Myasthenia Gravis Society of Canada

Myasthenia Gravis Society of Canada

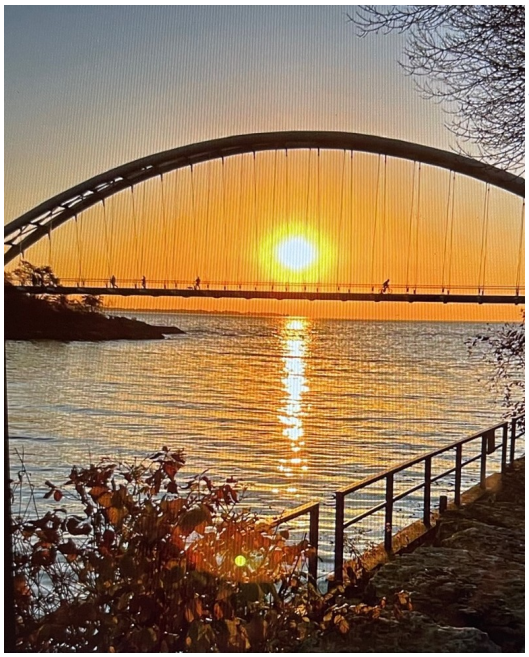
There is Hope Through

'CONTACT'

Printed in the interest of those Affected by Myasthenia Gravis

"Could It Be MG?"

Quarterly News **Volume 46 Issue 3** **Fall 2022**



Sunrise at the Humber Bridge. Another beautiful moment this fall. Photo by Tony Watkins.

In This Issue

A Leap Forward For Rare Disease

Targeted treatments for myasthenia gravis are finally offering new options for individuals with this neuromuscular disorder

By Sophie Lorenzo
The Neuro—Montreal Neurological Institute-Hospital Clinical Research Unit—McGill

By definition, a rare disease affects only a small number of people. Its scarcity means individuals with a rare disease are left looking for equally rare resources: research and expertise can be hard to find and scattered across the country. Treatments that could help slow

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the progression of symptoms are limited; health care teams tend to focus on managing symptoms that affect day-to-day life.

But while the diseases may be rare, the collective burden of illness is not. According to the Canadian Organization for Rare Disease (CORD), one in 12 Canadians has a rare disorder. Those 3 million individuals and their families face a debilitating prognosis that severely impacts their future. And among these rare conditions are neurological diseases, many of which are more common in Canada than elsewhere in the world.

Making rare disease treatable

One of the challenges with rare diseases is that little may be known about the mechanisms causing the condition. In addition, biomarkers may not yet have been identified to help facilitate early diagnosis and the prediction of clinical outcomes. As a result, clinical research is left to explore different potential pathways of action in the hopes of finding one that yields the most impact.

"If we look at cancer treatments, it took several decades to understand the mechanisms of the disease. A lot of research went into developing a new generation of drugs that have transformed the field of cancer treatment dramatically. And we are finally seeing the same success in treating rare neuromuscular diseases," explains Dr. Angela Genge, the executive director of the Clinical Research Unit (CRU) at The Neuro (Montreal Neurological Institute-Hospital).

The CRU's mission is to make all rare diseases treatable. Neuromuscular diseases represent almost 20% of all clinical trials at the CRU -- one of the largest neurological research centres in Canada which conducts over 110 clinical trials each year. A large roster of trials enables patients to have access to investigational treatments while they are in development, often when no other treatment exists for their disease.

Neuromuscular focus

An area of focus at the CRU has been better treatment options for myasthenia gravis (MG), a debilitating, autoimmune neuromuscular

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disease that leads to a loss of muscle function and severe weakness. In myasthenia gravis, an abnormal autoimmune response results in a decreased number of acetylcholine receptors. This in turn causes failed nerve transmission at certain neuromuscular junctions – that is, at the connection between nerve cells and the muscles they control. The damage eventually means that the brain and muscles can no longer communicate, causing loss of muscle function and severe weakness.

Individuals with myasthenia gravis may start with mild symptoms such as slurred speech, droopy eyelids, double vision and lack of balance, and progress to more severe symptoms such as choking, extreme fatigue and even episodes of respiratory failure. It can occur at any age, but most commonly begins for women before 40 and for men after the age 60.

A shift in treatment

Some individuals with myasthenia gravis do not respond well to available treatments, which usually involve the long-term suppression of the immune system. Until 2017, there had been no new drug to treat the disease in almost 60 years.

“This rare disease is difficult to diagnose and has been treated by general immunosuppressant therapy for decades. Finally, over the course of the last two years, we have a number of new therapies that are far more precise in their treatment of myasthenia gravis. This marks a real shift in treatment options,” says Dr. Genge.

The CRU has been involved in a range of clinical trials for myasthenia gravis, studying treatments that target specific aspects of the immune response. One such pathway focuses on the neonatal Fc receptor (FcRn). The treatment blocks this receptor, in turn reducing the harmful acetylcholine antibodies that cause myasthenia gravis symptoms. Both Vyvgart (efgartigimod), which received FDA approval at the end of 2021, and rozanolixizumab which posted positive Phase III results, use this approach.

Another avenue that has proved promising has focused on inhibiting the complement cascade, a group of proteins that are involved in

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activating the immune cells that produce antibodies. When activated in an uncontrolled manner, the complement cascade over-responds, leading the body to attack its own healthy cells. Two drugs studied at the CRU use this pathway: Ultomiris (ravulizumab) which has been Approved by the FDA; and zilucoplan which posted positive results of its Phase III trial and will be submitted for regulatory submission later this year.

"Finally, rare diseases are getting the attention they need from biotechs as well as pharmaceutical companies. These new options will substantially decrease the burden of the treatment on patients while allowing those who were previously only getting moderate benefit from the old therapy to have much more substantial improvement in their disease management to the point of having minimal symptoms," concludes Dr. Genge.

Join our Myasthenia Gravis Facebook Group (Canada)

Editorial: Cap Cowan

President & Newsletter Editor

Hospital Healthcare is changing. Patients should be aware of this.

You have to move to be healthy. Move or be moved? That is the new credo of patient relations healthcare. It has created a new acronym. PFC – short for Patient Flow Coodination. If you are admitted for the reason you came, a PFC will interview you. Basically they expect you to tell them what your positive expectation is to go home.

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Treat a patient, move the patient to recovery mode by your PFC with your ward's Occupational Therapist (OT) and Physical Therapy (PT) Assessment Assistant – and perhaps alternative facility for more PT recovery, if you're not ready to go home. Hospitals are primarily for treatment to help healing with your active participation not expecting the hospital to be your convalescence home. Your hospital treatment bed is made ready for the next patient.

So what if the unexpected happens to you? You fall or are in an accident? It looks on X-ray like surgery to avoid chronic pain the rest of you life. A close look shows a good chance the fracture might heal enough to get below chronic pain level so the planned morning surgery is cancelled and the medical decision is to go for 7 -8 week fracture recovery in an alternative facility. Patient is clear they will have to live with the result of it and hope for the best with support PT.

Soooo. How's your independence chart? Are you taking exercise seriously or basically letting your lazy side control your MG condition? That is the question. Try this:

Lie-Sit:	☐ Independent	☐ Supervision	☐ Assist:
Bed Transfer:	☐ Independent	☐ Supervision	☐ Assist:
Toilet Transfer:	☐ Independent	☐ Supervision	☐ Assist:
Mobility:	☐ Independent	☐ Supervision	☐ Assist:
Wheelchair:	☐		

We'll chat some more in our next issue. **Let's get moving. Even bed exercises. No excuses. Any way we can. Your input welcome. CapCowan@MGCanada.org**

B.C. First Province to Make June "Myasthenia Gravis Awareness Month" in 2020.

The Lieutenant Governor of the Province of British Columbia signed A Proclamation that recognized the need for "Myasthenia Gravis Awareness Month" on May 15, 2020. This was achieved by the Myasthenia Gravis Association of British Columbia, the voluntary agency, in May of 2020.

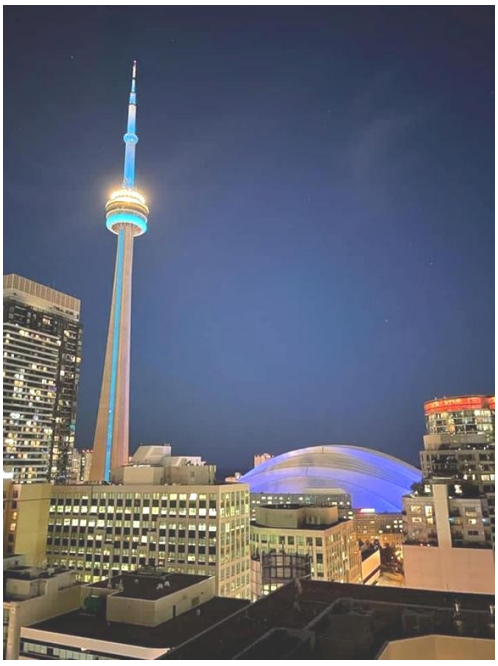
Newfoundland's Government House: "Glowing In Support of Myasthenia Gravis Awareness"

Government House, Military Rd, St. John's, Newfoundland, glowed in support of Myasthenia Gravis.

Samantha Harding, Communications Manager, at the Office of the Lieutenant Governor contacted the Myasthenia Gravis Society of Canada as a Canadian charity, after being approached by a person requesting that Government House have a day for supporting Myasthenia Gravis Awareness.

A big "Thank You" to the person who approached them to recognize a day for Myasthenia Gravis. **"As promised, please see the attached photo of Government House lit in teal. We will be glowing in support of Myasthenia Gravis Awareness… in June 2023."**

Toronto's CN Tower "Lights Up" in Support of Myasthenia Gravis Awareness



It was a thrilling sight to see the CN tower glowing in teal for Myasthenia Gravis in June.
A big thank you to the person who approached the CN Tower with the request and to Garry Morehouse for forwarding this photo to us.

Winnipeg "Lit Up" For Myasthenia Gravis Awareness.

June is MG month in Manitoba.

"The Winnipeg sign at The Forks was lit up in teal on June 24 in honour of June being Myasthenia Gravis Awareness month across Canada and the United States.

Appeals to the mayor's office resulted in Mayor Brian Bowman approving the request to illuminate the lights to help raise awareness of this rare and little known disease. Manitoba health minister Audrey Gordon also just recently proclaimed June as Myasthenia Gravis Month in Manitoba." (Free Press Community Review).

Thank you to Cheryl Girard, fellow MG patient and Community Correspondent for West Kildonan- Free Press Community Review, for this wonderful news.

Cheryl has published additional articles to stress the need for more MG research. "It has been about five years since I was diagnosed with MG and I have to say that the struggle is ongoing."

This sign is at "The Forks" - a popular downtown historic meeting place located where the Red River and Assiniboine River join.

There are good ships and there are wood ships, the ships that sail the sea...but the best ships are friendships, and may they ever be! ~Irish Toast~

Myasthenia Gravis Does Not Dictate My Worth. *I Will Defy It and Move On With My Life!*

2017 was my worst year ever.
I had a hip replacement, lost my wife and was diagnosed with MG.

Today, five years later at 77, I am back to a normal quality of life. Playing Pickleball several days a week. Walk 2 miles (3 KMs) a day several days. Exercise has been my lifeline.

My thoughts on exercise are:

Inch by inch it is a cinch
Set measurable goals
Know your limitations
Listen to your body

I go camping in my Camper-van. Awenda Provincial Park in September, is a great retreat… so tranquil, serene and still, nestled in the woods. It's good forest therapy.

I had a few other health issues along the way, irregular heartbeat and tendinitis of a glute muscle. I am MG symptom-free and switched IVIG infusions to every 12 weeks. All things considered; life is good.

Physical Activity Helps Manage Myasthenia Gravis.

Source: Excerpts from Brain and Health MYASTHENIA GRAVIS SPECIAL ISSUE, SUMMER 2022 BY JOHN HANC.

People with MG whose symptoms are controlled should be able to reap the benefits of physical exercise, says Anna Rostedt Punga, MD, PhD, professor

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of clinical neurophysiology at Uppsala University in Sweden and co-author of a 2020 study, published in Frontiers in Neurology, on how exercise helps people with MG.

Her research has found that exercise reduces fatigue, improves fitness, and increases muscular function, allowing for a more active life. Physical activity, she says, also boosts mood and cognition.

How to Exercise Safely with MG

For those who are skeptical that physical activity can benefit people with myasthenia gravis (MG), Garry Morehouse, who was diagnosed With the disease in 2017, has to say “Exercise has been my lifeline.” He plays competitive pickleball four times a week, and at age 77 he's still one of the top-ranked players among the 100 or so members of his racquet club. As for his illness: “I have no effects, no symptoms from MG,” says Morehouse, who lives in Midland, Ontario, in Canada.

With a highly individualized illness like MG, there's no guarantee that others with the disease will be playing competitive pickleball or racing a 10K anytime soon. But there is growing agreement that physical activity is something people with MG can and should be doing. To do it safely, consider these recommendations.

Talk to your doctor. Before you begin any exercise program, discuss your intentions with your neurologist.

Increase gradually. Start slowly. Take an easy walk to the end of the driveway or climb stairs in the house; then build from there. As your fitness and stamina improve, increase the challenge.

Work with a pro. A physical therapist or a certified personal trainer can help develop a regimen that's right for you. Either one should understand that any fitness routine may have to be modified to accommodate disease progression and fatigue.

“People with MG will perceive more muscle fatigue in the beginning,” says Anna Rostedt Punga, MD, PhD, professor of clinical neurophysiology at Uppsala University in Sweden, who researches

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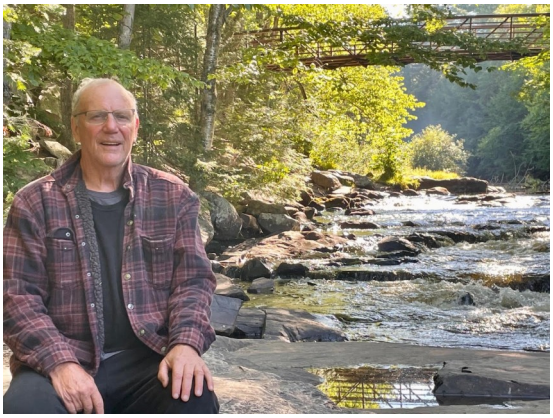
exercise and MG, **but "this will decrease, and approximately two to three weeks into the regimen, they will feel stronger and have more energy."**

Attend to fatigue. There is a healthy tiredness that comes from exertion and there's dangerous fatigue related to MG. Signs of MG-related fatigue are limb weakness and shortness of breath, says William G. Buxton, MD, a neurologist at the Pacific Neuroscience Institute Brain Health Center in Los Angeles. "Such symptoms can be a red flag to rest," he says. "And if they don't improve with rest, patients should contact their physicians."



Listen to your body. This advice is particularly true for people with MG, says Morehouse, who in addition to playing pickleball does strengthening exercises at home. "I don't tire very easily, but there are times when I get a little dizzy," he says. When that happens, "I just stop right on the court. People know, 'That's Garry. He's had enough'.

Here is a quote that keeps me motivated.

"I don't know how my story will end. But nowhere in my text will it ever read…"I gave up."

Garry Morehouse

Paraprosdokians

Knowledge is knowing a tomato is a fruit. Wisdom is not putting it in a fruit salad

You do not need a parachute to skydive. You only need a parachute to skydive twice.

I used to be indecisive. Now I'm not so sure.

Myasthenia Gravis: Tips for Speaking and Swallowing Information

Myasthenia Gravis Affects Speaking and Swallowing.

You may struggle with eating, swallowing and speaking. People with Myasthenia Gravis may experience weakness and fatigue of muscles in the lips, tongue, jaw and throat as a result of the difficulty of sending messages from the nerves to these muscles.

Tips For Swallowing

- If your doctor has prescribed a medicine called Mestinon, eat 30 to 45 minutes after taking it.
- Come to meals rested. If you have difficulty, stop eating and take a rest.
- Watch for difficulty when eating including: coughing, clearing your throat, food sticking in your throat.
- Talking during meals will also tire these muscles.
- Try eating six smaller meals during the day if eating 3 full meals is tiring.
- Swallow or take a sip of liquid to help clear food if you feel it sticking in your mouth or throat. Cough up any food if you need to.
- Multiple swallows may be necessary to clear the residue in your throat.
- Avoid chewing gum. This can tire your muscles for swallowing.
- If you have difficulty swallowing, you may need to change food textures (how the food feels in your mouth), you may need to eat pureed (blended) foods or minced (finely chopped) foods.

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- Food with two textures (for example: cereal and milk or some soups) needs more swallowing control. They may be harder to eat. If you have difficulty with these mixed foods try eating textures separately.

    a) When eating cereal, for example try the following:
        1. drain milk from spoon
        2. eat the cereal
        3. follow with milk on the second spoonful
    b) blend soups
    c) Change your meal. i.e. Eat cereal with yoghurt instead of Milk. The thicker texture is easier to manage.

- Include all food groups to maintain a healthy diet. Finely chop or blend meat. The less chewing required the less tiring.

- Monitor yourself to notice any changes in swallowing

See your doctor right away if:

- **you get a chest infection**
- **a fever**
- **your medical condition gets worse**

Tips For Speaking

Another area of frustration caused by Myasthenia Gravis is difficulty with speech. You may experience vocal fatigue with symptoms appearing or worsening with continued or extended speech. Your speech may be soft or nasal. You may slur your speech or speak in a monotone pitch.

The following are suggestions to consider to help manage your voice.

- Take lots of breaks to listen when speaking to people. This will give you a chance to rest.
- Consider the times you need to speak during the day. Mornings are often better.
- Schedule important talks 30 to 45 minutes after taking your medicines.

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- Rest after a long conversation.
- Try to use a quiet room so that you use less energy when you need to speak.
- Stand or sit closer to the person you are speaking to. You will use less effort than if you speak or shout to someone across a room.

**The above information on swallowing and speaking was referenced from the University Health Network of Toronto, Patient Education pamphlet "Tips for Speaking and Swallowing" written by Karen White and Carolyn Chalmers. The Mayo Clinic Patient Education, was also referenced.*

Medical treatment offers hope for those living with myasthenia gravis

TERRY FARRELL/Black Press Media

Linda MacMullen (seen here with her support dog, Bailey) is hopeful a new treatment for those living with myasthenia gravis will ultimately lead to more independence for her.

Photo by Terry Farrell

Courtenay resident Linda MacMullen was diagnosed with myasthenia gravis (MG) in 2001, after 10 years of showing symptoms.

The fact that it took health care providers a decade to determine her

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condition is a testament to the rarity of the disease.
RELATED: Comox Valley woman with myasthenia gravis says the condition is often misdiagnosed

MG falls under the autoimmune umbrella and there is no cure. According to the National Institute of Neurological Disorders and Stroke website (www.ninds.nih.gov), MG causes weakness in the skeletal muscles, which are responsible for breathing and moving parts of the body, including the arms and legs.

The hallmark of myasthenia gravis is muscle weakness that worsens after periods of activity and improves after periods of rest. Certain muscles such as those that control eye and eyelid movement, facial expression, chewing, talking, and swallowing are often (but not always) involved in the disorder. The muscles that control breathing and neck and limb movements may also be affected.

MacMullen says by lunchtime, she is often already tiring. **"If I have just had my IV treatment, I can walk maybe half a block, and if I haven't, somedays, I can't walk to the top of my driveway,"** she said. "I never know in the morning when I get up, what kind of day it's going to be." Her days may soon be getting better.

The recent news of a possible medical treatment has her dreaming of a more independent life for herself.

"We are trying to get the province (British Columbia) **to approve a medication that might put me into remission,"** she said. "It's very exciting. It's an FDA-approved drug – Rituxan (rituximab)… used for cancer. It's used for lupus and rheumatoid arthritis as well."

While MacMullen has not been given a start date yet for the program, she said it would be life-changing for her.

"When my neurologist said 'we are going to try to get you into remission,' I said 'After 20 years, is that even possible?' Now my brain is going, 'I'll be able to do this, I'll be able to do that.'

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"My family doctor was quick to point out that hopefully it would do that (result in remission), but it might not. But I wouldn't hesitate in trying."

The Ministry of Health confirmed to Black Press that coverage of rituximab for myasthenia gravis is available, under certain conditions.

- The use of rituximab for myasthenia gravis is off-label and requires Special Authority (SA).
- SA grants coverage to a drug, medical supply or device that otherwise would not be eligible for full coverage.
- All SA requests must be completed by a medical prescriber.
- SA routinely approves rituximab for the treatment of MG.
- Requests are reviewed on a case-by-case basis.

Terry Ferrell, Black Press Media

What did one candle say to the other candle?
I'm going out tonight.

Courtesy of John and Michael O'Driscoll

Books, Books, Books

There are now many books available on the subject from which you can find many different views of life with myasthenia gravis. Check out your library, bookstore, or online. ***(****In some cases books may be available in digital format).*

For Example: Coping with Myasthenia Gravis by Aziz Shalbani; Attacking Myasthenia Gravis: A Key in the Battle Against Autoimune Diseases by Ronald E. Henderson; Living with Myasthenia Gravis is Real: This is My Story by C.M. Lewis and a number of other titles.

Editor's Note: There is a book written in Canada by Deborah Cavel-Greant, edited by Michael W Nicolle MD, called "You, Me and Myasthenia Gravis". The Third Edition was published 2005. If you can locate a copy, this is still a very relevant and comprehensive reference book covering a wide base of facts to help understand, cope and live with myasthenia gravis.

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"Could It Be MG?"

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Please forward by mail or email to Membership@MGCanada.org

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