



Myasthenia Express



Myasthenia Gravis Manitoba Inc. October 2006

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**-Myasthenia Gravis
Manitoba Inc. Chapter**

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**Next meeting is on
November 16, 2006 at
the St. Boniface
Hospital in AG001 &
2 at 7.00 P.M.**

**Presidents Report by
Diane S Kowaliuk
October 2006**

Once again another year has gone by and I would like to thank the executive and the members for all their hard work for such a successful year.

The following are some of the highlights of the past year in our support group.

Our guest speaker, Kyle MacNair, BSc.Pharm, ACPR from Prescription Information Services of Manitoba, created our laminated drug alert card for our members. Sincere thanks to Dr. Gomori for reviewing and authorizing the creation of our drug card

The creation of the Myasthenia Gravis Coalition of Canada (MGCC) took place June 2006. Iris Biteen of Montreal is the founder and president of this newly formed coalition. The MGCC is comprised of the Myasthenia Gravis Association of British Columbia, Myasthenia Gravis Manitoba Inc. and the Myasthenia Gravis Chapter of Ontario. One

of their goals is to compile a national registry of MG health care providers and clinics, to better offer vital medical information to patients and their families across Canada. Iris Biteen is to be commended for her great effort in this achievement.

Lidia Cosentino, PH.D, Scientific Manager, of Telecris Biotherapeutics from Toronto, our guest speaker, gave a very intensive presentation on Intravenous Immuno-globulin (IVIG) treatment.

Our website address is: <http://mginc.mb.ca> which has a great deal of information pertaining to our schedules meetings, newsletters, and links to helpful websites.

Our telephone numbers is: 204 -582-5456

Sincere thanks to all the members who participated in our very successful bake sale at Polo Park on October 6 & 7, 2006.

I am proud to be part of this team and able to work with such wonderful people.

Diane S. Kowaliuk

1. Our Guest Speaker

At our September 14, 2006 meeting we had a very interesting speaker. Lidia Cosentino, PhD, Scientific Development Manager, of Telecris Biotherapeutics, from Toronto accepted our invitation and came to our meeting in Winnipeg to share her knowledge with our members. She gave a very intensive presentation on Intravenous Immunoglobulin (IVIG) treatment for Myasthenia Gravis.

Lidia was a very nice presenter. She had a well organized power point presentation on Myasthenia Gravis and specifically how all of the treatments work to improve the physical capabilities of the patient. She did focus on the role of antigens in the blood and how different blood plasma treatments affect the negative antigens. It was interesting to learn the make up of the blood plasma and what element affects an MG patient. We have a much better understanding of the IVIG treatment and the difficulties and expense associated with making sure of the high quality and safety of the IVIG plasma.

Lidia also spoke about how different the health system is in Canada to the United States and other locations and why this is a treatment that is available in Canada to the average person. She did identify the difficulty in getting a treatment certified by Health Canada due to the stringent test requirements which necessitate a placebo in the study. The placebo for those who are in difficulty and have a health risk is itself a risky proposition for the patient and it is easy to see why such tests are difficult to both, attract volunteers and medical staff who would be concerned with the health of their patients.

Here are some of the questions asked at the meeting by the members, which Lidia answered in great detail.

1) Why is it so expensive?

A) The blood has to be broken down into many components for other uses and the amount used for the IVIG requires many donors.

2) How many donors are required and how much does it cost?

a) It costs approximately! 10, 000.00 for each treatment.

3) Is it effective?

a) The IVIG is not a cure but when used with other treatments and in some cases have been effective after one or two administrations. However, the need for repeated treatments can be very costly. The doctors are still considering how to determine which patients would most likely benefit from the treatment and the long-term costs involved.

4) Are there any side effects?

a) The side affects to this treatment presently, are local and minimal, some head aches, localized pain and swelling at the site and cramps but they can be controlled by giving the infusion over a longer rate of time.

5) Is it covered by Pharmacare?

a) Presently it is covered by Pharmacare, until a future decision is made.

Thanks to Gary Parker and Doreen Amadatsu for their submissions.

Intravenous immunoglobulin (IVIG) Therapy in the Treatment of Myasthenia Gravis

Lidia Cosentino, Ph.D

Talecris Biotherapeutics

Myasthenia Gravis

The body is designed to defend itself against foreign or dangerous substances (pathogens) that invade it. Our immune system produces antibodies (proteins) that normally attack hostile viruses and bacteria in an effort to keep us healthy. However, antibodies sometimes mistake our own cells as being foreign and the body generates an attack against itself. Antibodies produced against oneself are called autoantibodies and are produced in people with an autoimmune disease.

In a myasthenia gravis patient, the immune system mistakes one of the body's own receptors on the muscle side of the neuromuscular junction as foreign. These receptors are located where nerves connect with muscles. When autoantibodies attack these receptors, the communication between nerves and muscles is disrupted and patients have episodes of profound muscle weakness. Currently there is no cure for myasthenia gravis (MG) but there are effective treatments that allow many patients to lead normal lives. The treatment is individualized for each patient and may include one or more of the following therapies: anticholinesterase agents, corticosteroids, immunosuppressant agents, thymectomy, plasmapheresis and intravenous immunoglobulin (IVIG).

IVIG information

IVIG is a concentrated preparation of pooled human antibodies made from the blood or plasma donations of healthy donors. Because a large number of plasma donations are combined to form the plasma pool from which IGIV products are made, IGIVs contain a large number of different antibodies directed against a wide range of infectious pathogens. Currently 4 licensed IVIG products are provided by Canadian Blood Services and Héma-Quebec: IGIVnex™ 10% (manufactured by Talecris Biotherapeutics from Canadian plasma), Gamunex™ 10% (manufactured by Talecris Biotherapeutics), Gammagard™ S/D, and Iveegam™ (both manufactured by Baxter). Currently in Canada the above IVIG products are collectively licensed for the treatment of primary and secondary immunodeficiency diseases, allogeneic bone marrow transplantation, B-cell chronic lymphocytic leukemia, pediatric HIV infection, Kawasaki disease, and idiopathic thrombocytopenic purpura (specific approved uses vary by product).

Although not approved for these uses, IVIG has been reported to be effective in the treatment of a number of autoimmune disorders including Guillain-Barré syndrome, chronic inflammatory demyelinating polyneuropathy, dermatomyositis, and multifocal motor neuropathy. Several studies have also reported a positive response to high-dose IVIG in MG patients. While the degree of response after IVIG therapy varies between individuals, the onset of improvement may occur within a week and last for a few weeks or months. Health Canada has not yet approved any IVIG product for use in the treatment of myasthenia gravis. The contents of this article are intended for information purposes only, to be used by patients who may have been prescribed and IVIG product by their physician. Your physician is the best person to advise you on the optimal treatment options for your specific situation.

Submitted by Lidia Cosentino, PH.D

Ask an Expert Question & Answers

Question:

I have MG and taking Cellcept. I think I have shingles and have a rash. Are MG patients taking medications that suppress their immune systems more likely to have shingles? If it is shingles, what medications can myasthenics usually take that will not exacerbate their disease?

Answer:

Yes, immunosuppressants cause people to be more likely to develop shingles. Turning down the immune system likely allows the virus to reactivate. Certain people are also predisposed to shingle, especially people with chronic disease that suppresses the immune system (myasthenia for example). Acyclovir, valacyclovir, and famciclovir can all be used and are relatively safe for myasthenia. But you should talk to your doctors as acyclovir can interact with some immunosuppressants.

Question:

Could you please explain in simple terms the process of MG and what is going on in the body? Then explain how prednisone and immunosuppressant drugs like cellcept are counteracting the process.

Answer:

MG is an autoimmune disease. This is a situation in which the body's immune defense system mistakes the patient's nerve-muscle connection (neuromuscular junction) as the enemy. The patient's own immune system then attack and damages or destroys the nerve-muscle connection, thereby weakening the patient. Prednisone, Cellcept and other immunosuppressant drugs blunt the immune attack on the neuromuscular junction. This allows the signal to transmit from nerve to muscle and for the strength to return.

Question:

What is the connection between Myasthenia Gravis and Fibromyalgia and Arthritis? I suffer from all of these and am wondering the connection between them so I can treat them effectively.

Answer:

Fibromyalgia is a clinical diagnosis based on widespread pain involving both sides of the body, with pain in at least 11 to 18 tender points. Myasthenia gravis is a disease of fatiguing weakness of muscle, manifesting as ptosis, diplopia, dysarthria, nasal speech, dysphagia and proximal weakness. There's no accompanying pain. There are autoimmune conditions associated with myasthenia gravis, such as rheumatoid arthritis. But wear and tear arthritis, the type we call osteoarthritis, usually does not have a higher incidence of autoimmune disease. Fibromyalgia can be associated with myasthenia, but one does not cause the other. One must be careful to not confuse the fatigue of fibromyalgia with the neuromuscular weakness of myasthenia.

The treatment for each disease is very different.

Internet source. Netwellness.

Pain In The Back

Back pain is a common condition that usually occurs as a result of strain or injury to the muscle and tissues in the back. The lower back is most often affected because it carries most of your body's weight and is constantly under stress from movement such as bending and twisting at the waist.

What causes low back pain?

Some common causes of low back pain.

Poor posture

Excess weight, including during pregnancy

Muscle tension

Sports or work related injury

Improper lifting or twisting

Wear on the disk of the spine

Osteoarthritis (break down of the cartilage in joints)

Osteoporosis (weakening of the bones that can lead to small breaks in the bones of the spine.

What can I do to help relieve my back pain?

Alternate 20-minutes applications of cold and heat to help soothe muscles and increase blood circulation

Avoid long periods of bed rest since this may slow the healing process

Do gentle exercises to help restore your range of movement. A physiotherapist should be able to help you pick the right exercises.

Take an over-the-counter pain medication such as acetaminophen or ibuprofen

How can I prevent back pain?

Maintain good posture

Exercise

Maintain a healthy weight

Use correct lifting and moving techniques

When should I see my doctor?

You have numbness in your legs or lower back

Your pain starts after the age of 50 and you have no previous history of back pain.

The pain is severe and lasts for more than a day or two

The pain is due to a fall or other accident

You have a fever, upset stomach or sweating along with back pain

The pain wakes you up

The pain shoots down your leg

Proper lifting techniques

Let your legs do most of the work

Squat down in front of the object while keeping your back straight

Tighten your abdominal muscles as you straighten your knees

Keep the object as close to your chest as possible

Your shoulders and hips should always be aimed in the same direction when you lift or carry heavy objects.

For more information, ask your Pharmacist

Chapter Meetings

Myasthenia Gravis
Manitoba Inc. chapter
meetings will be held on
November 16, 2006
January 25, 2007
March 15, 2007
May 17, 2007

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. Emergency Entrance at the rear of the hospital.

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 our resource person for information. Doreen Amadatsu at: 888-8628



Bake Sale

I wish to acknowledge my sincere gratitude to all the members, family and friends who were so willing to bake for our yearly bake sale at Polo Park Shopping Centre. And I commend all the members who came to help at the sale of all the delicious dainties. Because of your generous donations and help, our bake sale was a great success. Verna Kapkey

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 cause or worsen the symptoms of Myasthenia Gravis. If you have not received this card, contact Verna Kapkey at 582-5456



Directors

Myasthenia Gravis
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Directors:
Gary Parker
Verna Kapkey
Roger Ross

Seek Daily Joy

Experiencing joy is about paying attention to the small pleasures, appreciating the wonder hidden in the tiny moments of life. Small basic everyday things can bring you joy- the smell of fresh coffee, the sound of laughter, or the beauty of a rainbow.

We can learn a lot from crayons. Some are sharp, some are pretty and some are dull. Some have weird names, and all are different colors, but they all have to live in the same box.

A truly happy person is one who can enjoy the scenery on a detour.

