



# Myasthenia Express

## Myasthenia Gravis Manitoba Inc. March 2009

### Vol. 1 No.26



Verna Kapkey 339 Boyd Ave, Winnipeg, Manitoba Canada R2W 1P1  
1-204 582-5456

### Myasthenia Gravis Manitoba Inc. Winnipeg, Manitoba

Our next meeting will be held on **March 19, 2009** and **May 21, 2009**.

In November we had our annual elections and below are the new executive list.

After our meeting in November all the members were busy with the Christmas rush.

But in early January we called upon our members for support and assistance for our bake sale which was held January 24, 2009 at Garden City Mall.

Once again our members did not let the executive down, not only were members dropping off baking, we had members assisting at the bake sale table. All who attended had a great time. The support from the members baking and helping sell baking was extremely overwhelming. I would

### Presidents Report by Diane S. Kowaliuk

like you all to give yourself a pat on the back, another job well done.

Unfortunately, we scheduled our yearly get together party for the next weekend but had decided this was too hard for the members to attend another function so close together so we decided to reschedule for later in the year.

In March we are trying to get someone from Revenue Canada to speak about changes regarding disability for 2009 and provide updated forms. This meeting will be very informal please come with a list of questions.

At our May meeting we anticipate showing the conference that was held in the U.S. in 2008. Our chapter is working hard to get this DVD. Updates at our March meeting regarding this DVD will follow.

## **Executive List for 2009-2010**

President	Diane S. Kowaliuk	444-7802
Vice President	Verna Kapkey	586-6784
Secretary	Maureen Silk	667-3630
Treasurer	Maureen Silk	667-3630
Telephone Committee Chair	Maureen Silk Mary Ross	667-3630 488-0477
Fund Raising Committee Chair	Verna Kapkey Sandra Penner	586-6784 204-348-2960
Education Committee Chair	Verna Kapkey	586-6784
Hospital Visiting Committee	Ken & Joan McGregor	667-0323
Social Committee Chair	Connie Chubaty	582-8491
Newsletter Editor & Assistant	Verna Kapkey Connie Chubaty	586-6784 582-8491
Resource	Doreen Amadatsu	888-8628
Video Production	Gary Parker	896-6444
Coffee Committee	Karen Riehl Maria Choquette	895-7398 293-1008
Brochure Distribution	C.J. Emmonds	786-5000 (Pager #)

# Myasthenia Gravis

## What conditions might be confused with Myasthenia Gravis?

1. What is the difference between MG and Lambert-Eaton Syndrome?
2. What is the difference between Myasthenia Gravis and Multiple Sclerosis?
3. What is the relationship between fibromyalgia and chronic fatigue syndrome to Myasthenia Gravis?
4. What is the relationship between Myasthenia Gravis and Muscular Dystrophies?
5. What is the relationship of Systemic Lupus Erythematosus and Myasthenia Gravis?

## What is the difference between MG and Lambert-Eaton Syndrome?

Myasthenia Gravis causes muscle weakness that becomes significantly worse with activity. Double vision, swallowing and speaking abnormalities, difficulty walking and using the arms are common symptoms. Lambert-Eaton Myasthenic Syndrome (LEMS) may produce similar symptoms, as well as muscle aches and dry mouth, but double vision is less common. Patients may also have impotence, constipation, impaired sweating, blurred vision and difficulties with urination.

Myasthenia Gravis is an autoimmune disease in which antibodies damage the acetylcholine receptors and compromise the muscle side of the nerve-muscle communication point. LEMS is an autoimmune disease that affects the nerve and not the muscle. LEMS may be triggered by a lung cancer. An EMG test performed by an experienced neurologist differentiates Myasthenia Gravis from LEMS. Blood tests for certain antibodies may also help with their differentiation. Many of the treatments for the disorders are similar, although patients with LEMS may not respond as well. A thymectomy is not used to treat LEMS.

## What is the difference between Myasthenia Gravis and Multiple Sclerosis?

Both Myasthenia Gravis and Multiple Sclerosis are autoimmune diseases, but differ in that MS affects the central nervous system (brain and spinal cord), while MG affects the nerve-muscle communication point of the peripheral nervous system. The presence of both MS and MG in a single

patient is rare. With appropriate testing, your neurologist would be able to distinguish the two conditions. There is no clear connection between MG and MS.

## **What is the relationship between fibromyalgia and chronic fatigue syndrome to Myasthenia Gravis?**

The cause of fibromyalgia or chronic fatigue syndrome is not known and neither is known as an autoimmune disease. There is no clear link between chronic fatigue syndrome, fibromyalgia and MG. Chronic fatigue syndrome is characterized by a set of symptoms that may have many causes (that is why it is called a syndrome). Although both are manifested by fatigue, MG causes muscle fatigue that can be identified objectively by specific muscle tests, such as an EMG. Mestinon has been used for chronic fatigue syndrome, but my understanding is that it ultimately has not been shown to be effective.

## **What is the relationship between Myasthenia Gravis and Muscular Dystrophies?**

We are not aware of any relation between MG and Muscular Dystrophy. Muscular dystrophies are genetic diseases and having MG does not put you at risk for developing such a disease. In fact, the eye muscles, which we studied in patients with advanced DMD, are always spared, in contrast to the eye muscles in MG that tend to be affected early in the disease.

## **What is the relationship of Systemic Lupus Erythematosus and Myasthenia Gravis?**

Systemic Lupus Erythematosus (SLE) is a complicated autoimmune condition that may affect the nervous system in many different ways. MG and SLE can occur in the same patient. Myasthenia Gravis produces weakness while SLE produces any combination of joint pain and swelling, rash, kidney problems, eye and brain abnormalities, and others. There are blood tests to confirm the diagnosis of SLE.

## **How can stem cell research help Myasthenia Gravis patients?**

Stem cell therapies are being applied to the treatment of autoimmune diseases. A great deal of study needs to be done before there is common

use of the treatment. It is hoped that one day some parts of the findings from stem cell research might be used to help MG patients.

## **How do Myasthenia Gravis patients tolerate surgical procedures?**

In the experience of my patients, most procedures are usually safe for patients with good strength. Sometimes plasma exchange before major surgery to improve strength is a good idea. This may decrease the possibility of requiring breathing support (ventilator) after surgery. Close monitoring of the patient after surgery by the surgeon and neurologist is imperative. Pain control also is an important aspect when having a surgical procedure. Based on the type of surgery, activity such as walking, driving a car or lifting objects may be restricted during the recovery period.

Source Net Wellness

## **Diet and Nutrition**

## **Fatigue from too many supplements?**

### **Question:**

Hello, I`ve been taking multivitamins, vitamins B6, super B complex, C, and E, garlic and oil of oregano capsules, selenium, magnesium, and probiotics for my fatigue. However, I am wondering if taking this many supplements can actually cause fatigue. Should I stop taking one or more of these supplements?

### **Answer:**

I do not suspect that the supplements you are taking are causing your fatigue, however I do think you may be over consuming some nutrients and wasting your money. Many nutrients, such as the B vitamins, function to help our body release energy from our food (from the carbohydrates, proteins and fats). However, having excess B vitamins will not increase the release of extra energy (It's equivalent to putting extra gas in a car and it not running any faster). With nutrients, thinking that "if some are good, then more are better" is not true (and can be harmful). Instead of self prescribing supplements, I'd recommend seeing your doctor for a

complete evaluation of your health, current medications, your sleep patterns, and exercise habits. It would also be helpful to see a registered dietitian (RD) for a thorough review of your diet (including evaluating any gaps in your nutrition or food sensitivities). It is always preferable to obtain your nutrients from whole foods (fruits, vegetables, whole grains, non-fat dairy, lean protein) before considering supplements

Source Net Wellness

**Question:**

Could you please advise on what foods etc to avoid with Myasthenia Gravis. I cannot find any information on your site. Many thanks

**Answer:**

I do not know of any specific foods that may worsen myasthenia. Avoid foods heavy in magnesium if possible. A multivitamin everyday is a good idea and basic nutrition, with servings of fruits and vegetables, should help with overall function. If you are having trouble with swallowing with myasthenia, I would recommend avoiding thin liquids and "sticky" foods (i.e. peanut butter, white bread) as these may be hard to chew and swallow.

## Myasthenia Gravis

## Muscle cramps

**Question:**

I was diagnosed with MG 3 years ago. I occasionally have SEVERE muscle cramps in my legs & slight cramps in my arms. The leg cramps I notice most often when I have been on my feet for a long time. Recently I helped host a baby shower so I was up and down on a tile floor for 4 hours. My legs really cramped that night. My left arm also cramped slightly. Is this normal for MG patients? I know it wasn't too much Mestinon because I was actually late taking my dose. Any ideas?

**Answer:**

Low potassium, low calcium, low sodium, dehydration, and low magnesium can be associated with leg cramps. Vitamin D deficiency or hypothyroidism are also possible causes, both of which should be considered in the context of myasthenia gravis. Excessive pyridostigmine (Mestinon) use can also lead to leg cramps, but it sounds like you have ruled this out. It could also be just exertional, particularly if you have a low level of activity normally and then have days where you "over-do" it. Source. Net Wellness

## **Count your blessings - even when they're hiding.**

We all have misfortunes in life. It is how we deal with various events that make the outcome so very satisfying. We lose family and friends, and we learn to accept that, since we are unable to change the circumstances. We all have our sad moments, and this is inevitable, because later we enjoy the wonders of life, the happy events, and the good times, more greatly.

Being diagnosed with any type of illness is very hard to accept. Myasthenia Gravis is one of them. It is not a very common disease, and it is necessary to learn all you can about coping with the various symptoms that cause weakness and chronic fatigue. And we can, with a great deal of effort.

Suddenly our lives will change, we can no longer plan our daily events the same way we did when our health was stable. Anxiety in coping with stressful situations is overwhelming. There may be times a person may become depressed in dealing with the many stages of weakness associated with Myasthenia Gravis. Understanding and encouragement from family members is extremely helpful. It is so very vital to understand the illness and the treatment, to make life a little easier for everyone.

Once you have overcome the uncertainty, and aggravation of dealing with the many symptoms of Myasthenia Gravis, reach out and help another member deal in coping with the same illness. The rewards will be endless.

Sometimes we are forced to accept what's going on, no matter how much it hurts or how much it changes our lives. Do not hesitate to ask for help. We all need assistance some times in our lives.

Before we can change anything in our life, we have to recognize that this is the way it is meant to be right now. Whatever life is handing you right now, accept it. This is where your life is right now. Agree. Stop struggling. It's only when our eyes are open that the healing process can finally begin. We can only move forward if we know where our starting point truly is. Not where we wish it could be. Count your blessings, always.

Submitted by Verna Kapkey

**Myasthenia Gravis Manitoba Inc.**

Chapter Directors:

Gary Parker

Verna Kapkey

Roger Ross

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**Resource Person:**

Anyone needing social or health care services or any of the wide variety of organizations in our community contact our resource person for information.

Doreen Amadatsu at: 888-8628

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**Our drug alert card has been printed “Drugs that Cause or worsen the symptoms of Myasthenia Gravis.**

If you have not received this card contact Verna at 1-204-586-6784

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**Myasthenia Gravis Manitoba Inc. Chapter  
Membership Fees are as follows:**

**Family.....\$10.00**

**Per Person.....\$ 5.00**

Please submit your fees and donation to:

Myasthenia Gravis Manitoba Inc.

c/o Maureen Silk

614 Munroe Avenue

Winnipeg, Manitoba

Canada

R2K 1H8

**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.