Myasthenia Gravis serving as many as 30,000 Canadian effected by Myasthenia Gravis. We hope our “MG Fit” themed first National fundraising campaign will be a resounding success with all your help.

See “What is MG Fit?” articles and pledge form. Time to “$tep Up For MG Fit”. Pages 4, 5, 6, 7.

“Billion $teps all about Myasthenia Gravis” News Release to share everywhere we can. Page 1.

I’m asking all MG Canada members, family, friends, Health Care professionals and other Canadians to join or create an MG Fit fundraising Pledge team. Let’s move to another much higher level of dramatic increase in Myasthenia Gravis awareness, support, education and research. As chronic conditions go, MG is an enigma that deserves much better understanding, care and treatment than up until now. Much is better but much more is needed. Your personal help is needed to make this happen and financial reality is a major part of this.

It’s MG Canada’s purpose, passion and dream.
A strong, fearless, supportive Canadian Myasthenia Gravis caring people prepared to help each other with as much as it takes.

Continued on Page 13
Thank you Dr. Carolina Barrett-Tapia for your presentation at our MG Support February meeting. Portions of her presentation can be seen on video link at www.MGCanada.org. We appreciated ‘Dr. Carolina’s’ informative insight into her ongoing patient participation research and the expansion of scope to include several mind set ratings. Dr. Carolina has also consented to be an MG Canada Health Professional Adviser.

Myasthenia Gravis Society of Canada
MG Support Meeting
Sunday, May 28, 6 - 8 pm, 2017

Introduction of “$TEP Up for MG Fit” Fundraising Plus
Personal Journeys of 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 A-L 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
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.

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 may have been misdiagnosed with other conditions which can become life-threatening if they suffocate due to severe weakness of the respirator muscles.
Donor Form

“I am $tepping 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

*online donations will receive an automatic receipt*

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

Myasthenia Gravis Society of Canada
is registered charity #81155 1431 RR0001.

“Tax Receipts for donations of $10 and over are issued unless otherwise specified.”
Part II. Medical Treatment of MG
Highlights from slide presentation
(In our February Issue of Contact, Part I of Dr. Nicolle’s presentation was published which focused on what is and what is not Myasthenia Gravis. Part II continues with the highlights of his comments on medical treatment of MG. Guests were invited to ask general questions about MG, but not regarding specific personal treatments.)

Medical treatment of MG
• Most patients with MG do very well (eventually) with medical treatment.
• Side effects can be significant

The Thymus in MG
The thymus gland is often abnormal in MG
Normal role of thymus is to ‘educate’ immune cells (lymphocytes) to ignore self (tolerance) and only react against foreign antigens.

Continued on Page 7
Thymectomy in MG

- Two reasons to remove the thymus in MG
  - Thymectomy in early onset antibody positive AChR MG without thymoma to (hopefully) remove a hyperplastic thymus and improve MG symptoms - avoiding the need to take medications for long periods of time
  - Thymectomy to remove a thymoma
    - does not help symptoms of MG

The Thymus in MG.

Two types of abnormalities

- Hyperplastic
  - Thymic tissue is overactive and cells produce antibodies against the AChR
  - Most common in early onset MG – found in \( \frac{2}{3} \) to \( \frac{1}{3} \) of patients who are less than 50 yrs. at first symptom
  - A hyperplastic thymus is removed to help the MG
    - But we won’t know whether it is hyperplastic until it is removed!
- Thymoma
  - Tumour of the thymus
    - Much more common in late onset MG – found in \( \frac{1}{3} \) to \( \frac{1}{6} \) of patients > 50 yrs.
    - Usually benign when small and removal is curative for tumor – but does NOT help MG

Thymectomy in MG

Ideal candidate
- Early onset (50…65?)
- Generalized MG – not ocular
- AChR antibody positive – not MuSK
- Within 3 (?5) years of onset of symptoms

Controversies
- Does it really work?
- Ongoing international trial
- How to remove it?
  - Trans-sternal (breast bone), video-assisted, cervical (neck)

Thymectomy in MG: what I have been saying for 20+ years.

Until proven wrong, I advise early onset (< 50 yrs old at time of first symptom) MG patients with positive AChR antibodies who are within 3 years of symptom onset to consider trans-sternal thymectomy. In 40% of cases this may allow patients to come off medications without symptoms coming back.

Continued on Page 8
No better than medications but may produce same benefit without need to take medications for the rest of your life

Thymectomy in MG: An international randomized clinical trial

• Thymectomy in generalized AChR antibody+ MG patients who were less than 65 at disease onset and had MG for less than 5 years
  o Most would use 50 yrs. and 3 yrs. duration
• Best medical treatment compared to best medical treatment + thymectomy
  o Only trans-sternal approach used

• Group who had thymectomy:
  o Needed less prednisone
  o MG did better
  o Less likely to require other drugs to treat MG
  o Azathioprine
  o Fewer hospitalizations for their MG
• So this study confirms what most of us have been doing all along!

Outlook in MG
• Not curable – lifelong treatment may be required
• Highly treatable – 90% go back to normal eventually
• Several phases
  o Symptoms of MG before diagnosis
  o Improving symptoms of MG
  o Symptoms of side effects of medications
  o Doses lowered
  o Improved symptoms of MG and improved side effects
  o No symptoms, off medications – remission!
  o Relapse/exacerbation – always a possibility

What makes MG get worse
• It just happens some times
• Infections
• Stress – physical (surgery) or emotional
• Reducing doses of medications to treat MG
  o Especially if done too quickly
• Other medications
  o Some antibiotics
• Hormonal changes in woman

Continued on Page 9
Patience is required!
- Mestinon - hours to days
- Prednisone - 3-6 months
- Imuran - 12-18 months
- Mycophenolate - many (6-12?) months
- Methotrexate - ?
- Tacrolimus - ?
- Cyclophosphamid

Prevent the ‘bad’ (anti-AChR) antibodies from causing weakness
- Prevent bad antibodies from binding to AChR
  - Intravenous immunoglobulin (IVIg)
- Remove bad antibodies
  - Plasma exchange (PLEx)
- IVIg = PLEx in terms of effect
  - Some patients respond to one and not the other
- IVIg slightly better in terms of side effects
- PLEx may work slightly faster

Antibodies in MG and treatment
- AChR
  - May have a thymoma
  - Thymectomy should be considered in select circumstances
- MuSK
  - Thymus normal – don’t remove, very very low risk thymoma
  - ? Worsen or don’t respond to Mestinon in ⅓
  - Not my experience
  - ? More severe disease
  - Not my experience
  - ? Respond better to plasma exchange and less to IVIg
  - Not my experience
- Others – LRP4, Agrin, Cortactin
  - We know much less about whether MG is different with these antibodies or whether treatment should be different

Common side effects of common medications in MG
- Mestinon
  - Abdominal cramping, gas, diarrhea – Imodium helps
  - Sweating, tearing (eyes), muscle cramps, increased secretions from mouth, worsening asthma
  - Muscle cramps
- Prednisone (less than 1 in 4 will have significant side effect)
  - Mood changes – anxiety, depression, too much energy
  - Insomnia
  - Weight gain, full face
  - Osteoporosis – thinning of the bones
  - Prevention better than treatment
  - High blood pressure, high blood sugar, worsening diabetes
  - Skin: Delayed wound healing, easy bruising, acne, excess hair growth
Treatment of MG Continued from Page 9

- Muscle cramps
- Low potassium

**Mycophenolate**
- Anaemia (low blood)
- Harmless, reversible – need to monitor with blood tests
- Diarrhea (rare in MG)
- Very few other side effects

**Azathioprine**
- 1/100 flu like reaction in first two weeks
- Stomach upset – uncommon, rarely severe
- 15% liver enzymes increased
- Harmless, reversible – need to monitor with blood tests
- 10% white blood cells lowered
- Harmless, reversible – need to monitor with blood tests
- Skin cancer
- Avoid sun exposure
- Lymphoma – cancer of lymph cells – probably NOT a risk with AZA in MG

**Treatment Failure**

- Why is my MG not getting better
  - Are you SURE that you have MG?
  - If AChR and MuSK antibodies are negative, might not be MG
  - Is MG the cause of your symptoms?
  - Just because you have MG, it doesn’t cause all symptoms that you have for the rest of your life
  - Side effects of drugs
  - You’re not taking your drugs
  - we know this happens....
  - Not on enough drugs or on them for long enough

**Not MG**
- Report the symptoms you experience, not what you have read about.
- Keep an open mind – might not be MG even though you have been told that it is and been on treatment for MG
- I see 2-3 people a year who have been given a diagnosis of MG (some have had their thymus taken out) and who are not doing well - because they don’t have MG

**What can I do?**

- Educate yourself about MG
  - Many MDs have heard about it in med school but never seen a case
  - Ask questions
  - A lot easier to accept side effects if you understand why and that in the end you will get better.
- Describe your symptoms accurately
  - Don’t embellish and don’t hide
- Take your pills as prescribed OR talk to your doctor about why you don’t want to/can’t take them
- Keep your eye on the goal - patience!
Treatments on the horizon

• Rituximab
  o Like a long acting form of IVIg
  o Kills B lymphocytes, which produce antibodies against AChR or MuSK
  o Temporary
• Treatments which deplete complement
  o Eculizumab

Mechanisms of AChR abs in MG

<table>
<thead>
<tr>
<th>Blockade</th>
<th>AChRs still there but blocked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cross-link and internatization</td>
<td>AChRs reduced but can be replenished From muscle t/2 of 7-10 days</td>
</tr>
<tr>
<td>*Complement binding and destruction</td>
<td>AChRs reduced and may or may not be Replenished</td>
</tr>
</tbody>
</table>

Other Issues:

(If you really want me to talk for another three hours)

If you really want me to talk for another 3 hours
• MG and pregnancy
• MG in childhood
• Drugs that should be avoided in MG
  o None are absolutely contraindicated
• Exercise and MG
• Vaccines
  o Avoiding infections a good thing – yearly flu shot
  o If vaccines are not inactivated should probably NOT get them if on medications to suppress immune system (prednisone, Imuran etc.)
Blog Post: Submitted by Joyce Ovens

Fatigue With MG

On awakening an MG person normally has a lot of energy. If I can stay home in the morning, I always start the most important items on my ‘to do’ list immediately after breakfast. Being home all day is good because a rest period can be scheduled. If it is a day when there are appointments both morning and afternoon a rest period is not taken. Therefore, after preparing and having dinner, my energy is gone. The evening is spent quietly reading, watching TV or bookwork and usually falling asleep. If a rest period has been taken, the evening lasts longer and is more productive.

If I am having company for a meal, some tasks must be done ahead of time to prevent exhaustion when the company arrives. It certainly helps to be organized and write a list so nothing important is missed.

It is impossible to ignore exhaustion or fatigue as the body no longer functions normally. The good news is that a rest or sleep, even for a short period of time, results in a new more energetic person.

My goal is to have fewer items on my ‘to do’ list per day. So far, I am still learning and usually have at least two items that are carried over to the following day.

It takes time to get to know oneself and what works best for each person.

The important thing is to keep in contact with your friends on a regular basis. Maintain your interests such as gardening, cooking, reading or whatever keeps you enthusiastic. Remember to include some exercise every day.

I am lucky as my husband and I are able to walk at the Abilities Centre, which is a wonderful modern facility in Whitby, Ontario. The Field House includes six walking and running tracks outside three regulation basketball courts. People young and old walk. It is not unusual to see people using a walker, cane, crutches, wheelchair or even a baby carriage on the tracks. All of them enjoy the experience and give way to those less fortunate.

Neurologists see us as MG clients, but we all have purposes and goals in life which we strive to attain.

Best of luck to all my MG Associates.
A positive attitude helps to achieve your goals.

Joyce Ovens
Cont. from Page 2

Mindfulness Based Stress Reduction (MBSR) is an eight-week program that teaches mindfulness from a secular perspective. It was originally developed by Dr. Jon Kabat-Zinn at the University of Massachusetts Medical Center to help patients who were dealing with pain and other conditions. Dr. Kabat-Zinn explains that mindfulness works in this context because: “Mindfulness stands on its own as a powerful vehicle for self-understanding and healing. In fact one of its major strengths is that it is not dependent on any belief system or ideology, so that its benefits are therefore accessible to anyone to test for [oneself].”

MBSR is now widely taught in hospitals, as well as non-medical settings, such as schools, prisons, athletic training programs, and the workplace. It is often used in research studies that seek to assess the impact of mindfulness.

There is tremendous potential to employ ‘Mindfulness’ method to assist MG patients to improving our daily quality of life – by reducing anxieties, learning to cope with our new reality in the moments of living with our new reality, as MG patients with a chronic condition, helping ourselves to better companions, more considerate of others rather than just our own condition.

Much more on ‘Mindfulness’ in future Newsletters, MG blogs, MG Support Canada Facebook, live and video discussions, support meeting and other communiqué.

Very best to all as we venture forth with “$tep up for MG Fit’’. Email Give@MGCanada.org for more info. Sincerely, Cap Cowan, President
IN PERSON:  Upcoming Events:


Thursday, September 21, 2017. Myasthenia Gravis Manitoba is holding a support meeting at 7:00 pm at St. Boniface Hospital, 409 Tache Avenue, Winnipeg, South Entrance. 204 444 7802T

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.

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: tiinastuart@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

Fernanda Nascimento, St Catharines, ON. (905) 937-9762

Florence Pye, Carleton Place, ON, K7C 1P8. (613) 257-1847

Vikki LeDez, Sunderland, ON, L0C 1H0. 705)-357-0377 email: vledez@yahoo.ca

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.
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

Administrator Post: Hello snowflakes! Hope you're having a good day. It's sunny out :) I have some safety and legal concerns. I'm really happy that we're making full use of this support group, and we have each other. The answer to our concerns are most often only 1 click away.
- Those seeking answers on medications and possible side effects, please always remember that we're all different and we react to medications differently. So be careful on the ideas you take away from the conversations. Those experiences may not apply to you.
- Those sharing their experiences please keep in mind the safety and legality of what's being shared. For instance, it's unsafe and illegal when you are driving with Benadryl in your system. As can happen in those having IVIG treatments. Please also check our group description box where it says if you don't agree with someone's opinion - just move on. Don't launch attacks. Be kind, you will be attacking someone equally sick or in worse condition. If it bothers you too much please message me. ok folks.. this is all for now. love you all! have some awesome news to share soon.

I was wondering if anybody can tell me what to expect after I VIG. I am getting my first treatment tomorrow the next one Tuesday followed by thymectomy on the 16th. I was wondering if I can drive after that IVIG treatment or should I make arrangements? Thanks.