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
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 feeling’s, 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 effect’s 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 makes 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

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**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 save 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?”