



Myasthenia Express

Myasthenia Gravis Manitoba Inc. October 2007

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

**Myasthenia Gravis
Manitoba Chapter
Bake Sale
Will be held**

January 19, 2008
Garden City Mall
2305 McPhillips St.
Winnipeg, Manitoba
On
Saturday, 9.00 A.M.
To 6.00 P.M.

Our next meeting will be held on November 15, 2007 at the St. Boniface Hospital in rooms AG 001 & 2 in the basement, south entrance. The meeting will start at 6.30 P.M. and our guest speaker, Dr. Arnett will begin his presentation at 7.00 P.M. A question and answer period will follow. Bring your family and friends and enjoy the evening.

Presidents Report
by
Diane S.Kowaliuk
October 2007

Once again another year has gone by and I would like to reflect on some of our memorable accomplishments. I would like to thank all members for their commitment and support they shared with one another and I would like to thank the executive for their support and commitment to this chapter.

We lost two very important members of our chapter this year, Bob Amadatsu and Sister Marie Shewchuk and the support group would like to extend our

sympathies to their families.
At our November meeting we will have elections, and once again I would like to stress that the executive cannot be only a handful of people. We need all the positions filled to make this support group productive and successful. The position could be as small as the coffee committee or as large as the secretary position. Your support in this is greatly appreciated. Remember we have a large break down of positions to minimize the workload. I do hope all members will show their support by filling these positions accordingly.

Chronic Illness and going through the emotions.

Most people with chronic illness struggle with fatigue and emotional issues. Knowing that you will be dealing with this for the rest of your life is bound to cause emotions to flare. People end up being angry, anxious, frustrated or depressed. It is also common to feel a sense of disappointment and fear about the future. This is universal among people who have a chronic condition. Learning how to cope effectively with these inevitable feelings, is a huge part of maintaining a good quality of life. Some things are beyond our control, which makes it necessary for a person to make choices. Learning to say no when a person is not physically able to do something is a beginning.

People with chronic health conditions face challenges every day. They must manage their medical condition and also maintain their ability to complete the simple everyday tasks most people take for granted. Having a chronic illness can drain your energy, therefore, fatigue is a very real problem for many people. Often, it is misunderstood by those who do not have a chronic illness.

One thing the experts and those with a chronic illness agree on wholeheartedly is the importance of support. Family support is very crucial. It is not just the person with the illness who has emotional distress. It affects everyone close to that person. Always keep the lines of communication open. Tell your family and friends what you need and what you don't need, and remember this has changed their life as well.

A support group is very helpful as well. It is very comforting to talk with others who are dealing with the same type of illness and the stress that is involved. People discover that anger, stress and depression as well as fatigue is very common with an illness and we have to learn to deal with it in a healthy way. Coping with suffering is what is common and there's a deep healing that takes place when people discover they can relate to each other on that level. Most important, you learn you are not alone. Somewhere near you, there is someone who needs comfort and help. Sharing your feelings with them is a healing process in itself.

Myasthenia Gravis

What are the tests for Myasthenia Gravis?

1. What are the methods for diagnosing Myasthenia Gravis and how long do they take to perform?
2. How does Tensilon testing work?
3. What are some of the diagnostic radiological tests?
4. What is the acetylcholine receptor antibody test and how accurate are they?
5. What is the single fiber EMG?

What are the methods for diagnosing Myasthenia Gravis and how long do they take to perform?

The initial diagnostic exam for Myasthenia Gravis includes the following:

- Evaluation begins with examination by a neurologist. 1 hour.
- " Tensilon test. (A Tensilon test is positive in many patients who have MG, but may actually be negative in 20-30% patients with MG diagnosed by other methods.) 15-30 minutes in the physician's office.
- Acetylcholine receptor antibodies (a blood test). Acetylcholine receptor antibodies are positive in 90% of patients with general myasthenia. The results usually take a week to return from the laboratory.
- EMG (electromyogram) is a test to determine the electrical response from the muscle after stimulation of the nerve. 1 hour.

An additional test is:

- Single-fiber EMG. This test is only performed at specialized centers. The exam itself takes 1-3 hours to perform. A single fiber EMG is considered the best test, being positive in 95-99% of MG patients.

In rare patients all these tests are normal, but examination by a neurologist suggest Myasthenia Gravis. If the disease is mild or purely ocular (symptoms of the eye muscles), then the tests are more frequently negative than in the case of the generalized disease.

How does Tensilon testing work?

The Tensilon test is done by injecting the drug Tensilon into a vein and watching for rapid improvement of strength, usually of eye muscles. Improvement in strength of speech may also be considered a positive test. A patient feeling better after Tensilon does NOT necessarily mean that the patient has MG. Blood pressure and pulse need to be monitored during the test. A patient may have MG and a negative Tensilon test (no improvement with the administration of the medication), but then the diagnosis should be supported by other tests, such as the acetylcholine receptor antibodies in the blood, or by a positive EMG test. False positive (the Tensilon test suggests that the MG is present, but it actually is not) and false negatives (the Tensilon test does not improve strength even if MG is present) occur. False negative tests are more frequent. Possible side effects need to be explained to each patient.

What are some of the diagnostic radiological tests?

A CT (computed tomography) or MRI (magnetic resonance imaging) of the brain does not make a diagnosis of MG, but may help rule out other diagnoses. It is important to have a CT or MRI of the chest to make sure a tumor of the thymus is not present. PET scans are not useful to diagnosis of MG. These test brain function, which is normal in MG.

What is the acetylcholine receptor antibody test and how accurate are they?

The acetylcholine receptor antibody test is a blood test to measure the amount of antibody directed against the acetylcholine receptor. The test is measured in nanomoles (nM) per liter. Individual laboratories establish particular ranges of normal. These are always listed with the test result. For the acetylcholine receptor antibody binding test the normal range generally is 0-.03 nM/liter. Antibody tests are normal in 10-20% patients with the generalized disease and in about 50% of the patients with ocular (eyes only) myasthenia gravis.

There is a rough correlation between the level of the antibody test and the severity of weakness, but patients may have little weakness or be in remission but have increased acetylcholine antibodies.

What is the single fiber EMG?

The single-fiber EMG evaluates how well the nerve and muscle communicate. It involves insertion of a recording needle electrode into the area of the nerve-muscle communication point (the neuromuscular junction). There may be some discomfort with insertion of the electrodes (similar to an intramuscular injection or a shot that goes right into the muscle). A single fiber EMG is often done on an eye, forehead, or forearm muscle. If a person is in remission, the SFEMG is normal, but if there is weakness from MG, the SFEMG is usually abnormal. Patients with ocular myasthenia will have an abnormal SFEMG. The diagnosis of MG is made after accounting for all the clinical symptoms and signs as well as the tests performed. Most patients tolerate the procedure well. A single-fiber EMG is a more technically difficult procedure than the standard EMG. Studies of this method suggest that it may detect abnormalities in over 95% of MG patients. However, other diseases may produce similar abnormalities. The test should be done by someone with extensive experience.

For more information:

Go to the Myasthenia Gravis health topic, where you can:

- Read articles on this topic
- Browse the previously asked questions
- Ask your own question.



Myasthenia Gravis Coalition of Canada (MGCC)

The Myasthenia Gravis Coalition of Canada is a non-profit organization committed to provide information, education and support to Canadians who have Myasthenia Gravis and to their caregivers. The MGCC will maintain a national registry of Myasthenia Gravis healthcare providers and services and to gather and disseminate specific information on Myasthenia Gravis to the healthcare communities across Canada, as well as support research into causes and treatment of Myasthenia Gravis. Iris Biteen of Montreal is the founder and president of this newly formed MGCC. The MGCC is comprised of the Myasthenia Gravis Association of British Columbia, Myasthenia Gravis Manitoba INC. and the Myasthenia Gravis chapter of Ontario. MGCC has a web site listed below.

The toll free telephone number is; 1-866-999-6422
The web site is: www.mgcc-ccmg.org

Healthy Eating Tips For MG Patients

Below are some nutritional tips to remember if you have MG.

- MG patients should eat a balanced diet from the four major food groups.
 - Chewing may cause an MG patient to become tired when eating. Try to eat when your strength is best. (This time varies between MG patients)
 - Take smaller bites which require less jaw movement and saves your strength.
 - Try resting briefly after taking a piece of food into your mouth.
 - Softer foods will be less strenuous on your jaw muscles.
 - Try drinking a small amount of liquid with your food to soften it.
 - Avoid adding salt to food and other high-sodium foods such as commercially prepared soups, bacon, sausage, lunch meat, ham, and other pork products.
 - Always sit upright while eating or drinking-this will reduce your chance of choking.
 - Avoid hot or spicy foods. These may irritate your throat.
 - If coughing occurs, lean forward, close your mouth, and take small amounts of air in through your nose. A strong forceful cough will help push the irritating substance out of your throat.
 - If you begin to choke or cough, remain calm.
 - Drinking alcohol in moderation (one or two drinks) may be tolerable for some MG patients. However, others may not be able to have any at all. Check with your doctor if it is acceptable in your case.
 - Consult your doctor before starting any weight reduction plan.
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May your life be like arithmetic.

Friends added, enemies subtracted, joys multiplied and errors divided.

Myasthenia Gravis
Chapter Meetings

Myasthenia Gravis
Manitoba Inc. chapter
meetings will be held on
November 15, 2007
January 24, 2008
March 20, 2008
May 15, 2008

All meetings will be
held at 7.00 P.M. at the
St. Boniface Hospital,
409 Tache Ave,
Winnipeg, MB in rooms
AG 001 & 2.
Basement South
Entrance.

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

Resource Person:

Anyone needing social
or health care services or
any of the wide variety
of organizations in our
community contact
community resource
person for information.
Doreen Amadatsu at
888-8628



Being a Volunteer

It's not for the money;
it's not for the fame.
It's not for any personal
gain. It's just for the
love of fellow man. It's
just to lend a helping
hand. It's just to give a
little of self. That is
something you cannot
buy with wealth.
It's not for the medals
won with pride. It's just
for the feeling down
inside. It's for that
reward down in your
heart. It's just that
feeling that you've been
part. Of helping others
far and near. That's
what makes you a
volunteer.

Thank you, Volunteers

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.

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

Directors

Myasthenia Gravis
Manitoba Inc. Chapter
Directors:
Gary Parker
Verna Kapkey
Roger Ross

Grandma's Age:

Little Johnny asked his
grandma how old she
was. Grandma
Answered, "39 and
holding" Johnny
thought for a moment,
and then said, "And how
old would you be if you
let go?"

