



Myasthenia Express

Myasthenia Gravis Manitoba Inc. March 2010

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339 Boyd Ave, Winnipeg, Manitoba Canada R2W 1P1
(204) 582-5456 mginc@mts.net

Myasthenia Gravis Manitoba Inc. Winnipeg, Manitoba

Our next meetings will be held on March 18, 2010 and May 20, 2010.

In November we had our annual elections and on our website <http://mginc.mb.ca> is the list of our new executive. I would like to take this time to thank all the executive members for their support, co-operation and hard work; another fabulous job. Also to our members and families who take the time to attend our meetings and share their experiences, trials and tribulations.

At our meeting in November, we had a Neurologist, Dr. Gomori, do a presentation regarding Myasthenia Gravis; what a great evening as he shared a wealth of information and discussed treatments with our members and their families. For the members who were not as fortunate to attend we have a video you can borrow by contacting Verna Kapkey @ 582-5456.

January 22 and 23, 2010 we held a bake sale at Garden City Mall. What a wonderful response we had from the support group and their families by baking goods and also assisting at selling the baking at the sale. The executive

Presidents Report By Diane S. Kowaliuk

team would like to give each and everyone of you a pat on the back – another job well done. All who attended had a great time.



For our March meeting we have decided to have an actual support group meeting to share our trials and tribulations and get caught up on upcoming events, etc. In the last few months we have welcomed several new members and they need information from our existing members on how to cope with Myasthenia Gravis.

We also want to plan our spring get together as a social function since we did not have a Christmas Party in January. Please bring some great suggestions for restaurants, locations, parks and bring your calendars!

Diane S. Kowaliuk

Editor's Resignation Report, by Verna Kapkey

It is with a great deal of sadness that I must give up being the Myasthenia Express Newsletter editor. Communicating with everyone was a pleasant duty. Due to failing eyesight, the task of researching and creating the various articles for the newsletter has become too difficult for me, and it has come time to hand over the reins to someone more capable.

I took over the editorial duties of our newsletter in 2005 from Margo Mackie, who created our first newsletter in 1998. She provided practical education and information about Myasthenia Gravis and her every task was done with perfection. Our chapter members wish to acknowledge her dedication and excellent work she did over the many years. Margo also had to resign because of failing vision problems.

However, I am very pleased to be able to turn over the editorial obligation to a young and inspiring member of our Myasthenia Gravis Manitoba Inc. chapter, Corinne Elson.

Corinne has Myasthenia Gravis, and at present is in remission, and she has been a member of our Myasthenia Gravis Manitoba Inc. group since 1994. Corinne lives in Winnipeg with her husband Scott and she is a devoted mother of two handsome young boys. She works full time in the financial industry, and still finds time to do various volunteer duties.

I am so pleased that Corinne Elson took over this position on our executive as our newsletter editor, because she will go beyond her ability to add encouragement and emotional support as well as education to all members and their families. We thank you in advance Corinne, for sharing your knowledge and dedicated hard work with all of us.

Verna Kapkey

A Note from the New Editor:

I was a mere 21 years of age when I was diagnosed with generalized Myasthenia Gravis. Still a university student and barely an adult, it was a shock to say the least. What would it mean to the rest of my life? All my plans, hopes and dreams? Could I pursue a full-time career? Should I marry? Would I be able to have children and actually have the strength to care for them? I went through all the usual emotions one can expect when diagnosed with any chronic disease. Now, sixteen years later, I can happily report that I have a very blessed life. After a thymectomy late in 1994, the

progression of my MG stopped, eventually I was given the gift of full remission; I've been drug-free since 1997. I have a full-time career, a very happy marriage and to top it all off, I have a couple of pretty amazing young boys. My cup is not half empty or merely half full - it is overflowing, yet the road was and is not always easy.

At the time of my diagnosis, I had never heard of MG and I was terrified. In my quest for answers, I attended my first MG meeting. I met the most extraordinary group of people - some who have MG
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and some who support or have supported a loved one with MG. Through the emotional support and education provided by the group I was able to not only cope, but to have hope for my future. At the core of that group was and still is Verna Kapkey – the founder and constant champion of this organization.

When recently asked if I would take over the editing of this newsletter, I didn't hesitate. I'm thrilled to be healthy enough to take this on, to give a little back and lighten Verna's load in this small way. Although my busy life makes it difficult to attend more than a meeting or two each year, I am grateful for this organization and everything it has meant

to my recovery. Thank you Verna – your commitment, friendship and unfailing support are a blessing to us all!

Thank you to all who take the time to read our newsletter. I hope you will find it educational, enlightening and maybe even a bit inspiring. We can't always control the things that happen to us, but we can control how we react to them. I invite you to help inspire others by sending me your stories or comments for future newsletters. MG may limit our strength, but together we are very strong.

Corinne Elson

Newsletter Editor

Email: scelson@mts.net

Coping with Chronic Illness

The following quotes were taken from a Patient Education brochure produced by the *Clinical Center of the National Institutes of Health* in Bethesda, Maryland. The goal of the brochure was to help patients and their families cope with chronic illness. Regardless of the condition, we can learn from others' experiences, take comfort in the realization that our feelings are normal when facing illness and that there is hope to overcome the obstacles and to live again.

"I was extremely ill and my prognosis at the time didn't look very good. It was devastating. I just didn't know what was happening to my body. I kept thinking I'd wake up tomorrow and this would all be gone."

"I just didn't want to accept the fact that I wasn't going to get back to the way I was. I have a lot of pride, and I didn't want this illness to be a reality. I had never been on this side of a disability."

"You go to the doctor, and even if he tries to explain what you have, it's hard to retain it all. In the first place he may not have much time to talk with you, or he may not really know a great deal about your disease. Even if he does, you cannot retain all the large words you're not familiar with. You go out of there thinking you know something and by the time you get home, you can't repeat it."

"What helped me get past my grief and start coming up for air was the fact that I am curious about a lot of things. I wanted to know more about the disease."

"Most people don't want to ask for help. I don't. I've been independent all my life. Now when I have to ask for help, it is not easy. I hate it. So I started out trying to do it all myself. Then I realized, 'Now wait a minute, this isn't fair to other people. People get a lot out of giving.' So I needed to find a way to let other people give."

"You have to have a good outlook, a good sense of humor, some curiosity. That combination can create good coping skills."

"Even when it rains, look for the rainbows."

Frequently Asked Questions

Myasthenia Gravis

Q: What are the signs and symptoms of MG?

A: MG can affect any muscle, but the muscles that control eye and eyelid movement, facial expression, and swallowing are most often affected. In some people, the first symptom is weakness of the eye muscles. In others, having a hard time swallowing, talking, and breathing can be the first signs. Different people have different levels of muscle weakness. Symptoms may include:

- Drooping of one or both eyelids
- Blurred or double vision
- Problems walking
- Weakness in arms, hands, fingers, legs, and neck
- Change in facial expression
- Having a hard time swallowing
- Trouble talking
- Shortness of breath (feeling like you can't get enough air)

The onset of the disorder may be sudden. And the symptoms often are not immediately recognized as MG.

Some drugs can trigger or worsen MG symptoms.

Q: How can I help take care of myself if I have MG?

A: To help ease fatigue:

- Get plenty of rest.
- Budget your energy.
- Rest your eyes or lie down briefly a few times a day.
- Work with your neurologist.
- Work with your doctor to limit medication side effects and keep your general health good.
- Eat healthy foods from all the major food groups

Q: What is a myasthenic crisis?

A: A *myasthenic crisis* occurs when weakness affects the muscles that control breathing. This can create a medical emergency requiring either a respirator to help the person breathe or measures to prevent a person from taking too much air into their lungs. Weak respiratory muscles, infection, fever, or a bad reaction to medication can also trigger a crisis. The treatments described above—in particular, intravenous immune globulin and plasma exchange—can reverse the severe weakness of a myasthenic crisis.

Q: What research is being done?

A: The National Institute of Neurological Disorders and Stroke, within the National Institutes of Health, conducts and supports research on MG. Research findings have led to more timely and accurate diagnoses. New and enhanced therapies have improved management of the disorder.

Despite these advances, there is still much to learn. The ultimate goal of MG research is to increase understanding of the disorder. Researchers are seeking to learn what causes the autoimmune response in MG and to better define the relationship between the thymus gland and MG.

Q: What is the treatment for MG?

A: There are several therapies that can help strengthen the muscles of someone with MG. Most people with MG have good results from treatment. In some people, MG may go into remission for a while and muscle weakness may go away completely. In rare cases, people go into remission or improve without treatment.

Treatment for MG may include:

- **Medications.** Drugs used include *cholinesterase inhibitors*, such as *pyridostigmine*. These drugs help improve nerve signals to muscles and increase muscle strength. *Immunosuppressive drugs* frequently are used to suppress the production of abnormal antibodies. They must be used with careful medical supervision because they can cause major side effects.
- **Thymectomy.** This is the surgical removal of the thymus gland, which is abnormal in most persons with MG. This surgery is done for people with MG who have tumors, as well as for some who don't have tumors. The surgery improves symptoms in most MG patients who receive it.

Other therapies sometimes used to treat MG when weakness is very acute include:

- **Plasmapheresis (PLAZ-muh-FUR-uh-suhss) or plasma exchange.** This procedure removes abnormal antibodies from the blood. This provides relief from MG symptoms in many patients for a few weeks.
- **High-dose intravenous immune globulin.** This treatment keeps the immune system from damaging the nerve-muscle junction for a short time. This provides relief from MG symptoms in many patients for weeks to months.

Your doctor will decide which treatment is best for you depending on the severity of the weakness, which muscles are affected, and your age and other medical problems. With treatment, many people with MG can expect to lead normal lives.

Source: U.S. Department of Health and Human Services, Office on Women's Health, last updated May 2008



Seven days without laughter makes one weak. ~Mort Walker

Laughter is the sun that drives winter from the human face. ~Victor Hugo

*[L]aughter on one's lips is a sign that the person down deep has a pretty good grasp of life.
~Hugh Sidey*

Protein from tick saliva shows potential for myasthenia gravis treatment

29. March 2009

Looking for a better treatment for the autoimmune disease myasthenia gravis, researchers have found that a protein in tick saliva shows promise in limiting the severity of the disease in an animal model in a study published in the *Annals of Neurology*.

"This disease can leave patients weak and on breathing machines, and conventional treatments can be toxic," said Henry Kaminski, M.D., chair of the department of neurology and psychiatry at Saint Louis University and one of the nation's leading experts on myasthenia gravis. "There is a real need for better treatments. This study is a step in that direction."

Myasthenia gravis is a highly debilitating, chronic neuromuscular disorder that affects about 400 to 600 per 1 million people, and roughly 1,100 to 1,700 people in the St. Louis area. Symptoms include weakness in the arms and legs, chronic muscle fatigue, difficulty breathing, difficulty chewing and swallowing, slurred speech, droopy eyelids and blurred or double vision.

While drugs like prednisone, a corticosteroid, can be effective in treating the disorder, they also can carry a host of severe side effects, including pronounced weight gain, osteoporosis, glaucoma and diabetes.

Other treatments, intravenous immunoglobulin and plasmapheresis, which involve blood plasma, are expensive and can have rare but serious side-effects such as infections, heart attacks and stroke.

Doctors believe that myasthenia gravis is caused by an overreaction of the complement system, a component of the immune system that specifically defends against parasites, bacteria and other pathogens. Antibodies block nerve receptors at the neuromuscular junction,

the place where nerves connect with muscles, and then activate complement which prevents muscle contraction from occurring, causing weakness.

To impede the complement system's misplaced response, researchers hope a new class of drugs, called complement inhibitors, may stop the body's defense system from attacking itself.

Other researchers discovered that rEV576, a protein found in tick saliva, works as a complement inhibitor, allowing ticks to avoid setting off an immune response in their human host.

SLU researchers in collaboration with Varleigh Limited tested the protein on two groups of rats with mild and severe models of myasthenia gravis. The health of rats that were given the complement inhibitor rEV576 improved, with reduced weakness and weight loss.

Researchers hope rEV576 could have therapeutic value in human myasthenia gravis. And, because ticks apply themselves to people without causing a reaction, researchers are optimistic that rEV576 will not cause allergic reactions or other negative side effects.

"Complement inhibitors are a completely new class of drugs," said Kaminski. "This one will probably prove to be superior to what we've seen. Since complement is activated in many diseases such as Alzheimer's, stroke and rheumatoid arthritis, our studies may be important for other diseases."

<http://www.slu.edu/x29654.xml>

A Pocket Full of Nickels: Myasthenia Gravis Remission

On a good morning, we awake with a dollar's worth of invisible nickels in our pocket or perhaps we find them after our first dose of Mestinon. We must decide how to spend this precious supply.

Shall we shower, dress, make the bed, have breakfast, go to a job, and recklessly spend them all at once? Perhaps we should just use twenty-five cents, and dress without the shower or shave, leave the bed for later, spend five to fifteen cents for breakfast. We alone may judge from our recent experience.

Having decided, we act and our precious deposits are made into an invisible slot, filled with invisible batteries. These batteries kick in slowly and we drain their reserve. As the day progresses, we decided to do a small chore. The shave, shower, or shampoo? Five more nickels perhaps? The bed? One more nickel perhaps? Cleaning house? Going to work? How many more nickels will

we have to spend today? For many of us, we can barely afford one nickel at a time, today. If we have the luxury of time for a rest period or nap, we might awaken with a sudden new supply of nickels in our pocket.

Probably our next dose of Mestinon will provide us with a fresh supply. For others, we may find we have chosen unwisely and squandered our day's wealth. Or borrowed them from tomorrow, to do what had to be done. Or simply what we wanted to do to improve our quality of life.

The debt must be repaid, and time in bed will be the price. We can gamble them away, or spend them gratefully. When awake, morning after morning with pockets full of nickels, such an abundance that we no longer have to count them. We have achieved Myasthenia Gravis remission!

May you all have a "pocket full of nickels!"

AMPS: Greater Florida Chapter

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Days of Our Lives to bring back Maggie's MG

According to a February 9, 2010 article posted on the TV Guide Magazine website, Suzanne Rogers' character, Maggie Horton, on the popular daytime soap *Days of Our Lives* will see her storyline include a reoccurrence of Myasthenia Gravis. Rogers was diagnosed with MG in the mid-80's with symptoms affecting her from the neck up. "At the time, *Days* also gave the disease to Maggie to explain Rogers' shocking appearance, which included considerable weight gain and facial bloating due to her medication. Rogers has been in remission for several years. The same goes for Maggie—until now."

This time around, *Maggie* will experience more generalized MG symptoms including weakness in her arms and limbs. These episodes are scheduled to start airing sometime in March. One of the big challenges with MG is its relative obscurity; hopefully, with Hollywood's help, we can bring more awareness to the disease... **stay tuned Soap Fans!**

Resources:

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

The third edition of the book, You, Me and Myasthenia Gravis, by Deborah Cavel-Greant, is available for purchase for \$20.00. Contact Verna Kapkey at 204-586-6784 or mginc@mts.net

Our drug alert card has been printed “**Drugs that worsen the symptoms of MG**”
If you have not received this card contact Verna at 1-204-586-6784

Myasthenia Gravis Manitoba Inc.

Membership Fees:

\$10.00 -- Family

\$ 5.00 -- Per Person

**Please submit your fees
or donation to:**

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

Literature

If you, or someone you know has Myasthenia Gravis and needs information on the illness, we do supply literature, in the form of previous articles, pamphlets, etc. for members and their families.

Contact, Verna Kapkey at 1-204-586-6784 or mginc@mts.net

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.

