

the MaGazine



Welcome, MG Community

As we recognize Myasthenia Gravis Awareness Month, we're excited to share updates from across our community, including recent events, educational resources, research highlights, and personal stories. Thank you for being part of our community and for helping raise awareness and support for everyone affected by myasthenia gravis!



Spotlight on MG

Behind every MG diagnosis is a unique story. This month, we sat down with Sovay Desmarais and her husband, Chuck, to talk about their experiences navigating life with myasthenia gravis. Together, they share the challenges, adjustments, and moments of laughter that have shaped their journey, offering a heartfelt reminder of the strength that can be found in support, resilience, and facing life's obstacles together.



Monthly Updates

This month we're lighting Canada up teal! Explore the awareness walks and landmark light-ups happening near you below.

Victoria, BC — Legislative Assembly lights up teal | June 13th, Dusk - 1AM

Vancouver Island, BC — MG Awareness Walk | June 14th, 10AM

Summerside, PEI — City Hall Lights Up Teal | June 15th

Calgary, AB — Calgary Tower Lights Up Teal | June 21st

Edmonton, AB — Walterdale Bridge Lights Up Teal | June 22nd

St. Peters Bay, PEI — Circle Club MG Awareness Walk | June 28th

Planning an event that's not on our calendar yet? Contact us at mginfo@mgcanada.org to have it added.

| **Research**

New Kid on the Block? Subcutaneous Efgartigimod versus Intravenous Treatment

Efgartigimod has become an important novel treatment option for people living with generalized myasthenia gravis (gMG), but until recently it was only available as an intravenous (IV) infusion. The ADAPT-SC clinical trial evaluated a newer subcutaneous (SC) formulation, administered as an injection under

the skin, to determine whether it was as effective as the IV version. Researchers found that the SC formulation was non-inferior to IV efgartigimod, meaning it produced similar reductions in pathological antibodies and comparable improvements in measures of disease severity, including MG-ADL scores. The safety profiles of both treatments were also similar,

although injection-site reactions were more common with the SC formulation. These findings suggest that subcutaneous efgartigimod may provide patients with a more convenient treatment option while maintaining the clinical benefits seen with intravenous administration.

Click [here](#) for full article by Howard et al. (2024)



A Message from the Board

The MG Society has been very busy! We are hosting webinars to help our community learn more about Myasthenia Gravis and the new treatments that are becoming available. We have also welcomed several new volunteers and are collaborating with other organizations, such as Muscular Dystrophy Canada. If you know of any specialists who may be willing to present a webinar for our community, please contact us at mginfo@mgcanada.org.

“Together, small steps create big change.”

* [Click Here to Get Involved Now](#)

| **Community Spotlight**

On May 23, Muscular Dystrophy Canada (MDC) hosted its annual Walk and Roll event at Maffeo Sutton Park in Nanaimo, raising funds and awareness for Canadians living with neuromuscular diseases. Representing the MG Society of Canada were Linda MacMullen, Jim Mullen, and Sovay Desmarais. Jim and his wife, Liz, even made a stop during their holiday from Prince George to attend the event—a wonderful opportunity to finally meet in person after years of connecting virtually.

The day came with one unexpected

challenge: the event photographer was unavailable. Fortunately, Jim had brought along his camera and stepped in to capture the day (more photos to come!).

As an organization that supports Canadians living with neuromuscular disorders, including myasthenia gravis, MDC plays an important role in advocacy, research, education, and equipment funding. We were proud to take part in the event and show our support for MDC and the broader neuromuscular community.



WE WERE PROUD TO SUPPORT MDC AND ITS WORK ADVOCATING FOR CANADIANS LIVING WITH NEUROMUSCULAR DISORDERS.

— Sovay Desmarais

| Living with MG

Spotlight on MG: A conversation with Sovay and Chuck

For this month's Spotlight on MG, we spoke with MG Society of Canada board member Sovay Desmarais and her husband, Chuck, about life with myasthenia gravis. Together, they shared their experiences navigating diagnosis, adapting to daily challenges, and finding strength - and humour - along the way.

A Diagnosis That Came Quickly

Unlike many people with MG, Sovay's path to diagnosis was surprisingly fast. While working as a nurse, she woke up one morning with drooping eyelids and double vision. Within days she had seen her doctor, an optometrist, and a neurologist, who diagnosed her shortly after meeting her.

"There really wasn't time to be scared or worried. We just held on to each other and took it as it came."

What You Can't Learn from Google

While MG symptoms may be invisible to others, they affect nearly every aspect of daily life. Sovay explained that living with MG often means carefully planning how limited energy will be spent each day.

"MG weakness isn't just being tired. My muscles actually stop working, making simple tasks like eating or walking downstairs dangerous."

She also spoke candidly about self-care, admitting that giving herself grace can be difficult. Sometimes self-care means allowing herself time to cry, rest, and process difficult emotions before moving forward.

If you're living with MG and would like to share your own story, we'd love to hear from you!

Email mginfo@mgcanada.org to learn more.

The Caregiver Perspective

For Sovay's husband, one of the keys to balancing caregiving has been maintaining a sense of normalcy. Through his work, he is able to connect with colleagues and the public, providing an important social outlet and a chance to step away from his caregiving role for a time.

When asked what he was most proud of throughout their journey with MG, his answer came without hesitation.

"Her."

He spoke about Sovay's resilience, strength, and determination in the face of challenges that many people never see. Despite living with MG, she continues to support her family, raise their children, and persevere through obstacles while showing up for the people she loves.

For him, her ability to keep moving forward, and never letting MG define her, is what stands out most.



Finding Laughter in Difficult Moments

One theme that surfaced again and again throughout our conversation is humour. Whether it's symptoms acting up at inconvenient times or getting stuck in *less than ideal* places, laughter has helped them navigate even the toughest days.

"If I can either laugh or cry, then I choose laughter."

For both of them, humour isn't about ignoring hardship, it's about finding a way through it.

Mental
Health
Corner

How to be there for others

Caring for your mental health is just as important as caring for your physical health. Whether you're supporting a friend, family member, or fellow community member, the Be There 5 Golden Rules provide simple ways to show up for someone when they need it most.

'Be There' Golden Rules

1. Say what you see – "Hey, haven't heard from you for a while. How's it going? You doing alright?"
2. Show you care – "I care about you. What can I do to help? I'm here if you need anything."
3. Hear them out – "I hear you, that sounds super hard. Can you tell me more about that?"
4. Know your role – My job is to listen and be there, not to fix everything.
5. Connect to help – "Have you thought about talking to a professional or someone you trust in your community?"

Most importantly, remember to offer yourself the same kindness and compassion that you would offer a friend. Small moments of connection and understanding can make a meaningful difference. For more information and mental health resources, visit BeThere.org.

| Advice

Beat the Heat with These 4 Cool Tricks

Heat can affect everyone, causing that familiar sluggish, heavy feeling when temperatures rise. For people living with myasthenia gravis, however, heat can be much more than uncomfortable. Because MG already affects communication at the neuromuscular junction, hot weather can worsen weakness and make everyday activities a bit more challenging. With summer approaching, here are four ways to stay cool and enjoy the season safely.

1. Cooling Fabrics

Cooling fabrics work by quickly evaporating water, creating a cooling effect. While cooling cloths for the neck and head have been around for years, many products are now available, including hats, shirts, and shorts. Best of all, they only require a small amount of water - no batteries or refrigeration needed.

2. Ice Vests

These are exactly what they sound like: vests with specially designed pockets that hold ice packs. Different manufacturers use different types of ice packs and pocket configurations, but all are designed to help cool the body's core temperature. Additional ice packs can be swapped in as needed, allowing the cooling effect to last longer.

3. Find Some Shade

Staying out of direct sunlight is one of the simplest ways to stay cool, but it isn't always easy when enjoying outdoor activities such as festivals or beach days. Pop-up shade tents and beach umbrellas can help create shade wherever you are, while clamp-on umbrellas for chairs, walkers, or wheelchairs provide a portable option for staying cool on the go.

4. Stay Indoors During Peak Heat

When possible, plan outdoor activities for the early morning or later afternoon when temperatures are lower. During the hottest part of the day, staying indoors in an air-conditioned space can help reduce heat exposure. No air-conditioning? Fans can also help keep air moving, especially when paired with a bowl of ice. Other ways to keep cool include closing curtains, opening windows overnight, and limiting the use of heat-producing appliances.



Get Involved...

Awareness starts with each of us. Join an event, share our posts, tell your story, volunteer, or support the MG Society of Canada through a donation. Every contribution, big or small, helps raise awareness, support those affected by MG, and build a stronger community across Canada.

[Donate here](#)
