

CONQUER

News for our community

Past Proud, Future Hopeful



In 2022 Conquer MG celebrates its 50th year serving those who have myasthenia. The organization held its first patient meeting in August 1972 at the Standard Club of Chicago – with over 200 people in attendance. It was led by several MG patients and Dr. Benjamin Boshes of Northwestern Medicine. Clearly, people were hungry for information and connection. We’ve delivered on that commitment ever since – through pillars of support, education, awareness, and research.

With your support, our recent past includes research for a cure (13 studies funded since 2010 with nearly \$900,000), supporting MG patients in need (over \$100,000 paid for 150 requests since 2014), plus countless support groups, newsletters, seminars...and walks, garage sales, trivia nights, parades and cardboard boat races, too.

In the coming months you’ll see highlights of Conquer MG’s history of service, and a look ahead to new treatments and partnerships. Throughout this 50th year, as always, the focus will be on you, on your struggles and achievements as you deal with this rare autoimmune disease.

Turn to page 2 for the names of our early leaders!



FDA Approves New MG Treatment

In December 2021, the U.S. Food and Drug Administration approved Vyvgart (efgartigimod) for the treatment of generalized myasthenia gravis in adults who test positive for the anti-acetylcholine receptor (AChR) antibody.

In a clinical study of 167 MG patients, 68% of those receiving Vyvgart saw improvement with symptoms, compared to 30% who received a placebo. Although FDA approval only applies to AChR-antibody MG, the study also included smaller numbers of patients who have MuSK-antibody MG and MG patients who are seronegative (meaning they don’t test positive for AChR or MuSK antibodies). Patients in these groups also saw improvement with symptoms. Side effects of the therapy included respiratory tract infections, headache, and urinary tract infections.

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About MG

Myasthenia gravis (MG) can strike anyone at any age. MG is a highly misdiagnosed and undiagnosed autoimmune disease in which communication between nerve and muscle is impaired, causing weakness. Its primary symptoms are erratic, vary in severity and occur in any combination such as: droopy eye lid(s); double or blurred vision; weak arms, hands, neck, face, or legs; difficulty chewing, smiling, swallowing, talking; undue fatigue, difficult breathing or shallow respiration; or sense of balance difficulty. MG can masquerade as overwork, under-rest, anemia, vitamin deficiency, disease of the involved organ(s), or even emotional disturbances. Its cause is unknown; there is no cure.

Conquer Myasthenia Gravis was formed October 29, 1972, by a local group of caring individuals who wanted to help patients achieve the best possible quality of life, while living with and managing their MG. We are a volunteer-led organization.

OUR MISSION: To facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, public awareness, medical research, professional education, advocacy, and patient care.

Conquer Myasthenia Gravis
275 N. York Street, Suite 201
Elmhurst, IL 60126-2752
800.888.6208
www.myastheniagravis.org

FROM YOUR EXECUTIVE DIRECTOR

They were inspirational



So who are those folks on page 1? I had the pleasure of knowing Lorrie Schohn, the young woman in white, when she served on the Conquer MG Board in 2007. She created much of this organization's early materials about pregnancy and MG, based on her own experience. It's been a joy to learn about the kindness and care shown by Duane Seggerman (bottom left) and his wife Dorothy (not pictured) for others with MG. I've also heard about Louise Kaiser's dedication (seated, 3rd from left).

The photo was taken in 1975, and includes these members of the organization's Board and Medical Advisory Board. (L to R, standing) Paul Gilbert, Chair - 1972; Beverly Ehrke, RN; Malcolm Bowman, Chair - 1974; Elinor Benjamin; Mary Limosani; Howard Simon, MD; Richard Bulloch; Lorrie Schohn; Clayton Olson; George Wilson; Benjamin Boshes, MD. (L to R, seated) Duane Seggerman, Chair - 1978; Glenda Anthony, Chair - 1976; Louise Kaiser; Nadeanne Baumann; Louis Boshes, MD.

Volunteers are the heart of this organization – from its start to now!

Wishing you well,

Joan Wincentzen, Executive Director

Conquer MG Patient Assistance Program

This Conquer MG program will help cover the cost of medical bills, prescription drugs and durable medical equipment up to \$1,000 per person per year. We are accepting applications for 2022.

You may be eligible if you are an MG patient, reside in Illinois, Indiana, or Wisconsin, and have some kind of financial hardship. Medical costs don't have to be MG-related. Contact the MG office (800-888-6208 or info@myastheniagravis.org) for the application, or find it on our website.



Contact Update Form (PLEASE PRINT)

Mail to: Conquer MG, 275 N. York Street, Suite 201, Elmhurst, IL 60126

Name _____

Address _____

City _____ State _____ Zip _____

Email _____

- Please note the above change in my contact information.
- Please remove my name from your mailing list.
- Please send **Conquer** via e-mail instead.

Support Groups

Our groups:

- Offer information about MG and ways to cope with its symptoms
- Offer good listeners to care about your concerns
- Are open to patients and caregivers alike

GROUP	2022 DATES	TIME	NOTES
Men's Virtual MG Group	Tuesday, March 22	6:30 PM - 8:00pm CT	Led by Bob Rosecrans and neurologist Dave Randall, DO Contact us for the Zoom link.
Anywhere MG Group	2nd Tuesday of the Month: Apr 12, May 10, June 7, July 12, Aug 9, Sept 13, Oct 11, Nov 8, Dec 13	2:00 PM - 3:30 PM CT	Led by Kelly Aiken and Kathy Baer; Some meetings offer speakers, others focus on sharing concerns. Contact us for the Zoom link.
Chicago - North	Mondays/Wednesdays June 6, Sept 7, Dec 5	10:00 AM - 11:30 AM CT	Led by Linda Loland. Contact us for the Zoom link.
Chicago - South & West	Sundays May 15, Aug 14, Nov 13	1:00 PM - 2:30 PM CT	Led by Victor Yipp and Joyce Holste. Contact us for the Zoom link.
Northeast Wisconsin (an independent MG group)	Thursdays March 10, Apr 7, May 12, June 9	6:00 PM - 7:30 PM CT	Alleluia Lutheran Church; 6725 Elmro Rd, Green Bay, WI Contact leader Niki Grossheim at new4mg@gmail.com for details.
Northwest Indiana	Saturdays Quarterly Dates after March TBD	10:00 AM - 11:30 AM CT	Schererville - Dyer Library, 101 W Lincoln Hwy, Schererville, IN. Led by SeAndrea Ferguson.
Junta en Espanol - Spanish Language Meeting - Miastenia Gravis Grupo de Apoyo	Saturdays/ Sábados Mar 26, May 28, July 23, Sept 24, Nov 26	1:00PM CT 11am (pacífico), 1pm (centro), 2pm (este)	RSVP to leader Leah Gaitan-Diaz at lamgchampions@gmail.com

*Contact us at info@myastheniagravis.org (or call 800-888-6208) to receive the link and phone number to join these groups. Be sure to say which group(s) you want. At the meeting time, join via computer, tablet, or telephone.

New! Spanish Support

Leah Gaitan-Diaz got her start hosting an in-person Spanish language MG support group in California. A move to Texas showed her the need goes beyond state boundaries. Now she hosts an online group every other month. For access, you can email her directly at the email listed above.

Calendar Club Winners - 2021

May - Bill and Barb Gwodz, Julie McCracken, Sheila Mitchell, Natalie Striegel
June - Steve Malinovich, Darlene Niemczura, Anonymous (2)
July - Thomas Dammrich, Toni Martinez, Arlene Sangmeister, Clifford Zolna
August - Molly A., Marita Janzen, Darlene Perrone, Charles VanWinkle,
September - Sue Kennedy, Julie McCracken, Anonymous (2)
October - Paula Carlson, Eadie Gardner, Jim Griffith, Anonymous
November - Pat Girard, Sandra Hasemeyer, Anonymous (2)
December - Anonymous (2), Justin D., Carl D.
2021 Grand Prize (\$500) - Rita Striegel
2021 Runner Up (\$100) - Cathryn Madsen



MG Subtypes

Excerpted from a July 2021 presentation by David P. Randall, Director of Neuromuscular Neurology, Brain and Spine Institute, Advocate Medical Group, Park Ridge, Illinois

Do you know your MG “type”? The answer can point to your best treatment approaches.



During Conquer MG’s July 2021 webinar, David Randall, DO, explained how symptoms, antibodies, age at onset and other factors play a role in determining a patient’s MG subtype. Dr. Randall noted that certain antibodies associated with myasthenia gravis interrupt the normal process of how nerves communicate with muscles, which causes muscle weakness.

These factors define your MG subtype:

- Your Myasthenia Gravis Foundation of America (MGFA) Clinical Classification. A physician determines your classification by observing your symptoms.
 - o Class I - ocular symptoms only.
 - o Classes II, III, and IV - generalized symptoms (mild – moderate – severe), with subsets (A) primarily affecting limbs, and (B) primarily affecting swallowing and breathing. (That is, MG Class IIA means you have moderate generalized symptoms that primarily affect your limbs.)
 - o Class V – requires intubation (not including routine management after surgery).
- Thymoma. Is a tumor of the thymus present?
- Antibody status. Do you have any of these antibodies in your blood?
 - o Acetylcholine receptor (AChR)
 - o Muscle specific kinase protein (MuSK)
 - o LRP4 protein
 - o None (called “seronegative”)
- Age. Did your first symptoms occur before age 50 (early onset) or after age 50 (late onset)?
- Pregnancy status. This doesn’t determine your subtype, but is important to consider when choosing a course of treatment.

When this information is lined up, it can indicate what to expect with symptoms, and point to specific therapies. For instance, about 15 to 20 percent of MG patients have symptoms that remain only ocular. If symptoms don’t progress by the two-year point, most people in this group will continue to have an ocular-only diagnosis. This group is less likely to have detectable MG antibodies (50%). The initial treatment for ocular MG involves pyridostigmine. If that’s not effective, prednisone and sometimes azathioprine are added. A thymectomy (surgery to remove the thymus) is not indicated.

Dr. Randall went on to discuss each subtype and its treatments. To see the full presentation, visit Conquer MG’s YouTube channel <https://www.youtube.com/c/MyastheniagravisOrgIllinois/videos>.

Need Help?

In 2020, the Conquer MG Patient Assistance Program paid over \$15,000 in medical expenses for MG patients who are residents of Illinois, Indiana, and Wisconsin.

“I want to sincerely thank Conquer MG for accepting my application for patient assistance. I have used the money toward my home ventilator and respiratory care.” ---- A grateful recipient

The MG United Cookbook Is Here!

Created by people living with MG, for people living with MG

This limited-edition cookbook features three MG-friendly recipes created by **celebrity chef Sean Brock**,[†] who lives with MG.



Download the cookbook
at **MG-United.com** today!



Re-thinking Possibilities

for people with autoimmune diseases

At **ImmunoVant**, we are dedicated to enabling normal lives for people with autoimmune diseases. As a leader in FcRn inhibitor technology, we are boldly developing innovative therapies for a range of debilitating autoimmune diseases with significant unmet patient needs.



Explore our commitment to addressing patient needs at **[ImmunoVant.com](https://www.immunovant.com)**



Health

Recommendations for MG Patients

By (left) Madhu Soni, MD, FAAN, Associate Professor and (right) Rabia Malik, MD, Associate Professor Department of Neurological Sciences, Rush University Medical Center

Drs. Soni and Malik offer this general guidance for MG patients. Keep in mind each MG patient is unique. Be sure to consider these recommendations with your neurologist.

The source of your fatigue

Fatigue is a common symptom in myasthenia gravis, particularly later in the day. However, there may be other potential causes which, if present, require a different treatment approach. Sufficient sleep, for example, is part of the treatment regimen for myasthenia. Sleep is restorative and healthy for the immune system. Less than 7-8 hours or fragmented sleep may contribute to fatigue during the day. Awakening tired or unrefreshed, even after seven or more hours of sleep, may require evaluation for sleep apnea, the incidence of which is higher in those with neuromuscular conditions, including myasthenia gravis. Low thyroid function, inadequate nutrition from an unbalanced diet, certain medications, and depressed mood are some other potential contributors to fatigue and should be discussed with your physician.

Exercise

Although the hallmark of this disease is muscle weakness and fatigability with use, there are strong reasons to include exercise in your life if you have MG. Exercise can offer cardiovascular benefits and help with weight management; it also can help with muscle building and strengthening. You may want to exercise at a time of the day when you feel your best, which for most patients is in the morning. You might take pyridostigmine right before exercise. It may help to split your exercise regimens into shorter segments engaging different muscles. For instance, work on a stationary bike and then switch to using bands for arm strengthening.

Vaccines

Many MG patients are on immunosuppressant medication, which increases the risk of acquiring a severe illness. Vaccines against the flu, pneumonia and COVID-19 are considered safe for MG patients. We encourage you to get vaccinated to reduce the risk of MG exacerbation and crisis.

Planning pregnancy

Young sexually active women with MG who are taking

immunosuppressant medications such as mycophenolate mofetil should discuss contraception with their medical providers to avoid unplanned pregnancies. These medications may harm the development of the baby. If pregnancy is being planned, medication changes should be made carefully under the guidance of the treating neurologist.

New medications

Before starting any new prescription or over-the-counter medications, ask your provider if it could affect your myasthenia or interact with your other medications.

Bone health

Long term use of oral steroids can lead to bone thinning - osteopenia or osteoporosis. Since bone loss occurs with aging, this problem is made worse in the older MG patients and particularly in post-menopausal women. Ask your doctor if you should take calcium and vitamin D supplements. Periodic bone density scans should be obtained and an evaluation with an endocrinologist should be considered.

Becoming an MG Advocate

SeAndrea Ferguson



SeAndrea (center, surrounded by her family during the 2021 Virtual Viking Challenge) met virtually with her Senator during Rare Disease Week.

SeAndrea Ferguson of Merrillville, Indiana, teaches third grade and has led Conquer MG's Northwest Indiana MG Support Group for 10 years.

Last July, SeAndrea participated virtually in Rare Disease Week on Capitol Hill 2021, which was hosted by the Rare Disease Legislative Advocates (RDLA), a program of the EveryLife Foundation for Rare Diseases. Rare Disease Week is designed to educate and activate advocates and to foster relationships within the community. Last year's event included 600 advocates and resulted in 367 meetings with members of Congress.

SeAndrea explains, "I learned a lot about new bills they are trying to pass to help those with rare diseases. I got to meet with the Indiana Senator offices. I was able to share my (MG) story with Senator Braun (IN) which was awesome. He is a supporter of healthcare concerns so hopefully he will consider cosponsoring the new bills."

During the conference, SeAndrea learned how to prepare for a successful Hill meeting. She also heard about these bills of special importance to those with rare diseases:

- Speedy Therapy Access Today (STAT) Act of 2021 aims to accelerate development of therapies across the spectrum of rare diseases and facilitate patient access to such therapies.
- Newborn Screening Act would re-authorize and build upon the current federal newborn screening program.
- Aims to ensure patient perspectives are included in FDA benefit-risk assessments.

Through her participation, SeAndrea was able secure a \$1,000 grant from the EveryLife Foundation for Conquer MG. Thank you, SeAndrea!

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Vyvgart is the first approval of a new class of medication. It is an antibody fragment that binds to the neonatal Fc receptor (FcRn), preventing FcRn from recycling immunoglobulin G (IgG) back into the blood. The medication causes a reduction in overall levels of IgG, including the abnormal AChR antibodies that are present in myasthenia gravis.

You can learn more about Vyvgart in upcoming support group meetings, and in the Fall newsletter.

— “ —

Head up, heart open,
to better days!

- T.F. Hodge

Honoring Tracy

By Mike Shackelford



In her short tenure as Conquer MG Board Trustee, Tracy rolled up her sleeves with social media, the Viking Challenge, Wellness Committee, and represented Conquer MG at the virtual NORD conference.

Tracy Shackelford, my wife, passed away in August 2021 after a long battle with myasthenia gravis. She will be dearly missed by family and friends. She and I had nearly 30 years together (26 married), and she was a very special person. Let me share a little bit with you.

Tracy grew up in Wisconsin, mainly in the scenic La Crosse area. She was always outgoing and very intelligent. She received scholarships to the University of Wisconsin - Madison, where she got a B.S. and M.S. in Nuclear Engineering (pretty impressive stuff)! After graduating, she worked for ComEd, focusing on Nuclear Plant safety systems. After about six years there, we had a daughter, and Tracy decided she would rather focus on motherhood and all the joy that comes with raising a child. Eventually, she missed working, and studied for certification as a Nuclear Medicine Technologist (NMT), to work on PET-CT scanners. It amazed me how much one had to learn to get certified in this; no small accomplishment. She loved this job very much as she was able to help people, and she was very good at this.

While working as a NMT, the signs that she had MG appeared. First it was just a problem with vision in one eye, and over time evolved into full body weakness. Tracy was rightfully upset when she had to resign as an NMT, a job which truly brought her joy. Simple things like taking the dog for a walk, a bike ride, climbing stairs, and eventually even having the strength to brush her teeth became a daily challenge.



Tracy had great MG doctors at the University of Illinois - Chicago. She tried many types of medications and treatments, but nothing really seemed to work. Through all of the drugs, tests, and procedures that she endured, she always would try to maintain a positive attitude. The nurses loved to be with her. Tracy would also love to bake cookies or muffins when she had moments of strength to bring in to the nurse staff. Again, she was always thinking of others.

Tracy was active in the MG community. She was always giving advice in MG Facebook groups, or just being a friend to somebody who needed a boost. Additionally, we would attend several MG walks in the Chicago suburbs, which was a great way to meet people in person with similar stories and contribute to the cause. In 2020, she saw an opportunity to join Conquer MG as a member of the board, focusing on social media activities. She really loved her job and it made her very proud to contribute to this organization.

The loss of Tracy has created a hole in the lives of anybody that knew her. She was a kind spirit, always giving help and love to others. She was a fighter as are so many who suffer with MG. She never gave up hope though. Someday there will be cures or treatments which really impact quality of life for people with MG. It's important for us to all give to this cause so that can be a reality for the future, and talk with your friends about this disease, as it is not very well known to the public.

My MG Story

By Genevieve Costello



Genevieve's experience with chronic illness triggered a cascade of difficult situations. It takes resilience to persevere.

At 24 I was in my second year of grad school the night I realized I couldn't read my class notes properly. Lines doubled and danced on the page. My right eye felt funny. Did I have a brain tumor? The University doctor diagnosed eye strain and changed my contacts to bifocal glasses and sent me on my way. But I was feeling different somehow. A bit clumsy, bumping into things. No pain, just weird.

In the next few years I moved abroad to teach, had some professional successes, and traveled a bit. But I would go through my days fine in the morning, with my vision doubling at some point in the afternoon—usually still in the classroom, which wasn't ideal. This was the 1980s, and diagnostic exams for myasthenia were only based on clinical observation. I was eventually sent to an ocular 'therapist' who put me through exercises aimed at training lazy eyes— which of course made me worse. I lived with chronic headaches and my eyes hurt.

In France, I married and had a baby. After her birth I developed pronounced weakness in my left

leg and foot. In the morning I could bike 10 km, but after lunch I couldn't lift my leg up to a single step of our staircase. I started bumping into the narrow doorways of our home – always to the right. My doctor ran CT scans looking for a brain tumor and spoke to me about MS. I was scared and angry.

Eventually divorcing, I returned to the States with my jumble of unusual symptoms. My family called me psychosomatic. My daughter's father and I had split custody, but she was with me for the academic year. I started substitute teaching while back in school for a double master's in education. I had to tape lectures, since I couldn't hold a pen to take notes by the end of the day. I couldn't get any accommodations at DePaul initially because I had no diagnosis. There were nights I would sit in class just concentrating on my right hand, instead of the lectures. I would tell myself that I could certainly hold a pen and write if I just put my mind to it. This is true myasthenic thinking – mind over matter – problem was, I couldn't.

I was eventually diagnosed because of two falls in four

months for which I wound up in the ER. I had the same doctor the second time, and he walked me through the episodes very clearly and gave me my first "neuro test". Ignorance being bliss, I didn't think twice about the fact that he arranged a neuro appointment for me the very next day. And that the neurologist arranged a neuro ophthalmology appointment for me the next day after that.

The neuro op examined me for an hour, but when he gave me a shot of Tensilon and had me read the chart quickly I could read another four lines further and realized I was seeing clearer than I had for years. My blood test came back positive for MG titers, but all I remember from my eventual diagnostic report was the word incurable. This was the late nineties – no computer to run home to for hours of online research. Just a pamphlet and a script for Mestinon.

Mestinon made me stronger, but never helped my eye muscles. A year later they found a large mass on my thymus. I celebrated the first month of the new millennium in the hospital for three weeks for a thymectomy and post-op complications.

[continued next page](#)

My neurologist told me I would likely go into remission now, but it never happened. In fact, I got worse and developed bulbar MG. A public-school teacher now, and struggling with my responsibilities. I was started on cyclosporin and 100mg/day of prednisone. I stopped sleeping for the better part of a month, was jittery, high strung, emotional – not who you really want in a high school classroom, and my fingers and toes constantly burned.

Due to the side effects, I was switched to Imuran with the prednisone and Mestinon. A psychiatrist finally wrote prescriptions for sleeping medication and anti-anxiety meds. I was more regulated. In second grade my daughter Madeleine learned to pull a chair up to the sink and stand on it to do dishes after supper, when my standing was weak at day's end. Some weekends needed "Maman rest" days where we would cuddle up together on my bed to watch TV or she would read to me, while I recovered from the week and geared up for the next one. Or when I was recovering from plasmapheresis, which gave me more infections than relief.

Throughout my daughter's grade school years she had many sleepovers at friend's homes when I was "not well". I had to take my 10 sick days plus more unpaid ones every year, usually during flu and bronchitis season. My students would come to school sick... which sent me to the neuro ICU on many occasions. My immunity issues became more problematic at school, and I eventually collapsed with UTI sepsis one day and was discovered on the floor of my classroom by a security guard. Paramedics wheeling you down a school hallway at lunchtime makes one infamous!

In 12 years of ultra-high dose

prednisone I had gained 110 pounds, developed Cushing's syndrome and steroid-induced diabetes and cataracts. I was 42 years old and felt like I was 100. When I finally switched my medical care to Northwestern Memorial Hospital I was blessed to come across an amazing neurologist who redid all of my tests. He finally broke it to me that I had multiple suspect masses still in my chest, and that a new trans-sternal thymectomy was recommended. I had my 2nd thymectomy during summer break, with my daughter at her father's for the vacation. While my original tumor had been removed, my thymus had broken into parts and migrated throughout my chest and up into my neck- explaining why I had



never gone into remission.

I was switched from plex to IVIG as a treatment protocol, and for years IVIG has provided great generalized benefit with low side effects.

In 2011 I had two deep vein thrombosis (DVT) and a stroke, and my teaching career was over.

The transition from a 55-hour work week to disability with increasing hospitalizations and public aid convalescent home stays, almost drove me to suicide. I felt worthless, a burden on society and a future one to my daughter. I couldn't practice my art, couldn't

read my beloved books even with my prism glasses, because my vision doubled so easily. A few very dear friends made it through that period with me.

My Mestinon had to be discontinued a few years ago after colon surgery. Mestinon and a shortened colon are incompatible.

Due to recent surgery my prednisone is very low, which means that my Cushing's and steroid-induced diabetes have both corrected themselves. I have IVIG every 3 weeks and rituximab every 4-5 months. But I am symptomatic again. I've been working closely with a dietitian at the hospital on my weight loss, which is much easier on low dose steroids. I organize my day and my weeks based on where my strength is in my infusion cycle, and what the weather is, which seems to affect me strongly.

I recently spent time in San Francisco with my daughter and her fiancé. Madeleine carried my walker across planks on a creek and helped drag it through the redwoods just so I could experience places that I love. With my trusty rolling walker, I can conquer mountains!

I have become adaptable. I am resilient. I am often not in control of what my body chooses to do, and that is living with myasthenia.



Using Nutrition and Lifestyle to Balance the Immune System

By Danka Lekovic, Personal Trainer and Nutritionist

When you have myasthenia gravis, your immune system is in overdrive, creating antibodies that disrupt your nerve-to-muscle communication. Over time, taking care of yourself with proper nutrition, movement, sleep, and stress management can make a big difference in managing your MG symptoms. In May 2021, certified nutrition coach Danka Lekovic discussed ways to better balance one's immune system.

Lekovic explained:

- The immune system has a wide variety of functions including protecting our bodies from foreign invaders and toxins. The immune system is made up of organs and cells that require proper nutrition to do these jobs.
 - Having a healthy gut microbiome helps your immune system work better, which can better manage autoimmune disease.
- How do you get a healthy gut microbiome?
- Eat a diet rich in whole, unprocessed foods that includes quality protein, high fiber, fruits and vegetables in a variety of colors, whole grains and healthy fats.

- Say “yes” to foods that are unprocessed or minimally processed, and that are as close as possible to their natural state.
- Say “no” to ultra-processed foods that incorporate added salt, sweeteners, and fat, or that add artificial colors, flavors or preservatives – even though these foods are made to be “highly palatable” – especially tasty and tempting!
- Read nutrition labels. Look for fewer chemicals and less sugar.



Let's compare two yogurt products. The Fage yogurt lists skimmed milk and live active yogurt cultures, while the Yoplait lists 13 ingredients. The Fage yogurt contains 5 g carbs (low) and 18 g protein (high), compared with Yoplait's 26g of sugars (high) and 5 g of protein (low). The Fage yogurt will keep you full longer, and won't confuse your gut with non-food ingredients.

Other pointers

- Eat probiotic-rich foods such as unsweetened yogurt, cottage

cheese, or kefir, sauerkraut or kimchi, tempeh, miso, kombucha, and oil-cured olives.



- Vitamins A, C, D, B6, folate, and B12, along with copper, iron, selenium, and zinc have all been associated with helping immune function. A balanced diet supplies these in adequate quantities for most people.
- Eliminating toxins from your body keeps your gut barrier function healthy. That's why plenty of fiber (oh, those vegetables and fruits!) and water is so good for you. Plus they keep you full longer.

A healthy lifestyle goes beyond the food you eat. Your immune system benefits when you move (to the extent you're able), spend time in nature, meditate, and socialize. All these things help your immune system work smarter, not harder.

2022 Viking Challenge: In Person and Virtual

This year Conquer MG's Viking Challenge to raise MG awareness and funds will take place virtually and in person. The virtual event runs June 4-19. We'll cap this off with the in-person Viking Walk/Run - and celebrate our 50th Anniversary - on Sunday, June 19, at Berens Park in Elmhurst, Illinois. Watch for details!



Seven Suggestions for Staying Motivated

By Maria Zepeda, NBC-HwC

“Momma said there would be days like this...” and unfortunately for us there are more often days like THIS! I feel like that tune plays way too often in my head. Can you relate? Other than singing it out, which is a great way to feel better instantly, how else can we get past and stay motivated despite however we are feeling on any given day? Regardless of where you are or what you are seeking motivation for there will be some days when it’s extremely difficult to get going. So what to do about it? Here are seven ways that I use to help me out. Feel free to borrow, try one on for size or all!



- 1. Maintain perspective.** Some days we will be able to do more than others and it’s important to remember that when we are dealing with a flare-up. An easy way to be reminded is to keep a picture where you are having fun, or even better doing an activity that you can look forward to getting to when you are back to baseline.
- 2. Be flexible and go for the easy win.** If you normally are able to walk a mile or two, then on the not so good days or when you are feeling symptomatic, half of that is better than ok! Rather than feeling bad because you are yet again having symptoms, feel good about doing a mile or whatever you can get in.
- 3. No more BUTS.** If you find yourself thinking I wish I could go for a walk today but I am having a flare-up, simply rephrase: I am having a flare-up and I am still going for a walk even if it’s just for ten minutes.
- 4. Make me laugh!** Laughter is the great healer! Find your own make me laugh lifeline person, a joke or a movie clip, something comedic that’s guaranteed to have you cracking up. Not only will it distract you but it will help release stress and boost your mood! Laugh it up!
- 5. Let it go, let it go, let it go.** When you are feeling sad or unmotivated, rather than ignoring or suppressing your emotions acknowledge them. Try, yes I am stressed because I am having symptoms yes I am stressed because I am feeling fatigued. Then let it go. There is power in acknowledging that you are not feeling great that allows you to feel better instantly.
- 6. Take a time out - in a good way.** When you are feeling sad, unmotivated or upset, give yourself an allotted time to sit with it and then move on. If you need 10 minutes, an hour, or the whole day, give yourself the time and then plan on going back to your routine and commitments.
- 7. Dance or sing it out.** Just like laughing helps so does singing or dancing to your favorite song. It will serve as a distraction but it will also help lighten your mood.



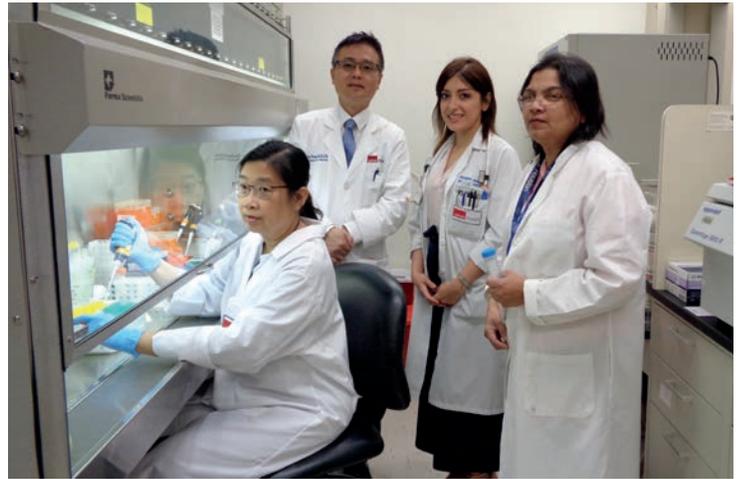
“Myasthenia Gravis: Finding Strength One Day at a Time:

Sarah Bolton is working with Conquer MG to create a video interview series with MG patients. The first interview features Garry Morehouse, who learned to regain his strength slowly but surely. This series will be posted on the Conquer Myasthenia Gravis YouTube channel.



HDACs May be Another Target for Therapy

An update from Conquer MG Pilot Grant recipient
Ruksana Huda, PhD



Conquer MG's 2019 Pilot Project grant (\$66,000) was awarded to scientists Ruksana Huda, PhD, and Xiang Fang, MD, PhD, University of Texas Medical Branch at Galveston. Despite COVID challenges, they and their team persisted.

Results of their study were published in the February 10, 2022 issue of *Frontiers in Neurology* in the article "Histone Deacetylase Isoforms Differentially Modulate Inflammatory and Autoantibody Responses in a Mouse Model of Myasthenia Gravis."

Professor Huda explained, "Many diseases, including autoimmune diseases, are caused by improper regulation of proteins, the essential components of cells in our bodies. Our study shows that MG and a mouse model of MG

contain abnormally high levels of a group of proteins called HDACs or histone deacetylases. When natural inhibitors blocked these proteins, an already established inflammatory protein (interleukin 6, IL-6) and many other autoimmune-associated harmful proteins were reduced. In mice with MG, some natural inhibitors of HDAC proteins also reduced autoantibody levels and improved muscle strength. These HDAC proteins or other damaging proteins identified in this study might also be good targets/candidates for the treatment of MG.

More Research News

A number of **new therapies** are moving through clinical trials. Positive results have been

announced from Phase 2 and Phase 3 trials for rozanolixizumab (UCB), zilucoplan (UCB), batoclimab (Immunovant), and ravulizumab (Alexion), to name a few.

Links between the gut microbiome and myasthenia gravis are being explored. Results of the study "Modulation of immune responses by bile acid receptor agonists in myasthenia gravis," supported by a grant from Conquer MG, were published in the September 18, 2020 issue of the *Journal of Neuroimmunology*. Contributing authors Betty Soliven, MD, and Kourosh Rezania, MD, University of Chicago, are members of Conquer MG's Medical Advisory Board. Study results point to Takeda G protein-coupled receptor 5 (TGR5) as a potential therapeutic target in myasthenia.



The Myasthenia Gravis Exercise Group

Did you know Conquer MG hosts this Facebook Group? Its aim is to encourage and motivate folks who have myasthenia gravis, as they pursue exercise to regain conditioning. Participants describe journeys from baby steps to uphill hikes, weightlifting, ice skating, and pickleball (thanks, Garry!). You'll find simple videos to follow for posture and stamina (thanks, Gigi!). Find the group online at [Facebook.com/groups/MGandexercise](https://www.facebook.com/groups/MGandexercise)

Keep in mind, if you are short of breath or have swallowing difficulty with exertion, or are experiencing worsening MG symptoms, then it is NOT the time to start an exercise program. If you're in doubt, talk to your neurologist. Although there are normal fluctuations with MG, and every day is different, if your MG is stable, then exercise can be part of your recovery.

In Appreciation

WE ARE GRATEFUL for everyone who supports Conquer MG's mission between May 1, 2021 and January 31, 2021. These donors recognized a loved one through their support.

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Upcoming Events

MONTHLY - 2ND TUESDAY

**Anywhere Virtual Support
Group Meeting**

JUNE 4-19

Viking Challenge

**This event will be both Virtual
and In-Person!**

ON YOUTUBE

**Myasthenia Gravis: Finding
Strength One Day at a Time**
