



Myasthenia Express

Myasthenia Gravis Manitoba Inc. March 2013

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President's Report

By Diane S. Kowaliuk

Once again another year has passed and we are getting ready for spring and income tax. Reminder to our members that disability tax credit may apply to some of our members and to discuss this with your doctor. The forms for the disability tax credit are on the website: www.cra-arc.gc.ca/menu-e.html.

Our next meeting will be held on Thursday, March 21, 2013 from 7-9 pm at the St. Boniface Hospital. Dr. Neal Campbell, Ocular doctor will be a guest speaker. After a brief presentation we will open the floor to questions and answers.

For our fundraising event for last year we had sold Grey Cup Tickets again and the members were great sellers. Great job!!!

Different processes have happened to some of our members over the last year. We have had a member go to the Mayo Clinic in Minnesota for further diagnosis and this has been a first for us in Manitoba. Myasthenia Gravis is a very hard disease to diagnose and to get control of.

Over the years I keep hearing at all our meetings the same statement "listen to our bodies". Well that is easier said than done as we always strive to complete our task and

when your body is tired it is very hard to accept the fact you have to stop and rest. Every situation is different as one process will work well for one of our members the same process with not work for other members. But as a support group we bounce ideas and brain storm. And when later as I reflect on the meeting, I think if one person took something out of our meeting that can help them, we had a very successful meeting.

I would like to thank all the members who share their experiences, trials and tribulations. Also I would like to thank all the executive members for their support, co-operation and hard work, another fabulous job.

We are planning our spring get together for our May 16, 2013 meeting day, as a social function since we do not have a Christmas Party in January. Pizza will be served at this meeting at St. Boniface Hospital.

Submitted by
Diane S. Kowaliuk
President

ANNOUNCEMENTS

2013 UPCOMING MEETING DATES

The following are the confirmed dates for our meetings for 2013 location is St. Boniface Hospital at 409 Tache Avenue – Basement south Entrance – AG001 & 2 by stairwell – **watch for our bright red signs.**

<u>Date</u>	<u>Time</u>	<u>Location</u>
March 21, 2013 – Thursday Dr. Neal Campbell, an Ocular doctor will be a guest speaker	7:00 to 9:00 P.M.	AG001 & 2 south end of basement
May 16, 2013 – Thursday Spring Get-Together – Pizza Party	7:00 to 9:00 P.M.	AG001 & 2 south end of basement
September 19, 2013 - Thursday	7:00 to 9:00 P.M.	AG001 & 2 south end of basement

Please try to attend each meeting, we appreciate your attendance, participation and assistance in so many ways. Bring your family and friends, and learn more about Myasthenia Gravis.

Elective Officers 2012-2013

President	-	Diane Kowaliuk
Vice-President	-	Verna Kapkey
Secretary	-	Maureen Silk
Treasurer	-	Maureen Silk
Telephone/Email Committee	-	Mary Ross & Leah Roche
Fundraising Committee	-	Veronique Yoko
Education Committee	-	Dennis Dempsey
Hospital Visiting	-	Doreen Amadatsu
Social Committee	-	Connie Chubaty

Newsletter	-	Leah Roche & Corinne Elson
Resource Committee	-	Doreen Amadatsu
Video Production	-	Gary Parker
Coffee Committee	-	Ruby Sancho, Liz Cisaroski, Karen Riehl
Brochure Distribution	-	C. J. Emmonds
Website	-	Gary Parker



Congratulations to the winners of the 2012 Grey Cup Raffle

On behalf of the Executive and members of Myasthenia Gravis Manitoba, Inc., we thank you for your support of our Chapter's fundraiser.

1st Quarter

Correct Score	Brian Corrie
Reverse Score	Carlee Malcolm

2nd Quarter

Correct Score	Al Fraser
Reverse Score	John Browning

3rd Quarter

Correct Score	Verna Kapkey
Reverse Score	Nori Loewen

4th Quarter

Correct Score	Lisa Siddall
Reverse Score	Yvette Fiola



The Myasthenia Gravis Foundation of America introduced a smartphone app designed to help you and your doctor better understand the effect of your ...myasthenia gravis on your daily life.

Take the MG Quality of Life survey and the MG Activities of Daily Living survey in myMG on a regular basis. myMG tracks your survey results and provides a snapshot for your doctor of fluctuations in your myasthenia gravis over a period of time.

myMG is available on iTunes and Google Play. A web-based version is also available at <https://mymg.myasthenia.org/home> for those without a smartphone.

The Myasthenia Gravis Foundation of America <http://www.myasthenia.org/>

Tips For Travel

Traveling when your myasthenia is active can be a challenge. But when you are prepared and have planned your trip taking into consideration your Myasthenia Gravis, travel can be made a little easier. Here are some suggestions:

- Wear a medical identification emblem.
- Keep this information in your wallet: a list of current medications, medical history, allergies, doctor contact information, and family contact information.
- Keep your medication with you, not packed in baggage that you check. Carry a full supply of all your medication for the entire trip and extra if possible.
- Maintain your medication schedule.
- Whenever possible, plan and book flight in advance. Talk to an airline representative in advance if you need help checking in, or if you need ground transport to get from one place to another in the airport.
- Call ahead to find out if hotels have handicap accessible bathrooms. Try booking rooms on the main floor or near elevators.
- Consider renting wheelchairs or mobile scooters.
- Pack light! Keep your luggage minimal, especially if you need help with it. Consider sending some things ahead to limit what you have to manage.

June is Myasthenia Gravis Awareness Month

June has been identified as Myasthenia Awareness month in Canada and the US and many organizations are promoting awareness with activities such as Walks and disseminating information about MG.

To learn more about this disease you can visit these websites

Myasthenia Gravis Coalition of Canada website:

www.mgcc-ccmg.org

MG Manitoba Inc. Website: <http://www.mginc.mb.ca>



COLD TURKEY - Prednisone Withdrawal

Some people wonder why they just can't stop taking Prednisone, and why it has to be gradually tapered off.

1st – You should never stop 'cold turkey' with this or any prescription drug without first consulting your doctor. In the case of Prednisone, if the dosage isn't gradually reduced or discontinued, there is a risk of there being 'withdrawal' symptoms. These may include,

- Severe fatigue
- Weakness
- Body Aches
- Nausea or vomiting
- Lightheadedness when standing (low blood pressure)

Prednisone is a corticosteroid medication used to treat many conditions, as well as MG. Doctors try to prescribe the lowest dose possible for the shortest period of time, because long-term use can cause serious side effects. However, possible long-term prednisone therapy may be needed in some instances.

Prednisone is similar to cortisol, which is a naturally-occurring hormone made by your adrenal glands. If you take prednisone for more than a few weeks, your adrenal glands will stop producing cortisol. By gradually reducing your dosage, you are giving your adrenal glands the opportunity to resume their own normal production of cortisol.

The time it takes to taper off prednisone depends on the condition being treated, the dose and duration or use and other medical considerations. A complete withdrawal from prednisone can take anywhere from a week to several months.

Be patient and always consult your doctor before changing how or whether you take your medications. If you experience any prednisone withdrawal symptoms or an increase in your myasthenic symptoms as you are reducing your intake, be sure to contact your doctor.

Source: Myasthenia Gravis Association of British Columbia Newsletter, Spring 2010

Excerpt from <http://www.mayoclinic.com/health/prednisone-withdrawal> and MGF of Illinois – Conquer, November 2009 – p.5

Wanted:

Your stories, feedback and comments

If you would like to share your story and experiences, suggest topics for future newsletters or just to provide feedback, please contact me at leahroche@shaw.ca. Everyone's MG experience is different, and we can all learn so much from each other

*Thank you
Leah Roche, Editor*

Please note:

This newsletter is intended to provide the reader with general information to be used solely for educational purposes, and that any medical views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Manitoba Inc. Chapter.

Always consult your physician or health care professional for medical advice.

