FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Summer 2025

ISSUE HIGHLIGHTS

- **Cutting-edge research shared at the MGFA's 15th International Conference**
- **Meet our new team members**
- **How does your antibody type impact your MG?**

TABLE OF CONTENTS

Myasthenia gravis (MG) is a neuromuscular, autoimmune disorder. Those with MG may suffer extreme fatigue and muscle weakness, impacting their ability to see, swallow, smile, walk, or breathe. Founded in 1952, the 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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From the Desk of CEO Samantha Masterson

Dear Friends and Supporters,

This year has provided truly historic milestones across the MG community—and certainly for the MGFA as well. In April, we hosted our annual National Patient Conference in Phoenix, Arizona for more than 400 onsite attendees and another 600 virtual attendees. Participants were treated to session presentations by MG experts and individuals living with MG as well as caregivers. It is always our largest—and most fun—gathering of the MG community every year! We were also excited to bestow our annual Volunteer and Service Awards to deserving leaders, amazing volunteers, and transformative partners.

We are proud to have hosted our very first Patient Advocacy Organization Summit that included MG patient advocacy leaders from 17 different countries. We also brought together nearly 700 MG researchers, clinicians, and industry professionals at our very first International Conference held outside the United States. The MGFA 15th International Conference on Myasthenia and Related Disorders showcased groundbreaking research and outcomes from 44 countries, with 241 posters and abstracts focused on MG and related neuromuscular junction disorders. This massive and collaborative undertaking resulted in an incredibly successful networking and educational opportunity for the MG experts in attendance.

June is always one of the most important times of year for the MG community: Myasthenia Gravis Awareness Month. During this meaningful month, the global community came together to educate and inform friends, neighbors, and colleagues about the challenges of MG. The community shared their MG stories, advocated on behalf of those living with MG, and sparked conversations by taking action to drive wider awareness of MG.

As we look ahead, we are truly excited about opportunities to bridge gaps in how patients talk about and understand myasthenia gravis through new educational resources, treatment tools, online materials, and regional events. So much more to come!

Sincerely,

Samantha Masterson

Samantha Masterson
President & CEO

Former Board Chair Brian Gladden Recognized for His Leadership and Contributions to the MGFA and MG Community

MGFA wishes to recognize and thank Chair Emeritus Brian Gladden for his many contributions to the MG Community during his time on the Board of Directors.

Brian served as Board Chair from 2021 to 2024, through an unprecedented evolutionary period of growth for the organization. He was diagnosed with myasthenia gravis in 2015 and first joined the Board of Directors in 2016. Through Brian's leadership and close partnership with the MGFA management team, the organization has achieved exponential growth over the past five years while reaching new audiences and supporters.

"I just cannot put into words how much Brian has meant to the MGFA during his time on our Board," said Samantha Masterson, the MGFA's president and CEO.

After his MG diagnosis, Brian heard about the MGFA through former Board Chair and CEO Nancy Law. After speaking with Brian, who has worked in a number of senior roles in the financial services industry, she recognized how valuable his expertise could be for the MG Community. Brian quickly understood his calling to become more deeply involved with the MGFA.

"Brian has positively impacted our strategy, mission, and programming in so many ways, and his imprint is evident on everything we deliver for the MG Community," Samm continued. "Thank you, Brian, for your years of guidance, your steady hand in helping to navigate opportunities, and, most of all, for your kind heart and dedication to the community."

Brian was integral to establishing the need for a new strategic plan in 2019, and he helped lead the MGFA Stakeholders Survey to capture the opinions and perspectives of the MG Community. This survey served as the groundwork for a plan of growth, diversification, and programming and technology initiatives.

He served as a guiding force as the MGFA hired professional staff members, and he offered his years of financial and executive experience to help establish processes, policies, and pillars that would help the MGFA grow and expand in subsequent years.

In recognition of his service to the MGFA, Brian received both the 2025 Ellsworth Award and the 2025 Outstanding Service Award. The Ellsworth Award is named for the founders of the MGFA and recognizes an individual who has rendered distinguished service to the MGFA over many years. The Outstanding Service Award is given to a committed board member whose board service has been integral to the success of the MGFA and the foundation it has become today.

Brian is the Chief Financial Officer for Zelis, a Bain Capital and Parthenon Capital-sponsored healthcare technology company. Prior to joining Zelis in early 2021, Brian was an Operating Partner with Bain Capital Private Equity, where he worked to create equity value across the portfolio companies of the North America Private Equity funds. Brian served as the Chief Financial Officer of Mondelēz International, was Chief Financial Officer at Dell and served in CEO and senior leadership roles at SABIC innovative Plastics and General Electric.

Brian Gladden accepted the 2025 Ellsworth Award and 2025 Outstanding Service Award at the 2025 National Patient Conference.

MGFA Board of Directors Appoints Robert Thomas as Chair

Justin Stachtiaris Elected Vice Chair

We are happy to share that the MGFA Board of Directors has appointed Robert Thomas as the new Board Chair. This news was announced at the MGFA National Patient Conference in Phoenix in April.

"Robert joined the board in 2022 and is an extraordinary business leader who was inspired by the challenges and resilience of the MG patient community. The combination of his compassionate philosophy on living life, his caring demeanor, and deep financial and leadership acumen make him the perfect choice to lead the MGFA Board of Directors for years to come," said Samantha Masterson, the MGFA's president and CEO.

Robert had served as Vice Chair of the Board as well as Chair of the MGFA Governance and Nominating Committee. After initially learning about the MGFA through a staff member, he immediately realized he could do more for patients and caregivers by leveraging his years of financial and business experience for this board.

Robert Thomas, Board Chair

He has served in leadership positions in a variety of large companies and city management organizations and has applied his knowledge and mentoring to help the MGFA continue to grow, serve, and support individuals diagnosed with MG. Robert is a dedicated and creative entrepreneur who established NUEnergy Payroll HR, a human resources and payroll management company, and he has served in senior executive roles for the City of Houston, ADP Inc., Fidelity Financial, and Bank of America.

"I am deeply honored to serve as Board Chair, and I am constantly uplifted and invigorated by the myasthenia gravis community," stated Robert. "What is really exciting is that the MG Community itself is there for individuals who are just initially diagnosed as well as those who have lived with MG for a long time but may not know what to expect in the future. They have a home with the MGFA—a community and support system that they can go to and be embraced by as they navigate this disease. This is why I am proud to have joined the MGFA Board of Directors."

As a result of Robert's appointment, Justin Stachtiaris now serves as Vice Chair of the MGFA Board of Directors. Justin was previously Chair of the Finance Committee and led the MGFA's Stakeholder Survey in 2019. He is currently an associate at Bain Capital in their Healthcare Private Equity Group, where he works with and invests in companies across healthcare software and life sciences research. Prior to joining Bain Capital in 2020, he spent three years at Bain & Company, where he worked with clients across pharma research, retail healthcare, and consumer products.

Justin Stachtiaris, Vice Chair

Justin recently shared, "I first became involved with the MGFA by leading the stakeholder survey in order to capture and analyze opinions, needs, and perspectives of the MG Community. We collected an array of important data points from more than 800 survey respondents and utilized the voice and suggestions from the community to build the MGFA's strategic plan back in 2019. I am extremely proud of this work in how it laid the groundwork for the MGFA's evolution. I am honored to be Vice Chair and look forward to helping the MGFA achieve its ongoing mission and commitment to the MG Community."

Read more about Robert, Justin, and the MGFA Board of Directors on the MGFA Our Leadership page: myasthenia.org/about-mgfa/our-leadership.

Welcoming Our New Team Members

We are delighted to welcome new faces to the MGFA team

Danielle Kerkovich, PhD, joins the MGFA as vice president for research and programs. Danielle has more than 15 years of experience in research and development, serving in leadership roles with the Department of Veterans Affairs, Beyond Batten Disease Foundation, and the International Fibrodysplasia Ossificans Progressiva Association. Danielle is responsible for developing MGFA's research and policymaking programs.

Rob Thomas is a transformative HR leader with nearly 15 years of experience across diverse industries designing human-centric people strategies that drive organizational performance. He joins the MGFA as the vice president of people operations, bringing his expertise in building talent infrastructure, compensation strategies, and talent enablement and management systems. Previously, Rob served as a fractional head of people to various start-ups and thriving businesses.

Erin Turner joined the MGFA last fall as the national manager for walks and community fundraising. She oversees the MG Walk and DARE to CARE programs. Erin has a passion for mission-based nonprofits that involve community building and support for like-minded individuals in the pursuit of a cause. She previously worked for Special Olympics and the advocacy organization Autism Speaks, among others.

Libby Martin-Ryan is the MGFA's new national manager of web and graphic design. Libby uses her artistic expertise to create compelling visual assets and educational resources for the MG Community. Libby also supports design and user experience on the MGFA's website. She has worked at both for-profit companies and creative agencies across industries such as healthcare, non-profit and museums, retail, and academia.

Medical and Scientific Advisory Council News

MGFA has announced scheduled changes to our Medical and Scientific Advisory Council leadership. Richard Nowak, MD, MS has been appointed chair of the council. Richard is a neurologist and faculty member at Yale School of Medicine and founder of the Yale MG Clinic. He serves as an MGFA board member and our Chief Medical Advisor and has served in leadership roles for the MGFA International Conference and impactful research-based initiatives.

Richard Nowak, MD, MS, Medical and Scientific Advisory Council Chair

Kelly Gwathmey, MD, Medical and Scientific Advisory Council Vice Chair

Kelly Gwathmey, MD will serve as vice chair. Kelly is an associate professor at Virginia Commonwealth University and is an MGFA board member. She has been a critical leader on MGFA programs, including the registry and patient-focused resource materials.

We would like to recognize and thank past council chair Kevin O'Connor, PhD for his many important contributions to the MGFA over his term. Kevin is a professor of neurology and immunobiology at Yale School of Medicine, an MGFA board member, and our Chief Scientific Advisor. His lab has produced new, groundbreaking research that will lead to improved treatments for MG. Kevin has served in leadership roles for the MGFA International Conference and Scientific Session, and has provided critical research guidance that has helped drive MGFA's research and grant funding agenda. Thank you, Kevin, for your extraordinary work during your term as council chair.

Kevin O'Connor, PhD, Yale School of Medicine

SUPPORT FOR MYASTHENIA GRAVIS (MG)

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Whether you're looking to hear more about MG, find a friend with the same diagnosis, or receive some motivation, there's a place for you in the More Than MG community.

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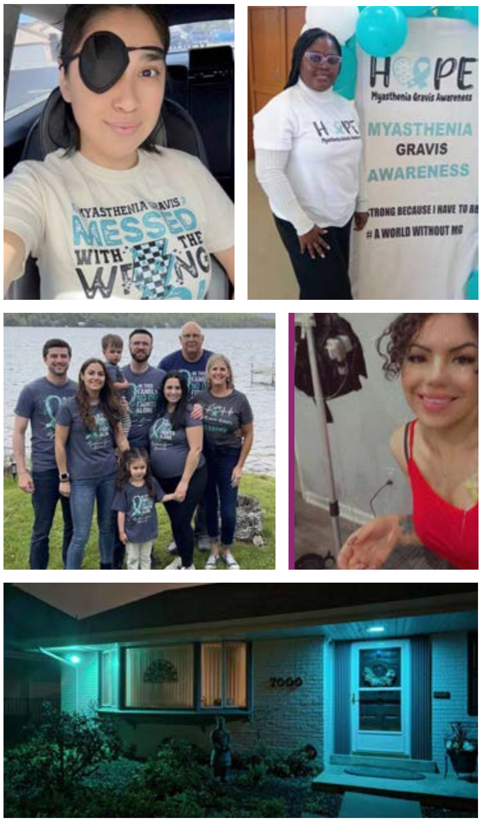

Turn Awareness into ACTION

JUNE IS MG AWARENESS MONTH

This June, thousands of people around the world raised awareness about myasthenia gravis—what it's like to live with this disease, how it impacts your life, and how the MG Community is fighting for "a world without MG."

From Taiwan to Transylvania, Alabama to Zambia, the MG Community shared stories on social media, talked to friends and neighbors, installed yard signs, and hosted local events—all to raise awareness about MG.

We challenged you: Let's raise awareness on every continent!

This June we asked the MG Community to help us raise awareness on every continent. And you did it! The campaign was just one way of showcasing how myasthenia gravis affects people around the world. The MGFA is committed to making an impact for all those who need education, guidance, and support as they navigate their MG journeys.

Check out photos from around the world

Niagara Falls lights up teal!

Hannah Ensor, MGFA volunteer ambassador, checked off the first continent by raising awareness with fellow travelers on her recent trip to Antarctica!

Why MG Awareness Month Matters

Why raise awareness about myasthenia gravis during MG Awareness Month? Here's what the community has to say.

> **"So that people can stop being so judgmental because we look young or healthy."**
>
> —Yvette

> **"Because I almost died undiagnosed when I had an MG crisis. I want to prevent that from happening to anyone else."**
>
> —Maria

> **"Because it breaks my heart to see my dad struggling."**
>
> —Gwen

Raising Awareness 365 Days a Year

Raising awareness doesn't have to stop on June 30! When you take action to raise awareness, whether it's June or December, you are making a difference for the MG Community.

- Use our "Facts about MG" graphics to illustrate your or your loved one's experience with MG.
- Print out and display our "I Fight for a World Without Myasthenia Gravis" poster and display in your window or at your work station.
- Create a social media or community fundraiser to support the MGFA's vital mission. (See box at right for tips.)

Download Resources

How to set up a community fundraiser

Support the MGFA's mission by organizing fundraisers at restaurants or stores in your community. It's easy!

- Visit the website of a chain restaurant in your area to see if they offer a "give back night" program. Or talk to the manager at your favorite independent establishment.
- Fill out the required forms. MGFA's EIN number is 13-5672224.
- Let us know about your fundraiser so we can help you publicize your efforts. Email mgfa@myasthenia.org.

You can also get creative and host a lemonade stand, sell something you make and donate proceeds back to the MGFA, or host a silent auction. Reach out for more ideas!

Pictured left to right: Keara, Kevin, Jr., and Kevin Mack

COMPASSION TURNED TO ACTION for the MG Community

When his teenage son was diagnosed with myasthenia gravis, Kevin Mack was in disbelief.

Not because he had never heard of the rare autoimmune disease. But because he knew more about MG than most people.

For several months, Kevin's counseling services company, Mack Counseling, had been taking calls from the MG community on the MGFA Helpline. People impacted by MG, in need of guidance and support, call the helpline to speak to a trained counselor. Kevin had learned about MG's difficult-to-diagnose symptoms and about the needs of the many patients and caregivers who call seeking help.

One day last year, Kevin's son Kevin, Jr. came home from school complaining that his eye felt heavy.

"Because we had been partnering with the MGFA, my wife Keara immediately thought it was myasthenia gravis," Kevin said. "It seemed too coincidental to me, but she did the ice pack test, and it worked—his droopy eyelid went away."

Soon after, they received a formal MG diagnosis from a neuromuscular specialist.

After helping hundreds of people with MG, they were stunned that this rare disease had touched their own family.

Like others facing the unknown after an MG diagnosis, the Macks turned to the MGFA. Through the MGFA Partners in Care program, they found an MG specialist. Through the MGFA's webinar series and website, they found educational resources about the disease. They joined a new MGFA virtual support group for youth and their families.

Inspired by the support they received and their experience working with patients and caregivers through the helpline, the Macks committed $5,000 to support the MGFA's critical mission. To encourage others to give back as well, they structured their donation as a matching gift.

Raising awareness about myasthenia gravis was one reason the Mack family wanted to tell their MG story. Only through greater awareness can there be change.

"On the helpline, people talk a lot about lack of awareness—even some medical professionals haven't heard of MG—but fundraisers and projects like DARE to CARE can spread awareness and ensure more people know what this condition is," Kevin shared.

Thanks to supporters like the Macks, the MGFA will be there for patients and families at all stages of their MG journeys.

> "Use the resources and support you do have. Don't be reluctant to ask people for help. People have joy in helping others."
>
> —Kevin Mack

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FINDING STRENGTH IN THE JOURNEY: Valerie's Myasthenia Gravis Story

I was 30 when I was diagnosed with myasthenia gravis. Before my diagnosis, I was a big runner. I remember the moment it hit me—one day, I couldn't run anymore. I just felt so fatigued.

Soon I started having blurry vision despite having perfect eyesight. I had issues with simple tasks like brushing my teeth and putting my hair into a ponytail. I felt such extreme fatigue—I remember crawling into a ball because my body felt so weak. I was dizzy. I couldn't pick up my 3-year-old son.

My older sister was diagnosed with MG when she was 18. She had a tumor on her thymus gland and had a thymectomy, and, fortunately, she went into complete remission.

Because of her experience, I pushed for an MG test. The doctor initially dismissed the idea—saying that siblings couldn't both have it—but my results came back with an incredibly high AChR antibody level. Even my parents were shocked to hear that I had MG because my symptoms were so different from my sister's.

Getting in to see a specialist took months, and during that time, I felt extremely depressed and helpless. I might wake up feeling okay, but by the end of the day, I was completely drained. I started IVIG treatments, which I relied on for about 3.5 years.

Now, I'm on one of the new compliment inhibitor treatments, which has been life changing. I can do most things I want to do, though I still have to be mindful of my limits and make sure to schedule in rest.

Living with MG has taught me not to take my health for granted. It has forced me to listen to my body more and appreciate the small moments with my family. One of the hardest parts of this disease is that it's invisible—people might see me and think I look fine, but they don't see the fatigue or the effort it takes to keep going.

If there's one thing I would tell others, it's to trust themselves. I knew something was wrong with me, even when doctors initially dismissed it. If you feel like something isn't right, follow your gut and advocate for yourself. I hope that by sharing my story, I can help others feel seen, supported, and empowered to keep moving forward.

> **If there's one thing I would tell others, it's to trust themselves. I knew something was wrong with me, even when doctors initially dismissed it.**

EXPLORE THE POSSIBILITIES

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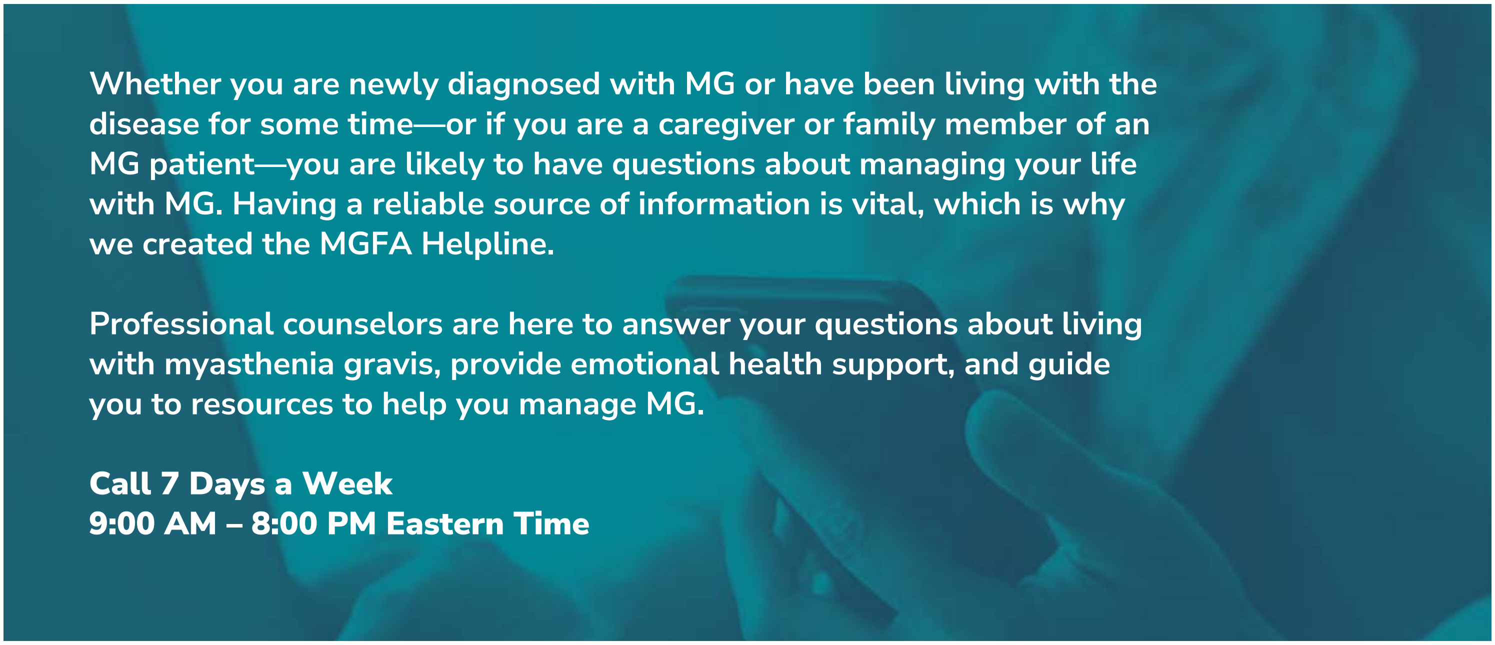

Whether you are newly diagnosed with MG or have been living with the disease for some time—or if you are a caregiver or family member of an MG patient—you are likely to have questions about managing your life with MG. Having a reliable source of information is vital, which is why we created the MGFA Helpline.

Professional counselors are here to answer your questions about living with myasthenia gravis, provide emotional health support, and guide you to resources to help you manage MG.

Call 7 Days a Week
9:00 AM – 8:00 PM Eastern Time

Johnson & Johnson Receives FDA Approval for IMAAVYTM (nipocalimab)

We are so excited to share that our strategic partner Johnson & Johnson has received United States Food and Drug Administration (FDA) approval of IMAAVYTM (nipocalimab) for the treatment of people ages 12 and older who are living with antibody positive (AChR+ or MuSK+) generalized myasthenia gravis. Johnson & Johnson states that this new FcRn blocker offers long-lasting disease control in the broadest population of people living with MG.

"We consistently hear from individuals living with myasthenia gravis who are hopeful for new treatment options that may help bring greater stability, independence, and predictability to their lives," said Samantha Masterson, president and CEO of the Myasthenia Gravis Foundation of America. "This treatment provides another option which could help address the constant uncertainty and heavy physical and mental toll that MG symptom relapse presents to patients and their families."

Read more about this amazing announcement and latest MG treatment.

Learn more

JOIN THE MG WALK

MG Walk – New York
September 13 at 10:00 a.m.
Roy Wilkins Park
Jamaica, Queens, NYC

MG Walk – Southern California
October 4 at 10:00 a.m.
Miles Square Park
Fountain Valley, CA

MG Walk – Washington, D.C.
November 1 at 10:00 a.m.
Ben Brenman Park
Alexandria, VA

MG Walk – Houston (Rescheduled!)
November 15 at 10:00 a.m.
Cullen Park
Houston, TX

REGISTER at mgwalk.org

VOLUNTEER

Want to make a difference? Volunteer to help out with the MG Walk! Hand out t-shirts, help with snacks or wayfinding, or talk to others in the MG Community. Email Erin at eturner@myasthenia.org if you are interested.

Carlos Ortiz (right) with his parents.

Why I Walk for a World Without MG

By Carlos Ortiz

I walk for myasthenia gravis awareness because this rare disorder has transformed both my father's life and our family's life in a significant way. Assisting my dad in navigating this condition has been a profound journey filled with challenges, uncertainty, and frustrating moments.

Rare diseases like myasthenia gravis can leave families feeling lost and overwhelmed by the medical system and the search for reliable information. After my father's diagnosis, I felt an urgent need to take action—not just to understand MG so I could support him, but also to find a community where he could discover others with a genuine understanding of the struggles accompanying this disease, as well as support and resources.

What inspires me most about this community is the strength and resilience reflected in the faces and stories of those affected by myasthenia gravis. Every step we take together reminds me that, while this is a rare disease, the determination to overcome it is anything but rare.

I firmly believe in my ability to leverage my skills and network to create meaningful change for the MG community—whether through raising awareness, securing resources, or voicing advocacy.

The MG Walk transcends a mere day of action; it symbolizes continual hope, represents a step toward answers, and shows my dad that he is never alone in this journey. This cause is close to my heart, and I will continue to champion it for as long as it takes.

MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT

FIND RESOURCES AND MAKE CONNECTIONS in Your Community

Join an MGFA Community Health Fair this fall

These free events are open to all in the MG Community who need resources or connections with others. Learn more about managing MG, meet other patients and caregivers, and hear from top providers in your area.

All events take place on a Saturday from 9 a.m. to 1 p.m. Register on the MGFA website.

Register for Community Health Fairs

Toronto Metro Area / Waterloo

August 23, 2025

Crowne Plaza Ontario Kitchner-Waterloo

Hosted in partnership with the Myasthenia Gravis Society of Canada

Boston

September 6, 2025

Boston Marriott Newton

Speakers: Amanda Guidon, MD, Massachusetts General Hospital – *Treatment Options for MG*

Michael Hehir, MD, The University of Vermont Health Network – *Taking Care of Yourself with MG*

DMV

September 13, 2025

Washington Marriott at Metro Center

Speakers: Joseph Choi, MD, Inova – *Treatment Options for MG*

Kelly Gwathmey, MD, VCU Health – *Taking Care of Yourself with MG*

Seattle

September 13, 2025

W Bellevue

Speaker: Christyn Edmundson, MD, Swedith Health Services – *Treatment Options for MG*

Chicago

September 20, 2025

Chicago Marriott Southwest at Burr Ridge

Speakers: Danielle Mitchel, MD, NorthShore – *Treatment Options for MG*

Carlos Lara, MD, University of Chicago Medicine – *Taking Care of Yourself with MG*

Houston

October 11, 2025

Houston Methodist Research Institute

Hosted in partnership with Houston Methodist. Full program information will be available soon!

Phoenix

December 6, 2025

Renaissance Phoenix Downtown Hotel

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HOW YOUR MG SUBTYPE Makes a Difference in Your Care

By Meridith O'Connor

The MG Community was privileged to welcome Kevin O'Connor, PhD, as the keynote speaker at this year's MGFA National Patient Conference. The department chair of neurology and immunobiology at Yale School of Medicine offered an insightful presentation on the subtypes of MG, what occurs physiologically in an MG patient, the distinguishable differences between the subtypes, and how newly approved treatments are being developed because of our understanding of the disease at a molecular level.

In the last decade, scientists like Dr. O'Connor and members of his lab have unlocked new understanding of the antibodies known to cause MG. These tiny cells can have a major impact on disease symptoms, progression, and treatment. For that reason, it's important for patients, providers, and family members to understand the types of MG and how your MG antibody can affect your journey.

Minimizing the Diagnostic Odyssey

The journey to a rare disease diagnosis can take years, putting individuals at risk for extraneous testing, financial ruin, and physical and emotional instability. Testing—of the blood and of muscle fiber "action potentials," in the case of MG—can not only tell you if you do have MG but also what kind.

Blood tests, including a more sensitive test called a cell-based assay, can detect different types of autoantibodies known to cause MG, including AChR, MuSK, and LRP4. A single-fiber EMG will detect abnormalities in your muscle function that can indicate myasthenia even without a positive blood test (called seronegative MG). There are also genetic tests that doctors can use to diagnose you with a congenital myasthenic syndrome, a rare genetic neuromuscular disorder.

Leaning on the care provider's expertise is fundamental to a proper diagnosis, but patients can play a unique role during this process by advocating for appropriate testing. Recognizing the subtypes and encouraging related testing not only empowers you during what can feel like a long, draw-out process, but also brings you one step closer to an accurate diagnosis.

Appreciating the Diversity of the MG Experience

Once officially diagnosed with MG, you may find that your symptoms are different from those experienced by your fellow community members. Of course, there are hallmark signs and symptoms of MG, but the heterogeneity of this disease, in part, can be attributed to the differences in MG subtypes. For instance, those with MuSK MG are more likely to have a severe onset of symptoms and to experience bulbar and facial weakness.

Acknowledging the variations of MG validates the lived experience of each individual and their care partners, in addition to empowering patients and providers to find the best treatment options possible.

Selecting Appropriate Therapeutic Options

Many of the new MG treatment options are targeted to specific antibodies. Knowing your subtype can help you and your doctor choose a therapy that has the best chance of treating your symptoms.

Some treatments are FDA approved for certain subtypes, not others, meaning you may have an easier time receiving insurance approval if you know your antibody status—or may need to work with your doctor to build a case for why you should receive the treatment "off label." While MG subtype isn't the only factor physicians rely on to determine the best therapeutic approach for an individual patient, it is a crucial factor. Depending on where you are on your MG journey, this knowledge can help you better understand recommended treatments and gain insight into your provider's clinical rational for pursuing certain options to achieve the best possible outcomes.

More than 600 MG Community Members Attend MGFA 2025 NATIONAL PATIENT CONFERENCE

MGFA hosted its annual National Patient Conference in Phoenix, Arizona this spring and a record-setting 600+ MG Community members attended both in person and virtually. Those who traveled to the lovely Arizona Grand Resort & Spa were treated to warm weather and multiple opportunities to learn and grow while coming together to hug old friends and meet new ones.

The conference kicked off on Sunday, March 30 with an inspirational and informative keynote from MGFA Chief Scientific Advisor Dr. Kevin O'Connor. Subsequent sessions on both days of the conference dealt with everything from legislative advocacy and new treatment insights to patient panel discussions and ways of "changing the MG conversation" to highlight amazing progress made in the past five years in terms of MG treatments. For the first time ever, strategic partners also provided patient "Experience Rooms" to learn about MG treatments, get tips for managing MG, and experience some fun and meaningful activities. These rooms and the exhibitor hall featured:

- The "Go for Growth" experience room, an inspiring space where individuals living with MG could nurture their growth, set meaningful goals, and rest and recharge.
- An adaptive yoga demonstration.
- Materials, guidance, and inspiration to create a "junk journal."
- A conversation on healthy eating with a registered dietitian.
- A pup-tastic pet therapy experience.
- Meeting an advocate to talk about how to adapt your hobbies to live your best life with MG.

Thank you to our partners Alexion, argenx, Johnson & Johnson, NMD Pharma, and UCB for hosting these Experience Rooms!

Congratulations to the 2025 Volunteer and Service Award Recipients

Each spring, we recognize extremely impactful volunteers and supporters. These committed individuals and companies have made a measurable difference for the MGFA and the MG Community. This year's awards ceremony was held during a Western-themed dinner at the National Patient Conference. Congratulations to this year's recipients!

Ambassador of the Year
Gene Casagrande

Ellsworth Award and Outstanding Service Award
Brian Gladden

Partner in MG Care of the Year
Dr. Kelly Gwathmey

Emerging Leader Award
Carlos Ortiz

Corporate Partner of the Year Award
Johnson & Johnson

Watch 2025 MGFA National Patient Conference Sessions

If you could not join us virtually or in Phoenix this spring, watch all the conference sessions on our YouTube channel. Highlights include:

- Our keynote speaker, Dr. Kevin O'Connor, discussed the different disease processes driving the subtypes of MG, including AChR, MuSK, and LRP4, as well as myasthenic disorders like CMS and LEMS.
- Melinda J. Burnworth from the National Organization for Rare Disorders shared tactical guidance for legislative advocacy and self-advocacy.
- MG patient and former OBGYN Vickie Petz Kasper talked about transforming your challenges and rewriting your story in an inspiring presentation.

Watch Sessions on YouTube

Save the Date

The 2026 MGFA National Patient Conference will be held April 12–14, 2026, at the Margaritaville Hollywood Beach Resort in Hollywood, Florida. Registration opens in late fall.

CONVENING MG RESEARCHERS FROM ACROSS THE GLOBE

MGFA hosts its first gatherings of researchers and patient advocacy organizations outside of the United States

The MG Community came together in Den Haag, The Netherlands on May 13-15 as the MGFA hosted the 15th International Conference on Myasthenia and Related Disorders—for the first time outside the United States. Nearly 700 MG experts, clinicians, medical professionals, researchers, and individuals diagnosed with MG—from 44 different countries—converged at the Postillion Convention Center to present the latest, groundbreaking and innovative research that could advance new treatments and methods of mitigating MG symptoms.

More than 240 research abstracts were submitted and accepted this year—an unprecedented number—demonstrating extremely impactful progress and innovation in research. All attendees agreed that now is an exciting and powerful time to be part of the MG community.

Guided by an expert Steering Committee, research presentations and sessions focused on a rich array of topics this year due to the expertise of our global presenters. Topics included the future of precision medicine, the use of artificial intelligence and technology to track patient symptoms, new types of autoimmune therapies and treatments, personalized care, and seronegative MG. The conference ended with a compelling topic—"Can We Cure MG?"—which focused on cutting-edge medicine like CAR T cell therapy.

Attendees and presenters were treated to a historic and impactful set of meetings, speaking sessions, and presentations. Research presented at the conference will open new doors, changing our understanding of MG, the way medical professionals treat it, and how the disease impacts patient and their families.

Additional highlights of the conference included a welcome reception for all attendees, a celebratory dinner at The Atrium in Den Haag, and keynotes from Sonia Berrih-Aknin, PhD, a leading immunologist from the Sorbonne; James "Chip" Howard, MD, FAAN, a neurologist and faculty member at UNC-Chapel Hill School of Medicine; and Stephen Reddel, MBBS, PhD, a neurologist at Sydney Neurology.

Special thanks to our Steering Committee, led by co-chairs Carolina Barnett-Tapia, MD, PhD, and Maartje Huijbers, PhD, and our sponsors, particularly our Presenting Partners Alexion, argenx, Johnson & Johnson, and UCB.

View the conference program and abstracts

At the conference, we recognized Dr. Angela Vincent as the very first recipient of the MGFA's Lifetime Achievement Award. The award recognizes a distinguished scientist, scholar, or clinician who has made significant contributions in the field of MG. Dr. Vincent was a clear choice as a pioneering force in MG research. Among her most significant accomplishments is the discovery of the MuSK-positive autoantibody as a cause of myasthenia gravis. She was also an early identifier of what is now known as seronegative MG. Her discoveries were impactful in their day and have stood the test of time.

MGFA also hosted its very first patient advocacy organization summit prior to the International Conference, which featured MG PAO leaders from 17 different countries. This insightful convening of patient advocacy leaders from around the globe helped to shine a spotlight on important medical challenges across the global landscape while serving to educate attendees on the amazing work that their organizations are achieving for MG patient communities. Through this summit, the groups identified several opportunities to work together—stay tuned for updates on our global collaboration.

Experience the International Conference through photos

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MGFA makes a difference for thousands of people around the world impacted by myasthenia gravis. Donations from people like you fuel this critical work. Make a tax-deductible gift today online at **myasthenia.org/donatenow** or call us at **(800) 541-5454**.