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 44 Issue 4** **December 2020**

Exciting Times With New Treatments Specifically for MG Being Developed

By Dr. Vera Bril, Neurologist, Professor U of T, Department Head of Prosserman Clinic, Toronto General Hospital, University Health Network.

Current Studies Now Underway

This is an exciting time for patients with autoimmune disorders of the neuromuscular system, such as those with myasthenia gravis or MG since new treatments are being developed for the first time in many years.

Continued on Page 2

Newsletter Contents:

Continued from Page 1 –Exciting Times With New Treatment

We know that patients who have MG get better with treatments that Change the immune system;

- **either suppress activity,** such as prednisone,
- **or adjust it** like plasma exchange (PLEX) or intravenous immunoglobulin (IVIG) and subcutaneous immunoglobulin (SCIG). The immune modulators (PLEX, IVIG, SCIG) work for short periods of time.
- **All have "burdens"** or potential side-effects associated with treatments.

Access

Access to PLEX is very limited as this is administered in hospital units and subject to hospital global budget issues. **Access** to **IVIG/SCIG** can also be at risk in times of shortage, such as may happen now due to the COVID pandemic and consequent reduction in plasma collections. **Also, both PLEX and immunoglobulins have broad action on the immune system** that may not be necessary to treat CIDP.

Most immunosuppressant drugs take a long time to work with a trial of at least 12 months before trying another agent.

Steroids such as prednisone work much faster within 1-3 months, but have multiple side-effects that are poorly tolerated by many patients.

Categories of Focused Treatments

More focused immune treatments are now being studied for potential use in MG. These include 2 main categories of agent:

1. **Those that work earlier in the cycle to drop antibody levels, called FcR inhibitors**
2. **Those that work at the end of the cycle to prevent membrane damage, called terminal complement inhibitors.**

FcR inhibitors act within cells to reduce the normal recycling of immunoglobulins. They interfere with immunoglobulins being returned to the circulation and promote destruction in a part of the cell called lysosomes. As a result, total immunoglobulin levels fall to about the same levels as seen after PLEX. They work

Continued on Page 3

Continued from Page 2— Exciting Times With New Treatments.

quickly, within 2 weeks, in most patients although some patients take longer to respond. Both subcutaneous and intravenous FcR inhibitors are being developed. The side-effects so far have not been severe and include things like headaches although not at the same level as many headaches after IVIG. Studies in MG have been completed in efgartigimod (intravenous) with positive results, and are underway in rozanolixizumab (subcutaneous) and other new FcR inhibitors.

Terminal complement inhibitors work at the end of the immune cascade and block the splitting of complement and formation of the "membrane attack complex" or MAC. The MAC damages the muscle-membrane and this is one reason that MG patients get weak. After the successful studies, eculizumab has been approved by Health Canada for use in patients with refractory myasthenia gravis (MG), i.e. those with very difficult to control MG. This drug is now being studied in other autoimmune disorders such as chronic inflammatory demyelinating polyneuropathy (CIDP). Other complement inhibitors are also being investigated for efficacy in MG.

Treatments More Focused on Myasthenia Gravis

These novel immune therapies are more focused than the ones we have now. These new agents work quickly within weeks as opposed to some immune therapies where the effect can take 6-12 months to be seen.

These new treatments may also have fewer side-effects in the long-term and that would be welcome to those who require chronic treatment of any type.

So, in summary, it is a very exciting time for patients with immune disorders affecting their neuromuscular system such as MG, as new treatments may well help and be less burdensome than what is now available.

Get More Information About Current Studies

If you are interested in more information about the current studies, please email membership@MGCanada.org or call 905 642 2545.

Happy Holidays

Taking Charge of Your Wellness

By Garry Morehouse

Exercises That Can Be Done During COVID

"Exercise is the best doctor you can ever have!" *~ Comment made by a speaker at the Conquer MG Educational Meeting*

Exercise and sports have always been a large part of my life. When I was diagnosed with Myasthenia Gravis (MG) in November of 2017, I searched for ways to incorporate them back into my daily life. Initially, indoor exercises worked best for me once my symptoms stabilized. I did sit-to-stand squats, resistance band leg exercises and used five pound dumb-bells. I added some yoga breathing as well as bridge and plank positions. Still to this day, my daily routine takes about 30 minutes. In time, I began to play indoor pickleball resulting in play for two hours a time, three times a week. Combined, these exercises and games improved my endurance, and mobility.

I walked the steps at the park five times a day when COVID started. Pole walking is a great outdoor activity.

When Covid hit in March 2020, I was able to maintain my well-established home exercise routine. I also switched up a few things in order to stay active. I started to pole walk again, a great low-cost exercise option. The poles aid in intensifying the

Continued on Page 5

Continued from Page 4—Taking Charge of Your Wellness

walking and if necessary, keep people at a two-metre distance! Throughout the summer I played pickleball at outdoor locations.

I walked the steps at the park five times a day when COVID started. Pole walking is a great outdoor activity.

Depending on your local government and health pandemic regulations, if gyms or shopping malls are open and permit safe physical distancing, a walking regime can easily be moved indoors. And there is home sweet home for your squats, stretches, yoga and your own choice of exercise.

It's been three years to the date since I was diagnosed. Walking with poles at the Y was the single most physical activity that enabled my recovery. I walked the track one KM a day seven days a week for three months.

2017 was a terrible year with a hip replacement in January, loss of my wife in July and then MG in November. I am thankful for each day that I can be healthy and active. As I celebrate my 75th birthday on December 8th, 2020, I decided to share the following good messsage. It helps keep me motivated.

"Not everyone is given a chance to grow old. So appreciate every single day of your life." ~ MyPositivityOutlooks

Boardwalk Bikers

First Snow Nov. 2020

MG Support Group Meeting
Ottawa & Region
Sunday, December 6, 2020, 3pm

The Next ZOOM meeting hosted by Ann Duggan. Anyone that wants the link can email.
Email Contact: mgottawa@yahoo.com

Myasthenia Gravis Society of Canada
MG Canada Support
"National Journey of Hope" Meeting
Sunday, December 13, 2020 at 3 pm

ZOOM meeting invitation link by Email hosted by Cap Cowan, MG Canada medical advisory and others.
Email Membership@MGCanada.org for your invitation link.
MG Canada members will get a personal invitation link by Email.

Congenital Myasthenic Syndrome (CMS) – Have You Heard of It?

The MG Society of Canada is creating a section for these types of syndromes in the newsletter and eventually on the website to help raise awareness and be of support to those with this form of myasthenia.

First things first, the definition of CONGENITAL is: (of a disease or physical abnormality) present from birth. This can be hard to believe

Continued on Page 7

Continued from Page 7—Congenital Myasthenic Syndrome

as some people are not diagnosed with CMS until into the adolescence or even into adulthood. However, symptoms are so widely varied and are often times overlooked or passed off as nothing of significance at younger ages. "I recall doctors telling my parents I was just a lazy kid that didn't like running," says Cynthia Davidson.

The effects of Congenital Myasthenic Syndrome (CMS) are similar to Lambert-Eaton Syndrome and Myasthenia Gravis, the difference being that CMS is not an autoimmune disorder. Generalized weakness or weakness is confined to specific muscle groups, as with Myasthenia Gravis. Everyone is different.

Here is some information as published on www.rarediseases.org written by Dr. Andrew G. Engel, MD, Department of Neurology and Muscle Research Laboratory at the Mayo Clinic:

*"**Congenital Myasthenic Syndromes are caused by alterations (mutations) in specific genes.** Genes provide instructions for creating proteins that play a critical role in many functions of the body. When a mutation of a gene occurs, the protein product may be faulty, inefficient, or absent. Depending upon the functions of the particular protein, this can affect many organ systems of the body.*

***Approximately 30 different genes are known to cause CMS.** These genes contain instructions for proteins that are essential for the proper function or health of the neuromuscular junction and the motor endplate. Some of these proteins are found in other areas of the body and, in those subtypes, other areas of the body in addition to the neuromuscular junction can be affected.*

In some individuals with CMS, no altered gene has been found indicating that additional, as-yet-unidentified genes exist that can cause a congenital myasthenic syndrome.

Treatment

There are no standardized treatment protocols or guidelines for affected individuals. Due to the rarity of the CMS overall and that

Continued on Page 8

Continued from Page 7—Congenital Myasthenic Syndrome

fact that certain subtypes have only been identified in a handful or fewer individuals, there are no treatment trials that have been tested on a large group of patients. Various treatments have been reported in the medical literature as part of single case reports or small series of patients. Treatment trials would be very helpful to determine the long-term safety and effectiveness of specific medications and treatments for individuals with CMS.

As stated above, it is critically important to identify the specific subtype in each individual as medications that prove effective for one type of CMS may be ineffective or even harmful in another. *More detailed treatment information for specific subtypes of CMS is discussed in the "Signs and Symptoms" section above under each individual subtype listing.*

Current therapies for CMS *include medications known as cholinergic agonists such as pyridostigmine or amifampridine (3,4-diaminopyridine), long-lived open channel blockers of acetylcholine receptor ion channel fluoxetine and quinidine, and adrenergic agonists such as salbutamol and ephedrine."*

Watch for personal stories and more information on CMS in upcoming newsletters! Submitted by Cynthia Davidson and Linda Scanlan.

Feel free to reach out to two of our members who have experience with CMS. If you are interested in reaching out to members Cynthia Davidson and Linda Scanlan, please email membership@MGCanada.org or call 905 642 2545 for contact information.

On Facebook?

Connect With Others from Across Canada Sharing their Experience of Living with MG

Join our Myasthenia Gravis Facebook Group (Canada)

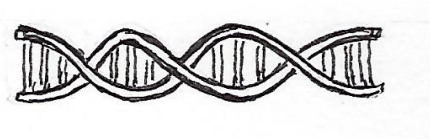
Hear from others affected by Myasthenia Gravis through this Support Group - another way to learn more through postings, discussion, and comments from patients and families living with Myasthenia Gravis.

Worth repeating.

Have You Recruited Anyone to Donate Blood Lately? Better Still, How About Recruiting Donors for Plasma?

Canadian Blood Services is a non-profit charitable organization that is independent from the Canadian government. The Canadian Blood Services was established as Canada's blood authority in all provinces and territories except for Quebec in 1998. Headquarters are in Ottawa.

Motto: Together, we are Canada's lifeline. Join Canada's Lifeline. Book now to encourage your friends and family to donate blood. Find a Donor Centre near you. Blood Donation can make a lifesaving difference. Even better, for making IVIG which many MG patients depend on, donate plasma.



MG Canada assisted with Canadian Blood Services/National Advisory Committee on Blood and Blood Products: National Emergency Blood Management Committee

"Dear valued stakeholder,
We are pleased to inform you that The National Plan for Management of Shortages of Immunoglobulin Products (Ig) – Interim Guidance was recently approved by the Conference of Deputy Ministers (CDM) and is now available on the NAC website.

The interim Ig plan was developed through the collaborative efforts of stakeholders from across the country who lent their expertise and guidance to this important work. Diverse perspectives were heard and incorporated, including those of patient groups, societies, Ig prescribers and other clinicians, provincial/territorial (P/T) ministries of health, Canadian Blood Services and others.

Continued on Page 10

Continue from Page 9— Blood/Plasma Donating

We would like to express our sincere and heartfelt thanks to everyone who took the time to submit their comments and attend online engagement sessions.

As per the interim guidance, the work to develop a full national Ig shortage management plan is anticipated to be completed within the next 24 months. The interim Ig plan and its learnings will serve as a framework to directly inform the development of the full plan. Appendix E of the interim Ig plan details considerations recommended for the development of the next iteration. As a stakeholder with interests and experience relevant to the use of immunoglobulin by Canadian patients, we hope you will consider any future requests to contribute and participate when such opportunities arise.

If you have any questions or concerns, please don't hesitate to contact us (NEBMCSecretariat@blood.ca).

Cheryl Doncaster & Laura Todd, NEBMC Secretariat "

National Advisory Committee on Blood and Blood Products | Comité consultatif national sur le sang et les produits sanguins

Canadian Blood Services

Editor Note:

MG Canada and our MG Medical Advisory Team responded immediately to the request for assistance. As a result of our active participation, MG Canada is acknowledged at the very top of the list of stakeholder participants and Myasthenia Gravis treatment with IVIG, is highly prioritized. There are many rewards to having MG Canada as 'Canada's Myasthenia Gravis National Patient Advocacy.' Your continued support is vital.

The MyRealWorld MG study – could you take part?

MyRealWorld MG is an international study exploring the impact of MG on people's lives. It's open to all adults who have MG and live in one of the following countries: US, Japan, Germany, UK, France, Italy, Spain, Canada and Belgium.

Study participation involves downloading the MyRealWorld MG app and using it to provide information about yourself and your MG over a period of up to two years. The app includes a medical profile, where you can record your treatment data, a monthly event tracker, and monthly surveys about your MG and its impact on your daily activities, mental health, and quality of life.

Any information you provide is stored securely. Before it is analyzed, your information is grouped with that of other participants and identifying details are removed.

The study is sponsored by the biotechnology company argenx, and is being run in collaboration with MG patient organizations from all study countries, including Myasthenia Gravis Society of Canada.

One of the key principles of the study is to raise awareness about MG by sharing the data widely, including with study participants. Updates on study progress and 'data nuggets' will be published regularly for participants to read in the Knowledge section of the app.

Since the study's launch in August, interesting data are already being generated:

- Around 70% of people currently taking part are female
- The average age when participants first noticed MG symptoms was 37, but they weren't diagnosed until a year later at age 38

Continued on Page 12

Continued from Page 11—The MyRealWorld MG Study

The MyRealWorld MG Study

- Just over half of people in the study would describe their MG as antibody positive.

As of the end of November, almost 700 people have enrolled in MyRealWorld MG from around the world. If you are interested in joining them and sharing your experiences of MG please visit myrealworld.com to find out more, or search for MyRealWorld in the Apple or Google app stores. Both English and French versions of the study app are available in Canada.

Emma Bagshaw
Senior Medical Writer
Vitaccess

MG Patient Positive Research Trial Rejection and New Hope. Myasthenia Gravis Patient Treatment Solutions. Who Said It Would Be Easy?

Agreement to Participate in 3rd Phase Trial While Keeping On Same Meds and Supplements. *'My Mind Says Yes.'*

By Cap Cowan, MG Canada President and Newsletter editor

My personal "MG Journey of Hope" volunteer contributions continue despite being rejected in September after the first 4 hours of evaluation and blood test results. As you recall, I was asked and

Continued on Page 13

Continued from Page 12—Editorial

agreed to be a volunteer again for a third trial study at Toronto General Hospital (TGH) to help research for improved treatment of Myasthenia Gravis.

1) My first volunteer trial participation was for comparative trials of IVIG suppliers about 10-12 years ago.

2) Second time as volunteer patient for more definitive referencing MG patient psychological assessment study about 6 years ago

3) This time as patient volunteer for "rozanolixizumab" 3rd phase clinical trial. (Most of the new biological treatments end with 'mab'.) See Dr. Bril's article on the new breed of treatments for Myasthenia Gravis, Pages 1-3.

Bad News Trial Volunteer Rejection and Good News Reasons Why. *'My Body Says No'*

Diagnosed and treated by Dr. Bril, for approximately 15 years, with a lot of side effects over time as fairly severe Generalized Myasthenia Gravis patient with little pre-existing conditions, this was another opportunity to help. After the first 4-hour trial assessment visit, I got a phone call a couple of weeks later before my next scheduled trial visit.

They were concerned about early results of my blood tests. Then a second call when all test results were completed. Basically because of a latent virus in my system, it would be high risk for me to proceed as a 3rd phase trial participant. Too dangerous. Furthermore, I was referred to an infectious disease Respirologist for treatment, which I have now begun. What?

Positive Research Pre-trial Rejection Offers Me New Hope

How could a positive research pre-trial rejection offer new hope? Ready for this? I was diagnosed with 98% likelihood of latent tuberculosis (TB)! Wow! Treatment has begun and will take at least

Continued on Page 14

Continued from Page 13—Editorial

4 months to eradicate from my body starting with 450 mg daily barrage of antibiotic Mycobutin. 2nd Wow!

My new, referred Respirologist TB specialist, told me TB is still the first or second largest killer globally! Especially in eastern Europe, Africa and South America. Since I haven't travelled to those locations, it is most likely I was exposed to someone who was from those areas and have been carrying latent TB, probably for several decades. Detection of TB is part of the screening for the trial. Having it with possibly 2 levels of the new trial drug, a much more MG targeted immune suppressant, especially since I was staying on both Prednisone and Cell Cept immune suppressants, could activate the latent TB virus in my system. Yikes!

So what's the Good News? Trial Screening Saved Me a Possible Health Crisis and Focused Some of the New Trial MG Meds advantages.

This experience offers new hope for MG patients. Rather than discouraging, it emphasizes the current difficulties with MG patient diagnosis, treatment, patient tolerance to current treatment options and patient acceptance of chronic condition, without proven scientific cure to date. MG symptoms are masked with several other possible conditions, so still difficult to diagnose.

Most current MG treatments use a variety of prescription meds and procedures, developed for many other auto immune diseases, other than Mestinon. There are no magic solutions yet.

The current new breed of MG meds offer hope

The current new breed of meds offer hope that by targeting MG specifically, while expanding assessment of pre-existing patient conditions, there will be much fewer side effects with hopefully much smaller dosages - and perhaps frequency of the dosages.

Pre-existing MG patient conditions do effect treatment and patient tolerance to safe MG treatment solutions.

Continued on Page 15

Continued from Page 14—Editorial

I guess my trial rejection was a positive contribution after all. ***'Trial researchers kept me safe.'*** **Advent of more effective MG targeted treatments with fewer side effects, are exciting to look forward to!**

Cap Cowan, MG Canada President
and Newsletter editor

Myasthenia Gravis Society of Canada

CapCowan@MGCanada.org

905 642 2545

Myasthenia Gravis "Help Line"

Telephone Support with an MG Patient

Whether you have recently received the news that you have Myasthenia Gravis, or you have been living with MG and want to share your experience, these members have offered their support. Please feel free to telephone them to discuss your Myasthenia Gravis experience.

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

Donate to Myasthenia Gravis Society of Canada.

Help Keep Us Going and Growing

A Huge Thank You For Support

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

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 at www.MGCanada.org

905 642 2545 **Registered Charity#81155 1431 RR0001**

Myasthenia Gravis 24/7 personal healthcare preparedness, especially in current Coronavirus crisis. Have several complete printed copy updates of your current prescription meds and dosage amounts with daily times. List supplementary treatment such as IVIG & other supplements you may take such as 81mg Aspirin and vitamins. Keep at least 5 days of daily meds ready when heading for emergency. Have your MG Canada Blue Card ready with "do and don't" recommendations regarding antibiotics and other treatments that might acerbate your Myasthenia Gravis. Ask for new cards at membership@MGCanada.org &/or it's automatic when renewing your membership. Stay calm.

Myasthenia Gravis Society of Canada
New/Renew Your MG Canada
Membership Application

Date _____ New Member _____ Renewal _____

Last Name _____ Male _____ Female _____

First Name _____ Date of Birth _____

Address (Include Suite #)_____

City _____ Postal Code _____

Phone _____ - _____ - _____ Cell Phone _____ - _____ - _____

Name of Spouse, Partner or Significant Other (Optional)

_____

E-mail Address _____ @_____

In order to reduce postage costs I would like to receive the quarterly newsletter "Contact" via e-mail, rather than by regular mail: Yes _____ No _____

Would you like us to call you? Yes _____No _____

For "Myasthenics Only" and for statistical purposes (held in strictest confidence):

My Neurologist is Dr. _____

Neurologist's Telephone No. _____ - _____ - _____

ANNUAL MEMBERSHIP FEE

$ 20.00 (1 year) $ _____ (12 months – Individual or Family)

or $ 50.00 (3 years) $ _____ (36 months – Individual or Family)

Donation $ _____ (optional

Total $ _____

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.

Tax Receipt issued for Donations of $10 or more.

Registered Charity #81155 1431 RR0001

Season's Greetings and thank you to all our MG Canada front line volunteers. That includes you, our Newsletter contributors, readers and influencers. Not surprisingly, MG Canada is now directly connected in various ways, to nearly 2000 Canadians. There are many ways to serve our fellow Canadian Myasthenia Gravis Patients, Caregivers, Healthcare Professionals, MG Researchers – especially, but not only in this continuing COVID 19 sur-reality. Day after Day. It takes a very large contingent of committed, to shepherd our Chronic MG condition. We're a dynamic interconnected circle of caring. Social media, Website, Newsletters, support sharing - all helps greatly. We've seen our Myasthenia Canada Facebook group continue to grow because we respect and share our experiences 24/7 with compassion and empathy. We're here for each other MG brothers and sisters. This is the season to say thank you for all that love and caring. **Sincerely, MG Canada Board of Directors. Happy and Joyful Holidays. Stay well and Safe.**

MG Canada's Newsletter 'CONTACT' is published by:

Myasthenia Gravis Society of Canada
c/o 247 Harold Avenue, Stouffville, Ontario
L4A 1C2 905 642 2545
www.MGCanada.org

Myasthenia Gravis Society of Canada

c/o 247 Harold Ave.
Stouffville, Ontario,
L4A 1C2

"Canada's National Myasthenia Gravis Patient Advocacy "