



Name Our Newsletter!



We are undergoing numerous changes and want your input to give our newsletter a **new name**.

Tell us your suggestions and any explanation you would like to include.

You can email them to us at:
mginfo@mgcanada.org

In the meantime, visit our current website at mgcanada.org to learn more about MG, access resources, and connect with the MG community in Canada.

WHAT'S NEW!



Changes are coming!
Message from the Board

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Shining a Light on MG
for Myasthenia Gravis
Awareness Month

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Remembering Cap Cowen

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MESSAGE FROM THE BOARD

MGSC is growing and changing to better support Canadians living with MG, their families, and caregivers.

MGSC went through a reflection period following our long-time leader's passing last year and the departure of several directors. We reflected on the relevancy of our organization in an age of readily accessible information and virtual chat rooms. Our research found that there was no other Canadian organization that provided comprehensive information and resources with peer support that is accessible to all Canadians. These findings and the energy and skills of the new board renewed our determination and helped us better define our path forward.

To ensure sustainability, growth, and relevancy as an organization a new organizational structure was developed, and our new mission and objectives were created to guide our programs and initiatives going forward. We will no longer be accepting members and dues. Past members will become subscribers of the newsletter and will continue to receive information at no cost. The board has identified two main objectives for the coming year. The first is to continue to build our internal resources to better serve our community. The second is to enhance our services.

We are excited to announce that we will be launching a new accessible bilingual website with up-to-date information and resources by early 2025. Stay tuned for more initiatives to be announced in the new year!

In the meantime, we are pleased to present this special edition of our new newsletter which aims to inform and obtain your feedback. We feel strongly that your voice and perspective is vital to our growth and relevancy and invite you to participate.

Finally, we would like to thank you all for your support during this transformation and will look forward to hearing from you in the months to come.

Sincerely,
Board of Directors



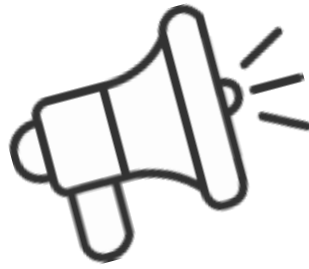
HISTORY

In 1984, with the help of the press and a contact at Muscular Dystrophy Canada, Linda Scanlon founded an MG patient group to support her daughter with Congenital MG and create a space where individuals living with the condition could connect. This group later became known as the Myasthenia Gravis Ontario Chapter (MGOC).

Over the years, dedicated individuals including Dr. Bernie Jafine, Claire Jafine, Bob Langlois, and Karin Hill-Whitson have served as Presidents, each contributing to the growth and development of the organization.

The growth and improvements are not possible without our amazing volunteers and the generous donations we receive. If you would like to be part of our team and make a difference in the MG community, we would love to hear from you. To learn more, visit us at mgcanada.org/volunteer/

STAY UPDATED



Shining a Light on MG: Reflecting on Myasthenia Gravis Awareness Month

The end of June marked another successful Myasthenia Gravis Awareness Month! Our community witnessed

incredible displays of unity.

Together, we raised awareness, shared experiences, and advocated for better lives for those living with MG. June may be over, but we continue work towards a brighter future for all those affected by MG.

Local Efforts in Courtenay, BC

Linda MacMullen is an inspiring individual living with MG. Her local efforts in Courtenay, BC [to raise awareness](#) of the cause included an organized walk in the community.

The walk was held at Courtenay's Woodcote Park on June 23rd. Thank you to all who came out to make the walk a success. We appreciate your support! Funds raised will support MG patients and caregivers and MG-focused events like online support groups.

Additionally, Bob Wells, Mayor of the City of Courtenay, proclaimed June 2024 as "Myasthenia Gravis Awareness Month" in support of the MG community.



"Walk for MG Awareness" participants in Courtenay, British Columbia.

DONATE
DONATE
DONATE



Help us improve our services and growth by donating today.

Donate today at:
mgcanada.org/donate/

VOLUNTEER
VOLUNTEER
VOLUNTEER



Check out the opportunities at:
mgcanada.org/volunteer

Events Across Ontario

MG patients across Ontario commemorated MG Awareness month with a variety of activities and events to raise awareness, raise funds, and celebrate new treatments and research advancements.

MG Community Golf Day at Sunnybrae

On Saturday, June 22nd, Sunnybrae Golf Club in Port Perry, Ontario, welcomed 13 golfers to play 9 holes and share in a lunch for a fun-filled day to raise awareness

for the MG community. Online donations were made by generous participants and supporters. Thank you, Manley Lavender, for organizing this event.



Sunnybrae Golf Club, June 22nd, 2024.

Let us know how you've raised awareness for MG in your community by submitting your story to: mgcanada.org/contact-mg

CN Tower and Niagara Falls Shine Teal for MG

Toronto's CN Tower and Niagara Falls lit up teal to raise awareness for MG. On June 3rd, Toronto witnessed the teal blue tower representing MG on June 3rd. Viewing was also possible on their [live feed](#). The Niagara Falls were sublime with the teal, white, and blue illumination on June 15th.

Raising Awareness at the Canadian Blood Services Plasma Centre in St. Catharines

On June 11th, Canadian Blood Services Plasma Centre in St. Catharines celebrated its one-year anniversary. At the event, MG Canada Director Bill Willard shared his MG story and received a recognition award for his team completing 128 plasma donations in 2023.

In June, Bill was also invited by the Canadian Blood Services

launch of "Sirens for Life" campaign in Niagara Falls, Ontario.



Bill Willard & First Responders at Sirens for Life on June 20, 2024.

This campaign challenges first responders to compete for first place in plasma donation. Bill emphasized the crucial role plasma plays in improving the quality of life for many individuals living with MG. Over 500 donations were provided by local first responders. A big thank you to Niagara Region first responders for their participation.

Journey Mapping Project for Black, Indigenous, and People of Colour (BIPOC) Individuals with gMG

Muscular Dystrophy Canada is leading a project to understand the experiences of those with generalized Myasthenia Gravis (gMG).

They are looking for individuals who have a confirmed gMG diagnosis who live in Ontario and

self-identify as a visible minority and/or BIPOC.

If you are interested in participating in this study, please contact Homira Osman (VP, Research and Public Policy at Muscular Dystrophy Canada) at Homira.Osman@muscle.ca.

MGFA Helpline Has Launched

The Myasthenia Gravis Foundation of America has recently launched a helpline for MG patients and caregivers

The MGFA Helpline is staffed by counsellors who can offer emotional support, answer questions about living with MG, and connect callers to resources.

You can call the helpline at 1-833-MGSTRNG (1-833- 647-8764) Monday to

Friday from 9am to 8pm Eastern Standard Time.

The helpline cannot provide medical advice but can direct callers to specialists, support groups, or other MG resources. The MGFA is also interested on hearing your feedback if you try the helpline. Share your thoughts on your experience with the resource by emailing them at mgfa@myasthenia.org.

SURVEY
SURVEY
SURVEY

Your Voice Matters.

We would like your feedback to inform the development of our website.



Please take a few minutes to complete our survey at:

www.surveymonkey.com/r/K92PWBF

Stronger together -
United to support,
inform and raise
awareness.



RESEARCH NEWS

Dr. Carolina Barnett-Tapia and researchers from the Prosserman Family Neuromuscular Clinic are looking to you to help them better understand how people living with Myasthenia Gravis (MG) make treatment decisions, and which aspects of treatments (e.g. efficacy, side effects, route) are more important to them. The research team hopes that the information gathered from this study will help improve medical decision-making during the routine care of MG patients and better understand their treatment needs.

The study consists of an anonymous online survey that will ask you about general demographic and MG related questions. You will be presented with hypothetical scenarios where you will have to choose between one of 2 treatments. If you wish to participate in the study or are interested in additional information, please click the link below:

<https://barnettoutcomesresearch.hostedincanadasurveys.ca/117429>
Please use Chrome to participate in the survey, as the survey may perform poorly when used in other internet browsers.

Stay tuned for more opportunities to get involved in MG research.

Help Shape Our Webinar Series

Myasthenia Gravis Society of Canada is looking for your input on what subjects we should include for our webinar series. Please email your suggestions to mginfo@mgcanada.org.

We are pleased to announce that Dr. E. Pringle will be presenting our fall webinar.



Join us for “What is MG and how do we treat it?” on Sunday November 24th, 2024, at 2pm EST.

Visit the [events section](#) of our website to register.

Did you enjoy this issue?
Would you like to stay connected with the Canadian MG Community?

Subscribe today to get our newsletter and updates at:

mgcanada.org/sign-up/

Did You Know?

Did you know that the dwarf “Sleepy” in the Walt Disney animation *Snow White and the Seven Dwarfs* was based on someone who had MG?

Visit the [MG United website](#) for more interesting MG historical information.



Join Our MG Community

You are welcome to join us during our weekly virtual informal chat. This is an opportunity for all Canadians who are affected by MG to share their knowledge, experience and support.

Visit mgcanada.org/events to learn more.

WORDS OF APPRECIATION

The Myasthenia Gravis Society of Canada is sincerely grateful for the support of Cap and his wife, Betty.

Their support has been invaluable to the MG community, and Cap's legacy continues to inspire our work at the Myasthenia Gravis Society of Canada today.



Cap's journey with MG began in 2008 when he attended an MGOC support meeting. Recognizing the critical need for a strong advocacy group, he volunteered to become President when the position became vacant.

In 2014, with the help of the directors, the MGOC transitioned into an independent national non-share capital corporation under the name Myasthenia Gravis Society of Canada. The charity designation, under the Income Tax Act, was subsequently obtained in 2016. This change allowed the organization to issue its own tax receipts to donors and use funds raised to support MG education and research directly.

Cap's unwavering dedication to improving the lives of people with MG was evident in his tireless efforts to educate others about the condition. He was always grateful for the support he received and committed his time to sharing knowledge and raising awareness.

Thank you, Cap, for your extraordinary leadership and commitment to advocacy. Your memory will forever be cherished.



Clyde (Cap) Cowen
12 January 1944 - 27 January 2023