

FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Spring 2023

Spring Edition Highlights:

Global MG Patient Registry

Help improve MG research

PatientsRising!

New MG Patient Help Line
and Advocacy Resources

MG Awareness Month

Turn Awareness Into Action this June

MG Community Events

Conferences, Webinars, Health Fairs

Research

Participate in Clinical Trials

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,

What a very powerful and special few months we have had together! The start to this new year, just like spring, has felt like a new beginning in many ways and a new season for the MGFA and our community. We are so grateful for each of you, our MG Community members, and we appreciate your ongoing support and partnership.

On behalf of the MGFA and our Board of Directors, we thank you for your participation in our National Patient Conference in March. So many of you joined us in New Orleans and even more tuned in remotely! It was truly amazing to be able to see you and speak with you and to hear you... thank you for sharing your stories, for inviting us into your lives, and for the gift of your thoughts and insights. It was the first in-person National Patient Conference for the great majority of our MGFA team, and we were beyond thrilled and excited to finally be able to meet so many of you. We listened, we learned, and we connected. Thank you so very much for this gift of precious time and togetherness.

We also would like to thank our speakers who lent their expertise to ensure that the sessions were relevant and impactful. Thank you to our most generous sponsors who continuously support the MGFA's efforts to bring topnotch programming and education to our collective MG Community. We would like to again congratulate the volunteer award recipients who were recognized for their service, collaboration, and dedication to our mission. It was an amazing and memorable few days together with so much to celebrate!

As we look ahead, we will continue to cultivate the seeds we have planted in the last few years for strategic initiatives that are growing and blooming! Our Community Health Fairs will be in-person this year and we have expanded them to eight locations across the country. We will even offer three hybrid events in conjunction with our regional conferences! In addition to the Community Health Fairs, we will provide a host of events and programs planned for the rest of the year including monthly webinars, regional conferences, our Scientific Session, golf classics, donor cultivation events, and more!

We continue to leverage technology through our MyMG Mobile app, the MGFA Online Community, and our MGFA Global MG Patient Registry. Our Online Community is currently in Phase 2, which means that we will be unveiling new “buildings” and spaces in this first-of-its-kind digital ecosystem. We are so excited to expand the online community, which has the ability to reach, connect, and educate our community members around the world. Our MGFA Global MG Patient Registry has been fully transitioned to a new platform, and we encourage all patients to enroll and be part of critical research that helps to inform new treatments and quality of life.

Finally, MG Awareness Month is right around the corner in June, and we look forward to interacting with so many of you as you continue to serve as ambassadors on behalf of the MG Community and shout it from the rooftops all month (and throughout the year)! We have lots of fun and engaging activities planned. Please visit myasthenia.org to learn more about how you can support, actively participate, and become more involved in general with the organization. We hope to see you in person but, if not, we have a number of ways to continue to connect virtually and remotely. Either way, we look forward to “seeing you” at upcoming events. Be well.

Sincerely,



Samantha Masterson | President and CEO



MGFA Alliance with PatientsRising! Features Patient Helpline and Advocacy Education



Patients living with myasthenia gravis will benefit from The Patient Helpline for support services as well as educational patient advocacy and legislative training to help navigate the health care system.

PatientsRising! is a Washington D.C.-based non-profit that provides education, resources, and advocacy for people living with chronic and life-threatening illnesses. As part of the MGFA's alliance, PatientsRising! will offer tools and strategies to empower people with myasthenia gravis to obtain support and services as well as professional training programs focused on patient advocacy. **MG patients will be able to access two distinct and valuable services:**



The Patient Helpline is a patient support and navigator program that provides online, email, and phone support to help connect patients to the services they need. It helps patients, caregivers, and allies find solutions when they are not sure how to find them on their own.

The Patient Helpline can...

- Find an organization that specializes in addressing your specific concern at the federal, state, or local level.
- Provide websites and phone numbers to problem-solving agencies.
- Share the solutions that have already been proven to help others.
- Listen with care and compassion to your need.

Education Resources, including various self-advocacy tools to use within the healthcare system and a Legislative Master Class training series (available later in 2023) to build advocacy experience when preparing for a “Hill Day” or legislative meetings.

These services are completely free-of-charge and available to MG patients and caregivers as part of this alliance.

“Myasthenia gravis patients are powerful advocates for the MG Community, so they want to lean in and fight for their needs while learning to become more effective advocates,” said Samantha Masterson, president and chief executive officer at the MGFA. “These services from Patients Rising will go a long way in helping MG patients maintain their ability to self-sustain while making an impressive impact on the rare disease community.”

“We are excited to offer our patient support and education services to myasthenia patients, and we greatly value our alliance with the MGFA,” said Jim Sliney Jr, Patients Rising’s executive director. “We’re certain MG patients will find great value in this alliance, to help them advocate for themselves and their families while obtaining the help they need to live a better life with MG.”

To find out more about PatientsRising!, visit patientsrising.org. Contact the MGFA if you have questions or want to utilize these services. MGFA@myasthenia.org.

Stuck? Call 800-685-2654 or email HELP@patientsrising.org

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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.



Enroll in MGFA Global MG Patient Registry to Find New Treatments



If you are part of the MG community, you probably saw the

exciting news that MGFA has relaunched our Global MG Patient Registry with partner Alira Health. The registry gives you an easy way to make a difference in the search for new and better MG treatments. Twice a year, patients who enroll in the registry will submit data about their general health and MG symptoms and treatments. This data will help researchers design research studies to develop improved treatments and better understand the mechanisms of disease.

So why should you contribute to the MGFA Global MG Patient Registry?

1. With more data from many patients, scientists will gain a better understanding of MG.

When you submit your health and symptom data to the registry, your information will be anonymously and securely combined with that of thousands of other patients, all around the globe. This information improves the clinical trial development process and enables opportunities for new discoveries to be approved sooner.

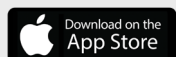
2. Researchers can design better clinical trials, bringing effective treatments to patients more quickly.

Researchers will use aggregated, de-identified data reports from the registry to design and build research studies and trials to test concepts. Without patient data, these critical trials cannot move forward, limiting new discoveries. If you opt in, you can also receive information about new clinical trials you may be eligible for.

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



Download Today



3. It's secure, safe, and confidential.

One reason we chose our development partner, Alira Health, is because they specialize in healthcare technology. The registry is safe, secure, and both HIPPA and GDPR-compliant. Patient data is protected and anonymized, so your health information isn't tied to your personal information when it's shared with researchers.

4. Submitting data is as easy as taking out your phone twice a year.

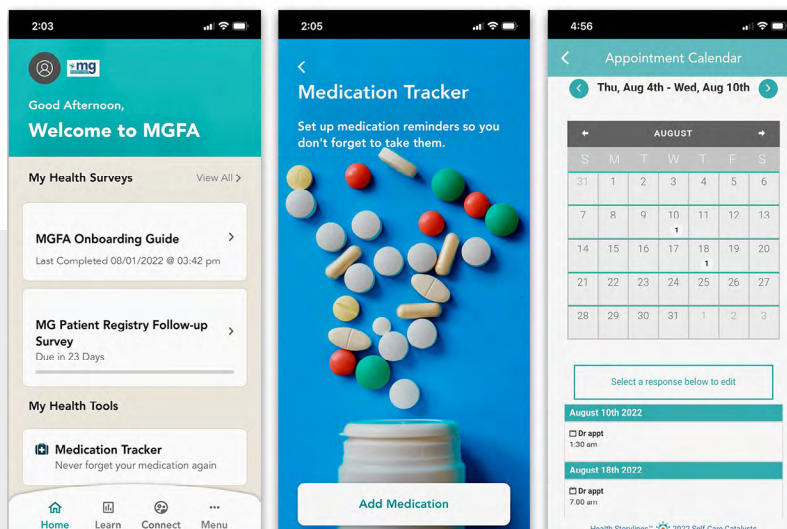
You can share your data right from your phone or tablet. Download the Health Storylines mobile app (Apple App Store / Google Play), and you can enter your updated health information when and where it's convenient for you. You can also use the Health Storylines website. Registry members only have to contribute their data twice a year, so there is a very low time commitment.

5. You are actually involved in finding new discoveries and new treatments for MG.

By adding data to the registry, you are directly contributing to efforts to discover new information and details about MG that can help guide new, novel ways to treat the disease. Through patient recruiting and data collection and analysis, researchers may find discoveries that lead to new treatments and technology that could ensure MG patients better manage MG and live a better quality of life.

Take action in the fight for a cure! Sign up for the registry today. **Visit [MGRegistry.org](https://mgregistry.org) to sign up**, enroll, and add your data. Or, if you are already a member of the registry, add your data during the summer cycle.

Have questions about the MGFA Global MG Patient Registry? Connect with us at mgfa@myasthenia.org.





MGFA BOARD AND STAFF GROWTH POWERS NEW PROGRAMS

Myasthenia Gravis Foundation of America is proud to announce new members of the Board of Directors and our Staff. These professionals bring valuable expertise that will assist in moving our mission forward. We are excited to welcome these new friends of the MG Community. Learn more about these Board and Staff members at myasthenia.org/About-Us/Our-Leadership.



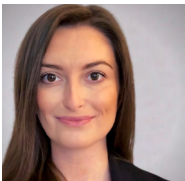
Callum Schjerning (*Newly-appointed to Board of Directors*)

Cal began his career as an enterprise sales professional with NTT, a global leader in the telecommunication industry. During his time there he helped organizations digitally transform their collaboration environment by implementing modern communication solutions. He recently transitioned into his current position at Tableau, a company specializing in Analytics and Business Intelligence solutions.



Kyle Sell (*Newly-appointed to Board of Directors*)

Kyle is a partner with Deloitte & Touche LLP where he has served a multitude of global clients during his 30 plus year career. He also serves as partner-in-charge of the New Jersey audit & assurance practice, primarily responsible for advancing the Firm's initiatives around audit quality, inclusion, operations, financial performance, and growth in the New Jersey marketplace.



Meridith O'Connor - *Assistant Vice President, Patient Engagement, Advocacy & Policy*

Meridith joins the MGFA as Assistant Vice President of Patient Engagement, Advocacy, and Policy. She has years of experience working within the nonprofit sector and is internationally recognized for her leadership in the patient advocacy industry. Propelled by her own MG diagnosis in 2005, Meridith sought to build a career supporting families faced with chronic illness.



Kate Stober - *National Director, Digital & Content Marketing*

Kate brings more than 15 years' experience in nonprofit marketing and communications to the MGFA. She has worked in healthcare, education, and cultural arts at organizations including Mayo Clinic, the University of Montana Foundation, and The New York Public Library.



Laura Chandler - *Operations Manager*

Laura serves the MGFA as its Operations Manager. After being diagnosed with Myasthenia Gravis in 2019, Laura has embarked on a personal and professional mission to better the lives of MG and rare disease patients through advocacy, policy, and research. She has volunteered through advocacy programs and events with the EveryLife Foundation for Rare Disease, Global Genes, and NORD; and currently serves as the Corporate Board Secretary for the Kentucky HOBY Youth Leadership Organization.



MGFA National Patient Conference Brings MG Community Together

Conference held in-person for first time in four years in New Orleans

Everyone across the MG Community has been waiting nearly four years for this moment. In 2020, the COVID-19 pandemic forced the MGFA to transition the patient conference into an online event. Though this approach was well-received by the MG Community, there was always “something missing” as conference attendees watched presentations and sessions via a Zoom on their laptops.

Finally, at the end of March 2023, we were able to bring the MG Community together in the historic city of New Orleans to learn more about MG... but more importantly... to rekindle friendships, give hugs, and welcome our friends whom we have not seen in a long time.

MGFA opened the conference on Sunday, March 26 with a volunteer training meeting. It was the first time in several years that MG volunteers could get together and share ideas while offering their experiences and insights into the needs of the patient community. The conference kicked off that evening with a heartfelt welcome by President and CEO Samantha Masterson, and an informative, insightful keynote by MGFA Chief Medical Advisor Richard J. Nowak, MD.

The traditional Volunteer Awards Dinner proved to be one of the true highlights of the week. Collaborative and dedicated MG Community

volunteers accepted well-deserved awards that showcased their many passionate contributions to the community. See our list of recipients in our Volunteer Awards article (Next Page).

The conference featured incredible patient stories focused on inspiration and determination, amazing new MG research and treatments, and methods for better managing and dealing with MG to help those diagnosed live a better quality of life. Conference participants also were treated to a Mardi Gras-themed dinner event that featured a brass band, photo booth, stilt performers on high and dressed up models celebrating the season and the attendees of the conference.

We were so excited and happy to host the conference this year. The energy in the room was palpable and undeniable, and all attendees were thankful to see their friends and colleagues in person again.

You can view all the session recordings on our website at myasthenia.org/Events/2023-mgfa-national-patient-conference or on our YouTube page @myastheniagravisfoundation8053. Visit the MGFA blog for additional photos at myasthenia.org/blog.

CONGRATULATIONS

to Our Volunteer Award Recipients for 2023

Recognizing Dedicated MG Community Members

During our annual National Patient Conference, the MGFA recognized and celebrated the powerful work that our volunteers accomplish every day. These special people and organizations were honored for their commitment and dedication to the MG Community. The awards spotlight patient advocacy and volunteerism, unprecedented medical advancements, and the positive impact our volunteers have on the entire community. Congratulations to the 2023 Award Recipients.



For more information on each award, visit myasthenia.org/Events/2023-mgfa-national-patient-conference

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 AlexiongMGEvents.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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Turn Awareness into **ACTION** JUNE IS MG AWARENESS MONTH

Take Action to Generate MG Awareness

June is MG Awareness Month around the world! Every June, the MG community comes together to create a unified voice for MG advocacy and education. This year, we're TURNING AWARENESS INTO ACTION.

Take action to make sure people understand the challenges faced by those diagnosed with myasthenia gravis and their caregivers. MGFA is offering a number of creative ways to show that **WE ARE MUCH MORE THAN OUR MG.**



Shine Bright for MG

If your community has a monument or building that lights up with different colors to acknowledge different causes, encourage them to go teal for MG awareness.



Give Presentations

Think civic associations, hospitals, religious groups, schools, and more. If public speaking makes you queasy, enlist support from a fellow MG volunteer. Get creative with your presentation – one of you could interview the other, or tag team giving MG facts and personal anecdotes.



A Little Goes a Long Way

Take 15 minutes to call or write to your local Senator or Congressperson and ask for their support on initiatives that support the rare disease community. Resources are on the MGFA Patient Advocacy page.



Volunteer

Visit www.myasthenia.org/Make-an-Impact to find out how you can Volunteer for the MG Community.



Get Crafty

Use sidewalk chalk to create an #MGStrong mural in your driveway or on the sidewalk in your neighborhood.



MGFA AWARENESS TOOLS

Proclamation Request and Format – Sample

City of _____ / Town of _____ / State of _____

WHEREAS, myasthenia gravis is a disorder causing extreme muscle weakness which can impact a person’s ability to see, smile, walk, talk and breathe, and it is often misdiagnosed. It’s controllable by medication and other treatments for most MG patients, and although rare, it can prove fatal; and

WHEREAS, because of its rarity (approximately 100,000 people are living with MG in the United States today), many Americans are often undiagnosed; and

WHEREAS, the Myasthenia Gravis Foundation of America, Inc. (MGFA) is a not-for-profit organization founded in 1952; and

WHEREAS, the MGFA’s mission is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, support groups, public information, medical research, professional education, advocacy and patient care.

NOW, THEREFORE, BE IT RESOLVED that I, _____, Mayor of the City of/Chairman, Board of Selectmen of the Town of/Governor of the State of _____, do hereby proclaim June 20XX, as:

MYASTHENIA GRAVIS AWARENESS MONTH

in the City/Town/State of __ and urge all residents to join with me, during the period, in an attempt to focus attention on the need for education, treatment, research, and ultimately, a cure, for this currently incurable disease.

IN WITNESS WHEREOF, I hereunto set my hand and cause the Seal of the City of/Town of/State of __ to be affixed this _____ day of _____ in the year of our Lord, Two Thousand XXX.

Mayor/Chairman, Board of Selectmen

Contact:

MGFA National Office Address:
290 Turnpike Road, Suite 5-315, Westborough, MA 01581

[April/May] XX, 20XX

TO:

Board of Selectmen **OR:** Mayor or Governor

Town of: _____ City of or State of: _____

The Myasthenia Gravis Foundation of America, Inc. (MGFA) is pleased to designate June as Myasthenia Gravis Awareness Month. Myasthenia gravis (MG), is a disorder causing extreme muscle weakness that can impact a person’s ability to see, walk, talk, breathe and even smile.

Please join with other municipalities in issuing a proclamation for **Myasthenia Gravis Awareness Month** in your **[town, city, or state]**. Attached is a sample proclamation that is being declared in several other communities nationwide. Thank you for your attention to this important matter.

Local contact: _____

Name: _____

Phone number: _____



MGFA AWARENESS TOOLS

Sample Pitch Email for Media

New Message

To _____ Cc Bcc

Subject [Town] Resident Inspires Community

Hello,

On [date] at [location], [resident] is [conducting activity, such as: “hosting a virtual gathering” or “organizing a vehicle parade”] and can share her experiences with how the incurable, autoimmune neuromuscular disease myasthenia gravis (MG) inspired her to become an advocate in her community. We hope you can cover this event on [date/time].

[Add more details, particularly any visual components.]

More information about MG and the Myasthenia Gravis Foundation of America are included below my signature. Please let me know if you are interested in covering this event or have questions.

Thank you,

[Signature and phone number] [Include Media Alert – see below]

Send

Media Alert

A media alert is similar to an invitation for newspapers, radio and TV news outlets to attend and cover an event. When creating this document, be sure to highlight the local impact of what you are doing and note the community/city where the event will take place. We included brackets around the items you may want to tailor to your event. Here is an example:

[City] Resident Highlights MG Awareness Month by [Activity]

WHAT: On [date], residents of [city/town] will take part in the [event name] to raise awareness about myasthenia gravis (MG). MG is a disorder causing extreme muscle weakness that can impact a person’s ability to see, walk, talk, breathe, and even smile. It strikes people of all races, genders, and ages. [Add 1-2 sentences about the event.]

WHEN: [DATE] and [TIME]

WHERE: [LOCATION] and [ADDRESS]

CONTACT: For more information, please contact [NAME, NUMBER, EMAIL]

WHY: Myasthenia gravis is rare and non-contagious. In MG, the body’s immune system attacks the connection between the neurons and the muscle fiber, which limits the ability of the brain to control muscle movement. The degree of muscle weakness can vary from person to person, and day to day. Due to the high number of misdiagnoses, the precise number of people with MG is unknown, but MG is estimated to affect approximately 100,000 Americans. There are effective treatments for most, but not all with MG. There is currently no cure.

[Insert 2-3 sentences describing a personal story, if applicable.]

Photo and interview opportunities available.



MGFA AWARENESS TOOLS

Sample Letter - Monuments and Buildings

[Date]

[Name of official and address block]

Dear [Name of official],

I am writing to you on behalf of Myasthenia Gravis Foundation of America to request your support and authorization to illuminate buildings, as well as [Name of well-known local landmark/s or monument/s], in teal on the night[s] of June [dates] to mark Myasthenia Gravis Awareness Month.

Myasthenia gravis (MG), is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile.

The Myasthenia Gravis Foundation of America is planning a variety of events this month to raise awareness of MG, including: [Insert events or activities your Support Group is doing — especially if open to the public]. On a national level, Myasthenia Gravis Foundation of America is also working with the government and other organizations to encourage iconic buildings and monuments to light up.

I hope that you will join us in our efforts to raise awareness of this serious disease. Thank you for your consideration, and look forward to your reply.

Respectfully,

[Your name, title, support group]

How to Write an Op-ed

Opinion Editorials (Op-eds) are articles written by local citizens, organization leaders, experts, or others who are knowledgeable about an issue. The topic of an op-ed is the writer's choice; of course, more relevant and timely op-eds are more likely to be published. By submitting an op-ed you can call attention to your issue. Check out your local paper for requirements regarding length and where to submit. Here is an example:

Title: RAISE Awareness and Take Action

My husband, Bob, lives every day with a debilitating disorder called myasthenia gravis, a disorder most people have never even heard of. Myasthenia gravis, a disorder causing extreme muscle weakness that affects all races, genders and ages, has no cure.

This disorder can strike anyone and can attack without warning. MG has weakened Bob so that he's unable to pick up our 4-year old daughter or participate in activities he used to love, such as running. Myasthenia gravis (MG) causes weakness in muscles that control some of our most basic movements: seeing, walking, talking, breathing and even smiling.

MG is frequently misunderstood and underdiagnosed, and because of this, it took nearly two years and seemingly endless doctor's appointments to get Bob the proper diagnosis. During this time, I was forced to put my career on hold and it opened my eyes to the impact this disease was having on our entire family, and the importance family caregivers have once a loved one becomes ill. I am asking for your help to raise awareness and take action.

AT THIS POINT INSERT A TIMELY REASON FOR YOUR LETTER, FOR EXAMPLE, SEE THE FOLLOWING PARAGRAPH OR, PROVIDE CONTEXT FOR YOUR LETTER BY MENTIONING JUNE IS MG AWARENESS MONTH, FOR INSTANCE.

[RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act (Senate Bill 1719; House Bill 3099) has passed the Senate but still needs to pass the House. This bipartisan legislation calls for the Secretary of the U.S. Department of Health and Human Services to develop, maintain and update an integrated strategy to recognize and support family caregivers. I urge you to take a few minutes to contact your Congressman/woman and urge him/her to support this legislation. It's the first step in better recognition and help for family caregivers. Note: You can confirm the status of the legislation at the Congress.gov website: <https://www.congress.gov/bill/114thcongress/senate-bill/1719>

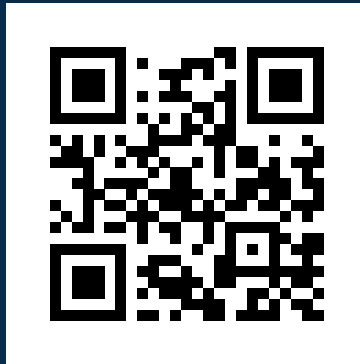
To find your representative visit: <http://www.house.gov/representatives/find>] Thank you for your help in advocating for increased attention to the needs of family caregivers.

VYVGART[®]
(efgartigimod alfa-fcab)
Injection for Intravenous Use
400 mg/20 mL vial

An FDA-approved treatment

Talk to your
neurologist about
VYVGART

Find out more



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This June, **DARE** your friends and family to **CARE** about making a difference for people with myasthenia gravis. **Challenge them to help you raise 30 gifts of \$30 in 30 days.**

Every \$30 raised supports the Myasthenia Gravis Foundation of America's ongoing mission of creating connections, enhancing lives, improving care, and finding better treatments for MG.

June is MG Awareness Month, the perfect time to dare your network to care about the MG community.

Joining is as easy as creating a fundraising page and sharing it with your friends and family. You can create your own page or join as a team – think your company, civic club, or extended family – any group who wants to work together to compete in the challenge. And there are lots of prizes for fundraisers who meet goals along the way!

To participate, go to myasthenia.org and look for the Dare to Care Challenge or use the QR code above to find our challengers. Our goal is to raise \$100,000 during the Dare to Care Challenge. Let's do this!

For those who can't Dare to Care this year, we challenge you to Dare to Give. Every \$30 gift gets us one step closer to our goal. Your support matters.

Make a gift of \$30, \$60, \$90 or more to help a fellow MG Community member reach their challenge goal!

Visit myasthenia.org/Dare-to-Care to donate online.

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



Scan here to fundraise

INDIVIDUAL

First \$30 gift - MGFA Awareness Sticker

\$30 / 7 days = \$210 - Dare to Care T-shirt

\$30 / 14 days = \$420 - MGFA Branded Hat

\$30 / 21 days = \$630 - MGFA Branded Hoodie

\$30 / 30 days = \$900 - MGFA Branded Yeti Tumbler

TEAMS

\$30 / 30 days = \$900 - t-shirt for entire team

\$1200 - MGFA branded hat for entire team

\$3000 - Gift Card for Catered Lunch or Breakfast

\$5000 - Gift Card for Catered Lunch or Breakfast

Recognition Items for Top 3 Individuals and Teams

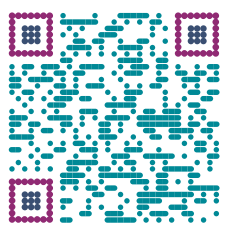
Recognition in Newsletter, Blog and Social media outlets

Your support helps 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 Fair Program, MG Friends, Support Groups and Patient Conferences.
- Help us achieve our goal to raise \$100,000 during the Dare to Care Challenge. You can make a difference.

MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT



Scan here for info on registration

2023 COMMUNITY HEALTH FAIRS

May 20, 2023 - Greater New York Area

June 10, 2023 - San Francisco Bay Area

August 12, 2023 - Charlotte Area

Sept. 9, 2023 - Seattle Area

Sept. 9, 2023 - Chicago Area

Oct. 7, 2023 - Houston Area

Oct. 14, 2023 - The Greater DMV

Nov. 4, 2023 - Tampa Bay Area

NATIONWIDE • FREE • REGISTER TODAY

Do you have questions about MG? Join us at an MGFA Community Health Fair!

At these free events, you can...

- Interact with MG patients and medical experts to get your questions answered.
- Find information and educational materials.
- Connect with local businesses that cater to MG patients and specialize in your needs.
- Learn more about MG research and treatment developments from MG experts and corporate industry leaders.
- Join the “MG Experience” to learn methods of sharing our MG challenges with others.
- Connect with MG Community members, share stories and guidance, and learn more about managing this disease.

myasthenia.org/community-health-fairs



RESEARCH UPDATES



MG CLINICAL TRIALS

Apply to Participate and Drive New MG Research

Clinical research on myasthenia gravis moves us closer to a world without MG. Research studies expand scientific knowledge about the disease and how to treat it, and brand-new treatments have been approved by the FDA in the last few years.

This research is only possible thanks to patients who step forward to participate in clinical trials.

By participating in a trial, you not only gain access to potentially beneficial treatments that aren't yet on the market, but also help scientists understand this complex disease in new ways.

Per the NIH, trials are the primary way that researchers determine if a new treatment is safe and effective in people. Clinical research might also test new ways to diagnose disease, determine who is at risk for developing a disease, and try to improve quality of life for those with chronic disease.

Trials are organized into four phases.

- Phase 1 trials are very small and test experimental treatments evaluating initial safety and side effects.
- Phase 2 trials continue to evaluate safety along with efficacy.
- Phase 3 expands the number of people being treated, looking to bolster evidence of the treatment's success and determine the proper dosage.
- Phase 4 trials take place once the FDA has approved the treatment, and its effectiveness and safety are monitored in a large, diverse population to continue to track possible side effects.

While some trials for MG patients require participants to be anti-AChR antibody positive, there are an increasing number of options for MuSK, LRP4, and seronegative patients. Several open trials are recruiting for pediatric patients, as well.

We encourage you to learn more about options and talk to your medical team to find out if a trial is right for you.

Visit myasthenia.org/Research/Clinical-Trial-Opportunities for a selection of currently recruiting trials. Additional trials may be available at clinicaltrials.gov. Inclusion criteria apply for every study; check to determine your eligibility.



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Janssen gMG Trials



At Janssen, we are **relentlessly** focused, **actively** listening, and **expertly** helping to develop innovative solutions for those living with rare diseases, including generalized myasthenia gravis (gMG).



Learn more about gMG trials at globaltrialfinder.janssen.com



How to Be an Advocate for Yourself & Others with Myasthenia Gravis

by Laura Chandler, MGFA Operations Manager



Rare Disease Day happens once a year on February 28, but advocacy doesn't happen just once a year. There are tons of ways to involve yourself in advocacy every day.

Learn as much as you can about myasthenia gravis

There are over 7,000 known rare diseases, so even superhero doctors, nurses, healthcare workers, and EMTs can't be experts in every single one. The more that you know about myasthenia gravis, the better you're going to be able to manage your own health, monitor your symptoms, and translate your needs to your care providers. Educate those you meet – kindly and respectfully – as you go.

Be proactive about your health

MG symptoms fluctuate. Pay attention to when you feel best and when you feel worse. Track your symptoms and pay attention to things that may trigger or exacerbate them, as well as things that help keep them at bay. I recently started using the MyMG Mobile App – it helps me notice things I normally don't pay attention to. This helps me better schedule my day around my fluctuating symptoms and avoid things that make my symptoms worse.

Share your story, findings, and feedback

Share your story with anyone who will listen. Talk about MG with your friends and coworkers, and share your story on social media. Share your feedback with the MGFA to make it known what resources you need, what programs you would like to see, and what legislative obstacles stand in the way of your healthcare. Share your data in the MGFA Global MG Patient Registry (mgregistry.org) so that your experience can lead to new, groundbreaking research, technologies, and treatments.

Build a community

Find a way to connect with people who understand you. The MG Friends program pairs people with MG and their caregivers to talk about MG management over the phone. MGFA Support Groups take place all over the country, in person and over Zoom. The MGFA Online Community hosts chats and events where MG patients can

share their experiences. MGFA Community Health Fairs connect people with each other and with different kinds of support resources in their area. The annual MGFA National Patient Conference is an opportunity to convene with patients and caregivers like you from all over the country.

Do what you can

If policy interests you, get involved with legislative advocacy. You can sign up for action alerts and follow bills that impact healthcare, write emails to your legislator, or even get involved in drafting future legislative policy to change the landscape of public health and healthcare.

If policy isn't your jam, you can still be an advocate in everyday life. Advocacy can simply be explaining MG, telling someone why you use a cane or wear an eyepatch, saying no to taking on a commitment, or requesting information from your doctor about a new treatment. Your "ask" could be for a relative to check out the MGFA website to learn more about your disease, or for a boss to help find solutions for mitigating activities that cause you fatigue. Increasing awareness of MG, telling your story, and articulating your needs is advocacy in a nutshell.

Laura serves as MGFA's operations manager. After being diagnosed with myasthenia gravis in 2019, she has embarked on a personal and professional mission to better the lives of MG and rare disease patients through advocacy, policy, and research.





to further understand the MG experience only increased as we navigated this new lifestyle.

The label “myasthenia gravis” substantiated the physical elements of my disability. After two years of misdiagnosis and no one believing my reality, having the words to give my experience a frame of identity was monumental. Yet the words “myasthenia gravis” just became terms to describe my physical debilitations. I quickly learned that these strange words will never protect me from judgment, justify the decisions I make, or shield me from the emotional pain this disease allows. That falls on me.

My misdiagnosis may have been the reason I started advocating, but it is the inequities of living with a rare disease that compel me to continue doing so. The MG community has made historic strides in research and developing treatments, but there is still plenty of work to be done. I choose to celebrate Rare Disease Day by favoring improved diagnostic processes, backing targeted therapies, creating access to better mental health care, and illustrating the support rare disease patients need on the other 364 days of the year.

Meridith serves as Assistant Vice President of Patient Engagement, Advocacy, and Policy. Propelled by her own MG diagnosis in 2005, she has built a career supporting families faced with chronic illness.

Highlighting Seronegative MG, a Rare-of-the-Rare Disease

by Kate Stober, MGFA National Director, Digital and Content Marketing

Having a rare disease can feel overwhelming. But having a rare form of a rare disease – making you the “rare of the rare” – is a particularly lonely struggle.

Many people with seronegative myasthenia gravis face this experience. These patients – roughly 10% of those diagnosed with MG – do not have detectable anti-AChR or anti-MuSK autoantibodies in their blood. These are the two antibodies

known to cause MG symptoms.

As the science progresses, some seronegative patients have been found to have proteins such as agrin or a different antibody, anti-LRP4, causing their symptoms, but for many others the exact cause remains elusive.

Because their myasthenia is not diagnosable with a blood test, seronegative MG patients often go longer without an accurate diagnosis, even with typical MG symptoms such as eye drooping, double vision, shortness of breath, and difficulty chewing and swallowing.

The quest for answers – and relief from symptoms – can take months or years.



“In the earlier phases of my symptoms, it was not easy to put the pieces of the puzzle together,” says Cheri Heitman-

Higgason, a former nurse who was diagnosed with seronegative MG in 2015 after a long diagnostic journey. She was tested for anti-AChR and MuSK autoantibodies, underwent repetitive nerve stimulation and single fiber EMG testing, and was finally diagnosed with MG after traveling to see an MG specialist.

Cheri and others with seronegative MG talk about the pitfalls of this process, from working with insurance on approvals for tests to being misdiagnosed with anxiety or a psychiatric disorder. The process leaves many feeling defeated.

“Seronegative MG exists and has the same symptoms as antibody positive MG,” says Cheri. “When we are not seen or heard, it can be very dehumanizing.”

Her comments are echoed by others in online support groups, articles, and social media posts, where patients share similar stories:

“MG is rare. But being seronegative MG is even more rare. Our fight for recognition and treatment is that much harder. We don’t all present the same way, and the disease fluctuates throughout the day.”

“Don’t assume just by looking at us on the outside that nothing is wrong. We aren’t making it up.”

“Seronegative MG needs much more awareness!”

Delay in Treatment

A delay in diagnosis leads to a delay in treatment, especially adequate treatment. Patients who go without adequate treatment face clinically worse outcomes. A recent study, published in the Journal of Neurology, Neurosurgery, & Psychiatry, demonstrated that people with MG who received early, fast-acting treatment within six months of symptoms fared better than those whose treatment was deferred.

Cheri notes her treatment plan includes a noninvasive ventilator, which helps her breathe. Without a diagnosis, she wouldn’t have access to these life-saving interventions.

“This is so important to my daily life, but without a diagnosis, it is not available to us,” she says.

Seronegative MG patients also do not have access to many of the newer medications, which are only FDA-approved for people with anti-AChR or anti-MuSK antibodies.

“As a friend says, we are fighting the same war as other MG patients without the same arsenal of

treatments,” says Cheri. “I would like to see a day where those with seronegative MG are able to get diagnosed earlier and be treated earlier and more adequately, before they lose years of better quality of life and their careers like I and so many others have.”

As awareness of seronegative MG grows, more people are likely to receive accurate diagnoses and receive the help they need. Research is also growing in this important area, with experts exploring other proteins and antibodies that may cause symptoms. That knowledge will drive the development of additional testing and better treatments for all MG patients.

Advice for Others

Having journeyed so far and experienced so much on her path to diagnosis and proper treatment, Cheri offers this advice to others:

Never give up!

Make sure you have had all the testing: AChR, MuSK, LRP4, repetitive nerve stimulation, single-fiber electromyography (SFEMG), and chest CT (to name a few) and that you obtain and keep a record of all results. If your condition allows, having blood and EMG tests prior to starting immunosuppressant medications or disease modifying treatments – which could potentially alter the antibodies in your blood – eliminates the possibility of such treatments interfering with test results.

Discuss testing for other rare diseases with your provider. Many rare diseases have similar symptoms but different treatments. Other rare diseases, including LEMS and CMS, can be diagnosed with additional labs, genetic testing, imaging like MRI of the brain and spine, lumbar puncture, etc.

Be open to other possibilities in order to make every attempt to get to the root of the problem, whatever

it may be. Try to find a physician who will work with you.

Remember not to demand a diagnosis but work together with your provider.

If a provider is not working out, getting another opinion is often more helpful. I have not found assistance from anyone who originally discounted me.

Be open-minded with your new provider. Go to the appointment prepared with a list of questions and concerns. A fresh perspective can help you get a diagnosis.

Since symptoms with MG are variable, document your symptoms clearly and include aggravating and alleviating factors. A written diary, as well as photos and videos, may be helpful.

And again, as difficult as it is, NEVER GIVE UP. I wish it were not so difficult. But believe in yourself and keep going until you find the answers you need.

Don’t let your seronegative MG be a lonely struggle!

Join the MGFA Seronegative Support Group, which meets quarterly on the first Saturday of the month. Email the group leaders at snmggroup@gmail.com with questions.

Join a Facebook group or message board for people with seronegative MG to interact with others who are going through the same experiences.

Use Partners in MG Care (myasthenia.org/Partners-in-MG-Care) to help find a care provider who specializes in myasthenia gravis diagnosis and treatment.

Learn more about seronegative MG. Webinars on the MGFA YouTube page are a great place to start – visit [youtube.com/@myastheniagravisfoundation8053](https://www.youtube.com/@myastheniagravisfoundation8053) and search “seronegative.”



Traveling with MG

Traveling with an illness like myasthenia gravis can be challenging, but with some planning and the right tricks up your sleeve, you can enjoy your trip safely.

Bring your MGFA Emergency Packet. If you don't have one, request one at myasthenia.org/MG-Community/-MG-Emergencies. This packet contains an emergency alert card that explains MG and provides a list of cautionary medications. There are also several brochures about MG written for EMTs and other medical professionals. This will help should you find yourself in a crisis or needing medical care.

Plan ahead. Look up hospitals in the area where you're traveling. You can check the MGFA MG Partners in Care directory for MG specialists in the area in case you need one. Make sure you understand your insurance coverage for out-of-network care. Also make sure you bring extra medication and any medical devices you might need.

Build rest time into your itinerary. Shawna Barnes, who has had MG for over a decade, likes to take a day to rest when she arrives at her destination and another day before she leaves, especially if her travels involve long days of driving.

Make flexible (and refundable) plans. When offered, always get the travel insurance. Get the refundable ticket and hotel room. You never know when a flare up might happen, and planning for a trip can be a stressful trigger. Make sure it's easy to change your plans.

Review disability assistance and services available through your airline. You can request wheelchair assistance throughout the airport if needed. If you're flying alone, you can also request a pass for someone to help you through the airport to your gate – ask at your airline's ticket counter.

That goes for theme parks, too. If you're visiting a theme park this summer, call visitor services or check their website for disability support services. Disney theme parks, for example, offer a Disability Access Service that lets you virtually save your spot in line – without having to stand in the line – if you aren't physically able to. Most parks, zoos, and aquariums have scooters or wheelchairs you can rent, too. If you're in a wheelchair, you can often access rides and attractions via a different entrance line.

Considering a cruise? Pace yourself, suggests travel agent and MG patient Dawn Warner. "There can be a lot of walking on the mega ships," she shares on her website. She suggests resting in shady spots as you explore and to consider requesting a room in the middle of the ship. Some cruise ships also have mobility scooters available to rent on board, as well as accessible rooms.

Going somewhere warm? Remember to chill! The heat can exacerbate MG. A cool vest can literally be a lifesaver. Keep extra ice packs in a cooler in your car to easily swap them out.

Thinking about a big trip overseas? Consider a tour company that specializes in accessible travel. These companies plan and organize trips for people with a mobility impairment or complex health issues.



What's New in the MGFA Online Community?



New Building Grand Opening • Neighborhood Chats • Industry Offices • MG Info

Check out all the new offerings in the MGFA Online Community! Imagine stepping into a completely one-of-a-kind virtual neighborhood where the MG Community can join together, connect, share ideas and discoveries, and access MG-specific educational materials such as live broadcasts, webinars, and information libraries – all in one place!

We are proud and excited to offer a number of updates and brand new information for our community members. Check out the new places to see across the campus.

New Urgent Care Center on West Campus that offers MG crisis information to help you prepare for MG emergencies – Opening This Week.

New West Campus – A new section of the campus that includes an Urgent Care Center as well as a Multi-National Center and Pediatric Center (Buildings open at a later date).

Brand new offices in the Industry Center. Partners Regeneron and UCB have officially opened their offices with new information and content. Check out

all the amazing research in all the industry center offices.

Neighborhood Chats – These chat events will take place throughout the year and will deal with topics such as the MG Registry, seronegative MG, caregiving, patient advocacy, health management, and many others.

Nutrition and Fitness – Coming soon will include short live webcasts that focus on low impact training and fitness as well as recipes and ways of cooking to help manage your MG.

If you have not become a member yet, register today and check out all our open buildings and spaces including the Nancy Law Patient Services Center, Town Hall with MGFA programs, the MGFA Museum, the Wellness Center, Plaza Theater, and our Memorial Garden where you can honor loved ones who have passed away.

[Experience the MGFA Online Community! Register Here, myasthenia.org/MG-Community/MGFA-Online-Community.](https://myasthenia.org/MG-Community/MGFA-Online-Community)



LET'S BE COURAGEOUS, TOGETHER



Meet Priscilla Forrester.

Diagnosed with MG in 2020, Priscilla gives back by serving as a lead for our new Community Health Fair program, which connects MG patients with local resources. She is also a donor and avid fundraiser for MGFA.

Like many people with myasthenia gravis, accountant Priscilla Forrester suffered debilitating symptoms for years before she knew what was wrong. "I felt like I was suffering in silence," Priscilla shares. "I wasn't even talking to friends and family about what I was going through."

In 2020, she was finally diagnosed with MG and could start her journey toward recovery. And she realized she didn't have to go at it alone. She found the courage to open up to her network of family and friends, to ask for help, and to take a bold step: organizing an event team when she wasn't sure she could walk around the block.

"Connecting with other MG warriors on their journey and spreading awareness about this rare disease is why I enjoy volunteering and fundraising for the MGFA. The Foundation's website is one of the resources I relied on when first diagnosed and giving back by volunteering has been an amazing help in my healing."

No one with MG should suffer in silence. That's the power of the MG community. And you, our donors, ensure this important work continues. Together we have the courage to imagine a future once thought impossible – a world without MG.

For individuals with generalized myasthenia gravis (gMG) finding the strength to complete tasks in your daily life can seem impossible at times. The FLEX Study is investigating a drug treatment called batoclimab for adults living with gMG to manage their symptoms. The second period of this research study may provide the opportunity for participants to self-administer the injectable study drug.

In this clinical research study, doctors want to evaluate the investigational drug to placebo, which looks like the investigational drug, but contains no active medication. The investigational drug has not been approved for the treatment of generalized myasthenia gravis or any other disease. It is considered experimental and can only be given to patients in clinical research studies. The results of this clinical research study will provide more information about batoclimab and its effect on mild to severe generalized myasthenia gravis.

Who is eligible to participate in this clinical research study?

You may be eligible to participate if you:

- Are 18 years of age or older
- Have been diagnosed with mild to severe generalized myasthenia gravis (gMG)
- Have been treated or are currently being treated with medication for gMG
- Meet additional study criteria.
- Study staff will determine eligibility based on additional study



FLEX

To learn more about the clinical research study and to see if you may qualify, please visit our website at www.flex4MG.com



THE MG FRIENDS PROGRAM

Have you or someone you know been diagnosed with MG?

Now what? Do you have questions?

Do you feel like you are on an “MG island” alone?

Well, you are NOT alone – You already have an MG Friend.



The MG Friends program connects people with myasthenia and their caregivers to experienced, trained MG patients who can share common experiences and help you manage your myasthenia. Are you looking for personalized phone support to help? Connect with an MG Friend right away.

How It Works

MG Friends are here to support you! This FREE peer-to-peer phone support program helps ensure that you have the information you need to face this diagnosis and improve your quality of life.

MGFA will match you with an MG Friend who has similar needs so you can obtain information that closely matches your current situation. You can contact that person and engage in live, one-on-one phone or Zoom conversations and build a productive MG friendship.

Are you a caregiver or a family member of someone with MG? You deserve an MG Friend, too! We have volunteers who are in caregiving roles and can support you.

A Personal Connection

While Support Groups are critical to service delivery, many people are not able to access or travel to support groups. And many feel more comfortable talking one-on-one than sharing experiences in a group setting. MG Friends provides the opportunity for a person with questions and concerns to connect to someone else who understands—no matter where they live in the United States.

Share ideas, goals, fears, and experiences in a private, non-recorded environment.

Learn about and implement new management techniques.

Benefit from other people’s personal MG experiences.

Do you have questions? Contact us at MGFA@myasthenia.org or at 1-800-541-5454.

Enroll in MG Friends:

myasthenia.org/Enroll-in-MG-Friends-Form

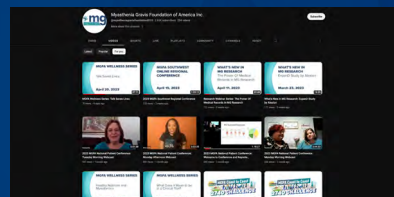
If you have lived with MG and want to share your experiences with newly diagnosed people, enroll here.

Become an MG Friend

myasthenia.org/Become-an-MG-Friend-form

visit myasthenia.org/MG-Friends for more info.

MGFA WEBINARS



MGFA provides free wellness and research focused webinars to the MG community. To register for an upcoming webinar or to watch any previous webinar, visit our website:

Research Series: myasthenia.org/Webinars/Whats-New-in-MG-Research

Wellness Series: myasthenia.org/Webinars/Wellness-Series

YouTube: youtube.com/@myastheniagravisfoundation8053



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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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MGFA is there for you when you need resources, information, and the support of others who know what you are going through. Help us ensure our work continues far into the future. When you make a gift to MGFA through your will or trust, you will make a difference for the MG community. Make a bequest in your will, name MGFA as a beneficiary, or consider other estate gift options. Contact Craig Strenger at cstrenger@myasthenia.org today so we can answer any questions you have or help you set up your gift.

