President’s Message

Living with MG. Our new norms as chronic condition MG patients and related care givers.

Greetings Fellow Snowflakes.

I’m having a great MG Snowflake summer, 13 years since diagnosis, surviving well in my ‘new MG norm’ and hope that all of you out there are also – or trying to the best you can.

Another of my current MG norms is participation on our new “MG Support Canada Facebook Group” organized and constantly under the watchful eyes of Odette Montelibano and many other new participating friends including Bonnie Prentice. It is truly a work of love. You should join the conversation, even if you prefer to be a fly on the wall. It’s a wonderful new dynamic for Canadian MG patients and caregivers - by request and invitation only. Continuous thank you Odette.

Inclusion with our “Myasthenia Gravis Support Group Canada” through Facebook is tremendously rewarding. It’s my important new benchmark of how, day to day, we Snowflakes are coping, sharing and interchanging our experiences. Certainly there is a broad range of stability or lack of it.

Why our new Facebook MG Support Group is such a major leap forward for MG Canada is that it helps us enlarge and fulfill our purposes as a national MG Society which are:

- To promote health by providing individuals with Myasthenia Gravis (MG) access to information and group support programs.
- 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.

Support Meeting and Annual Meeting

Sunday, October 4, 2015

At Loblaws Bayview Village, Toronto.

See Page 3
President’s Message—Continued from Page 1

- To receive and maintain a fund or funds and to apply all or part of the principal and income there from, from time to time, to qualified donees as defined in subsection 149.1 (1) of the Income Tax Act (Canada); and to do all such things as are incidental and ancillary to the attainment of the above purposes.

We have successfully begun a 24 hour conversation among Canadian MG patients and caregivers. Join the conversation. As Odette says “It really is a closed members-only access group, designed to protect the privacy of members who are sharing their life experiences in the forum. Please do link to the group-- Use this URL: https://www.facebook.com/groups/1380379838949713/ and link text is Myasthenia Gravis Support Group Canada. There is a message at the sidebar on how MG patients and caregivers can join. Bonnie (Prentice) and Odette have developed this process as the group grew because of experiences of people wanting to join in the past... screening out some questionable characters that were just cruising, looking to scam us of miracle drugs, hack our accounts etc.”

Quality of my new MG normal life, summer 2015, includes lots of golf. Lots of fishing – the most Bass I’ve ever caught per outing – and some of the biggest – at least 2 trophy size. Lots of reading – read most of Jo Nesbo detective translations. Currently reading “The Progress of Love” short stories by Alice Munro. Lots of movies although quality has been a bit rough recently. Betty and I both enjoyed the movies “Mistress America”, “The Gift” and most recently “Out of Compton” -beware the language and situations may shock you. We also get our chances with Grandchildren but never enough.


Spreading the MG Canada word is a constant process, but gradually we’re getting known across Canada. I was contacted by Dr. Siddiqi in Edmonton to participate as a guest speaker at their 5th annual MG Education Day, Saturday, September 26. See the brochure. We also heard from Dr. David Park, who heads the Ottawa Brain and Mind Institute. They’re hosting a mid-September 5 day symposium.

MG Canada is growing and spreading out to support Canadian MG patients and Caregivers Nationwide. It’s a pleasure to affiliate with a growing network of MG chapters across Canada. Vancouver. Edmonton. Winnipeg. Ottawa. Montreal and of course our Toronto roots. Thank you for your constant encouragement and support. We need many tendrils reaching out with determined patience and persistence, to achieve our dream of Canada-wide universal access for MG diagnosis, treatment and support.

Cap Cowan, President, Myasthenia Gravis Society of Canada

www.MGCanada.org
CapCowan@MGCanada.org Phone 905 642 2545 anytime.
Myasthenia Gravis Society of Canada

MG Support Meeting

Sunday, October 4, 2015, 6 - 8

Meet, Greet, Share Experiences + Annual Meeting

Loblaws Community Meeting Room, Bayview Village Mall,
2877 Bayview Village, 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 Village Mall.

All Welcome!

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

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

Other Ways to Connect….

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, the following members have offered their support. Please feel free to contact them to discuss the MG experience.

Ages under 40
Tiina Elder, Mississauga. (905)-565-5875 email: tiina.stuart@gmail.com
Jill Thomson, 9804 – Avalon Rd. S.E., Calgary, AB, T2J 0V6. (403) 286-0056
BY PHONE:  Continued from Page 4... Other Ways to Connect

Ages 41 – 60
Phillip Sanderson,  P.O. Box 206, 27 Adelaide St., Harriston, ON,  N0G 1Z0.  (519) 338-3356

Ages 61 – 74
Fernanda Nascimento, 509 Linwell Rd., St Catharines,  ON,  L2M 2R5.  (905) 937-9762

Florence Pye, 11-126 Sussex St., Carleton Place, ON,  K7C 1P8.  (613) 257-1847

Vikki LeDez, 75 Bond Street, Lindsay, ON,  K9V 3R4.  (705)-328-2586 email: vikki.ledez@yahoo.ca

Age -- Over 74
Ondra Shuwera, 5 -615 Whitaker St.,  Peterborough, ON,  K9H 7L5.  
(705) 876-8481

ONLINE:  Myasthenia Gravis Support Canada

On Facebook, you can connect with others affected by Myasthenia Gravis through the Myasthenia Gravis Support Canada Facebook page.  This group, set up and maintained by Odette Montelibano with the assistance of Bonnie Prentice, is 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.

IN PERSON:

Upcoming Events:

September 17, 2015  Myasthenia Gravis Manitoba Inc. is hosting a Support Meeting, St. Boniface Hospital, 409 Tache Avenue, Basement South Entrance, Rooms AG001 & 2

September 26, 2015  6th Annual MG Education, Saturday, September 26th, Lister Conference Centre, University of Alberta, Edmonton, Alberta.  Contact Aimee Soloway at 780-407-8388 or info@mymg.ca.


November 19, 2015  Myasthenia Gravis Manitoba Inc. is hosting a Support Meeting, St. Boniface Hospital, 409 Tache Avenue, Basement South Entrance, Rooms AG001 & 2.
Personal Experiences

Helpful Information Regarding Anaesthetic

If you require arthroscopy on a knee, a knee replacement or a hip replacement; ask for a spinal anaesthetic rather than a general anaesthetic. My neurologist insisted that I be given a spinal anaesthetic as he wrote "with MG patients this is the anaesthetic of choice." He related that MG people are better in a regular routine so that they do not have a crisis.

During the pre-surgical review at the hospital the RN informs each person which medications should be taken with a little water and the time prior to surgery to take them.

The arthroscopy is a day surgery but the discharge does not take place until each person is ready to leave the hospital. All staff worked together as a team and this is very noticeable in Bowmanville Hospital.

Of course a routine of exercises follow the surgery to help strengthen the muscles.

I hope this will help future MG friends when surgery is required.

Submitted by Joyce Ovens
For persons who have myasthenia gravis (MG), the disturbance of voice, speech and swallowing is more than an inconvenience. It is a disabling and often embarrassing interruption or deterioration of daily functions that are vital to survival and quality of life. It also affects the way people view us and interpret our attitude and possibly our intentions. Understanding how MG may influence voice, speech and swallowing is important for persons who have MG, as well as those who care for them on a professional or personal level. Understanding helps in coping with and treating MG.

The Myasthenia Gravis Foundation of America has published a new brochure “Effects of Myasthenia Gravis on Voice, Speech and Swallowing.” Written by two experts at the Medical University of South Carolina Evelyn Trammel Institute for Voice and Swallowing, the brochure is a significant addition to the foundation’s collection of educational materials. This article provides highlights of the new brochure.

**Dysphonia** is a broad term used to describe a voice disturbance that causes a change in vocal quality that may sound like hoarseness. It affects about two percent of persons with MG.

**Dysarthria** is a problem with articulation, or a problem with how speech sounds are pronounced. It affects about ten percent of persons who have MG. Dysarthria is often characterized as “slurred speech” and can be caused by incoordination or muscle weakness.

**Dysphagia** is the medical term for the swallowing difficulty that is common in individuals with MG. It can have serious implications that range from drooling, food residue in the mouth or throat, gagging, coughing when eating or drinking, to life threatening complications such as aspiration pneumonia, which is a lung infection caused by food material (saliva, food, liquid) in the lung.

Because care for MG is individualized, treating voice, speech and swallowing difficulties varies according to the nature and extent of other symptoms. The effect of interventions is often related to the effectiveness of treatment of the overall MG. In the case of speech and voice disorders, speech-language therapy may be used in addition to the pharmacological therapies used for treating the MG. This therapy may involve an active therapeutic program and/or compensatory strategies to increase understandability.

The mechanism of swallowing is a complex process which involves approximately 50 pairs of muscles...
coordinated manner in order to prevent saliva, food or liquid from entering the airway (aspiration). MG may cause muscles to fatigue as a meal progresses or when certain foods require a lot of chewing. Persons with thymomas (tumors of the thymus gland) may have dysphagia, particularly if the tumor is compressing the nerves and muscles involved in swallowing.

The assessment of a person’s swallowing problems may be referred to a speech-language pathologist to determine how the muscles of the face and throat are working. An initial evaluation may look at how a person drinks and eat foods of various consistencies. If further studies are needed, a modified barium swallow or fiberoptic endoscopic evaluation of the swallowing may be performed.

Similarly to treatment of voice and speech disorders in MG, treatment for dysphagia is based on the individual, the underlying cause and severity of the swallowing problem. In addition to pharmacological therapy for the MG, fatigue of the swallowing muscles can be reduced by smaller and more frequent meals, resting prior to eating, and avoiding talking while eating. Many other strategies may be employed such as consuming cold foods and liquids, alternating a small bite of solid food with a small sip of a liquid, and drinking thicker liquids. It also may be helpful to plan meals around the peak of medication, e.g. one hour after taking Mestinon/pyridostigmine. Individuals who have trouble swallowing pills crush them and mix them with applesauce or pudding. Additionally, liquid or dissolvable gel cap forms may be available. Talking with a pharmacist can help with choosing the right manner for taking medication.

For the full text of the brochure, go to http://myasthenia.org/LivingwithMG/InformationalMaterials.aspx
To obtain hard copies call 800-541-5454.
Authors:
Kendrea L. Focht, CScD, CCC-SLP, CBIS, Medical University of South Carolina
Evelyn Trammel Institute for Voice and Swallowing
Janet A. Myder, MPA, Member of MGFA Communications; Editor, E-Update; Co-Chair, Low Country South Carolina Myasthenia Gravis Support Group

Myasthenia Gravis Foundation of America, Inc.

Published with permission of the Myasthenia Gravis Foundation of America, Inc.
Saw my Neuro team today. I was first hit with MG a year ago Monday and was admitted to ICU at that time. Waited for xfer to UH in London from my local hospital and after three weeks wait and three weeks of MG doing its best to make me worse, I finally arrived at UH on a Friday afternoon and on Monday morning rounds the Neuromuscular team diagnosed me within minutes as MG. Spent next few months in ICU until well enough to be transferred to normal care for final three weeks and then discharge home on Feb 20 2015.

I kept asking what recovery time in ICU would be but never got more than "let's work on this next step for now" answer. Went thru Imuran for a month then that was stopped as was affecting liver, had several IVIG sessions, three sessions of Plasma Exchange, Started with mouth ventilator and feed line then feed moved to nose and finally to G0tube in belly. Then the vent was switched to a trach tube and finally the mouth was free of objects but by then the vocal cords had suffered some damage so my voice will never be the same again just weaker version. Sent home on feed tube using Tetrapaks of feed from Feb 20 until swallow test completed on April 1 with decision that I could take anything by mouth for first time since previous August. Still needed a suction machine to clear secretions from throat as I was not allowed to swallow in case of going down into airway instead of stomach. That cleared up within a few weeks and I was back to normal chest clearing via standard cough and found it wet enuf I just naturally started swallowing saliva and small secretions caused by Mestinon.

So after seeing all the info in five MG support groups I joined over last couple weeks, I was prepared to meet the Neuro team today for follow-up. One of my questions was how severe was MG on me on scale of 1 to 10. Answer a 9+ which I suspected based on the comments all you have written here.

So a big Thank You All for helping me understand what happened to me and giving me hope for an improved (but not normal) lifestyle. I'll never go camping again due to work involved, but did have a great week at a cottage two weeks ago that will become my new norm.

Reprinted with permission of Bob Henry.
Finding a Voice Cont. from Page 8

for this mysterious difficulty on several occasions, on one morning his situation became a lot more serious.

“He woke up unable to swallow or breathe,” his wife Lenore says of the frightening incident.

Immediately admitted to his local hospital, Bob was soon transferred to the Intensive Care Unit (ICU) at LHSC’s University Hospital where he was diagnosed with Myasthenia Gravis – a chronic autoimmune neuromuscular condition that affects voluntary muscles.

Basic tasks like eating, speaking, and even breathing were exhausting for Bob. His muscle weakness, coupled with the tubes required for ventilation and feeding made it impossible for Bob to speak.

“I could think clearly and I could hear clearly,” says Bob. “But I could not talk, which was very difficult.”

Like Bob, many ICU patients are unable to verbally communicate at this most critical time when they most wish to be heard by their health-care team and family.

“At a time when critical decisions are being made on behalf of patients, their condition often prohibits their ability to ask questions, express their wishes, or speak to their families,” says Emily Barrett, a speech-language pathologist at LHSC.

Bob first used traditional, non-verbal communication techniques such as tracing letters of the alphabet on his stomach to form words, and pointing to the letters on a letter board. But he soon became frustrated and fatigued by the amount of time required to trace sentences and the occasional inability of others to understand.

At one point, Bob tried a pad of paper and a pen, but his hand tremor made it impossible for him to write legibly or stay on the page.

“I was trying to communicate my needs and wants, but people couldn’t always figure out what I was saying,” he explains. “I had to take a whole new look at talking and trying to say what I needed.”

Cont. on Page 10

When Bob couldn’t speak, Emily and Bob communicated through “ICU Talk” in a London Health Sciences Pilot Project.
Emily approached Bob and asked if he would like to be involved in a new Pilot Project exploring the usefulness of specially modified iPads to help patients in the ICU communicate with staff and family. Bob eagerly agreed – and what happened next opened up a whole new world for him.

Using a uniquely designed program called ‘ICU Talk,’ played on software called ‘The Grid,’ Bob was able to use the iPad to quickly communicate ideas, ask for assistance and greet his visitors by tapping a finger on one of the pre-programmed buttons, which had been customized to include his common requests and the names of those he interacted with regularly.

After receiving the iPad, the struggle to communicate eased. He began to actively engage with his health-care team, family and visitors.

“When Bob communicated with his letter board, every message was a struggle,” says Emily. “But with the iPad, I got to see him engage more in decisions with his health-care team. Being given a voice can be very powerful and very significant so that was really exciting to watch and be a part of.”

“The iPad made my progress better because I was able to communicate much more easily,” says Bob, adding that he was also able to give important information to his wife on insurance, finances and household affairs. “I’d have discussions with my wife about things that hadn’t been done before this happened,” he says.

Using his technological background and experience as a patient, Bob also helped to take the technology one step further. He provided insight and ideas on modifying the iPad so it was more effective. He leveraged the ‘Notes’ application to track all aspects of his care, including his medications, exercises and important discussions. The iPad also provided Bob with an unexpected but important outlet for his unique sense of humor. He would write the beginning of a joke and encourage staff to adlib the ending because, “Laughter is the best medicine,” he says.

Now that Bob’s condition has improved and he is back at home, he has relinquished the iPad back to the ICU. Armed with his own personal iPad mini, he continues to track his journey to recovery. He’s also become an advocate for the iPad project – and is able to look back on one of the gravest periods of his life with a sense of pride.

“I’m just so glad that I was able to contribute,” he says of being a part of the project and his active involvement in improving the technology.

Continued on Page 11
Finding a Voice Cont. from Page 10

“The project helped me and I’m glad that I could play a part in making sure it helps others. It’s bigger than me now.”

He’s also become an advocate for the iPad project—and is able to look back on one of the gravest periods of his life with a sense of pride.

This article was reprinted with permission of “Inside” the London Health Sciences Centre Newsletter. Link: www.lhsc.on.ca

MG Patient Education Day in Edmonton

Dr. Z Siddiqui and the MG Program Team are hosting their 6th Annual Education Day on September 26th. Presentations are from experts on a variety of topics related to MG. For inquiries or to register to attend, contact Aimee Soloway at 780-407-8388 or info@mymg.ca
Report on MG Canada Support Meeting
May 24, 2015
Loblaw’s at Bayview Village Mall,
Toronto

The guest speaker was Alan Dresser, Pharmacist, Teacher, Chair of the Board Directors of Stevenson Memorial Hospital, President of Dresser Group of Companies, Mason and Lodge Member. He was also an umpire for the Blue Jays. Alan Dresser graduated in 1983. One of his exam questions was on MG. Alan said that in his career, he had only two patients with MG.

Definitions & Info
It is an auto immune disease
It affects women under 40 and men over 60 (usually)
MG is life altering but not life shortening (usually)
You have been diagnosed and prescribed. Now what?

- Five Stages of Grief (sometimes 7)
  Denial (Shock)
  Pain and Guilt
  Anger
  Bargaining
  Depression, Reflection, Loneliness
  Bottoming Out and Turning Upward
  Reconstruction
  Acceptance and Hope

- Denial
  Must be some mistake.
  Pain and Guilt
  The religious tend to feel that it was something that they did. Some are frightened.
  Anger
  Blame somebody
  Somebody will pay

- Negotiating
  Frequent stage of medical non-compliance
  How can I beat this?

Key stage for medically trained – Caregivers – Patients
Experiment with dosage and lifestyle

- Upward and Reconstruction
  Change the sails
  Measure of success with therapies
  New Routines

- Acceptance and Hope
  The new course is set
  Adaptations are made
  Energy is conserved physically and emotionally
  Medical progress

How it Works
Google ‘neuromuscular transmission’
In myasthenia gravis the receptors are blocked by antibodies which results in reduced transmission.

How Antibodies Work
Antibodies are competitive inhibitors of receptors.
Antibodies compete with Acetylcholine for receptor sites like musical chairs.
Medication process attempts to have antibodies lose the competition for receptor sites.

Continued on Page 13
Methods of Attack

Rest builds up ACh in vesicles.
Anti-Cholinesterase slow down the breakdown of Acetylcholine. ACh stays on receptor longer to keep ab off.
Immunosuppressant's slow down or prevent the production of antibodies.

Anticholinesterases
Pyridostigmine (Mestinon)
Neostigmine

Immunosuppresants
Prednisone or prednisolone
Imuran, CellCept, Neoral
Cyclophosphamide

Biologics
Next step?
Identification of genes on DNA that are responsible for MG
Biologics will amend or correct DNA to prevent message to produce antibodies

Thanks to Mr. Alan Dresser, Pharmacist, for his Power Point presentation.

Questions and Discussions with Al Dresser

1. Prednisone works on most antibodies, but it makes it more difficult to fight infections. A high dose of Prednisone increases the retention of fluid, which is hard on the heart. This can lead to renal failure. Prednisone causes a puffy face and legs. Low dose of Prednisone is 15 to 20 mg daily. Prednisone is easier on the body than Imuran.

2. Cost/coverage – When younger, you often have benefits at work or your spouse has benefits. If necessary, apply to Trillium.

3. Frequency of dosing – twice a day is the optimal number.

4. To reduce pain it is better to go transdermally.

5. Side effects are often dose related. This has to be worked out based on the person. You need a pharmacist who will talk with you and also listen.

6. Would Mestinon ever be available as a patch? Mestinon is absorbed in the blood and peaks in the blood. It lasts about 4 hours. Then a second dose is required.

7. Imuran is an immune suppressant. It causes one to retain fluid. Imuran is used for transplants. Anyone on Imuran should have blood work checked every three months. In fact all MG patients should have their blood work checked every 3 months.

8. Intravenous Immunoglobin(IVIG) is a product derived from human blood. It is used primarily for MG patients in crisis when it provides quick, but temporary relief of symptoms for more than 75% of patients.

9. Tricyclics are an old class of antidepressants. They can be used as a sleeping pill and does not make you groggy the next day.

10. Cataplexy – is a transient attack of extreme generalized muscle weakness which occurs in MG patients.

Continued on Page 14
Other Business

- The new video, a gift from McMaster, was played prior to the presentation. It was made by a student on Plasma Exchange and HIV Exchange in MG.
- Introductions
  Tara Buonpensiero is making great progress on her Health Professional portfolio including the MG Canada, National MG Health and Professional information Data Base.

  Odette Montelibano, Director of Communications, has started a new Facebook Site. Fifty-four people were involved this morning.

- Cap is planning to attend the annual September MG Education Day, Saturday, September 26th, 2015 in Edmonton, Alberta and will be speaking on behalf of MG Canada.

Prepared by Joyce Ovens

Thank You to Joyce Ovens for Preparing this Report.

Al Dresser, Pharmacist, was an informative guest speaker at our May meeting.

Smile

A woman and her husband interrupted their vacation to go to the dentist. “I want a tooth pulled, and I don’t want any pain killers because I’m in a big hurry,” the woman said. “Just extract the tooth as quickly as possible, and we’ll be on our way.”

The dentist was impressed. “You’re certainly a courageous woman,” he said. “Which tooth is it?” the woman turned to her husband and said, “Show him your tooth, dear.”
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
MYASTHENIA GRAVIS SOCIETY OF CANADA

Notice of Annual General Meeting for
Myasthenia Gravis Society of Canada
(a.k.a.MG Canada)
scheduled for

Sunday, October 4, 2015 at Loblaws Community Room,
Bayview Village Mall, 2877 Bayview Toronto at 6:00 PM

Your Board of Directors: Cap Cowan, President; Tara Buonpensiero, Director; Odette Montelibano, Director; Lucien St. Martin, Director; Jim Houston, Director.

All are welcome. Learn about our progress. Share ideas. Exchange fellowship. Info at 905 642 2545.

Myasthenia Gravis Society of Canada
c/o 247 Harold Ave.,
Stouffville, Ontario, L4A 1C2