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 45 Issue 3** **September 2021**

Challenge the Challenges

My MG Story:

Cynthia Scott Jemmet R.N.

When Cynthia was challenged to write her life story, she chose writing about living with Myasthenia Gravis from the Age of 17. Here is her story, Part 1 of 3, telling us about her journey to diagnosis.

Family Background and Last Year of High School

My place of birth is Trinidad, second largest island in the West Indies…. the last of seven children, raised in a Catholic home is St James, a suburb of Port of Spain, the capital of Trinidad.

My high school years were spent in a Catholic high School for girls' only, very strict female teachers. My last high school year was bitter sweet. I was taught by a homeroom teacher, who had the privilege of teaching my older sisters, whom she reminded me were quite smart. I know I was just an average student so, I tried very hard to fill those shoes my sisters wore. I had to be in good graces with this teacher who also knew my mother.

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Miss Guillaume (Teacher) was very neat in appearance, respected her students, but her key phrase was "Those who failed to prepare, must prepare to fail". This last year was very touching for an average student like me. We had to burn the midnight oil to be in her good books.
I hated criticism, it made me emotionally upset having to work harder than my sisters to produce better grades.

Hardly ever dating at seventeen, I always enjoyed doing fun things with my older sisters, that is, when they didn't mind my being with them. One of these fun things was a boat ride. One beautiful Sunday morning accompanied by my second oldest sister, Olga, who reminded me of a nun. She prayed like a "Catholic nun" whenever she was not standing or sitting, her knees were on the bed, or on the floor. Other members of a Catholic group accompanied us on this boat ride.

A very pleasant young man, a little older than me, "Len" by name who befriended me some time earlier was also on this boat ride. As the boat docked, we all sat out on the beach for an interesting lunch. Len decided to sit beside me. My conversation with Len was concerning the hardships at school during my last year. **During this conversation, I began to experience the strangest feeling in my left eyelid, a sudden limp feeling, a real tired feeling and a weak feeling.** I thought I was tired and just needed some sleep. I thought a good night's rest would fix everything.

On seeing me with Len, she severely reprimanded me for taking off without her for lunch. I explained that Len is from our village, a well known musical family in the village.

I realize life at seventeen was not easy; pressure in school; pressure at home; pressure even in recreation, not even to relax on a boat ride with a Catholic family. However that day was over with the arrival of another dawn. I was again sitting in the classroom.

I did have a good night's sleep and awoke feeling great. The tiredness and weakness of the left eyelid disappeared. During morning, Miss Guillaume observed a difference in my left eyelid. She ignored that for the moment. I myself did not feel any difference at this time.

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After lunch, the left eyelid drooped considerably and I knew the feeling on the boat ride luncheon had returned. This marked drooping caused my teacher to comment. By late afternoon, the left eyelid was almost closed. School was out that day and I went home for another good night's sleep.

Observation of Condition and Hospital Admission

My mother, observing my droop eyelid, thought I was coming down with a cold, which in those days the 50's, might result in droopy eyelids, although, only one eyelid was affected.

One day, in the classroom, Miss Guillaume realized the condition appears again, thinks this is serious, and sent me to the hospital's emergency department, accompanied by another mature student. In those days, this Department in the British county was termed "Casualty".

I was detained for investigation, since this condition was not observed by any of the doctors in that part of the West Indies. The Casualty Department informed my mother that I was there for observation. She visited and gave a history that the very same condition manifested itself when I was teething as a baby. My mother continued to explain that both eyelids drooped at that time, and the known Paediatrician commented that a return of this condition might manifest itself in late puberty.

Every type of blood work was taken to rule out certain conditions. I was treated for a vitamin deficiency. On discharge from Hospital after one week, both eyelids were droopy. I was instructed to attend outpatient clinics to receive vitamin B injections every day. **It was during the daily treatment and injections of vitamin B that the eye Physician, Dr Chong, decided to try a special medication to rule out the condition of a muscular and nerve condition called Myasthenia Gravis.** This inspired the doctor only after I

Cynthia Scott Jemmett, R.N.

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explained that on awakening early in the morning, both eyelids were very strong and both eyes were open. The weakness showed itself during the late morning and thereafter.

Dr Chong, a very learned Chinese physician, decided to administer the drug "Prostigmine Bromide" intramuscularly. This drug, when tested on Myasthenia Gravis patients, works like a miracle after 20 minutes of injection. A true Myasthenia patient feels the difference, "tired and droopy" eyelids become very strong. The patient is seeing through open eyes.
(To be continued in the December issue of "CONTACT".)

"Challenges affect us as long as we reside on this planet. It is up to the individual to face them, work at restoring order, or give up and feel defeated.

From my viewpoint, I believe each challenge should be tackled, work with (each) one on every facet, until the best results are obtained.

Defeat must never be the answer, one must evolve always as winners."

MG Canada September 2021 Newsletter Editorial

"Challenging the Challenges"

Cynthia Scott Jemmett left us a message on our answering service about her newly self published '70 year personal Myasthenia Gravis journey'. MG engaged conversation and personal journey stories help. Cynthia is 87. She's had MG since she was 17! We're proud to publish her story starting on page one.

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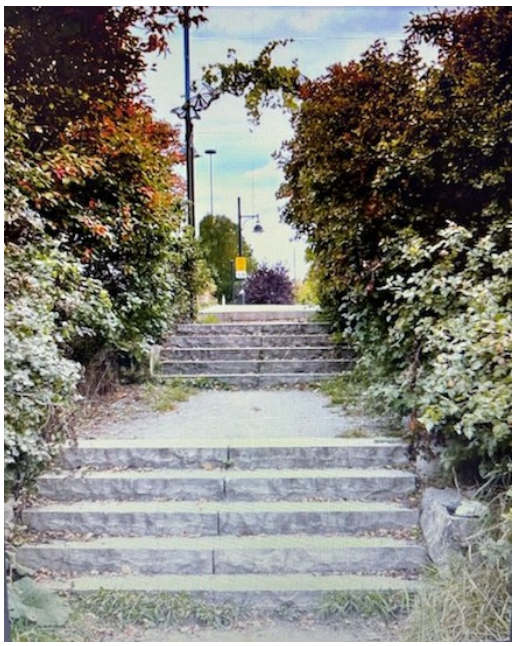
MG Canada Patient Engagement: How about you? Perhaps you remember the fear and anxiety of strange series of symptoms that ultimately were diagnosed as Myasthenia Gravis. Maybe you're still at that stage in your progress quest for stability again. Maybe you are lucky and so far exhibit mainly ocular symptoms that require mild treatment so far. But for most of us, we evolve to full general MG and the various cocktail of treatments that work to varying degrees and in relationship to other pre-existing health conditions.

You may recall, I volunteered for a 3 way trial. My MG had been fairly stable for over 10 years. I'd rate level 7 new norm. Last October, 2020 I went in to start the trial with a pre-evaluation work up including blood tests. I failed the criteria to participate because of a probably latent condition that might put me at extreme risk if I participated in the trial. After being referred, the latent condition was treated for 3 months. Since then my overall stability has deteriorated to emergency MG crisis in June and very recently. Again. Overall physical weakness has left me challenged to even walk – to a new low. Lower than pre-diagnosis 17 years ago. **I'm on the mend but will share some of the physio that's helping me to get mobile again. 'See Cap's on the Mend after MG Wheels Came Off!'**

Our MG Canada Medical writer, Dr. Cheryl Zimmer writes about the base MG treatment for at least 50 years. **Mestinon. For some with milder MG, such as ocular, it's all we need to stabilize.** For most others such as myself with General MG, Mestinon is vital to daily combination with other treatments including prednisone, immune suppressants such as Cell Cept, and many more. With a new generation of pharma products, it's hard to say yet how much that will change the use of Mestinon.



These steps were an invitation to explore. Photo by Tony Watkins

Read continued articles by Lindsay Peets & Cynthia Davidson —

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Too long for one article, but too important to abbreviate. Enjoy part 2 of their articles

Lindsay Peets *is our most recent MG Canada Director with lots of new ideas to share.*

Cynthia Davidson *has the ultra rare genetic version of Myasthenia we are pledged to keep as part of our MG Canada national advocacy family.*

Dr. Carolina Barnett-Tapia is part of UHN Toronto's Prosserman team *on sharing leading edge of holistic MG treatment and patient self esteem assessment and encouragement. She will be our guest speaker September 26 for our Cross Canada National MG Canada Zoom support meeting 2-5 pm EDT. Sign up to be included for MGCanada members and requested and approved invitation only participation.*
(email Membership@MGCanada.org for your invitation link.)

So what else is new at MG Canada?

Linda MacMullen, long time MG Canada member and Director, has agreed to represent us on our Canadian Blood Services advisory commitment. We all know how important IVIG is to our treatment options. Linda is an RN with very personal depth of experience on plasma used for Immuno Globulin for IVIG treatment. She will report concurrently on developments.

Donations are up again for this year and our CRA year end continues to report responsibly and positively.

Your MG Canada Board of Directors has approved buying Dr. Oger's final current stock of his brilliant Myasthenia Gravis illustrated hand book.

Next month we'll review a study of immune suppressants with MG pregnancy in conjunction with Sunnybrooke Neurology

Time to look at the research progress on 'retinal diagnosis of Myasthenia Gravis' study we endorsed, which assisted getting the research grant a year ago.

In March we discussed what has changed the most in the last 10 years. **We should soon have our new Website www.MGCanada.org** up and running. It's new format and our ability to edit the content more easily and

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frequently, we hope will add to our increase in Canadian MG patient engagement with each other all across our great country.

1) COVID concerns are still at the top of the current list of MG patient issues.
2) Remarkably faster Myasthenia Gravis diagnosis and treatment.
3) Inconsistent spectrum of national diagnosis by regional geography.
4) Increase in female and mature senior participation in MG conversation.
5) Sharing reveals persistent need for early MG symptom information.
6) Fear of probable and confirmed MG, coupled with need for early patient reassurance, is still cause of big hurdles for newly diagnosed MG patients, coping with MG diagnosis and their treatment options.
7) Living with chronic MG to the highest levels possible
8) MG Canada Sustainable Education for our Professional Medical infrastructure

Worth repeating: Myasthenia Gravis Canada National Patient Advocacy *"Why it's more important than ever! Because when you tell someone you've got Myasthenia Gravis you still get the blank stares – too often at hospital emergency. Because rarely can anyone spell it, never mind be aware of it. The fear is there by everyone including Health Care Professionals. No, it's not contagious. No, it is not genetically inherited. Yes, it can be treated."*

Canadian MG patient engagement. It's about helping each other by being engaged with our fellow Canadian MG patients, families, friends, public and Health Care Professionals. We know our MG Canada Awareness Campaign helps tremendously. With your help, we know all our asserted efforts including social media and our website www.MGCanada.orghelp us all engage with you 24/7.

Onward! Sincerely, Cap Cowan, President, MG Canada and Editor, our National Newsletter "Contact" continuously published over 45 years for Canadian Myasthenics. Contact me anytime.

Myasthenia Gravis Society of Canada,
CapCowan@MGCanada.org 905 642 2545

Welcome Lindsay Peets

New Member of Your MG Canada Board of Directors Team

My MG Story by Lindsay Peets, Part 2

(See June Issue of "Contact" for Part 1)

In addition to helping develop MG Canada as a whole, my priorities lie in providing advocacy, information and support to younger MG patients and their families. Some of the things I hope to do include:

Improving information distribution among younger Canadians with MG.

- Utilize unused/under-developed media (Facebook, Twitter, You Tube, cloud-sharing, etc.)
- Digitize/update/redesign prepared information packages for easy sharing and greater appeal.
- Create new documents/videos/packages/etc regarding critical information relevant to a younger MG demographic.

Increasing enrollment/participation among a younger demographic

- Increase MG Canada's presence online and through avenues geared towards younger patients
- Collaborate with specialists to provide information regarding support groups to new patients

Creating a more relatable support system for younger myasthenics

- Organize guest speakers to discuss specific issues young MG patients face, including broader topics like disabled identity
- Create additional sources of support outside support meetings, including group chats, mentoring programs, crisis response protocols to support members, optional group bonding/social events, etc.

Advocating for the interests of young MG patients, particularly women

- Support research into improving knowledge/treatment of MG as it relates to pregnancy, menses, comorbidity for young patients,

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- Develop relationships with other young myasthenics advocacy/ support groups like MAYA
- Contribute to curriculum/conferences/advisory boards regarding MG, disability, chronic illness, neuromuscular diseases, intersectional medicine, etc.
- Increase public awareness of MG and its impact on young communities.

I am committed to constantly improving my methodology and direction to better reflect the needs and priorities of the community. Ultimately, a support society like MG Canada is nothing without its members.

If you have any questions, feedback or suggestions, please don't hesitate to contact me! Like most millennials, I am reachable through pretty much any avenue you can imagine. Unlike many millennials, I'll even answer a phone call!

You can reach Lindsay through Membership@ MGCanada.org.

The Creation of a Thousand Forests is in One Acorn. . . Ralph Waldo Emerson

Mestinon: The Triumphs and Tribulations

By Dr. Cheryl Zimmer

Mestinon is the commonly known brand name of pyridostigmine bromide, an acetylcholinesterase inhibitor, and the mainstay to manage the symptoms of myasthenia gravis (MG).

Those of us with MG are in fact very lucky to have a medication to manage our condition. And it is even more interesting that its

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primary purpose is to manage our symptoms of muscle fatigue and weakness. This is compared to many of the other medications that we take, which are primarily used to treat something else, but can be used off-label to address the autoimmune component of MG.

MG is considered an orphan or rare disease, which is defined by Health Canada as a disease that affects fewer than 5 in 10,000 people nationwide.[1] Financially, it is not feasible for drug manufacturers to invest in orphan drugs to treat rare diseases, as there is little monetary gain. The enormous cost of the drug to the consumer and/or insurance company may make purchasing it for therapeutic use prohibitive.

How does Mestinon work?

According to the product monograph for Riva-Pyridostigmine, a generic version of the drug available from Laboratoire Riva Inc. in Quebec, "pyridostigmin enhances cholinergic action by facilitating the transmission of impulses across the neuromuscular junction."[2] It accumulates in the junction and is processed slowly with prolonged effects. It is very fast acting with an onset of 20 minutes and a duration of action of approximately 6 hours, although many patients require more frequent dosing.

The Uncomfortable Side Effects

It is absolutely no surprise to those of us that take pyridostigmine, that it has many undesirable side effects, particularly abdominal cramps, diarrhea, nausea, and vomiting. In a 2019 study, the investigators interviewed people with MG to determine the impact of side effects of their various therapies on daily life. Of the 242 participants, 69% reported taking pyridostimine.

Dr. Cheryl Zimmer

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The study was not designed to determine which MG treatments resulted in which side effects, but one of the most prevalent and impactful side effects was diarrhea/gastrointestinal (GI) upset.[3] Diarrhea can be managed using hyoscyamine sulfate (Levsin), which is often prescribed to treat a variety of other stomach/intestinal problems. Loperamide (Imodium), on an as needed basis, may also work well to combat GI issues.[4]

Other side effects of pyridostigmine include muscle cramps, twitches, sweating, salivation, increased bronchial secretions, tearing, flushing, as well as urinary urgency and incontinence. These effects are directly attributed to the cholinergic response of the skeletal muscles and central nervous system.[4]

Neostigmine

Perhaps you are wondering what the difference is between pyridostigmine and neostigmine. They have the same mechanism of action, but pyridostigmine bromide is absorbed more easily through the GI tract with fewer GI side effects. It also has a longer half-life, so the treatment lasts longer, with fewer peaks and valleys of effect.[2]

The History of Mestinon

Initially, an earlier derivative of the pyridostigmine bromide called physostigmine was used for an entirely different purpose. It was the antidote for curare poisoning!

Curare is a liquid prepared from the *Chondodendron* plant in Ecuador and Peru or the *Strychnostoxifera* plant in the Gianas and Africa. It was originally used on the tips of arrow to paralyze prey in the 9th century, it was used to incapacitate animals during research.[4] "Physostigmine is derived from the Calabar bean, a dried ripe seed of the *Physostigmavenonosum* plant, which can be found in tropical West Africa."[4] It is used to treat septic shock and at one time was used to treat glaucoma, but more effective treatments with fewer side effects are readily available.[5]

Fortunately for us, in England in 1934, Dr. Mary Walker suspected correctly, based on the similar neuromuscular symptoms, that the antidote for curare poisoning and the treatment for MG might be

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the same. She attempted to treat her MG patients with injectable physostigmine, then oral neostigmine, with definitive, yet short lasting affects. Pyridostigmine bromide was finally introduced to the market in the early 1950s.[6]

Interestingly, veterans of the 1991 Gulf War were given pyridostigmine bromide, which was routinely taken as a preventative measure against the nerve agent soman, which inhibits cholinesterase. It is speculated that pyridostigmine, in combination with several neurotoxins, chloroquine, and multiple vaccines may have led to impaired liver function, resulting in Gulf War Illness. The symptoms of which include chronic pain, musculoskeletal weakness, headache, fatigue, cognitive deficits, alterations in mood, and numerous multi-system complaints.[7]

Conclusion

Pyridostigmine is a very powerful drug. For those of us with MG, its existence is a triumph, allowing us to open our droopy eyelids, swallow our food and water, and climb the stairs. We must take the good with the bad, and the side effects can be bad, but hopefully manageable. Talk to your doctor if they are not, and before changing or stopping your medications.

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Dr. Cheryl Zimmer

My Journey with Congenital Myasthenic Syndrome (CMS) Part 2.

"The Treatment"

Cynthia Davidson

(Part 1 described Cynthia's path to the diagnosis. See the June Issue of "Contact")

Treatments are extremely limited in CMS and everything (except Mestinon, in some cases) used to treat autoimmune MG do not normally work for congenital forms, hence the reason I was not responding well to everything that had been tried to date. My new treatment was now Mestinon combined with a drug called Ephedrine. This worked better but I became accustomed to a life of having two strong weeks and two weak weeks every month that typically coincided with my menstrual cycle.

My weakest time ever was shortly after I stopped breastfeeding my son (strange enough, while I was breastfeeding him, I was at my absolute strongest but that is another story). I was so weak I needed help getting dressed, in the bathroom, getting up/down stairs, pretty much help with everything. I began to seek out a new neurologist and was referred to Dr. Ganesan who took one look at my file and didn't even know what to say! As he was reading, his mouth fell open and he said "I have absolutely no clue about this Congenital form of MG.". It was the first time I truly respected a doctor, usually I would get the "Yes of course I can help, let's try this. That should work!". Dr. Ganesan then referred me on to Dr. Mark Tarnopolsky at the McMaster University Medical Centre.

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Continued from Page 13—My Journey by Cynthia Davidson

Dr. Tarnopolsky has been absolutely amazing. He, too, was very honest with me and unsure about how to help. I knew of one other person with CMS who was taking an experimental drug called (at the time) 3,4-diaminopyridine and said I wanted to give it a try. We were able to source it through the government via a Special Access Program. This drug worked wonders for me and it still is to this day although there have been several issues with accessing it and now the cost has risen to over $10,000 per prescription (300 pills) – this is also a whole other story that I would be happy to share in the future.
In my 40th year (I am currently 47), a new panel of genetic testing became available for diseases that fall under the Muscular Dystrophy umbrella. Dr. Tarnopolsky sent an application to the government to ask for approval for this testing and we were happy when it was approved! A simple blood test and a few months later revealed that I have an "ultra" rare Congenital Myasthenic Syndrome, a genetic combination that has never been reported before. Tests were also run on my parents to get a better understanding of exactly what was found. This again, is a whole other story!
I am happy to report that overall I am well and have accomplished a lot in my lifetime (I have LOADS of stories!!), and, while I still have my up days and my down days, generally speaking, life is great and wonderful. I appreciate strong days and take my time to rest on weaker days. I hope to share more in upcoming issues to help inspire people with this aliment to appreciate all the good things in life despite having Myasthenia Gravis (or in some cases, Congenital Myasthenic Syndrome)!! **Cynthia Davidson**

When Myasthenics Are Too Weak To Exercise - At Least Move!

I felt like part of a Joe Cocker LP loosely paraphrased "What *do you do when you hardly can move – get a little help from a friend?"* Most of this summer I spent getting physically weaker and weaker. My general Myasthenia Gravis condition has been in major regression to the

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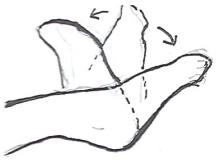
point of two emergency runs and 10 days each for treatment. Most recent discharge September 2, 2021. After 10 years of relative stability and a self rated 7 out of 10 new norms – my health wheels came off. A serious problem if too weak to even lift a jam jar at the table. Forget chewing - anything. Not a recommended way to lose weight either.

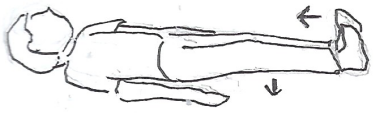
During my recent stay at Markham, Stouffville, Uxbridge Hospital – now tagged 'Oak Valley Hospital', my treatment was collaboratively teamed with Toronto General's UHN Prosserman team. Regardless of my personal plight, I met an amazing number of super dedicated health care professionals trying to help get me well again. I've got a way to go but on the mend, I hope. Gurney living 24/7 is extremely sedentary. What to do?

Enter Meher Battiwally, Physio Therapist who suggested physical movement solutions with explanatory diagrams to help. **Basically put. Any movement is good movement versus no movement at all.** Forget the formal exercise routine approach when you're on purees and higher viscosity liquids, etc., etc. The following are many different moves suggested by Ms. Meyer, that can help get us going again.

Part I - Supine Exercises



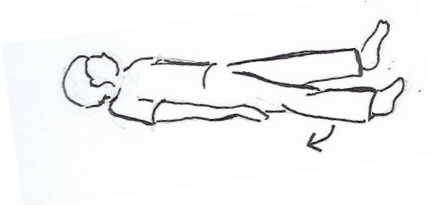
Ankle Pumps: Pull toes/foot up toward your body as far as possible. Point toes away from your body. Repeat.



Static Quadriceps Set: Lay on your back with your legs straight. Push your knees down firmly against the bed and bend your ankles up. Hold five seconds. Repeat.

Static Gluteal Set: Lying on your back with your legs straight. Squeeze buttocks firmly together. Hold **Heel Slide:** Bend your knee and slide your heel toward your buttocks. Lower your let back to bed surface. Repeat.

Heel Slide: Bend your knee and slide your heel toward your buttocks. Lower your let back to bed surface. Repeat.



Hip Abduction: While keeping your leg straight, bring your leg out to the side. Slide leg back to middle position Repeat.

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All donations 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 *www.MGCanada.org* ***905 642 2545***

Join our Myasthenia Gravis Facebook Group (Canada)

Call MG Canada Phone Support

These Members welcome calls from those wanting to connect.

Aleem Remtulla , Toronto, ON 647-390-0522
Tiina Elder, Mississauga, ON 905-565-5875
Jill Thomson, Calgary, AB. 403-286-0056
Phillip Sanderson, Harriston, ON 519-338-3356
Vikki LeDez, Sunderland, ON 705-357-0377
Fernanda Nascimento, St. Catherines, ON 905-937-9762
Pat Griffiths, Ottawa, ON 613-237-1649

We need Telephone Support Contacts across Canada.
Interested? Inquire 905 642 2545

Myasthenia Gravis Society of Canada
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Last Name _____ Male _____ Female _____

First Name _____ Date of Birth _____

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Neurologist's Telephone No. _____ - _____ - _____

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Myasthenia Gravis Society of Canada "National Journey of Hope"

Sunday, Zoom Meeting:

September 26 at 2-5 pm EDT

Guest Speaker
Dr.Carolina Barnett-Tapia MD PhD

Meet Lindsay in person during 2-3 pm
Open Mike, followed by 3-4 pm feature guest Dr. Carolina Barnrett-Tapia, and 4-5 pm Questions & Answers.

Email Membership@MGCanada.org for your invitation link.

MG Canada's Newsletter 'CONTACT' is published by:
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"Canada's National Myasthenia Gravis Patient Advocacy "