

12 Season's Greetings Gift Wishes from MG Canada

- 1. **Make a Donation** to MG Canada. Do it now while you're thinking about it.
- 2. Encourage Donating Plasma to Canadian Blood Services.
- 3. Volunteer to help someone. Drive. Visit. Bring a meal.
- 4. **Start an MG Canada support group** in your community. Just coffee a great start. We can help.
- 5. Get a health checkup with your GP. Full deal with 3-month monitoring including blood tests.
- 6. **Renew your MG Canada membership**. 3 years, best value.
- 7. **Volunteer** to be a helper for our MG Canada National Conference, Fall 2020 <u>MGInfo@MGCanada.org</u>
- 8. Write your MG story and send it to us.
- 9. **Distribute some MG Awareness literature** in your community. We'll send you copies free.
- 10. Follow your MG Canada Holiday Tips for stability
- 11. Exercise. Go for a walk every day. Outdoors or indoors.
- 12. Send us a greeting note. We love hearing from you.

Membership@MGCanada.org Call anytime 1 905 642 2545

Happy Holidays from all of us at MG Canada!!

Happy Holidays MG Canada Editorial:



Myasthenia Grav

We Canadians are gloriously different, and we are grateful for all that. We've learned to be cautiously positive about who we are and our future outlook as a Nation, even though with all the recent diplomatic bullying from USA, China and others, we have plenty of reasons to be cynical.

Your Myasthenia Gravis Society of Canada believes that only as "Canada's *National Myasthenia Gravis Patient Advocacy*", can we hope to truly support all Canadian MG patients. Certainly we can't count on other nations for direct support. Many are willing to share resources but it's up to us to adapt them and create to our unique Canadian nation's needs – and that's exactly what we are doing.

Some don't get it. It's pretty easy to grasp. We have a Nationally legislated Universal Health Care System. The United States for example, does not. Having our medical system requires much direct diligence because each of our provinces run the system and each has variances of policy and coverage within National guidelines. It is up to us as Canadians to be diligent Canadian MG patient advocates. If we're not, we could face losing coverage of some of our health care medications and caregiving. Further more as new treatments are approved, policy needs encouragement to include in Healthcare coverages – Nationally and provincially. We met a US MG patient last spring who moved to Oregon to be sure he could get access to IVIG treatments. In Canada, for the most part we have access to health care supported similar treatment in all our regions. But we can't take it for granted – or play coy with it.

And so it should go for our MG Canada patient advocacy growth.

Be friendly with everyone but concentrate on helping Canadians. Keep our eyes on our purposes and benefits by staying focused. Resist the temptation to embrace ideas that are not in our best Canadian MG patient interests. Continue with vigour, enthusiasm and optimism, our efforts for a strong cross Canada network of Myasthenia Gravis patients, caregivers and Health Care professionals. Working together for all Canadians. Embrace ideas that are totally inclusive. When we disagree make sure we resolve differences. Never forget we have an obligation to serve all MG patients. That is what MG Canada is all about. And when we disagree, make sure we always use reconciliation. Always a dispute resolution solution. Always good for everyone. Constantly move forward together.

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MG Canada is our unique Canadian Health Society – custom made just for us. Everyone deserves to be served. Always.

Merry Christmas. Peace on Earth. Good will to all of us. Make an MG Canada donation to show your support. We need all the help we can get. Sincerely, Myasthenia Gravis Society of Canada.

Volunteer to help and participate. Membership@MGCanada.org Cap Cowan, President, CEO and Newsletter Editor Myasthenia Gravis Society of Canada CapCowan@MGCanada.org 905 642 2545

Myasthenia Gravis Society of Canada Toronto Area Support Meeting Sunday, December 1, 2019 6:00-8:00 pm Registration: 5:30—6 pm.





Speaker: Dr. Hans Katzberg, MD, MSc, FRCP©, Associate Professor of Medicine (Neurology), University of Toronto, Toronto General Hospital/UHN

Support Meeting for those living with Myasthenia Gravis, for caregivers, family, friends, interested others.

Loblaws Community Meeting Room, Bayview Village Mall, 2877 Bayview Avenue, Toronto, M2K 2S3.

(Meeting Room is located upstairs, S/W corner of the store, Elevator access.) Public Transit Access, subway access at Bayview Station on the Sheppard Subway. Free Parking,

For this meeting, we request those members who are able, with last name starting M-Z, bring a food item to share. Loblaws has asked that any food served come from their store.

Info at 905 642 2545

www.MGCanada.org

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Toronto Support Meeting Welcomes Dr. Hans Katzberg on Sunday, December 1, 2019



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Dr. Hans D. Katzberg is a neurologist and clinician investigator at the Prosserman Centre for Neuromuscular Diseases and Krembil Brain Institute at the University Health Network. He is an Associate Professor of Neurology at the University of Toronto and his clinical and research interests include assessment and treatment of immune mediated neuropathies. *(See Page 3 for Support Meeting time and place!)*

Myasthenia Gravis Canada

Ottawa Support Group

Organized by Pat Griffiths Email: patgriffiths@rogers.com

Our future Ottawa Support Meetings are scheduled below:

1. **Support Meeting:** Sunday, December 1, at 1 pm for lunch at Rockin' Johnny's at 1309 Carling Avenue at Westgate Mall Informal get together with no speaker.

February 23, 2020

2. Support Meeting: Sunday, February 23 from3 to 5 pm in Room 1A at 101 Centrepointe Drive at Ben Franklin Place.

Dr. Pierre Bourque, an Ottawa neurologist treating patients with myasthenia gravis, will speak. He will discuss the usual course of MG, the usual treatment of the illness, why the neurologist chooses one medication over another, and situations when a person with myasthenia gravis should go to the emergency room.

Report on October 6, 2019, Ottawa Support Group Meeting

Report written by Pat Hayles (reviewed and approved by physiotherapist Jacquie Levy, who has also approved for it to be published in MG Canada's newsletter).

The Ottawa and area MG support group had their third meeting in early October.

In addition to the time spent discussing member experiences, they welcomed a guest speaker, Jacquie Levy, who provided some very encouraging information on Exercise and MG. Jacquie is a trained and licensed physiotherapist who is a Physiotherapy Clinical Neurosciences Specialist and operates a physiotherapist practice, Action Potential Rehabilitation, that works with many patients with autoimmune and progressive diseases.

The subject was of particular interest to the group as, until recently, the common thinking was that repeated use of muscles could result in muscle weakness and could bring on muscle fatigue, possibly even exacerbating our MG condition.

Jacquie provided us with a list of recent research studies (listed below) that showed that the thinking about exercise and MG, like that of many other neurological conditions, such as MS and MD, is changing.

Early indications are, that *for those in a stable or controlled*, MG condition, exercise could help to prevent cardiovascular de-conditioning and to maintain body strength, and therefore our ability to function better every day. We of course all understand the importance of checking with our doctor before starting on an exercise program, and we were reminded of the need to know our body and pick the right time of day so our bodies could best cope with additional exercise.



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Jacquie demonstrated several practical ideas that we could incorporate in to our own routines.

• Walking more – even with a stick or walker is probably the best exercise there is

• Sit to stand from chair in one movement to help balance, and prevent falls – done five to ten times

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Continued from P. 5- Ottawa Support Meeting Report

- Balance exercises standing on one leg, or moving one foot in front of the other (near a counter top if needed) to again build leg strength and balance
- Step ups

Other possible ideas are working with gym equipment where we are in control of the speed and range of movement. Tai chi or yoga, but again we have to self monitor and if in doubt check with our health care provider before beginning.

References

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Farrugia, M. E., Marco, M. D., Kersel, D., & Carmichael, C. (2018). A Physical and Psychological Approach to Managing Fatigue in Myasthenia Gravis: A Pilot Study. *Journal of Neuromuscular Diseases*, 5(3), 373–385. doi: 10.3233/jnd-170299

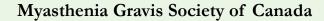
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Naumes, J., & Macko, C. H. (2016). Exercise and Myasthenia Gravis: A Review of the Literature to Promote Safety, Engagement and Functioning. *International Journal of Neurorehabilitation*, 3(3). doi: 10.4172/2376-0281.1000218

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The Benefits of Exercise for Folks with MG | MG-MI.





GBS/CIPD Host Informative Event

MG Canada was invited to register as participants at the GBS/CIPD 2-day National Conference October 26,26, 2019. Three of us spent Friday at the evening's social/silent auction/buffet, and all of Saturday attending most of the speaker presentations. We learned and experienced a lot of insight and current updates on several similar treatments as with MG. Both GBS and CIPD are treated at the same Prosserman Clinic at Toronto General as Myasthenia Gravis. They are rare autoimmune diseases attacking the nerve coatings. New treatments can arrest the effects but not restore damaged nerve coatings as yet. Since MG Canada is planning its own National Conference for late fall 2020, it was an excellent opportunity to learn and share.

Many Topics presented by Health Care professionals and patients relative to MG included:

"How to talk to your specialist"

"Medical Cannabis in treatment of pain"

"Self administered Subcutaneous immuniglobin"

"Effects of Aging in GBS, CIPD, MMN

"Immunizations"

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"The benefits of exercise – more important then ever"

"Chair Yoga"

"Securing the supply of Plasma for Canadians"

Presenter Wilma Koopman Presenter Dr. Robert Sealey Presenter Wilma Koopman

Dr. Vera Bril Presenter Dr. Hans Katzberg Presenter Mona Walls

Nancy Edwards Dr. Sylvain Grenier

Chest, back and ankle weights simulated how a GBS patient feels. The weight is exhausting. MG Canada Director Tony Watkins tries it out.

December 2019

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We will follow up with more in-depth articles on some presentation in future. Thank you organizers, executive , and volunteers for your informative, friendly, welcoming conference.



"I Am Thankful for Every Day"



An holistic approach to wellness with Myasthenia Gravis; my personal story Fostering hope for people living with MG

Garry Morehouse

In November 2017, I was diagnosed with Myasthenia Gravis (MG). In the beginning, I was hit hard by this disease. The drug Mestinon literally 'picked me up off the floor' to where I had been falling. IVIG infusions brought me to 80% recovery. For the uninitiated, IVIG is a concentrated preparation of human antibodies, produced from plasma pooled from thousands of blood donors.

Initially, I looked to drug therapy as my savior, only to be disheartened when learning that clinical trials for new medication take ten years. Though the current drugs had brought me to stability, at 73 years of age, new drugs are not realistically on my radar.

My personal belief about getting well is as much about with whom you surround yourself, your attitude, and your exercise regime, as it is about your medication. I wondered if perhaps exercise had provided the power to help the infusions work more effectively? I renewed my sense of determination and my positive attitude, encouraged by the findings of clinical trials on exercise which state exercise can decrease fatigue, increase strength and improve functional mobility, reduce stress and alleviate depression. (Source: Exercise and Myasthenia Gravis--A Review of the Literature to Promote Safety, Engagement, and Functioning)~Authors; Charlene Hafer-Macko, Sarah Foidel and Julia Naumes.

I am a lifelong advocate of daily exercise. No surprise that it has become my lifeline in managing this rare disease. Daily exercise improved my gait and enabled me to get back to active healthy living. Exercise just seems to 'clear the air' for me.

My top five exercises are:

- pole walking which helps me with balance and coordination;
- plank exercises for building core muscle strength;

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Continued from Page 8-Garry Morehouse

- chair squats to build leg muscles;
- leg raises to improve lower abdominal muscles; and
- breathing exercises to help relax and reduce tension and stress.

Other exercises I perform include, bridge exercises, the use of resistance bands, 10lb dumbbells, a recumbent cycle and a rowing machine. A holistic approach to my wellness also includes goal setting and measuring progress. I achieved my goal to play pickleball again.

I began to eat a nutritious and balanced diet, which according to Health Canada, is one of the best ways to protect and promote good health.

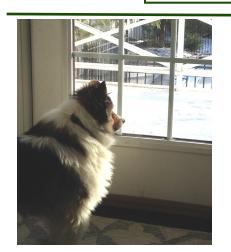
Friendships have been important to me and I maintain a wide circle of supportive friends through pickleball. It's a good social sport. Social media allows me to stay connected to family members who live at a distance and with old and new friends. My spiritual life has been supported through many offers of prayers; one person prayed for me daily for three months. She thinks my recovery is a miracle; I graciously and gratefully accept that belief!

In just over six months, I became symptom-free and maintained stability for the past year. I am thankful for each day. I am much more mindful of my surroundings and environment. I listen to my body. If I feel I have had enough, I stop right away. Sleep is my friend. I get ten hours a night plus a few power naps on my recliner with my cat. I don't get fatigued easily. I can play competitive pickleball for two hours at a time.

I don't take my health for granted but admit to some degree of looking over my shoulder in fear of a relapse. Having said this, I am able to live a normal quality of life for which I am grateful. I wish the same for all who have joined the MG

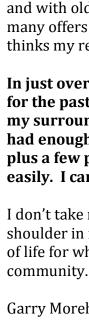
Garry Morehouse

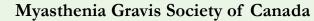
"To clarify "symptom-free" means that I have "no symptoms" of MG. I am not taking any medication per se but I still have IVIG infusions every eight weeks. Garry"



Don't let a little snow stop you!







You Can Help Secure Canada's Plasma Supply

MG Canada Holiday Gift Idea.

Encourage Donating to Canadian Blood Services for Plasma. Did you know that Canadian Blood Services is totally funded with your tax dollars by the Provinces of Canada and your volunteer donations of blood and plasma? This MG Canada article is adapted from Canadian Blood Services brochure at October 2019 GBS/CIPD National Conference in Toronto, which 3 MG Canada members were invited to attend.

Support by your family and friends donating blood or more specifically plasma, can greatly help you as an MG patient. Why? Because Blood contains plasma from which Immune Globin is produced. Many Myasthenia Gravis patients take IVIG (Intravenous Immune Globin). It is making MG patient life better.

There is an ongoing need to secure Canada's Plasma Supply. With your help and network of friends and family, you can help support the delivery of lifesaving plasma products to 1000's of Canadian patients in Canada, where and when they need them.

Plasma is the protein-rich liquid in our blood that can treat a growing number of illnesses and injuries. Immune globulin (lg) is a plasma product that is in great demand. Ig treats various primary and secondary immune disorders, autoimmune diseases, neurological conditions and other diseases with immune origin such as Myasthenia Gravis. As researchers discover more conditions that can be treated with plasma and new treatments that can be made from plasma, the need for plasma donors continues to rise to help meet the growing global demand for these life saving products.

What is plasma? Plasma helps other blood components circulate throughout your body. It supports your immune system and helps control excessive bleeding, which is why plasma donations are important to help treat bleeding disorders, liver diseases and many types of cancer.

Plasma products are helping patients with immune deficiencies, for blood disorders, nervous system disorders, hemophilia, kidney and liver diseases, severe burns, surgeries, newborns with Rh disease and much more. You can donate blood or more specifically plasma. Visit <u>www.blood.ca/plasma</u> to learn more.

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Myasthenia Gravis Society of Canada

Continued from P. 10- Canadian Blood Services for Plasma

Here is a broader list of the many applications for your gifts of blood and plasma as IVIG. Cancer. Tetanus infections. Nervous system disorders. Hemophilia. Rh disease (in newborns). Severe burns. Kidney diseases. Liver diseases. Chickenpox and measles. Surgeries. For Blood Disorders. Immune Deficiencies such as Myasthenia Gravis.

Who can donate? Any healthy person who meets eligibility criteria and minimum height and weight requirements can donate plasma as frequently as every seven (7) days. Donors who are temporarily deferred from donating blood due to their recent travel history outside Canada may also be eligible to donate plasma.

What's it like to donate plasma? The process for donating plasma is similar to donating blood. The main difference between a whole blood and plasma donations is the collection method – apheresis. Only the plasma portion of your blood is collected; the rest (red cells, white cells and platelets) is returned to you.

This Myasthenia Gravis Society of Canada Holiday, ask for the gift of life. Encourage everyone to Donate to Canadian Blood Services for Plasma.



MG Canada Seasonal Wish:

Stay 'Myasthenia Gravis Stable' During This Holiday Season

Who needs a trip to emergency over the holidays? Here's a few tips that work.



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- **1. Stick to your meds** schedule no matter what. Daily and within hourly time frames – even when you're traveling. If you haven't been doing that you should be all the time anyway.
- 2. Take all your meds, all the time. Don't mess with the mix.
- If you don't already, prepare your meds at least for 7 or 14 days. Same for both staying at home or travelling.
- **4. Take it easy on treats and food quantities**. Real easy. My doctor's best diet advice to me was "Take smaller amounts and push away." I know. It's tough when everything's so enticing.
- **5. Watch your intake diet.** Stick to foods you know work for you. Extreme caution for other goodies that are so tempting like Christmas cakes, cookies and treats spread everywhere.
- **6. No booze or very little**. Max 1 per day with food. Fake it. Drink mix without alcohol.
- **7. Stay calm and rested.** Even with guests visiting, if you feel a bit tired, excuse yourself and lie down for awhile. They'll understand.
- 8. Review your emergency list to include list of current prescription meds and add whatever vitamins and supplements you are taking also. Print or write it out. Make copies. Share with your spouse, relative, caregiver, Health Care provider.
- 9. Have your MG Canada wallet card ready at all times with list of do and don't medications. Be Positive. Laugh. Love. Enjoy the season. Happy Holidays!



"Attached is an article that I have prepared and have had approved by Steve Tanner of Durham College. I trust that you will find it appropriate to include in the next MG Contact. Steve has modified my original version and has given us permission to use it as is. No modifications are to be made to the text, but formatting alterations are acceptable so that it fits into our newsletter. Steve Tanner has also made reference to a web site that may be of additional interest to our members. It is: <u>https:// www.myvmc.com/news/potential-role-medicinal-cannabistreating-neuromuscular-disease/</u> Joyce Ovens"

What Is Cannabis?

Myasthenia Grav

A fragrant flowering plant in the same family as hops. Two key sub-species: Sativa and Indica. Used for over 27,000 years for fiber (hemp), as a medicine and recreationally. Became illegal in Canada in 1923

Chemicals Within Cannabis

- Cannabis plants contain 144 compounds called cannabinoids may aid in treatment of pain, neurological disorders, sleep, appetite stimulation, etc., as more research is conducted
- THC and CBD are two of the best-known (most researched) cannabinoids:

THC is psychoactive (creates a "high" feeling}

CBD is non-psychoactive (may counteract THC high feeling.)

• Cannabis also contains over 200 kinds of terpenes (oils that produce scents) and 23 flavonoids that produce taste - many of these are also understood to have medicinal effects.

How Is Cannabis Consumed?

• Smoking: Traditional method of using cannabis and has an almost immediate effect.

Potential negative effects on respiratory system Inexpensive

Not used for patients with pulmonary damage.

• Vaporization

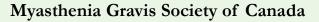
Quickly gaining popularity as an alternative to smoking Less harmful to lungs

Same quick relief as smoking

Good for instant relief of issues such as chronic pain

Vaping units can be expensive and need charging.

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Continued from Page 13-What Is Cannabis?

• Oil/Spray

C

Concentrates of cannabis can be added to food or drink *(but not sold o anyone else – cannabis edibles are expected to be legalized in Canada by mid-October 2019); oil* capsules and sprays have a faster effect than edibles, but not as fast as smoking or vaping

Can be expensive

Can be used in a suppository

Tend to be used to give CBD to patients with epilepsy, especially children

• Edibles

Edibles are often difficult to use as they are hard to dose – meaning, it is important to ensure the oil is mixed well in the food product to avoid highly concentrated parts of the product, and not so concentrated parts

Longer time for relief after indigestion

Longer last than other methods

Can come in various forms, such as cookies, popcorn, ice cream, gummy bears and chocolate bars

Popular for elderly and children

Fresh or dried leaves/bud can be ingested in infused teas, juices, smoothies and sodas

• **Topicals (creams);** cannabis topics are expected to be legalized in Canada by mid-October 2019

Lesser known form of medical cannabis on the market Tinctures: Salves, ointments, lotions and sprays Transdermal patches Helpful to many with pain and inflammation No ingestion and free of any psychoactive properties Helpful for fibromyalgia, arthritis and similar pain issues

Government Responsibilities

• Federal

Provides national oversight

Regulates production

Sets national laws around possession limits, personal growing, cannabis tracking, medical cannabis

• Provinces/Territories

Defines and regulates distribution (wholesale and retail) Sets workplace safety requirements

Can set more restrictive laws - e.g. age limits, possession limits

• Municipal

Sets and enforces by-laws on zoning, business licensing, building codes, etc.

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Myasthenia Gravis Society of Canada

Continued from Page 14—*What Is Cannabis?*

Enforcement of consumption regulations and impaired driving laws

Accessing Cannabis in Ontario

• Medical use:

A medical document (like a prescription) is required from a physician or nurse Practitioner

Must be purchased from a licensed producer (i.e. company with a medical sales license)

• Adult Use:

Available online through the Ontario Cannabis Store Effective April 2019, private retail sales are now available throughout the province

Important: Even though cannabis is now legal, <u>buying</u> from someone who does not have a license to sell is <u>illegal</u>.

Social Issues - Legally Growing at Home

In Ontario, up to 4 plants may be grown in a single residence for personal use, **but** there may be implications:

- Mortgages up to the lender to decide.
- Home insurance most policies already include a clause that voids coverage if cannabis is grown in the home no clear direction yet on legal home growing
- Condominiums many condo boards recently passed bylaws to
- Prohibit smoking and growing, to avoid grandparenting
- Landlords leases can prohibit smoking and growing (better to do so immediately with new tenant to make eviction easier)

Abridged from a presentation made by Steven Tanner, Manager, Cannabis Program Development, Durham College – with permission. Joyce Ovens

Editor's Note: Cannabis is illegal going into the United States. As always, articles in the Myasthenia Gravis Society of Canada Newsletter express the views of the author and are for information only, not medical advice. Patients should consult with their physicians for medical treatment.

On Facebook?

Interested In Joining Myasthenia Gravis Facebook Group (Canada)?

On Facebook, connect with others affected by Myasthenia Gravis through this Support Group - another way to learn more through discussion, posting and comments at Myasthenia Gravis Facebook Group (Canada).

Donate to Myasthenia Gravis Society of Canada. Help Keep Us Going and Growing

A Huge Thank You For Support

Myasthenia Gravis Society of Canada received Memberships, Donations, MG Fit Pledges, "Celebration of Life" Memorium Gifts, and other charitable donations.

All gifts help to realize the goals of Myasthenia Gravis Society of Canada: To help those with Myasthenia Gravis, a chronic condition. To educate caregivers, family, the public & Healthcare Professionals. To encourage research into cause and cure for MG.

Donations can be mailed to Myasthenia Gravis Society of Canada, 247 Harold Avenue, Stouffville, Ontario, L4A 1C2. Or donate online at www.MGCanada.org 905 642 2545 Registered Charity#81155 1431 RR0001 Is your membership due for update? Please email membership@MGcanada.org

IN MEMORY OF:

We are saddened to hear that Florence Pye (nee Shanks) of Carlton Place in Ottawa passed October 15, 2019. The donation of her time as a Peer Support Contact for the Myasthenia Gravis Society of Canada for the Ottawa area was much appreciated. We thank her for her generosity.

It is with heavy hearts we hear that Peter Edmund Winnett passed on November 4, 2019. Peter was a Director of Myasthenia Gravis Ontario for several years. He committed many hours for Myasthenia Gravis advocacy. He was dedicated to his family and shared a love of travel and good food.

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MEMBERSHIP APPLICATION			
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First Name	Name Date of Birth		
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My Neurologist	is Dr		
Neurologist's Te	elephone No BERSHIP FEE		
\$ 20.00	(1 year) \$	(12 months – Individual or Family)	
<u>or</u> \$ 50.00	(3 years) \$	(36 months – Individual or Family)	
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Please complete as much of the form as possible.			
All information will be kept in the strictest confidence.			
It is important to keep your membership and record of information up to date and accurate each year. Please advise any changes during your renewal period.			
Questions or Changes? Call 905 642 2545 or e-mail to membership@MGCanada.org			
Mail completed form and payment to:			
Membership Coordinator – Myasthenia Gravis Society of Canada			
c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2.			
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c/o 247 Harold Avenue, Stouffville, Ontario, L4A 1C2 Phone 905 642 2545 www.MGCanada.org Do you have an MG article of interest to "Contact"? Please forward to membership@MGCanada.org

Articles in the Myasthenia Gravis Society of Canada Newsletter express the views of the author and are for information only, not medical advice. Patients should consult with their physicians for medical treatment.



