

Myasthenia Express

Myasthenia Gravis Manitoba Inc.

March 2018 Vol. 2 No. 6



339 Boyd Ave., Winnipeg, Manitoba Canada R2W 1P1

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Email: mginc@mts.net

President's Report

By Diane S. Kowaliuk

Our support group has members who come and go and it is wonderful to hear from members who have learned how to find the happy medium to control the fatigue. Our biggest challenge is listening to our bodies. When you are tired, rest and when you are feeling better, don't do too much and stay within your limits. Our support group is for all the family and it is great to see family members attend to learn what their siblings are dealing with and how to help them deal with this illness on a daily basis.

We have had a very busy year for our support group. Our fundraiser with the Grey Cup tickets was extremely successful and a great "Thank you" to all the members and their family who have assisted selling tickets for our support group.

Leah Roche, our chapter members would like to express our gratitude for all your hard work regarding the newsletter and congratulations to Cheryl Girard on taking over this new position.

For our March meeting we are going to have an open discussion on ourselves. However on May 17, 2018 we are going to have a wonderful guest speaker and pizza night. Mark your calendars.

Last year we had wonderful guest speakers, Cory Guest, from the Winnipeg Fire Paramedic Service, (Personal Safety) and a speaker on fraud & scams from the Winnipeg Police Service.

Diane S. Kowaliuk

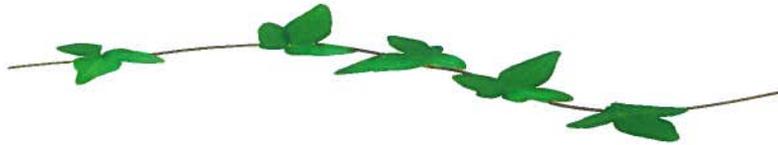
From the Editor's desk



This is just a little note to say thank you to Leah Roche who has been putting together the newsletter for the MG support group. I would also like to say thank you to her for being so wonderfully inspiring and helpful regarding coping with Myasthenia Gravis. Also a big thank you to Diane for all that you do and to the rest of the support group for your amazing tips and support.

Spring, hopefully, will soon be on its way bringing much needed sunshine, warmth and greenery back into our lives. It is my hope you find a little bit of inspiration here as you all have inspired me.

Warm regards,
Cheryl



Wanted: Your stories, feedback and comments

If you would like to share your story and experiences, suggest topics for future newsletters or provide feedback, please contact me at girard.cheryl@gmail.com

Thank you
Cheryl Girard, 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.



Myasthenia Gravis Manitoba Inc. Support Group Meeting Dates

The following are the confirmed dates for our meetings for 2018

The meetings are held at St. Boniface Hospital – 409 Tache Avenue, Winnipeg
Room AG001 & 2 south end of hospital (basement south entrance)

Thursday, Mar 15, 2018: 7:00 pm

Thursday, May 17, 2018: 7:00 pm

We appreciate your attendance, participation and assistance. Invite your family and friends to learn about and share your experience with Myasthenia Gravis.

Executive Officers - 2018

The following members agreed to take on positions for the 2018 term:

President - Diane Kowaliuk

Vice-President - Verna Kapkey

Secretary-Treasurer - Maureen Silk

Fundraiser - Maureen Silk

Telephone Committee - Mary Ross

Email Committee - Cheryl & Ray Girard

Newsletter - Cheryl & Ray Girard

Education/Resource - Cheryl & Ray Girard

Hospital Visits & Cards - Diane Kowaliuk

Coffee Committee - Liz & Dick Cisaroski

Brochure Distribution - C.J. Emmonds

Website - Grace Hooker

15 positive tips for living with Myasthenia

By Cheryl Girard



Here are some tips that have been gleaned from several Myasthenia Gravis association websites. I hope you find them helpful.

1 - **Eat well.** Eat a diet with plenty of vegetables, fruit, low in sugar, cholesterol and especially salt if taking prednisone. Healthy smoothies made from vegetables and fruit are great. Eat less processed foods.

2 - **Rest.** Making time for rest is crucial and is so helpful. Nap. The more you rest, the more it helps you. Relaxation techniques such as meditation, gentle yoga, Tai Chi or just tensing and relaxing your muscles may all be beneficial for you. Rest your eyes when reading or working on the computer.

3 – **Pace yourself.** Decide which are the most important things for you to do and do them when you are at your best – usually in the morning for people with Myasthenia Gravis or MG. Cook extra meals on the days you feel the best and freeze for when you are having a bad day.

4 – **Be positive.** Some days are harder than others but try to be positive. Look for the good things. A wonderful Oscar Wilde quote is “When it rains look for rainbows, when it’s dark look for stars.”

5 – **Avoid stress.** Easy to say and hard to do. Stress comes into all our lives. But since it has been said that stress so often can worsen MG symptoms, try to find ways to de-stress, learn about and build relaxation techniques into your daily routine.

6 – **Keep a diary.** Make notes on how your MG is doing, reactions to your medications, new symptoms, etc., for your own benefit and for when you see your general practitioner or

neurologist. Also write down any questions you have for your visits as it is so easy to forget when you are there.

7 – Stay in touch with others who have MG. Join a support group or reach out to others who have MG. They can be extremely helpful and can offer tips that have made their lives better. Other people who do not have MG may not always understand what you are going through.

8 – Knowledge is power. Read as much as you can about MG on reputable websites such as various MG associations. The more you understand, the more you will be able to deal with your condition.

9 – Accept help. When you feel weak, unsteady or tired, accept help when family offers it to you. Do not push yourself beyond your limits.

10 – Baby steps. You will have bad days. And you will have better days. It is best to take small steps to manage your MG than to expect enormous or rapid improvement. One day at a time.

11 – Watch the weather. Since it is said that extreme weather conditions can adversely affect muscle function, try to avoid being outside when it is too hot or too cold.

12 – Avoid triggers. If you know what triggers your MG, for example, extreme weather, fatigue, stress, illness, overdoing it, try to avoid such things. Look after yourself.

13 – Carry a card. Always have a card on you that identifies your condition and a list of medications that could possibly worsen your MG.

14 – Exercise. Work out within your limits and follow the advice of your doctor as to how much and what type of exercise you can do. Walking is great, within reason, and helps you to feel better.

15 – Don't give up the things you love. Sometimes having to give up on certain things may only be temporary. Try to do what you love in small doses whether it is gardening, walking, traveling or whatever else you enjoy. Make adjustments and always discuss it with your doctor.

Sources: <https://www.myaware.org> (a UK charity dedicated to the care and support of people affected by Myasthenia); www.myastheniagravis.org - Conquer MG, (formerly known as the Myasthenia Gravis Foundation of Illinois.)

Hope, Coping and Quality of Life



Wilma J Koopman, RN (EC), MScN NP of the MGFA Nurses Advisory Board conducted a study to explore the relationship between hope, coping and the quality of life experienced by adult patients with MG.

The initial diagnosis of MG is fraught with questions, primarily because it takes so long for a 'true' diagnosis to be achieved. Many patients are stopped in their tracks and "What now? And why me?" The shock and lack of knowledge of this elusive disease add to heightened levels of anxiety. Often multiple medications are required and their frequency and potency change until personal equilibrium is achieved.

The study selected its 100 participants from the London Health Centre in London, Ontario MG Database. All MuSK AB positive patients were invited to participate as they are low in number. 57 were male and 43 were female: the average age was 61, 78% had generalized MG, 24% ocular. 83% were AChRpositive, 8% were MuSK positive and 9% were sero-negative. Among the group the following medications were taken: Mestinon 92%, Prednisone 78%, Azathioprine 57% and Cellcept 21%.

Questionnaires given to the participants included demographic information, measure of their ability to perform activities of daily living (MG-ADL), a score on Hope (Hope Herth Index), main strategies of coping (Jalowiec Coping Scale) and their quality of life scores (MGQOL< SE36v2)

The mean scores indicated a high level of hope with positive readiness and expectancy as the most frequently used 'coping mechanism'. The other three most effective were being optimistic, confrontive – relating to facing the problem and working to solve it, and self-reliance. So like many areas of life, trying to think positively, keeping a sense of humour, focusing on the good things and keeping your life as normal as possible are reliable coping mechanisms.

It is important to notice this group had mild disease and few symptoms of active disease. Most identified with a 'good tolerability of their MG symptoms.' Participants in this survey were hopeful and wished more healthcare professionals understood the need to promote strategies to inspire and thereby improve the quality of life for their MG patients.

The full study and charts may be viewed at: <http://cann.ca/issues/?IID=volume38-issue1-2016e> Canadian Journal of Neuroscience Nurses.

This article was reprinted with permission from the Fall 2017 MG Newsletter of the Myasthenia Gravis Association of British Columbia.



Inspiration Corner

"Today we fight. Tomorrow we fight. The day after, we fight. And if this disease plans on whipping us, it better bring a lunch, 'cause it's gonna have a long day doing it." - Jim Beaver, author of "Life's that way."

"By the end of the day, we can always find something to be thankful for." - Unknown.

"In the midst of winter, I finally learned that there was in me - an invincible summer." - Albert Camus.

"Today, make a list of ten nice things you could do for yourself. Now select one and do it. You have absolutely nothing to lose from experimenting with self-nurturing and everything to gain." Sarah Ban Breathnach.

Grey Cup Raffle Pool Ticket Winners:

Congratulations to the following winners of the 2017 Grey Cup raffle:

1st Quarter (West 6 East 0)

Correct Score Lorne Lowe
Reverse Score Jon Kuryluk

2nd Quarter (West 17 East 8)

Correct Score Bernadette Rosales
Reverse Score R. Halfdanson

3rd Quarter (West 24 East 16)

Correct Score Connie Chubaty
Reverse Score Marjorie Rivera

Final Score (East 27 West 24)

Correct Score Kevin Steinke
Reverse Score Anita Warkentin

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

Charitable Donations

Myasthenia Gravis Manitoba Inc. is a non-profit charitable organization. Donations are graciously accepted and provide us with the means to educate our members and the community regarding Myasthenia Gravis.

If you are considering a donation there are some choices available. Payroll deductions are convenient and you can add Myasthenia Gravis Manitoba, Inc. to the United Way list of charities. Also when someone passes away, some families often request charitable donations be sent in lieu of flowers to a charity of your choice. A charitable tax receipt is provided with all donations over \$10.

Become a Member

For \$5 a person or \$10 per family you can become a member of the Manitoba MG Support Group.

Members are entitled to vote at the annual meeting or at any special meetings of the corporation. Members receive a copy of the newsletter, Myasthenia Express. Membership fees are for the year starting October 1st and ending September 30th.

Please complete the form below and return it with your annual membership fee to:

Myasthenia Gravis Membership
c/o Maureen Silk
614 Munroe Avenue
Winnipeg, Manitoba
R2K 1H8

MYASTHENIA GRAVIS MANITOBA INC. MEMBERSHIP APPLICATION

Last Name: _____ First Name: _____

Street: _____

City: _____ Province: _____

Home Phone: _____ Postal Code: _____

E-mail Address: _____

Relation/friend with MG: _____

Family Member names if family membership: _____

Membership fee enclosed: _____

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A charitable tax receipt is provided with all donations over \$10. Thank you.

Donation enclosed: _____