



There is Hope Through
‘CONTACT’

*Printed in the interest of those
Affected by Myasthenia Gravis*

“Could It Be MG?”

Quarterly News

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The Struggle is Real



Dr. Cheryl Zimmer

- Considering a Trial?
- Clinical Trials Open
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- My MG Journey by Cynthia Scott Jemmett, R.N.

We are quite aware of the weakness and fatigability of our voluntary muscles. It is the hallmark of myasthenia gravis (MG). But what about generalized fatigue? How many of you feel drained, exhausted, even weary at times? I imagine that many of you, even those with well managed MG, are nodding your heads. Well, you are not alone. As I write this article today, my fatigue is tangible, consuming, and overwhelming, but I am pushing through.

Let’s discuss MG and fatigue.

Fatigue is the state of extreme tiredness. It is not the same as being sleepy, which is the drowsy feeling one may have late at night watching TV or reading a book, which indicates that it is time to go to bed. Rather, fatigue is the desire or need to rest. “Veg out? Yeah. Be still like vegetables, lay like broccoli,” to quote the fabulous movie - Pretty Woman. A research team that published at least two articles on MG and fatigue defined central fatigue (rather than muscle fatigue) as experiencing a lack of physical and/or mental energy, with difficulty sustaining voluntary activities.^{1,2}

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To determine the prevalence of fatigue in MG, I searched PubMed and surprisingly found at least 10 papers written on the subject in the last 5 years alone. A systematic review of 21 studies found that the prevalence of patient-reported fatigue varied between 42% and 82% in MG patients, which was significantly higher than in the control group, which had a prevalence of 18% to 40%. When broken down by disease severity, the prevalence increased from 32% in patients in pharmacological remission to 72% in those with symptomatic generalized MG.¹ With regard to other correlations, depression, stage of MG based on the Myasthenia Gravis Foundation of America),³ and female gender were correlated with greater fatigue.^{2,4}

There are a number of different patient questionnaires on cognitive and physical fatigue impact and severity.

The two that I came across most frequently, and which were often paired together, were the 40-item Fatigue Impact Scale (FIS) and the 9-item Fatigue Severity Scale (FSS).⁵ The latter was originally designed for people with multiple sclerosis (MS) or systemic lupus erythematosus (SLE), two other autoimmune disorders.⁶ The questions for the FSS are graded on a scale from 1 (strongly disagree) to 7 (strongly agree), so that a high score means a greater level of fatigue severity.

The questions include in the past week:⁷

- 1. My motivation is lower when I am fatigued.**
- 2. Exercise brings on my fatigue.**
- 3. I am easily fatigued.**
- 4. Fatigue interferes with my physical functioning.**
- 5. Fatigue causes frequent problems for me.**
- 6. My fatigue prevents sustained physical functioning.**
- 7. Fatigue interferes with carrying out certain duties and responsibilities.**
- 8. Fatigue is among my three most disabling symptoms.**
- 9. Fatigue interferes with my work, family, or social life.**



Dr. Cheryl Zimmer
Medical Writer for Myasthenia
Gravis Society of Canada

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The final score is tabulated, then divided by 9 for the number of questions. On average, people with depression alone score about 4.5. However, those with fatigue related to MS or SLE average about 6.5.⁷ Taking this one step further, recent studies have shown that fatigue in MG can reduce quality of life (QoL).⁴ Based on the 15-item MG-QoL, one such study concluded, “The strong association with disease severity suggests that fatigue should be recognized as an element of the symptomatology of MG.”²

This proves that the struggle is real! So, what do we do about it?

First, advocate for yourself by consulting with your neurologist to confirm that your MG is optimally managed, then take your medications diligently, as prescribed. Plasma exchange (PLEX)¹ and Eculizumab (which inhibits the activation of proteins that are believed to cause damage to the neuromuscular junction) have been shown to improve perceived fatigue, although there is a scarce amount of evidence so far.⁸

If you are experiencing any other conditions that are associated with fatigue, such as depression or sleep disturbances, including insomnia or sleep apnea, discuss these with your physician and seek treatment. Please do not suffer in silence. For many disorders, although not studied much in MG, cognitive behavioural therapy (CBT), which is a type of psychological treatment that helps change thinking and behavioural patterns, has been proven useful.⁹ **Yes, the power of positive thinking. And of course, get fresh air, exercise appropriately when you have the strength, and eat a healthy, well-balanced diet.** Most importantly, be kind to yourself and know that you are not alone.

***Most importantly,
be kind to yourself and know
that you are not alone.***

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Newsletter Editorial: January 2022 - Season of Hope:

Myasthenia Gravis Society of Canada, a.k.a. MG Canada is always about MG patient advocacy and how it relates to quality living with this neuromuscular chronic condition. We MG patients own it – so far for life, once diagnosed and treated.

I find after 19 years as a diagnosed Myasthenic, some categories of my patient challenges are more obvious than others. Dr. Cheryl Zimmer's article on 'Fatigue' is a great example. "Fatigue is the state of extreme tiredness." For us, an intriguing reality.

In optimistic MG patient "Hope Wish List" terms—'Fatigue' could be an MG wish list biggy for 2022. **In this issue we explore the world of new drug MG patient research trials underway in North America** where there is active patient recruiting—who, what, why, when, how to volunteer. Factors to ask about and consider when thinking of participating. We will be publishing more online in several blogs. Without patient research support we would have no valid references to recommend—or not. A quiet form of heroism. With rare conditions, sampling size is a big problem. Volunteering for trials can be a great gift.

Cap Cowan, President and Newsletter Editor

Myasthenia Gravis Society of Canada Invited to be a member of National Advisory Committee, Canadian Blood Services

Blood and Blood Products Study on Immune Globulin (IV and Subcutaneous) Products.

Thank you to Linda MacMullen who has accepted the challenge to attend the National Advisory Committee on Blood and Blood Products (NAC) for Immune Globulin (IV and Subcutaneous) Products

The following is Linda's report on her participation.

"I was honored to be asked by Cap Cowan, on behalf of the Canadian MG Society, to be the representative with the Canadian Blood Services. It is a very interesting process and I am learning lots.

The Canadian Myasthenia Gravis is a stakeholder in the Canadian Blood Services and we were asked to participate in discussions to aid in the purchasing of certain blood products. **We are participating from a patient perspective.**

One of the treatments that are used to treat MG is IVIG and Subcutaneous IG (SCiG). **IVIG is the main treatment I am using and has been used frequently to help people in crisis....**

Linda MacMullen"

Myasthenia Gravis Society of Canada Website:

www.MGCanada.org

Thank you for all your enthusiasm and response on our new www.mgcanada.org website. We invite your participation (through membership, blogs, volunteerism, donations, your MG story...)



Myasthenia Gravis Society of Canada.

MG Clinical Trials Open and Recruiting as of November 2021

Our thanks to Laura Iliescu, MSc, Associate Director, Patient Advocacy Strategy, Centre for Rare Diseases for this update of current MG Trials.

Trials in CANADA

As of November 2021, a number of clinical drug trials are recruiting participants in **Canada**. Details about these studies can be found at clinical trials reporting websites (such as [ClinicalTrials.gov](https://clinicaltrials.gov)), in addition to several others). Your MG Neurologist and/or related MG treatment clinics may be involved in one or more of these trials. In addition, the drug development companies sponsoring these trials may also have a

webpage dedicated to the therapy they are actively developing. **MG patients and MG treatment advocates, can help quality research by volunteering wherever and whenever possible**



Mystical landscape.

Photo by Tony Watkins

- **Sponsor: University Health Network.** Safety and efficacy of Cuvitru 20% subcutaneous immunoglobulin in patients with myasthenia gravis (MG). Recruiting.
- **Sponsor: Takeda.** A Study of TAK-079 in People With Generalized Myasthenia Gravis, Recruiting.
- **Sponsor: Viela Bio.** Efficacy and Safety of Inebilizumab in Adults With Myasthenia Gravis, Recruiting.

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Sponsor: Janssen Research & Development, LLC. A Study of **Nipocalimab** Administered to Adults With Generalized Myasthenia Gravis. Recruiting.

Trials in the UNITED STATES

As of November 2021, a number of clinical drug trials are recruiting participants in the **United States**.

Details about these studies can be found at clinical trials reporting websites (such as [ClinicalTrials.gov](https://www.clinicaltrials.gov)), in addition to several others). Your MG Neurologist and/or related MG treatment clinics may be involved in one or more of these trials. In addition, the drug development companies sponsoring these trials may also have a webpage dedicated to the therapy they are actively developing. **MG patients and advocates for MG treatments can support development by raising awareness wherever possible.**

- **Sponsor: Alexion Pharmaceuticals.** Study of **ALXN1830** Administered Subcutaneously in Adults With Generalized Myasthenia Gravis. Recruiting.
- **Sponsor: DAS-MG, Inc.** Study of Pyridostigmine With **Ondansetron** in Subjects With Anti-AchR Positive Myasthenia Gravis, Recruiting.
- **Sponsor: Cartesian Therapeutics.** **Descartes-08 CAR-T Cells** in Generalized Myasthenia Gravis (MG) , Recruiting.
- **Sponsor: Viela Bio.** Myasthenia Gravis **Inebilizumab** Trial, Recruiting.
- **Sponsor: Janssen Research & Development, LLC.** A Study of **Nipocalimab** Administered to Adults With Generalized Myasthenia Gravis. Recruiting.
- **Sponsor: Takeda.** A Study of **TAK-079** in People With Generalized Myasthenia Gravis, Recruiting.
- **Sponsor: argenx.** Evaluating the Long-Term Safety and Tolerability of **Efgartigimod PH20 SC** Administered Subcutaneously in Patients With Generalized Myasthenia Gravis, Recruiting.
- **Sponsor: Fred Hutchinson Cancer Research Center | National Cancer Institute (NCI).** **Autologous Peripheral Blood Stem Cell** Transplant for Neurologic Autoimmune Diseases. Recruiting.

Participating in Clinical Trials Is PERSONAL.



Clinical trials can be a source of hope and care for patients, families, and friends affected by rare disease. You've probably heard that it's important to consider all of your options if you are thinking of joining a clinical trial. It's also important to consider how easy or difficult each trial would be for you and for the people close to you who matter—and to ask what can be done to make the harder things easier. It can help to know what kind of support is possible so you can know what to ask for.

The following checklist has been developed by PRA Health Services, Centre for Rare Diseases, to give you both information and confidence as you explore clinical trials that may be right for you. Because every clinical trial is different and will require different things from participants, some of the following questions may not be applicable to the trials you are interested in. However, they should give you an idea of the types of things that may be asked of you during a clinical trial.

This list will help you to ask questions about:

- What you'll have to do to find out if you can get into the trial
- How you'll get to the trial's medical center for visits
- What assistance you'll have during each trial visit. The medical tests that will be performed during the trial
- What you'll be required to do at home during the trial
- What happens when the trial ends

When to Ask..

The best time to ask these questions is before you start going through the process to find out if you can be accepted into a specific clinical trial. This process is called the "screening process" or the "eligibility process." **There's no wrong time to ask for what you need.**

This information is provided by ORA Health Services. The Centre for Rare Diseases. More information will be provided in future issues.



My MG Story:

Challenge the Challenges—Part 2

Cynthia Scott Jemmett, R.N.

Cynthia Scott Jemmett wrote her life story of her 70 year personal Myasthenia Gravis journey. Part 1 covered her journey to being diagnosed at the age of 17 in Trinidad. Part 2 tells her story of treatment and choosing a career.

Treatment of Myasthenia Gravis

The oral administration of “Prostigmine Bromide”, was started immediately. During the daily administration of vitamin B injections, in order to be closer to the hospital, I was invited to live with my best school friend, a classmate who lived in the City. As a result, I was away from school, while my girlfriend was able to continue school to write her exams for completion of her school year. This was also the end of the high school year.

I was sad. Although I lived with her and her parents, I was off school for a while and was very lonely, even at that short time, I missed my school friends.

Conditions after Diagnosis

My doctor forbade me to return to school, since reading and studying promote weakness of the eyelids in Myasthenia Gravis patients. I did not complete school. I was devastated.

I was determined to complete my education in whichever way possible. Without a high school certificate, a profession could not be (obtained) achieved. At that time, my thoughts were definitely heading towards a legal secretary. I love courtroom procedures.

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On Leaving School

July the year 1952, I was completely away from school, doing nothing except praying and thinking thoughts of my future. This was a challenging time for me. I intended not to accept this challenge, and decided to ignore all the doctor's orders and "do my thing" exactly as I desired.

Returning to School

In January of 1953, I disobeyed all doctor's orders and established myself in a secondary high school (non Catholic), as my private high school refused to accept me due to my medical problems.

My admission to this school was mainly to write and pass my final year. This was another difficult time for me, new friends, new teachers, and new location, the constant medication, and competing with the boys. This school was a mixed school of girls and boys.

My teacher, Mr Farrar was also male, very tall and soft spoken. He knew of my medical conditions since, I told him, and discouraged me from proceeding with classes. Instead, he offered to marry me (laugh). Of course, marriage was not the answer to "drooping eye lids", although every woman would like to be married some day. I did not think Mr Farrar was the answer. He made a few visits to my home, dated me once when I was then eighteen, but to no avail. I did not fancy my school teacher in that way.

Thank goodness during the last term of that same year, Mr Farrar was transferred. Another young man, the Principal who encouraged me to stay in school, and write the exams, replaced him. This I did slowly moving along with a cane for support, eyelids drooping for five consecutive mornings, to the Examination Centre. I felt confident, I reached my goal and I succeeded.

The year was over and I awaited results.

Chapter 2: Contemplating a Career

I was encouraged by my best girlfriend to write the admission entrance for Nursing Program. She also was awaiting results of school exams. This was not too tough for me as my

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oldest sister was already a nurse and was quite successful in her career. I had picked up a few things about nursing from her, here and there.

I was successful in this undertaking. I passed with flying colors, yet I was not allowed to enter the nursing field. I failed the Medical examination for nursing. The doctor who failed me was Dr Chong, who was my physician who attended to me and made the early diagnosis of Myasthenia Gravis. His words to me were “Elsa, you are a brave girl, and a very ambitious one, but not a strong girl. I suggest you settle for marriage, no children, and very little house work, as this will be too hard on your neurological system. At least you will not be reading and studying.” I was furious about the Doctor’s assessment, though deep within me, I thought the doctor could be right. On the other hand my best friend, gave me some encouragement. She thought I could do it i.e. pass the nursing medical examination as she did. She was a healthy young woman, and we were good friends.

My first choice was to be a legal secretary. I loved the activity with Judges and Lawyers, but this would have separated me from my high school girlfriend of five years. I lived with her family, mother and grandfather, who took care of me during the daily jaunts to the hospital for those neurological injections and visits. My girlfriend and I realized that we could or would not have had the privilege to work for the same lawyers.

Since the failure dampened my spirits, I knew for sure life was going to be a challenge and challenges I will face. The next step was how to succeed in a medical examination. I must never be defeated, drooping eyelids or walking cane. I have to be a success in life.

I read in the newspaper, that another medical examination for nurses was being held in Southern part of the island, the second largest City of San Fernando. I was already successful in the written entrance examination in Port of Spain, the Capital City. Off I went taking my Certification with me for reference.

The night before departure, I prayed that the good Lord would make good for me this time for the medical examination. Prayers are usually answered in one way or another. At this time, the left eyelid was the weaker one. That morning, I awoke with a large (Chalazion) or “boil” on my upper left eyelid. I laughed uproariously

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I said to myself “Ha Ha! This will do it.” I jumped in a cab, smartly dressed, of course, to make a good appearance. I did not forget my sunshades.

The medical examiner was a Doctor from England, who lived in Trinidad for a long time. Dr Mottley examined me carefully, and kept staring at me very curiously. He then asked, “Do you feel the sun on the left side of your face?” “Of course I do, why do you ask?” The doctor replied that the left side of my face appeared to be slightly paralysed, that’s because of the left eye paralysis. I knew that.

Another question from Dr Mottley; “what happened to your left eye?” “Oh I see, I retorted. A boil came out on my left eye lid this morning”.

I passed the medical exam with flying colours and I was on my way to being a registered nurse. Another challenge met, another challenge successful. I enjoyed good health as I entered San Fernando General Hospital as a student nurse in January 1954. Sad to say my best friend, who entered nursing in Port of Spain passed away in her second year of training from Bone Marrow Cancer on one of her hips. I could have given up the profession on many occasions, but even with hard work, I was not a quitter. **I challenged the challenges.**

Cynthia Scott Jemmett, R.N.

" As long as you live, keep learning how to live."

Lucius Annaeus Seneca

Seneca was a major philosophical figure of the Roman Imperial Period.

Just Move!!

Home-based Exercise in

Autoimmune Myasthenia Gravis



Submitted by Garry Morehouse

Here are the findings of a randomized controlled trial on Exercise and MG: *Highlights:* Adults with stabilized

MG and no contra-indication to exercise, were eligible. Participants received usual care alone or usual care and exercise. The exercise intervention consisted of three weekly 40 min sessions of an unsupervised, moderate-intensity home rowing program over three months. 43 were randomly assigned, 23 to exercise

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and 20 to usual care. Though exercise was well tolerated, the intention-to-treat analysis revealed no evidence of an improved quality of life.

Conclusion: This randomized clinical trial with intention-to-treat analyses, demonstrates that a three-month, home-based unsupervised exercise program is well tolerated and does not contribute to exacerbations in adults with stabilized MG. This is a major result as benefit and risk of exercise is a major concern for individuals with MG. Further research is necessary to evaluate different dosages of exercise and their effects, in this population.

Source: S. Birnbaum (Institute of Myology, Paris), R. Porcher, P. Portero et al., the MGEX Study Group. Research is available at <https://pubmed.ncbi.nlm.nih.gov/34304969/>

Though 120 minutes on a rowing machine is good, it may not be vigorous enough to indicate an improved quality of life for anyone. I started walking two times around a track and gradually increased it to 20 times every day at the YMCA for six months. In the fall when the YMCA closed due to COVID, I started to hike on a trail for an hour several times a week. I went with a friend and made it enjoyable. It was not a marathon.

Walking with poles helped with my mobility, balance and improved my gait. My morning routine also consists of 20 sit-to-stand squats, a 40 second plank exercise, and a short breathing exercise. I can now play pickleball several times a week.



The important thing is that you find something that you enjoy that gets you moving. It's also a lot more fun to exercise if you have someone to go with you, so see if a friend is interested in being your partner.

Respect your MG and stability while becoming more proactive in your wellness programs. It makes a world of difference in your overall health.

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TOP 10 HEALTH BENEFITS OF WALKING 30 MINUTES A DAY



Infographic Credits: AirTract.Com. by permission supplied by Garry Morrison

I was diagnosed with MG four years ago. I just turned 76 and am MG symptom-free. I am thankful for each day that I can be healthy and active.



“If persistence is the investment, success is the return. I am trying to defy health issues through exercises and squeeze as much fun as possible into the aging process.”

Disclaimer

My article on Exercise is based on my personal experience and research and is not to be taken as approved by the medical or physiotherapy professions. And I have no skill sets in either.

It is noted that MG is often called the “snowflake disease” because it differs so much from person to person. The degree of muscle weakness and the muscles that are affected vary greatly from person to person and from time to time. One

should consult with your physician before embarking on an exercise program.

Submitted by Garry Morehouse.

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Fernanda Nascimento, St. Catherines, ON 905-937-9762

We need Telephone Support Contacts across Canada.
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Articles in the Myasthenia Gravis Society of Canada Newsletter “CONTACT” express the views of the author and are for information only, not medical advice. Patients should consult with their physician for medical treatment.

In Memory

Our heartfelt sympathy to family and friends on the loss of their loved ones. The following memoriam contributions to the Myasthenia Gravis Society of Canada are greatly appreciated.

Jill Dupuis:

Bob & Lorna Bolger
Angela Rea/Andrew Soloman
Christopher & Wendy Runions
Lisa Mollica-Daiber
*(additional donations acknowledged
in the March issue)

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Low, Murchison, Rodnoff. LLP
Edward Sojonky
Marilyn Dawson
Kenneth Peterson

Barbara Smith

Cynthia Adams

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

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Myasthenia Gravis Society of Canada “New Year- New Resolutions”

A special “Thank You” to all our MG Canada front line volunteers. There are many ways to serve our fellow Canadian Myasthenia Gravis Patients, Caregivers, Healthcare Professionals, MG researchers. It takes many people to care for our Chronic MG condition. We hope to return to in person meetings sometime this year. In the meantime, we have our new Website—www.MGCanada.org—completed in fall of 2021, Myasthenia Canada Facebook group and more. Stay safe. Thinking of volunteering? The more we have the more we can do. For info contact Cap Cowan, President and Newsletter Editor. Email: CapCowan@MGCanada.org.

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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.



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“Could it be MG?”

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