

FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Summer 2024



Summer Edition Highlights:

MG Walks are Back!

3 walks in 2024

MG Patient Data

MGFA sees important outcomes from new MG patient data in registry

MG Awareness Month

Patients and caregivers take action

Community Events

Conferences, roundtable, health fairs

MG Research

Learn about current MG research

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient.

FROM THE DESK OF THE CEO

Dear Friends,

Each time I write the letter for the next Focus on MG edition, I cannot believe how fast the months go by. Here we are half-way through the year and there is *so much* to share and, certainly, to be grateful for. On behalf of our team at the MGFA, and our Board of Directors, it is such an honor and a privilege to serve you, our MG Community members. We appreciate your ongoing collaboration and support. Together we are MG Strong(er)!

It was a very busy spring filled with growth, new beginnings, and continued evolution here at the organization. Below are some of the highlights from recent months.

- MGFA **launched a new three-year strategic plan** that includes outcomes around increased patient services and programs, Centers of Excellence to encourage innovative research, and increased sustainable revenue, with an overarching theme of globalization as we continue to expand our global footprint;
- MGFA hosted its **Annual Patient Conference with record breaking attendance** in Tampa at the end of April. Approximately 1,000 MG Community members registered across both in-person and virtual participation around the world;
- MGFA is **executing a game-changing strategic initiative to translate a number of key resources**, including our website, support materials, and our MGFA Online Community into a variety of languages;
- MGFA **will launch the MGFA Patient Helpline** to ensure that our most vulnerable community members can receive the assistance that they need and be directed to critical resources through the help of trained professionals;
- MGFA **expanded our Community Health Fairs program** and will host 11 across the country this year...we are half-way through our fairs already;
- MGFA **re-introduced our MG Walk program** and will have walks in Boston, New York, and Tampa this year. After being on hiatus since the pandemic, this was a welcome addition to our event portfolio and well received by the Community...like welcoming back an old friend;
- MGFA continues to **leverage technology** through our MyMG Mobile app, the MGFA Online Community, and our MGFA Global MG Patient Registry. This spring we opened the Pediatric Center in our Online Community, and we just recently opened the International Center!
- MGFA **expanded its grants program by adding a third funding cycle** which offers grants specifically for our MGFA Global MG Patient Registry...if you are an MG patient and have not yet shared your data in our registry, we encourage you to do so...patient reported data is the *most unique perspective* we can offer to research;
- Finally, **MGFA kicked-off MG Awareness Month** in June and we have so many exciting ways for our Community to engage and participate...visit our website to learn more!

It has been a very busy time for all of us! We simply could not share achievements like the above without your collaboration, *participation*, and dedication to our collective vision....

A World Without MG. *Thank you.*

Sincerely,

Samantha Masterson
President and CEO



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If you or someone you know is experiencing sudden or gradually increasing symptoms of muscle weakness, it could be a sign of MG or another serious condition. Talk to your doctor if you are short of breath, have difficulty smiling, talking or swallowing, or cannot walk any distance without having to rest.



MGFA FUNDS GROUNDBREAKING MG RESEARCH

In January, the MGFA announced our latest grant recipients. Three researchers were selected as part of the 2023 grant award cycle.



Ryan Hibbs, PhD
University of
California, San Diego



Ricardo Maselli, MD
University of
California, Davis



Xin-Ming Shen, PhD
Mayo Clinic in
Rochester, Minnesota

Their work represents an exciting step forward in our understanding of myasthenia gravis and congenital myasthenic syndromes.

In this grant cycle, the MGFA expanded the eligibility criteria to accept letters of intent and applications globally, leading to more robust and exciting project and collaboration possibilities from diverse perspectives.

“We’re very happy that expanding the award criteria brought in outside perspectives to MG research, including researchers who are diving into the structural biology of the acetylcholine receptor and into the potential genetic components and implications of CMS,” Kevin O’Connor, PhD, chief scientific advisor to the MGFA, said. “These projects are working to fill gaps in our current understanding of MG and are bringing in scientists and scientific fields that have not previously been in the conversation.”

MGFA offers several different funding opportunities through its grants award program. In the fall 2023 cycle, MGFA funded one Nancy Law Impact Award and two High Impact Pilot Project Awards.

Recipients were selected from a record number of applicants representing scientists in Canada, Italy, Germany, Portugal, the Netherlands, Sweden, and the United States.

The research grants program at the MGFA grew exponentially in 2023. MGFA more than doubled the amount of funding offered. In addition, the grant review process was aligned with NIH standards.

“We brought our policies and procedure for application, scoring, and review into alignment with the standards of the NIH, and convened a study section of expert reviewers to ensure that MGFA funds contribute to the most meritorious research projects,” said Samantha Masterson, president and CEO of the MGFA.

MGFA’s grants program is part of the organization’s mission to enhance lives and improve care through scientific discovery.

Since its inception in 1952, the MGFA has led the charge to support the most promising scientific endeavors — funding research, engaging young scientists and clinicians, and spearheading a comprehensive patient registry. Research has led to significant improvements in diagnostic techniques, treatments and therapies, and improved disease management.

Contribute Directly to Groundbreaking MG Research

Enroll in the MGFA Global MG Patient Registry - Powered by Health Storylines

Myasthenia gravis affects fewer than 1% of people in the United States. There are many unknowns and questions about MG, and we do not have enough information about the disease to close those gaps. But one way to find answers is through research that uses patient-reported data in the MGFA Global MG Patient Registry to discover and support treatments that could greatly improve life for those living with the disease.

What is the MGFA Global Registry?

The registry is a longitudinal, ongoing study that is truly inclusive and open to all adults (over 18) diagnosed with MG. People with generalized or ocular myasthenia gravis and any antibody status (AChR, MuSK, LRP4, or seronegative) are eligible to participate. This ongoing MGFA research study will not exclude certain patients like other studies.

It is also one of the largest collection of myasthenia gravis patient-reported data and information, and represents an important way for patients to share their experience and perspective about their disease with the medical community. MG patients from around the world can privately, safely, confidentially, and securely enter their data, which is protected as part of a HIPPA-compliant, secure database.

Why Participate in the Registry?

Because it could get us closer to a world without MG. When you enroll in the MGFA Global MG Patient Registry, you now have a loud voice – you will be empowered by directly helping the MG Community.

MG patients are the real experts of their disease. For that reason, patient-reported data is the most valuable perspective on the disease and will help researchers discover new treatments and ways to manage MG.

“We understand how MG impacts our bodies more than anyone else. Sometimes we feel ignored or not heard by those around us, but by adding our data to the registry, we are helping guide new research and discoveries that could change the course of MG in the near future.”

- Kathi Timothy, MGFA Outreach Coordinator

How Can Participation in the Registry Benefit Me?

You will contribute valuable information to the medical and research community, as well as gain access to a large library of health-tracking tools through the Health Storylines registry app. The registry collects data through standardized surveys every six months, as well as through the more frequent use of the health tools within Health Storylines.

You can take advantage of these tools to manage your MG all year round by tracking your medication, symptoms, mood, and more. You will have full access to your health data in the form of reports that you can use to help you make informed decisions about your health. The registry data made available to researchers is always anonymous and aggregated so no one can attribute your data directly to you.

You have two options to join and enter MG patient data:

Option #1: Visit the Online Registration Form and Survey at MGRegistry.org. Add patient data from your laptop, PC, or tablet through a web browser.

Option #2: Download the Health Storylines app for your Apple or Android device. You can enter data right from your phone.

If have any questions about the Global MG Patient Registry, please email the MGFA team at mgfa@myasthenia.org.

Tools are available in the **Health Storylines mobile app** to help you manage your MG.



Scan to visit mgregistry.org



MGFA hosted our National Patient Conference this year in Tampa, Florida from April 28 – 30, 2024.

The annual National Patient Conference is an incredible opportunity for the MG Community to connect and learn. Over a thousand people registered to join us either in person or virtually. Each year we hear from MG experts, learn about exciting new research, discuss MG management, and connect with each other.

There has been so much momentum in the MG space in terms of treatment development recently; the atmosphere at the conference was positive and full of hope.

watch sessions



SAVE THE DATE: Next year's National Patient Conference takes place March 23 – 25 in Phoenix, Arizona.

CONGRATULATIONS to Our 2024 Volunteer Award Recipients





MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT



Our free Community Health Fairs are designed to help you and your loved ones navigate MG. This year we are visiting **11 different cities**. Join us at one of our remaining fairs in 2024! RSVP at myasthenia.org/Community-Health-Fairs.

- Each event includes educational presentations led by MG experts, followed by lunch and a chance to visit exhibitors at your own pace.
- Hear from and talk with medical professionals, access educational and wellness resources, and meet others in the MG community.
- Connect with each other, share stories and guidance, and learn more about managing this disease.

2024 MGFA Community Health Fairs

9-7-24 Greater DMV

9-14-24 Chicago

9-14-24 Seattle

10-12-24 Houston

11-2-24 Tampa Bay Area

Register here



Catch Up With the MG Community

Learn more and share your story on our website, Instagram, Facebook, X, LinkedIn, and YouTube.

www.myasthenia.org



YouTube





MG Walks Are Back!



After a four-year hiatus, we're thrilled to bring the MG Walk program back. The MG Walk is an amazing day of fellowship and fundraising. When we come together, we create a powerful force for good. MG Walks raise critical funds for MG research, as well as education and support resources for those affected by MG.

Whether you start a team, register as an individual, or donate to a friend, you are supporting an incredible cause. We're closer than ever to a world without MG. But to get there, we need you.

Register today at myasthenia.org/MGwalk and join us at one of our remaining walks this year.

Register here



2024 MGWalk Schedule

BOSTON
MAY 18

NYC
SEPT. 21

TAMPA
NOV. 2





MGFA Convenes First Stakeholder Roundtable Series Meeting in Boston

This April, MGFA hosted the first in a series of roundtable meetings in Boston that brought together leading industry companies, medical and research professionals, MG patients, and several of the most influential MG experts across the MG Community. The first-ever Stakeholder Roundtable Series meeting provided an opportunity for attendees to share collective vision, intellect, and resources, with a focus on improving quality of patient care for those diagnosed with myasthenia gravis. The event was moderated by Dr. Pushpa Narayanaswami of Beth Israel Deaconess Center / Harvard Medical Center. The roundtable produced important discussions and new collaborative opportunities to build patient educational materials. More to come as we will host another roundtable in the fall.



MG Patients Appointed as Volunteer Community Ambassadors

The MGFA Ambassador Program is an initiative that seeks to increase engagement, embrace the patient perspective, and foster meaningful relationships between the MGFA and those within the MG community. This new program will ensure the MGFA is amplifying the patient voice throughout organizational endeavors and working to forge stronger bonds that enable the organization to make a lasting impact and improve the quality of life of those living with MG.

MGFA Ambassadors are passionate members of the MG Community who have demonstrated their commitment to the MGFA mission and their desire to grow with the organization to create the greatest impact in the lives of those touched by myasthenia gravis. Ambassadors are champions of the MGFA mission who have been called to share not only their personal journeys with MG but also offer their critical insight to raise awareness, expand education, inform advocacy work, increase support, and promote the value of clinical research.

These inspiring ambassadors will:

- Represent the organization and advance the MGFA mission.
- Collaborate with the MGFA team by actively participating in fundamental projects guided by the organization's strategic plan.
- Drive community participation and articulate the value of MGFA's programs, services, and events.
- Demonstrate what it takes to be an exemplary volunteer and encourage community members to utilize their voice by engaging with the MGFA.

Learn more about our Ambassadors at myasthenia.org/Support-the-MG-Community/Volunteer.





DARE to CARE, our signature fundraising event, is back!



This June, **DARE** your friends and family to **CARE** about making a difference for people with myasthenia gravis.

Challenge them to help you meet your fundraising goal during the 30 days of MG Awareness Month. Each gift supports the Myasthenia Gravis Foundation of America's ongoing mission of creating connections, enhancing lives, improving care, and finding better treatments for MG.

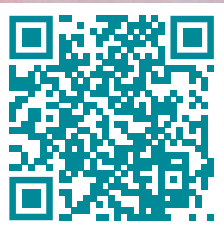
When you join this community fundraising challenge, you help the MGFA:

- Create and share much-needed educational resources.
- Fund cutting-edge research to make life better for those living with MG.
- Raise awareness and advocate on behalf of patients around the world.
- Provide support to patients and caregivers through programs like the MGFA Community Health Fairs, MG Friends, Support Groups, and the MGFA National Patient Conference.

Joining is as easy as creating a fundraising page and sharing it with your friends and family.

Visit myasthenia.org/Dare-to-Care to sign up and see this year's fundraising prizes! Join any time during the month of June.

Register here



*To discuss other ways
to give, contact Tasha Duncan
at TDuncan@myasthenia.org*



Thousands of people worldwide come together to raise awareness of myasthenia gravis in June each year.

We share what it's like to live with this rare disease, what challenges and obstacles we face, what hopes we have for the future of MG care, and how we stay #MGStrong!

Last year, our content reached **over a million people** around the world! That doesn't include all the activity YOU lead on social media and in your local communities.

EASY WAYS

TO TAKE ACTION DURING MG AWARENESS MONTH



Raise your voice! Share facts about MG or tell your own unique story on social media.



Show your teal. Wear your MG Warrior gear, put up a yard side (download a template on our website), or use your MGFA tote bag. Then be ready to answer questions (download an MG fact sheet to help).



Share educational materials. Educating your local firehouse, police station, dentist office, or emergency department staff could make a difference for a person with MG in the future. Email mgfa@myasthenia.org to request brochures.

UPLOAD PHOTOS, VIDEOS, AND NOTES TO OUR MG AWARENESS BOARD



Your outreach, willingness to tell your stories, and determination to make a difference make this campaign a success every year. You are MG Awareness Month's most important participants! Let the MG Community know what you've done this month! Share on our new awareness board, accessible from our website.

Find all this info and more at myasthenia.org



My plan for MG Awareness month is to give hope to others, especially younger people, who have recently been diagnosed or who are dealing with MG. As someone who was diagnosed 14 years ago at the age of seven, living life in remission is something I never thought would happen.

- Aiden Gonzalez, New York City

Looking to connect with others in the generalized myasthenia gravis (gMG) community?



Making Connections

Education and support for
generalized myasthenia gravis

Register for a free webinar
or in-person event at the
link below*



Register at AlexionMGEvents.com

Based on the event you'd like to attend, you could receive information about one or more of the following:



Disease education
from a physician



Stories from people
living with gMG



Tips for managing
symptoms

*These events are open to gMG patients and caregivers in the United States.

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Remembering the Incomparable Tom Larsen

The Rocket Man

By Kate Stober

MGFA and the MG Community lost a dedicated volunteer and champion advocate when our friend Tom Larsen passed away on February 1, 2024 at the age of 82.

Tom was an enthusiastic and long-time volunteer with the MGFA. We recognized Tom in 2022 as Volunteer of the Year and, in 2014, we featured and recognized him for his exceptional fundraising efforts. He was also awarded the 2024 Impact Award posthumously.

He enthusiastically participated in the MG Walk in the Washington, D.C. metro area, rallying his friends and family for support and cheering on other participants in their fundraising efforts. His team, “Tom’s Rockets – Blast Off for the Cure!,” was consistently a top fundraising team every year.

“Tom’s enthusiasm for fundraising for the MGFA was contagious. He was so proud of his walk team and of the fact that he was the ‘rocket man’ (he was an actual rocket scientist!),” shared Dova Levin, MGFA’s national senior director for educational and patient programming.

Tom spent 22 years in active duty as an Air Force officer, followed by 26 years as a defense consultant in Washington, D.C. He received his PhD in aerospace engineering from Purdue University. His long and interesting career solving problems for the military certainly set the stage for his next chapter as an “MG problem-solver.”

He was diagnosed with MG in the early 2000s. Like many others, he turned this life-changing diagnosis into an opportunity to help others and support the MGFA’s vision of A World Without MG.

“Tom was incredible with the MG Community,” said MGFA National Director Genna Mvalo, who got to know Tom several years ago. “He was always up for an MG Friend call, spreading encouragement to newly diagnosed MGers, and happy to advocate for others. I will miss teaming up with Tom and his great sense of humor!”

Anita Steele, who has run the Manassas Virginia MG Support Group since 1998, remembered how



Tom stepped in to help run the group during the pandemic.

“As the pandemic hit and our group could no longer meet in person, he kept it going with Zoom meetings, when I was unable,” she said. “He assumed the leader position without taking credit for doing so.”

Anita got to know Tom well over the years and deeply appreciated his friendship and leadership.

“I met Tom when he joined our Northern Virginia (later renamed Manassas) MG support group. He was instantly engaging. He became a constant. He was someone you could count on to be there when you needed him. He became my co-leader. His focus on education and helping others locate resources to help them manage MG was endless. He was always available to take phone calls, and his compassion was evident in all that he said and did.

“He tirelessly fundraised, often sitting outside any store that would allow him to do so for hours and hours in order to meet and educate people and raise money for MG.

“But above and beyond all he did for MG awareness, he became a friend. He was caring, concerned, dedicated, and selfless. His drive to help others was endless, and he often did so when he was not feeling well himself.

“Our Manassas group, our MG community, and all of us fortunate to call him a friend have lost a champion. Not just of people with MG, but of how to be a kind, good, and decent human being.”

Tom’s family plans to continue his legacy of support for the MG Community and the MGFA. We are forever grateful for his friendship and partnership, his support and commitment to fighting MG, and his great sense of humor.



GETTING MY SMILE BACK

A new mom faced challenging and confusing medical symptoms



By Hannah Ensor

A few months before I had my daughter in the summer of 2021, I started noticing facial weakness. I was unable to smile for extended periods of time, had difficulty chewing, and even had difficulty drinking out of a straw.

I didn't realize how abnormal this was until about a week after giving birth, when I noticed my speech slurring. All my previous symptoms began to worsen as well.

This was the start of a long journey involving multiple doctors, tests, bloodwork, and a deep fear that I would never find out what was wrong and why my body would not cooperate. All of this was going on in the background of my maternity leave and return to work, while also adjusting to being a mom.

For the entire month of October 2021, I feared I had MS, as the neurologist wanted to rule that out. I had numerous tests, MRIs, and about a gallon of blood drawn. We learned I thankfully did not have MS, but we still didn't know what it was.

Without a doubt, not being able to consistently smile was the most difficult for me emotionally. In countless pictures I look like I am grimacing, despite my best attempts to smile.

All my symptoms were intermittent but happened almost every day for months.

Multiple medical practitioners told me it was likely stress. One mentioned long Covid. Several mentioned postpartum hormone shifts. No one really knew. In December, my neurologist said to track my symptoms and come back in three months, but shortly afterwards things started to take a turn for the worse.

Over Christmas break I developed hand and finger weakness. Once again, I was told not to worry. A couple of weeks after that, I caught Covid for the second time despite being fully vaccinated and boosted. The week I had Covid I noticed blurred

vision, increased hand and finger weakness, continued issues with facial weakness, and arm weakness.

I kicked my research into overdrive, reading medical articles and scouring websites to try to find an answer. The weakness began to worsen and spread beyond my wrists and fingers.

I concluded that the only illness that checked all the boxes was an incredibly rare autoimmune disease called myasthenia gravis (MG).

I contacted my primary care office and practically begged for an antibody test to rule out MG. She ordered the bloodwork, and I went a full anxious six days waiting for the results. The night before my follow up with the neurologist I got the bloodwork back... And it was astonishingly high for AChR binding antibodies – the most common antibody found in myasthenia gravis.

I took the bloodwork back to my neurologist, and he started a whole workup to either rule out or confirm MG. Part of that workup included starting a medication called Mestinon. He explained that if the medicine works, I have MG. Within hours of starting Mestinon, I noticed an improvement. The two weeks that followed were like night and day to my previous eight months of symptoms.

In March 2022 I was formally diagnosed with generalized myasthenia gravis.

This is me and shows the impact MG has. The image on the left is from a week before my initial MG bloodwork came back. I had just eaten dinner, and we wanted to take some pictures on the pier during the sunset. I tried so hard to smile... And no matter what
(continued on page 14)





I did, my facial muscles just wouldn't cooperate. I was so devastated – the picture was beautiful, but I looked so unhappy. My muscles were not allowing me to convey my real emotions.

The picture on the right was the day after I started medication to treat the symptoms of MG. I was able to eat a meal without difficulty, drink through a straw, not slur my speech, and smile effortlessly. It was the most hopeful I had been in months.

The two main takeaways I have from this diagnosis journey are:

- 1. Advocate for your health.** Don't take no for an answer. If you think something is wrong, you're probably right. Don't give up and don't be afraid to research it yourself. Myasthenia gravis takes on average two to three years to get diagnosed. Other autoimmune diseases can take even longer (on average, four-ish years!). If I hadn't done my own research, it could have been years before I was able to get treatment.
- 2. Everyone has struggles going on behind the scenes.** You may not see these on social media or in daily interactions. We are all navigating this life and doing the best we can. Be kind to each other.

I had a thymectomy in April 2022 and am currently on a few different medications for my MG. I still deal with fatigue and muscle weakness, but I am so happy to finally be getting treatment for my symptoms.



Since my diagnosis, I have given back to the MG community through volunteering with the Myasthenia Gravis Foundation of America to ensure that no one else suffers without a diagnosis or treatment. I also actively work to bring awareness to MG, including sharing my story with colleagues so they understand what it's like to live and work with this disease.

I don't know what the road ahead looks like, but I am so thankful to my friends and family who are supporting me during this journey!

Is It Safe to Exercise with Myasthenia Gravis?

By Nick Mo

The information provided here is for educational purposes only and does not substitute for professional medical advice. The content reflects the unique experiences of the author and is not necessarily the opinion, views, or recommendations of the MGFA. Please consult with your doctor and healthcare professionals for specific recommendations and advice pertaining to your healthcare/treatment.

When I was diagnosed with myasthenia gravis, the doctors told me to be cautious about repetitive movements, such as exercises. My neurologist was under the impression that exercises would flare up the disease, and so I gave them up... momentarily.

After six continuous months of potent immunosuppressive therapy, my disease was under control. And then I began a regular but graded gym routine to make up for all the "lost" exercise time. And I was feeling better than ever.

While this won't be everyone's experience – and as a medical student, I always recommend following your doctor's advice and guidance – getting back to exercise was an important part of my healing process. Not just physically, as I regained strength lost during my weakest periods, but mentally as well. Even limited movement has potent effects on your wellbeing that can improve your quality of life.

Exercise has many well-known benefits on health, but it remains understudied as a therapy for myasthenia gravis. Some in the medical community may point to medicine over alternative therapies. There are methodological difficulties, too, like the small sample size involved in any rare disease study and the fact that MG severity can differ so widely among patients.

But just because studies in MG patients are limited, exercise should not be ignored as a potential therapy for this disease.

The limited research that does exist shows exercise is generally safe and effective for people living with myasthenia gravis. One 2017 study showed that exercise benefited patients with mild MG during the activity.¹ Subsequent studies have confirmed this in patients with generalized weakness of MGFA



For some gentle, low impact exercises you can do at home, visit the Fitness Center in the MGFA Online Community.

inspiratory and expiratory pressures compared with the control group.⁷

Finally, physical exercise may lead to a positive immune response that may counter autoimmunity.⁸

Exercise gave me one additional, remarkable benefit as a person living with MG. After exercise, I experienced what I call “the endorphin orchestra,” where exercise elevated my mood.

To understand why this would be helpful, we first need to understand that fatigue is a product of both subjective and objective state. While people with MG may have normal or near-normal repetitive nerve stimulation tests, they are still afflicted with longstanding fatigue.⁹

Abundant research has shown the effects of exercise on mood, cognition, and fatigue. Physical exertion has an immediate, short-term boost in mood, which can persist up to 12 hours. The result is a compound effect on motivation that can power one through the day.

Don't underestimate the power of a positive outlook and the impact of those endorphins on your mood and overall wellbeing. (See Dr. Rosenfeld's presentation at the 2023 MGFA National Patient Conference on the MGFA's YouTube channel!)

While exercise should be done carefully, and in a graded fashion, it can work wonders for helping you manage your MG symptoms in conjunction with your regular treatment plan.

The author is a certified personal trainer and medical student who has lived with MG since 2015.

classification II-IV.^{2,3,4} The reason for this is not properly understood, but exercise has been shown to allow both heightened mind-muscle connection and nerve function, with a corresponding improvement in the synapses in the neuromuscular junction.^{5,6} We can already see why this would be helpful in patients with MG, where the nicotinic acetylcholine receptors are blocked by autoantibodies in these synapses.

Exercise also has a slew of secondary effects not directly related to the pathogenesis of MG that may still help combat the symptoms of the disease and side effects of medication. For example, physical activity can help fight weight gain and muscle wasting from immunosuppressive medications such as prednisone. Strength-training can increase both muscle strength and muscle mass over time. Balance exercises can help you stay steady on your feet if you're feeling weak.

Aerobic exercises can improve cardiorespiratory fitness in some patients, which may fight the respiratory weakness MG brings on. One study, for example, randomized MG patients into a training group (diaphragmatic breathing exercise) and a control group for a two-month intervention. The patients in the training group improved their respiratory muscle endurance and maximized

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How to Keep Physical Fitness in Your Life

By Kate Stober

As a personal trainer and bodybuilder, Barry Stalker was used to his muscles acting in a certain way. For 25 years, he lifted weights, training to get the bodybuilder look – a sculpted physique, with bulging arms, chest, and legs. Then, on January 5, 2015, everything changed. He woke up and couldn't see properly.

“My right eye was wall-eyed, and my eyelid drooped as well,” he says.

He saw an eye specialist who couldn't say what the problem was. A few days later, his jaw went numb, and he felt like he couldn't breathe. At



the hospital, a doctor put the symptoms together and suspected myasthenia gravis. After a referral to neurology and a few tests, the diagnosis was confirmed. Barry had a thymoma, a tumor of the thymus gland that can cause MG. In the weeks that followed, his symptoms got worse. He struggled to speak, swallow, walk, and see. He was so weak he struggled to take the Mestinon his doctor gave him to help control the symptoms.

“I went from being able to squat 400 pounds to my wife having to help me off the sofa,” Barry shares.

In the spring of that year, he had a thymectomy. This procedure to remove the thymus can dramatically reduce symptoms for some patients, but it can take time to see improvement – up

to one to two years. After the surgery, Barry's doctors tried to slowly wean him off medications, including prednisone, to assess how the procedure had impacted his disease. This corticosteroid medication is particularly tough on the body, with side effects like weight gain, mood changes, and facial swelling.

“I was taking so much my face hurt to smile,” Barry says. “I relapsed twice while trying to get off the steroids.”

All of this took a tremendous toll on his mental health, Barry says. He had trouble sleeping and dealing with the complete 180 degree turn his life had taken. It took several years for his MG to stabilize. During that time, he began building a mindset to get through the difficulties of his disease. It started with acceptance.

“When I draw my last breath, I'll have MG,” he says. “Understanding that, it's like grieving – it helps you move on. I can never do what I did in my former life.”

These days, he lives in the present, enjoying the daily pleasures of life with his wife, Caroline, and their young son. He wryly says that life with a baby wasn't too much of a change for him since he's permanently tired already.

“When you Google ‘myasthenia gravis’ and find out that you can die from this – you have to keep that in the back of your head. It makes you appreciate every day more.”

He's also gone back to the world of training and weightlifting. While his neurologist was tentative about Barry being too physically active,



Barry (middle) before his MG

Barry feels that the overall health benefits of exercise, including improvements to mental health, are worth it. He started easy and integrated exercise back into his life slowly.

“Looking after myself physically, with the bodybuilding perspective, put me in good stead to come out the other side and start doing some exercise again,” he says.

While he can't lift a fraction of the weight he used to in his bodybuilding heyday, he consistently maintains a workout routine that involves weight training. He's learned to monitor how he feels on a day-to-day basis.

“Some days, I get there and I'm like, right, can't do that. I can go up to that line, but not further, or there will be a repercussion.”

He's resumed his work as a physical trainer in London, helping clients across the spectrum of physical health attain their own fitness goals. He charts his training sessions and offers advice on his Instagram, @barryprotraineruk. He says that talking about MG on social media has opened up conversations with other patients looking for connection, information, and solidarity. He says the mental part of myasthenia gravis is hard for many of them, too. Being part of the MG Community online helps.

His advice?

“Be optimistic, but realistic. MG is always there with you. My mindset – fight this the best you can do.”



Running the Colfax Marathon for a World Without Myasthenia Gravis

By Kate Stober

Dan Rollman was diagnosed with myasthenia gravis in his late 40s. It came as a shock.

“When I was diagnosed with MG, I had never even heard of the disease. It took six months to learn how to pronounce it,” Dan says wryly.

He experienced severe muscle weakness, impacting his ability to talk, chew and swallow food, keep his eyes open, and exercise.

He could not read bedtime stories to his young daughters because they couldn't understand his voice, and he lost 35 pounds because he had so much trouble eating. He was unable to work because he couldn't consistently communicate with others.

He had taken up running during the pandemic but could no longer enjoy this hobby as the disease took its toll.

“I endured two of the most challenging years of my life, with many low moments attached.”

It culminated in an MG exacerbation that put him in the ICU on life support.

“It was, without question, my closest taste of death. Coming out of the hospital, I found myself overwhelmed by gratitude for life,” Dan shares.

Fortunately, he began to recover



after this hospital stay. He started a new treatment regime that improved his symptoms enormously.

With deep appreciation for his survival, he began to lean into exercise, appreciating every breath he could now draw deep into his lungs, every step he could take without collapsing.

He started slowly – recovery from a near-death experience takes time – but he began to run again.

“After going through a couple of years when my health was severely limited, I celebrated running just a few hundred feet,” he says.

He was cautious, testing the waters each time he stretched his runs, waiting to see if exercise impacted his symptoms. With time, he felt stronger and healthier than he had since he was first diagnosed.

“The last year has been pretty darn normal,” Dan says. “I feel grateful for the medical team that has been in my corner. The medications, after some trial and error, seem to be working pretty consistently.”

The idea of running a marathon had been in his head for a few years. He signed up for the 2024 Denver Colfax Marathon with some trepidation, but on May 19, he completed all 26.2 miles. His wife, Rachel, also completed her first half-marathon.

Dan and Rachel ran for “A World Without Myasthenia Gravis,” fundraising to support the MGFA’s mission of creating connections, enhancing lives, improving care, and curing MG.



“The resources from the MGFA were and continue to be extremely helpful to me and my family. To be able to find sources of education and a community to learn from has been deeply meaningful. We wanted to find a way to give back to an organization that’s been tremendously helpful to us,”

Dan says.

Dan and Rachel both feel incredibly fortunate for his state of health, and Dan hopes that his story inspires others living with myasthenia gravis to keep the faith for remission.

“Going through a period in which health limits our physical abilities is brutally difficult, but one must hold faith that there can be light at the end of the tunnel.”

Want to raise funds for myasthenia gravis awareness? Run or walk for A World Without MG! Join one of the MG Walks this year, or reach out to Tasha Duncan at tduncan@myasthenia.org if you would like to fundraise as part of a marathon, triathlon, or other race.



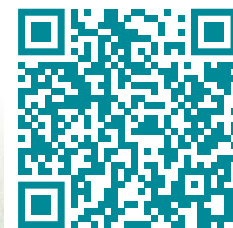
Grand Opening of the MGFA Online Community International Center



If you are a native Spanish, Italian, or French speaker, you can now access MG educational materials and emergency information in your language in the International Center of the MGFA Online Community. Click on this beautiful virtual building on the West Campus, and enter our lobby to view the flags that represent select materials translated in these languages. By clicking on each flag, you will access a list of important materials, including MG brochures about emergency management, EMT considerations while in crisis, how to prevent an MG crisis, and other resources. We welcome you to review and download materials to help you better manage your MG.

If you have not yet become a member of the MGFA Online Community, learn more and join today at myasthenia.org/MG-Community/MGFA-Online-Community or via the QR code at right.

Join here





WHAT'S YOUR ANTIBODY STATUS?

YOU SHOULD KNOW

advocate for the care and treatments you need to manage your myasthenia gravis. People with MuSK MG, for instance, may have different symptoms, such as increased weakness of face and throat muscles and more rapid progression of the disease. For that reason, Dr. Muppidi says that early treatment is crucial in these patients to prevent muscle atrophy.

Understanding how each antibody works in the body will help you understand which therapies will be most beneficial for you. For instance, MuSK MG responds well to rituximab, but pyridostigmine may not be as effective as it is for patients with AChR MG.

Knowing your antibody status – and sharing this information with your care team – helps ensure you receive the right treatment plan.

Dr. Muppidi goes into detail about these topics in the webinar. We encourage you to watch and learn how different antibodies can cause myasthenia gravis symptoms, as well as the effectiveness of treatment options based on antibody status.

Visit our YouTube page at youtube.com/@myastheniagravisfoundation8053 or scan the QR code to watch this presentation.

Last December, Stanford Medicine neurologist Dr. Srikanth Muppidi gave a presentation about antibodies as part of the MGFA Wellness Webinar series.

As a doctor who treats MG, Dr. Muppidi hears from new patients who aren't sure if they have AChR, MuSK, LRP4, or seronegative myasthenia gravis.

“This was eye-opening – I just assumed everybody knew about their antibodies,” Dr. Muppidi said.

He believes knowing your antibody status helps you

Watch webinar

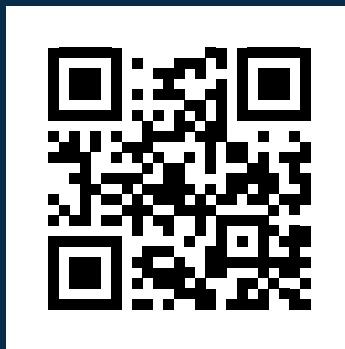


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MGFA Going Global

with International Rare Disease Communities

Myasthenia gravis is a rare disease that impacts patients and caregivers all over the world. Individuals diagnosed with MG look to the MGFA for guidance, resources, and educational materials – no matter where they live – and we are honored to engage and assist MGeers outside of the United States. We are so honored to have been invited to participate in the annual INSPIRE Rare Disease roundtable event in Milan, Italy in the fall of 2023. This inspiring event brought together rare disease patients and patient advocacy organizations from across the United States and Europe to discuss the challenges and needs of those diagnosed with a number of rare diseases, including MG.

Samantha Masterson, president and CEO, and Michael Antonellis, vice president of global marketing and communications, represented the MGFA at this impactful event. The many participants of the event collaborated on the design and creation of a rare disease “portal” and educational resource that can link patients and caregivers to patient advocacy organizations to provide the means to better manage their rare diseases.

The team also was also given the opportunity to participate in the annual MSMilan Patient Community Day to listen to and engage with European-based rare disease patients to experience their medical journeys and learn more about treatment and management needs. Truly an eye-opening and heartfelt event – and an opportunity to share the MGFA’s value and leading role within the MG Community.

MGFA has committed in 2024 to translate many key patient educational materials to make them available for patients in select countries. Visit the MGFA Online Community International Center to download the first translated materials.





Find the Support That's Right for You

Having a rare disease doesn't need to be a lonely journey. Talk to others who can offer advice or just lend an ear. MGFA offers different support options, so find the one that's right for you.

Support Groups

Groups meet online or in person, in locations around the country. There are specialty groups to meet the needs of caregivers, those whose primary language is Spanish, people with seronegative MG, children and their families, and young adults.



Find your support group at myasthenia.org/MG-Community/Find-MG-Support-Groups

MG Friends

The MG Friends program connects people with myasthenia and their caregivers to trained volunteers able to connect one on one, over the phone or email. Share some information about yourself, and we'll match you to the right Friend.



Sign up at myasthenia.org/MG-Community/MG-Friends-Program

Kids and Parents Share Stories and Find Community



Growing up with a serious disease like myasthenia gravis affects every aspect of your life.

"It feels devastating," says Shanika Palm, whose daughter Kaleeya was diagnosed with juvenile MG two and a half years ago at age eight.

Kaleeya balances school, friends, and video games with IVIG infusions, MG symptoms, and side effects from her treatments. Her struggles with exhaustion make it hard to do as much as other kids her age.

"The fatigue that comes with MG daily is probably the biggest beast. She's really tired when she comes home from school," Shanika says. "The older she gets, the harder it will get because she can't participate as much."

Children and teens diagnosed with myasthenia gravis or congenital myasthenic syndrome face different challenges than adults with MG. For that reason, they need different support.

That's why the MGFA launched a new Pediatric Support Group in January. Shanika volunteers as the support group leader. The new group meets quarterly in the MGFA Online Community.

The group is a safe, caring environment for youth living with MG to meet others going through similar experiences. MG and CMS are exceedingly rare in people under 18 years old, so children from around the world have already found the group – families are signing on from across the U.S. and Canada and as far away as Nigeria.

A meeting just for guardians of juvenile MG patients is also in the works, so parents and caregivers have a place to discuss the unique needs of caring for a child with a chronic illness.

"When you have a community to lean on, it helps," Shanika says.

Email mgfa@myasthenia.org for more information about the Pediatric Support Group.



Watch a Webinar

MGFA webinars keep you informed about the latest in MG management, treatment developments, and research.

Watch recent webinars on our YouTube page:

“Exercise and MG”

with Dr. Sarah Wright, Children’s National

“Making the Most of Your Doctor Appointments”

with Dr. Heather Finlay-Morreale, University of Massachusetts Chan Medical School

“Know Your Antibody”

with Dr. Srikanth Muppidi, Stanford Health Care

“Overview of Clinical Trial Participation”

with Dr. Jonathan Hogan, Senior Medical Director at Cabaletta Bio

“New Treatment for Generalized Myasthenia Gravis”

with Dr. Gil Wolfe, University of Buffalo School of Medicine



Find Patient Resources and Assistance

MGFA partners with organizations to help MG patients and caregivers get the support they need. These partners can help cover the costs of medical treatments, provide guidance, and help you learn how to advocate for yourself and others. For more, visit myasthenia.org.

Financial Assistance

The Assistance Fund

(855) 845-7608 | tafcares.org

Helps cover FDA-approved medications that treat myasthenia gravis.

RareCare, NORD’s Patient Assistance Program

(203) 571.3167 | MG@rarediseases.org

Rarediseases.org/patient-assistance-programs/financial-assistance

Helps cover health insurance premiums, deductibles, coinsurance, and copayments.

PAN Foundation

(866) 316-7263 | Panfoundation.org/disease-funds/myasthenia-gravis

Provides financial assistance for out-of-pocket treatment costs.

Other Resources

Patients Rising

(800) 685-2654 | HELP@patientsrising.org

Call or email the patient helpline to find a navigator who can help you self-advocate or find the care and treatments you need.

EveryLife Foundation

(202) 697-7273 | Everylifefoundation.org

Learn how to advocate at the state and federal level for legislation and policy that advances the needs of people with rare diseases, including MG.

JAN: Job Accommodation Network

(800) 526-7234 | Askjan.org

Ask questions about workplace accommodations and the Americans with Disabilities Act.



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Myasthenia gravis (MG) is an autoimmune neuromuscular disorder. Those with MG suffer profound, debilitating physical symptoms such as extreme fatigue and muscle weakness that impact their ability to see, swallow, smile, walk or breathe.

Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure for MG while improving the lives of those living with the disorder.

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