the MaGazine

MYASTHENIA GRAVIS
SOCIETY OF CANADA

SOCIÉTÉ CANADIENNE DE LA
MYASTHÉNIE
GRAVE

WHAT'S NEW IN THIS EDITION?

Spotlight on MG

P5. Each edition will feature an interview with a person living with MG sharing their wisdom, experience, and unique story. In this issue we talk with Linda Macmullen, Chair of the board of directors for MGSC

Caregiver's Corner

P.2 A place to share the unique point of view of a care giver to someone with MG. In this issue we share the experience of Mary Pomeroy-Brown and her nearly 40 yr journey as a caregiver to her son with MG.

P.3 Why does it take so long for medications approved elsewhere to become available here? We explain the process for drug approval in Canada.

P4 Did you know about the different types of myesthenia Gravis?

P.5 Up coming new and repeat events for June, MG awareness month.

WINNER OF THE NAME OUR NEWSLETTER CONTEST!

You may have noticed something new at the top of this page. Barbara Damer, family to an MGer, came up with the name, saying, "It just popped into my mind." We hope our readers like it as much as we do!

Our Survey

If you haven't yet had a chance to take our recent survey, now is the time to have your say! Your input is key to our success.

MARY'S STORY: A Mother's Journey

This article tells the profound story of my journey as a mother navigating the ups and downs of life, filled with both heartache and hope. My story isn't just about nurturing my child to reach his full potential, it's also a deep and ongoing battle against the constant fear of losing him. It was a fear that reshaped my understanding of parenting after the devastating loss of my seven-month-old infant son, Christopher, to the rare genetic disorder Myasthenia Gravis. They told me at that time, that this was so rare, that I would never have another child with Congenital Myasthenia Gravis and for me to treat the loss of my son "Christophor" as a crib death. They were wrong. This experience of such a heart wrenching loss, forced me into a role of survival, fierce advocacy, and unwavering protection, when my fourth child Andrew was born in fetal distress, and subsequently spent his first six months in the neo natal ICU. This is my story—a testament to the strength of the human spirit and the powerful impact of deeply caring for another, especially as a mother.

The day I brought Andrew home from the neonatal intensive care unit stands vividly in my mind, forever marked with a blend of solemnity and cautious hope. After six long months, the moment to take my baby home had finally arrived—not in the jubilation one might expect but cloaked instead in a quiet gravity that seemed to slow time itself. As I drove away from the children's hospital—the trip taking only ten minutes but feeling infinitely longer—I was acutely aware of every passing second. Andrew, small and fragile, nestled in his car seat, was a tangible reminder of the new reality we were about to face. In response, my husband took one hand off the steering wheel to grasp mine—a simple act, yet one filled with shared strength and understanding. Together, we allowed tears to flow, acknowledging the uncertain path ahead. Up until that day, I had never doubted my capabilities as a mother. With three older children, I had navigated the challenges of motherhood with energy and confidence, surrounded by laughter and love. But this was different. The trunk of our car was laden with medical equipment, each device a reminder of the continuous vigilance Andrew's condition would require. I was no medical professional—just a mom thrust into a battlefield for which no training could have prepared me. From that day forward, my journey became one of relentless challenges, each obstacle seemingly insurmountable, yet each day also brought small victories and profound moments of joy. I held onto the words someone told me during those early days, "You never know how strong you are until being strong is your only option." These words became my mantra, guiding me as I navigated the labyrinth of Myasthenia Gravis with my son. We learned that the power to face each day comes not from fearing the unknown, but from embracing each moment with love, courage, and an unwavering will to persevere.Intensive care units, intubation, doctors on speed dial, flu season fears, these became the backdrop of our lives, a world filled with uncertainty and fear. There were days when I found myself questioning everything: my abilities as a mother and caregiver, our family's future, Andrew's fight, and even my own strength.

Doubt settled in like a heavy fog, suffocating the hope I desperately clung to. Yet, amid that chaos, the one guiding light that always drew me back was Andrew’s beautiful brown eyes. Just one look into those expressive eyes could help me refocus, readjust, and find the energy I so desperately needed. They sparkled with life, filled with a vibrancy that spoke to my soul. In those illuminating moments, it felt as if he smiled at me and communicated everything through the depths of his gaze—a silent promise that together we would navigate whatever lay ahead.

Some might label my role as that of a caregiver, yet I see it as an intrinsic part of being a parent. This distinction between "parent" and "caregiver" often blurs for me. At our core, parents are caregivers; we nurture, protect, guide, and uplift our children through life’s hurdles and joys. This role intensifies when confronting a rare disorder alongside your child. Isn’t it true that the unconditional love and relentless advocacy we provide is simply an extension of our parenting?

As Andrew began to grow, so did my understanding of his journey with Myasthenia Gravis. From the very start, my priority was to arm myself with as much knowledge as I could. Decades ago, long before the age of instant online searches, this meant visiting university and hospital libraries, diving into medical texts and research papers. Understanding the disorder was one hurdle; understanding how it would manifest in my own child was another. Navigating life as a caregiver for Andrew shaped not only his life, but transformed mine in profound ways. As Andrew's understanding of Myasthenia Gravis grew, so did my resolve and adaptability. This journey required more than just managing a medical condition; it demanded that I learn to anticipate the unpredictable and cultivate an environment where Andrew could thrive despite the odds.And thrive he did: Looking back on my 37 years as Andrew's parent and caregiver, I've navigated a path filled with both significant challenges and immeasurable rewards. My journey has taught me patience, acceptance, and the importance of celebrating each victory, no matter how small. Over the years, I’ve missed holidays, birthdays, and countless social events due to the demands of managing a rare disorder like Myasthenia Gravis. Each day brought new uncertainties; planning sometimes felt futile when tomorrow was unpredictable. The lessons learned, the challenges faced, the battles won, and I wouldn’t change a single thing. It is the most worthwhile journey I could have ever imagined. Yes, there are still timesI am overwhelmed, struggling, and wondering why, but these are the times when all I have to do is have a conversation with Andrew. He is like my therapist now and when I still struggle, I look into his eyes for strength. Life is a journey!

RESEARCH AND NEWS

The Drug Approval Process in Canada

While it can be frustrating to watch new medications becoming available in other countries at a seemingly rapid rate, especially if you have exhausted all the current options, understanding the process can help to make it make sense. The Health Products and Food Branch, HPFB, is the government agency responsible for approving new drugs in Canada. For new drugs to be authorized for sale in Canada, they must first pass a series of steps in the HPFB review process.

The process starts with pre-clinical research and testing, if that is successful, the drug moves on to clinical trials on people. Then, if the drug passes clinical trials, a new drug submission will be filed with HPFB, and the review will start. First, HPFB reviews all the information submitted. Next, the safety, benefits, and risks are evaluated. Then HPFB reviews the information for patients and prescribers including the drug monograph.

Finally, if everything looks good, the drug will get a DIN or drug identification number.The drug is then evaluated by each province to decide if they will cover the cost of the drug. There is a program to expedite approval for treatments for serious or life-threatening diseases that have few or no treatments. There is also the Special Access Program which grants compassionate access on a patient-to-patient basis to drugs not yet approved in Canada.

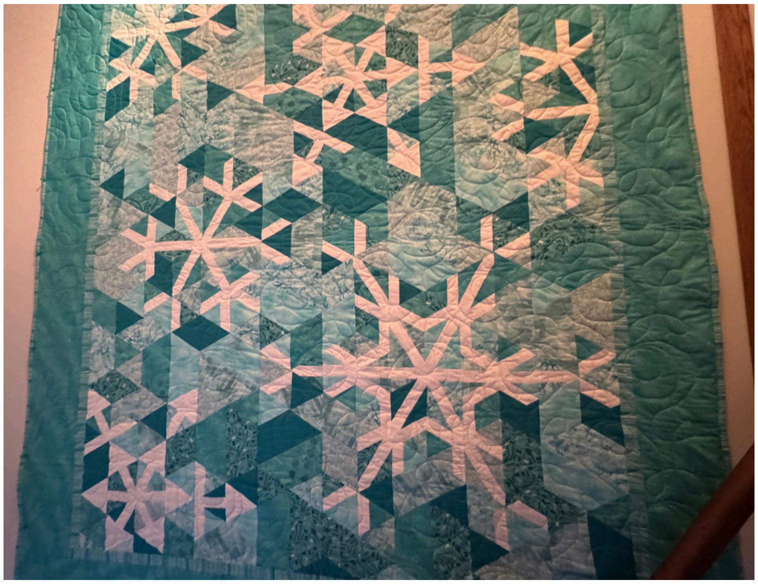
For those who have not been able to get control of their MG with available treatments, the approval process can seem to take forever, but when you see all the steps involved in ensuring drugs in Canada are safe and effective, the timeline makes a little more sense.

[1] Health Canada, “How Drugs Are Reviewed in Canada,” Government of Canada, February 12, 2015, https://www.canada.ca/en/health-canada/services/drugs-health-products/drug-products/fact-sheets/drugs-reviewed-canada.html.

Spotlight on MG

LINDA MACMULLEN

Before Linda MacMullen was diagnosed with MG, she worked hard to help and support others in her capacity as a nurse. After diagnosis, it only made sense that she would turn her calling to help others towards the MG community. Just before the pandemic hit, Linda started a virtual support group, and as the pandemic continued, the group became a lifeline for many living in isolation, even expanding to include a weekly adaptive yoga class. Post pandemic, the group now meets on Wednesday afternoon/evenings and Linda continues to welcome newcomers with open arms. Linda also hosts a walk in her community to raise funds and awareness of MG, with 2 walks before the pandemic and 3 since making this the 5th annual walk.



Linda was given a beautiful snowflake quilt handmade by member Bill Willard's wife to thank her for her hard work.

Linda was presented with a plaque to recognize her hard work and dedication to MGSC

Linda has taken on the difficult but important role of Chair to the Board of Directors. Recently, Linda was presented with a plaque to recognize her years of dedication, hard work, and love that she has given to the MGSC, patients, and caregivers. She was also gifted a beautiful quilt hand made by Bill Willard's wife as a thank you for all her work with the board. In spite of living with difficult to control MG, Linda has spent her limited energy caring for others and that's why she was chosen for our first spotlight article.

DID YOU KNOW

THERE ARE 5 TYPES OF MYASTHENIA GRAVIS!!

1- Autoimmune Myasthenia Gravis : Its an autoimmune condition where the cause isnt well understand but likely cause is the production of certain antibodies (immune systems proteins) This is the most common type.

2- Neonatal Myasthenia: A fetus gets certain antibodies from their birth mother who has Myasthenia Gravis. An infant may have a weak cry or sucking reflex at birth. These are temporary symptoms and usally go away after 3 months.

3- Congenital Myasthenia: It isnt an autioumme condition and instead a genetic change causes this type.

There are two subtypes of autoimmune Myasthenia.

4- Ocular: The muscles that move your eyes and eyelids weaken. Your eyelids may droop, or you may not be able to keep your eyes open. Some people have double vision. Eye weakness is often the first sign of Myasthenia Gravis may evolve into generalized form for nearly half of all people diagnosed with this type.

5- Generalized : Muscle weakness affects your eye muscles and others in your face, neck, arms, legs and throat. you may find it difficult to speak or swallow , lift your arms over your head, stand up from a seated position, walk long distances and climb stairs. -Melissa Kennedy

GET INVOLVED!

NEW AND UPCOMING EVENTS:

LIGHT UP EVENTS

- Summerside City Hall light up teal for MG June 5-12, 2025, Summerside, PEI
- Pacific Coliseum June 1, Vancouver BC- tentative!
- Victoria Legislature June 30, Victoria BC-tentative!
- Would you like a light up event in your community?Email your ideas to info@mgcanada.org.com

WALKS

- Vancouver Island Walk for Myasthenia Gravis June 15, 2025 9:30am-2:00pm Hosted by Linda MacMullen at Woodcote Park, Courtenay BC.
  All welcome, donations appreciated
- Walk for Myasthenia Gravis in Summerside, PEI, June 28

OTHER EVENTS

- Health Fair Hosted by Myasthenia Gravis Foundation of America in partnership with MG Society of Canada August 23,2025 9:00am to 1:00pm - Crowne Plaza in Kitchener Waterloo, 105 King St, East Kitchener Ontario
- Linda MacMullen gets a proclamation from the Comox Mayor declaring June as Myasthenia Gravis Awareness month and is usually featured in an article in the local newspaper
- Various Walk and Roll for Muscular Dystrophy Canada (MDC) events happen across the country this summer. MDC includes Myasthenia Gravis under the umbrella of their programs raising funds and doing research for MG

DONATE!

We are a nonprofit organization and count on donations to grow and run our programs.
PLEASE DONATE AT:

https://www.canadahelps.org/en/charities/myasthenia-gravis-society-of-canada/

VOLUNTEER

WE EXIST BECAUSE OF VOLUNTEERS LIKE YOU!

Whether you have MG, are a family member or care giver, with a little or a lot of time.

Please reach out to:
www.mgcanada.org/volunteer

Meet the TEAM

Linda MacMullen
Director and Chair of the Board

Eric Lacroix
Treasurer and Director to the Board

Melissa Kennedy
Director and Secretary to the Board

Samantha
Volunteer

Sovay Desmarais
Volunteer