FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Fall/Winter 2023

Fall/Winter Edition Highlights:

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FDA Approved This Summer

MG Patient Data
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FROM THE DESK OF THE CEO

Dear Friends,

As we head into the final months of the year, we want to thank you for your ongoing support and commitment to our collective mission...a world without MG. It would be impossible to not acknowledge what a monumental year this has been with our coming back together at our National Patient Conference, in person, for the first time in four years, and with the continued evolution of the MGFA. It has been a year of inaugural programs and events you have been there to witness and participate in and support! This year has also marked the final year of our current strategic plan... so much progress has been made and we are proud and grateful to be on this journey with each of you.

Some highlights to date from 2023 that we would like to share include:

We came together at our National Patient Conference in March in New Orleans. It was so amazing to see everyone who attended, as well as the hundreds of virtual attendees, and to be able to have meaningful conversations face-to-face. For some of us, it was the first time meeting community members in person...and for others, it was welcoming old friends back home. The MGFA National Patient Conference has always been a forum of coming together, celebrating and caring for one another, and sharing how we can be most impactful together.

We celebrated MG Awareness Month in June with friends around the globe who turned action into awareness! Thank you for our friends who served as MG ambassadors across the United States, Europe, Eastern Europe, and Taiwan! From hosting community events to structure lightings in Mobile AL, Boston MA, and Myrtle Beach SC... we shone a bright light on MG Awareness AND, we launched our DARE to CARE campaign during June Awareness which raised over $50,000! Thank YOU!!

Our MGFA Online Community, our one-of-a-kind digital ecosystem, expanded to include the West Campus which includes a Pediatric Center, an Urgent Care Center, and our International Center! We are excited to share that we will be translating important educational information which will live in the International Center, as well as showcase our global partnerships in this new space!

Our new MGFA Community Health Fairs, launched in 2022, expanded to include new sites in New York City, Charlotte, Houston, Seattle and Chicago. Our Community Health Fair in Chicago was done in collaboration with Conquer MG and it was an amazing partnership! All ships rise together!!

We hosted our inaugural MG Insider Event which brings together key stakeholders who have been invested in the organization for many years to learn about MGFA's research focus.

We embarked on Phase 2 of the MyMG Mobile App, which included new features such as facial recognition, text multi-factor verification, Fitbit integration, and multi-national onboarding.

Our patient registry, which is the primary centralized patient date repository for MG, has expanded to become the MGFA Global MG Patient Registry. This key and critical resource in the research space will continue to influence and impact research to move the field forward.

In November, we hosted our annual Scientific Session as part of the greater AANEM Annual Meeting which brings together the scientific and clinical communities. And, within all of these wonderful updates and sharing of our progress as an organization, I would very much like to like to hear from you...I love meeting and hearing from our constituents and invite you to connect. Should you wish to learn more about MGFA, or become involved in a more meaningful way, we are here to help and to support your needs. Thank you for being a friend to MGFA and for supporting our collective mission. It is an honor to serve in my role as an MG ambassador.

Warm Regards,

Samantha Masterson
President and CEO

Meet Our Newest MGFA Board Member

Welcome Dr. Kelly Gwathmey

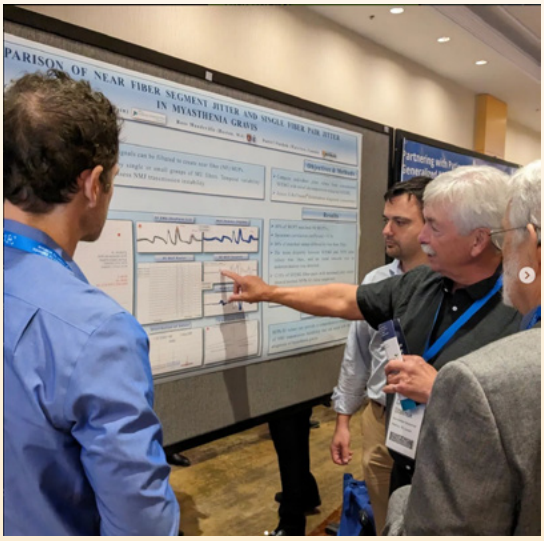
Kelly Gwathmey is an associate professor of neurology at Virginia Commonwealth University in Richmond, Virginia. She studied neuroscience and behavioral biology at Emory University in Atlanta. She then attended Eastern Virginia Medical School in Norfolk, Virginia. Her neurology and clinical neurophysiology training was completed at the University of Virginia. Following this, she completed a neuromuscular medicine fellowship at both Brigham and Women's Hospital and Massachusetts General Hospital in Boston. At the University of Virginia, she started the multidisciplinary MDA clinic, was co-director of the ALS clinic, and was the fellowship director for both the Neuromuscular and Clinical Neurophysiology fellowships. Kelly joined VCU in January 2019 and currently serves as neuromuscular division chair, neuromuscular medicine program director, and EMG Laboratory director. Dr. Gwathmey sees a wide spectrum of neuromuscular patients and performs electrodiagnostic studies (nerve conduction studies and electromyography). Her research interests include environmental risk factors in ALS and quality-of-life instruments. She has supported the MGFA for several years as an advisor and most recently as a member of the MGFA Global Patient Registry Advisory Council.

MGFA Bringing Together the MG Scientific Community at the Scientific Session

In November, the MGFA hosted our annual Scientific Session at the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM) annual meeting. The session, located in Phoenix, was focused on professional myasthenia gravis education. Hundreds of research and clinical professionals as well as scientists, industry representatives, and academics attend each year.

This event gives medical professionals the opportunity to learn from colleagues about current, pre-publication research on myasthenia gravis. The half-day session showcases the groundbreaking, unprecedented research work being done that could lead to new discoveries and improved treatments for those with MG.

Dozens of MG professionals presented their research this year. Dr. Anna Punga gave the keynote, "Unraveling the Puzzle: Game-changing Biomarker Development in Myasthenia Gravis."



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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.

Two New MG Treatments FDA Approved This Summer

This summer brought exciting news – two new treatments have been approved for generalized myasthenia gravis.

Samantha Masterson, MGFA's president and chief executive officer, notes that people living with MG continue to experience significant unmet medical needs, and expanding the number of FDA-approved treatment options is an important priority.

"The MG Community is energized and excited to have new, effective FDA-approved treatments available," she says. "Thank you to our industry partners, UCB and argenx, for their continued commitment to bring new treatment options to patients."

UCB Offers Treatment for AChR and MuSK MG Patients

In June, the U.S. Food and Drug Administration approved UCB's RYSTIGGO (rozanolixizumab-noli). This drug, delivered by injection, is approved for adults with AChR or MuSK generalized myasthenia gravis.

The approval came after a large, phase 3 study showed that treatment with RYSTIGGO led to improvements in activities including breathing, talking, swallowing, and being able to rise from a chair.

Rozanolixizumab-noli is in a class of treatment called neonatal Fc receptor (FcRn) blockers, which also includes argenx's VYVGART and VYVGART® Hytrulo.

FcRn blockers attach to and block the neonatal Fc receptor. This reduces Immunoglobulin G (IgG) antibodies, including the AChR and MuSK antibodies that cause MG symptoms. When harmful antibodies are removed, they can no longer disrupt nerve-muscle communication.

Argenx's New Injection Treatment Provides Convenient Treatment Delivery

Also in June, argenx announced that VYVGART® Hytrulo (efgartigimod alfa and hyaluronidase-qvfc), a subcutaneous injection for adult MG patients who are AChR antibody positive, was approved by the U.S. Food and Drug Administration.

VYVGART Hytrulo makes it possible for patients to receive VYVGART via an injection instead of an IV infusion. The subcutaneous injectable treatment is a direct response to patient and provider calls for a more convenient way to administer medication.

VYVGART was the first FDA-approved FcRn blocker treatment available for generalized myasthenia gravis patients and has been on the market since early 2022.

To support access for patients to its medicines, argenx has priced VYVGART Hytrulo in line with VYVGART.

Thank You for being part of the first MG Blizzard Week!

We hope this new, week-long opportunity to give back was joyful and meaningful to you. Funds raised will support MGFA's important mission to create connections, enhance lives, improve care, and cure this "snowflake disease."

mg™ MYASTHENIA GRAVIS FOUNDATION OF AMERICA

BLIZZARD week

October 1st - 7th, 2023

Ever wonder where the term "snowflake disease" comes from? Like a snowflake, each person with MG experiences the disease differently. No two are alike!

Listen as Rona, who was diagnosed with MG in 2000, shares how the snowflake became an enduring symbol for myasthenia gravis thanks to the patient community and a special woman named Grandma Bev.

Watch at www.youtube.com/shorts/4fyNGDp31y8 or scan the QR code.

Cartesian Highlights Positive Results in Recent Published MG Study

Modifying Patient T-cells Creates Novel Approach to Treating Myasthenia Gravis and Other Diseases

To keep the MG Community updated on new research discoveries, we want to tell you about newly published research in The Lancet Neurology.

Cartesian Therapeutics, an MGFA industry partner, announced the publication of positive results of the first successful clinical trial of RNA cell therapy for patients with autoimmune disease. By modifying patients' T-cells with mRNA (a form of rCAR-T therapy), the study authors have created a novel approach for potentially treating myasthenia gravis (MG) and other autoimmune diseases.

The data demonstrates potent and durable clinical improvement in patients with MG, representing the first successful Phase 2 trial using RNA cell therapy.

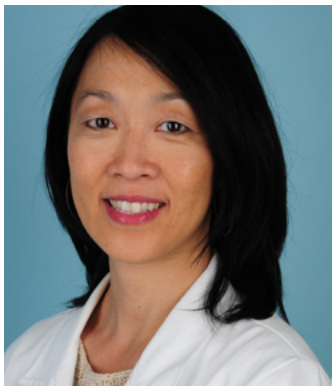
"We are grateful to our community of MG patients and physicians for enabling clinical development of novel therapeutics such as rCAR-T," said Samantha Masterson, president and CEO of the Myasthenia Gravis Foundation of America. "A safe, personalized therapy with durable clinical benefit would be a welcome addition to the growing toolkit of MG treatments."

The results described in The Lancet Neurology paper suggest that rCAR-T may be useful in treating a variety of other autoimmune diseases and may overcome many of the risks and toxicities associated with conventional DNA-based CAR-T cells. A news release about this study is available on the Cartesian website (scan QR code).

You can also download the full manuscript from the MGFA In the News page (scroll down to the article titled "Modifying Patient T-cells Creates Novel Approach to Treating MG and other Diseases" or use the QR code at the top).

To learn more about Cartesian's study with rCAR-T and review other open and recruiting clinical trials that you can apply to, visit the Clinical Trials page at myasthenia.org/Research/Clinical-Trial-Opportunities.

Targeting B cells may help people with MuSK Myasthenia Gravis



Last year, the MGFA dedicated $1 million to research activities, including grants to exceptional scientific minds who are pioneering research in myasthenia gravis and related neuromuscular disorders.

One of those is Aimee Payne, MD, PhD, a specialist in rare autoimmune skin disease.

She received the inaugural Nancy Law Impact Award in 2022 to support her research exploring a precision medicine approach to MG.

A professor of dermatology at the University of Pennsylvania, Dr. Payne is evaluating how to target MuSK autoantibody-producing B-cells while preserving healthy B-cells. This work could potentially help patients with MuSK MG find significant relief from their symptoms – perhaps even cause remission – without depleting their immune system.

Dr. Payne talked to MGFA about her background, her work with CAAR-T cell therapies, and why she's excited about this prospective treatment for myasthenia gravis.

Q: How and why did you get into scientific and medical research?

I became interested in medical research when I was in college at Stanford University. My mentor back then, Gilbert Chu, studied rare genetic syndromes where you can't repair your DNA after it's damaged by sunlight. Those patients end up getting severe sun sensitivity and skin cancers at an early age. So that got me hooked on how the basic science of DNA repair can mesh with the clinical care of patients.

I ended up applying to MD/PhD programs after college to learn how to become a physician scientist. I ultimately became a dermatologist who studies rare autoimmune skin diseases, specifically pemphigus, where your body mistakenly makes antibodies that attack your skin cells, causing them to fall apart and blister.

Q: How did you end up working on myasthenia gravis?

We developed a targeted therapy for pemphigus and then began to think how we could apply that to other, similar antibody-mediated diseases. Myasthenia gravis really jumped to the top because it's one of the best characterized autoimmune diseases, based on decades of work by people affiliated with the MGFA – basic researchers, translational researchers, clinical researchers – aiming to better understand how autoimmunity occurs in MG.

There are really a lot of parallels between pemphigus and myasthenia gravis, particularly the MuSK subset, and that's what got us focusing on MuSK MG. We started collaborating with people in the community to develop a targeted therapy for MuSK MG.

Q: Your research has focused on using CAAR-T cells to target the B-cells that produce anti-MuSK autoantibodies. Tell us about your approach.

We have invented a precision-medicine approach for antigen-specific B-cell depletion in MuSK myasthenia gravis that we call chimeric autoantibody receptor therapy, or CAAR-T. Anti-C19 chimeric antigen receptor (CAR)-T is FDA-approved for the treatment of B-cell leukemia and lymphoma, and that approach is very effective for cancers. It also leaves a patient potentially immunosuppressed for the rest of their lives; some of them have to get lifelong IVIG infusions to maintain normal immunity. But the remarkable nature of the cures that were induced by that therapy got our attention.

So, the idea was, instead of wiping out all of your B-cells, could we just eliminate immune cells that are expressing anti-MuSK autoantibodies?

We have taken several key steps to move research forward. We showed proof of concept in mice, which were given an experimental form of myasthenia gravis in which we induced an antibody response, and published those results in Nature Biotechnology in January 2023.

We collaborated with other researchers, such as Dr. Kevin O'Connor at Yale, to engineer target

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cells in the laboratory to express human B-cell receptors that target MuSK and see if we could kill them. We also ended up collaborating with MuSK MG physicians to give us blood samples containing anti-MuSK B-cells from these patients to see if these CAAR-T cells could kill them in a dish. And then we worked with several clinicians and researchers in the field to help us design the clinical trial protocol.

Based on that, we were able to launch the Phase 1 study, which received FDA clearance for the investigational new drug application in 2022. We're bringing on new sites by the month. Right now, we're working with sites at UC Irvine, UC Davis, University of Kansas, and University of Oregon.

Q: How does this potential treatment approach benefit patients?

Pemphigus used to be fatal. Before steroids, you could actually blister off all of your skin and mucous membranes. You couldn't eat. You were like a burn patient in the hospital. It was a terrible outcome.

Now that steroids and rituximab are available, patients are no longer dying from their disease, but they are potentially suffering from the immunosuppression caused by the therapies that I prescribe to control the disease.

If you talk to physicians who treat pemphigus or MG, one of the concerns is that most therapies suppress your immune system broadly. This was really highlighted during the pandemic, when rituximab was associated with a four to five-fold higher risk of hospitalization or death from COVID-19 just because it impaired the immune system. So that was the problem we were trying to solve from the patient and the physician perspective.

For me, precision medicine has always been the holy grail of what we're trying to achieve. With a precision approach, we're leaving most of your B-cells alone and just targeting less than 1% of your normal B-cell population.

And one powerful advantage of engineered cells is they have the potential to persist for a lifetime after infusion – or at least months to years. The hope with CAAR-T cell therapy is that, if it is effective at achieving this MuSK-specific B-cell depletion, we could safely put disease in remission after a single infusion.

Q: What excites you about being an autoimmune disease researcher today?

MG is a super exciting space. There's a broad range of therapies that are advancing to clinical trials.

The diversity is great for many reasons. Obviously, we hope that will bring better therapies to patients, but also, from a biological perspective, we're learning a lot about the biological pathways of MG. The ultimate goal is not to make patients a little bit better – we really want to cause long-term remission of disease.

Q: What does it mean to you to be a MGFA grant recipient?

Organizations like MGFA are so critical because you're increasing the awareness of MG. Tens of millions of people in the country have diabetes, but only tens of thousands have myasthenia gravis and people may have never heard of the disease.

In study sections when funders are considering grant applications, you might hear, "That's such a rare disease, MuSK myasthenia gravis – why don't we fund studies that are going to affect millions of people? Won't we get more bang for our buck?" That's why it is so helpful for patient organizations to support research funding in these rare disease fields.

I'm honored that MGFA recognized the connection between our work with pemphigus and how it applies to myasthenia gravis. It's invaluable because I don't think that this kind of research is typically supported by traditional grant-funding mechanisms.

MGFA Sees Important Outcomes from New MG Patient Data in Registry

The MGFA Global MG Patient Registry was established in 2013 and is a longitudinal, online registry containing myasthenia gravis patient-reported health and symptom data.

Patients from around the world safely and securely add their data, which is protected and private as part of a HIPAA and GDPR-compliant platform, powered by Alira Health.

The registry can be accessed at MGRegistry.org.

"As a person diagnosed with myasthenia gravis, I am honored to enter my health data to find better treatments. The registry provides an extremely pleasant experience and is critical to new research discoveries." – Paul Strumph, MD

Why Should Those Diagnosed with MG Enroll in the Registry?

The actual, up-to-date MG patient data in the registry has enabled researchers to improve their understanding of myasthenia gravis while developing new treatments to help patients manage their MG. Data from members of the MG Community like you directly influences and informs the clinical trials process. Without patient data, these critical trials cannot move forward, and we would not have new discoveries or treatments.

What's in It for You?

MG patients describe feeling empowered and excited about directly contributing to groundbreaking research to help the MG Community. Your contributions to the registry can help the entire MG Community. Medical insights from the registry will be communicated so you can understand how your MG experience compares with others in the MG community. Also, all published research will be shared so you can see how the registry is driving new discoveries.

How Do You Participate?

Enroll in the registry if you have not done so by going to MGRegistry.org. You can use the online questionnaire form or download the Health Storylines mobile app for your smartphone. You are asked to complete registry questionnaire surveys twice a year to input your health and treatment data and contribute your day-to-day MG experiences. All descriptive data is de-identified, aggregated, and not directly accessible to external organizations or project sponsors.

Has Research Been Published Using Registry Data?

Yes, there have been a number of published research pieces that report on aggregated, combined data from the registry. Publications such as Muscle & Nerve magazine, Journal of Neurology, and Neurology Today have published a series of research study outcomes that showcase new discoveries and groundbreaking work within the MG space. We are also working on new projects and studies that will highlight new research.

As more and more patients enroll in the registry, the data will provide much better and broader cross sections of health data, generating even more valuable outcomes.

For more information, talk with your doctor or neurologist or contact the MGFA at mgfa@myasthenia.org.

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

Download on the App Store

Google play

Scan to visit mgregistry.org

MY MG STORY

I PERSEVERE BECAUSE THERE'S HOPE

By Meena Outlaw

I was diagnosed with myasthenia gravis in 2014. It took a lot of work to get diagnosed, for treatment to work, and to finally regain my independence.

I have daily challenges living with myasthenia gravis, but I persevere because there's hope.

We've come a long way after many years of working to bring awareness about this fickle disease. We can't do this alone. As a support group leader, I have learned that it takes a community to help keep our spirits up, and for our caregivers to forgive us for the days we just need to rest.

My children were affected by this condition because they lost out on some of their time with me. Nevertheless, as a mother my goal was to always stay positive and strong for them. My husband still worries about me because the initial diagnosis gave him trauma. Yet his strength and love has been so consistent and everlasting for me as I continue this journey of fighting for a better quality of life.

As time passed and I have responded well to treatment, I'm gaining back my life, and I'm slowly beginning to make up for lost time. Not just with my family, but for myself, in living my best life now. I've returned to work, I'm traveling again, and even furthering my education.

However, my quest to bring resources and knowledge to those who have been diagnosed with myasthenia gravis stays firm. As others have supported me in my journey, I will always pay it forward in supporting everyone from those who are newly diagnosed to veteran myasthenia patients.

It's important for other people who don't have myasthenia gravis to remember not to judge. Don't mistake our fatigue and no-shows for inconsideration. Often our lives are vague, because we really are living our symptoms one day at a time.

One day I can be up and a few hours later I can be down, tired, and just needing to rest. If I am not participating, it's because I'm resting to conserve energy so I can share moments later.

There's still a lot more awareness needed about myasthenia, especially in the medical community. Not all physicians know how to treat myasthenia gravis. Treatment is not one size fits all.

Caregivers must be supported because often they carry the load when we cannot.

I'm excited for my future with myasthenia gravis. I can only see further improvement as new treatments are introduced. My biggest hope is that one day, every person with myasthenia can receive optimal treatment targeting all antibodies.

Meena Outlaw leads an MGFA Support Group in Houston, Texas.

Researcher Investigates MG Mechanisms of Disease Thanks to Donor and MGFA Support

As a child in Iran, Dr. Fatemeh Khani Habibabadi was always interested in the world around her. Life and how the human body works fascinated her.

At university, she studied cell and molecular biology, life at its most basic level, then went even deeper for graduate studies, focusing on molecular genetics. It was here that her fascination with autoimmune disease piqued while exploring the molecular approach to studying multiple sclerosis.

"I worked on the interaction between noncoding RNAs and proteins that are known for their protective effects on multiple sclerosis patients," Dr. Habibabadi says.

After completing her PhD, she wanted to pursue her research in autoimmune neurological disorders and applied to join the lab of Dr. Kevin O'Connor at Yale University School of Medicine. Dr. O'Connor leads the O'Connor Laboratory in the Department of Neurology and Department of Immunobiology.

The laboratory consists of a team of researchers – junior faculty, postdoctoral fellows, graduate students, and undergraduate students – investigating the role that the immune system plays in autoimmune neurological diseases.

"We are interested in broadly defining the mechanisms by which B cells – and the autoantibodies they produce – participate in the pathology of MG by identifying the specific type of B cells that produce MG autoantibodies, detailing how MG autoantibodies give rise to disease symptoms, and studying how patients respond to immune modifying therapies," Dr. O'Connor says.

Dr. Khani joined this collaborative group of researchers in 2022. In the same year, she was awarded the Jackie McSpadden Post-Doctoral Fellowship. The MGFA awards this fellowship to promising MG researchers thanks to generous support from the McSpadden family.

Through the award, the MGFA and the McSpadden family hope to attract promising investigators to pursue MG research, expanding the number of researchers focused on this disease. Jackie McSpadden was a passionate, active volunteer in

the MG community. When she passed away, her family created the fellowship to honor her legacy and improve the lives of people with MG and related neuromuscular junction disorders.

In the O'Connor Laboratory, Dr. Khani is focused on providing the framework for deciphering precise roles of autoantibodies in MG pathogenesis. Ultimately, this work aims to help patients by predicting treatment efficacy and disease progression.

"I'm working on three mechanisms of action related to AChR autoantibodies. I hope to determine if they have a role in identifying patients who will respond better to certain treatments or predict non-responders," she says. "It's important because patient response to treatment is very different in each person diagnosed with MG."

While some people with AChR autoantibody-positive MG respond well to the newer medications now available, others do not find relief from their symptoms.

Dr. Khani is working on specimens from clinical trials investigating candidate treatments for MG, including complement inhibitors and

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B cell depletion therapies. Through this work, the team hopes to develop a better understanding of the disease, which could pave the way for new medications that might benefit a wider range of patients.

This research has uncovered the variability among patients in terms of both the quantity of AChR autoantibodies in the blood and, more importantly, how efficient they are at causing disease symptoms. Researchers have also learned that both the amount and efficiency of the AChR autoantibodies may change over time within individual patients.

Dr. Fatemeh Khani, right, with her husband Mansour Toorani and MGFA supporter Danny McSpadden.

Dr. Khani's early findings demonstrate the complexity of MG and emphasize the significance of personalized medicine, which considers the characteristics of autoantibodies present in each patient. The initial findings from this research are expected to be published soon.

Private funding helps this exciting work take place.

"External funding is everything for a lab. The MGFA helped me continue my research on MG for three years, which is awesome. Without that, it might have been impossible for me to continue my research. I really appreciate that, and I'd like to thank the McSpadden family who made this generous donation."

Learn more about the MGFA's research agenda at myasthenia.org/research.

MG Golf Tournament is a Family Affair

For 31 years, the Helen and Leonard A. Golden Memorial Golf Classic has brought together family, friends, neighbors, and colleagues in New Jersey to raise funds for myasthenia gravis research.

The annual tournament was created in honor of Helen Golden, who suffered from myasthenia gravis symptoms for years before her diagnosis, and her husband Leonard Golden. The type of person who fought things head on, Helen came up with the idea of hosting a charity golf tournament to raise awareness about MG.

Today it is the largest and most successful golf fundraiser benefiting the MGFA.

When the family started the tournament in 1992 thanks to Helen and Leonard's son-in-law, Sam Gershwin, no one expected it would continue so long or become so successful.

"The first year it rained, and they had maybe eight golfers, but nonetheless the charity tournament was born," said Jason Gershwin, Helen and Leonard's grandson, who became chairman of the annual event 18 years ago. Three generations of the Golden-Gershwin family have worked together to run the tournament.

"It's really exciting to witness and, frankly, quite powerful," Samantha Masterson, MGFA's president and CEO, said. "The sense of giving back and being dedicated to something that is bigger than oneself is evident with this family."

Jason remembers riding around in a golf cart as a child and being tasked with taking pictures of the event. His involvement deepened as he got older, and he took the reins as the event's leader in his mid-twenties.

His twin sons Zach and Owen, now 15, have grown up at the tournament.

One of Jason's favorite memories is the time when his boys were little, and baseball legend Yogi Berra, who attended the classic for many years, autographed their Yankees bibs.

Everyone in the family plays a role, from recruiting attendees and silent auction packages to staffing the registration table and greeting attendees at the clubhouse.

Even his "work family" has rallied behind the event – each year staff from his company, R4 Capital, come in droves to sponsor and attend with their friends and clients. *(continued on page 15)*

Members of the Golden/Gershwin family all participate in making the event a success

"My favorite part about this event is perpetuating the legacy of my grandparents, and doing it with my family – my parents, my sister, my wife, my sons, my in-laws, aunts and uncles – and with my work family," Jason said. "And then hopefully to pass it on to my sons. They never met their great-grandparents, but they want to be involved. That it's important to them to keep running the outing is probably the most rewarding aspect of it."

Running a successful event for so long requires a strong group of volunteers with various skillsets and the dedication to create a fun, memorable experience. The family has worked hard to make the Golden Classic a can't-miss event.

Jason said that running a first-class event is essential to attracting people with no personal connection to myasthenia gravis. The more people enjoy a day on the golf course, the more funds are raised to support MG research and education, and the more people walk away with an understanding of what MG is.

"We offer a great course, great giveaways, great food and raffle and drinks, so people say, 'Wow, that was a really fun day,' and mark their calendar for next year," Jason shared.

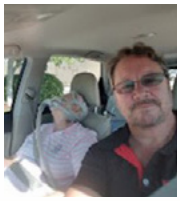
He says guests come back year after year. They know they're in for a great time in service of a great cause.

If you're interested in starting a charity golf tournament or other community fundraiser to benefit the MGFA's mission, reach out to Tasha Duncan at tduncan@myasthenia.org or fill out the Become a Fundraiser form.

Caregiving:
The Struggle is Real

By David Waters

My wife Anita and I are now in our sixties; we met in our late forties. We hit the ground running early in our relationship. Anita had already published a book about her first two mission trips to Ghana, West Africa. That opened the flood gates for me, and we published another book about my life within the first nine months of meeting. We traveled as far west as Hawaii and east to Africa. North to Nova Scotia and south to Belize. Anita was always happiest in the most inclusive and diverse conditions. A memory that stands out is a small dinner in our home with new friends from Sri Lanka, Mexico, China, and Ghana.



Today, I am a caregiver for the best human I've ever known, my wife Anita, who was diagnosed with MuSK+ MG in 2018. Witnessing the onset of what seemed like life-threatening symptoms and the frustrations of finding any solution was the scariest time of our lives. Mind you, during this time I was the only caregiver for my mother, who suffered from dementia. I am a disabled Marine veteran diagnosed as bipolar and as having PTSD from a helicopter crash, who at times needs caregiving myself.

I have a passion for supporting those in the "newly diagnosed" category today. The onset of MG turns your world upside down. From my perspective as a caregiver, MG life is all about caregiving. In an ideal scenario, a person is diagnosed and treated under a physician's care. The patient learns their limitations and cares for themselves. And the caregiver fills the gaps.

It grieves me to hear of relationships failing under the stress of the life-changing symptoms of any type of MG. MG patients don't have a choice. Caregivers do. Not everybody is up to the task, and I have discovered caregivers need care, too. MG, like an addiction or other life altering condition, affects the entire household. Immediate and major adjustments need to be made and endured.

To demonstrate how much of an impact MG has, we went from this to this in the blink of an eye.

A caregiver will often realize and accept that MG is not going away before the patient accepts it. There is a toll on every aspect of life. It consumes your psyche. All your energy is in seeking information to understand what you're up against. You scour the internet, read medical journals and medication trial results, and learn more medical terms than you ever cared to. Your sleep, intimacy, finances, diet, and exercise are all out of balance. You're balancing on a ball and juggling flaming knives – hyperalert.

My wife went from the highly educated, witty, super active woman that I met and married to being unable to hold her head up. She had difficulty chewing, double vision, and when she spoke, she sounded like Elmer Fudd. She began having difficulty breathing to the point where she couldn't sleep. She'd sit on the side of the bed in the middle of the night and gasp for breath. She couldn't bathe or dress herself.

Three trips to the ER in thirty days in the back of an ambulance, finding frustration in the lack of knowledge by medical personnel about MG will get you into an incredibly aggressive or completely defeated state of mind. I was scared to death that my wife was going to die. She lay on a gurney still barely able to breathe, using a CPR resuscitator bag on herself, and no one was doing anything to help!

Anita was finally diagnosed the day she was discharged the second time, still suffering from the same symptoms. Prescribed a useless medication that had the same symptoms for under dosage as over dosage.

We sought help elsewhere. Online research revealed Duke University Medical had a highly respected Neurology department specializing in MG. I drove Anita to appointments, four hours one way. She rode along using a battery-operated breathing machine, aka a bi-pap, that we obtained from a pulmonologist she'd already been seeing for asthma.

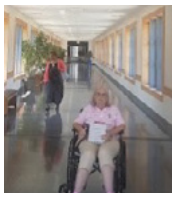
In a wheelchair that we'd brought along, I pushed her down the long, unfamiliar hallways of a distant hospital.

Wide eyed, I absorbed everything the doctor told us. By the end of the visit, we understood the treatment. We both breathed a sigh of relief. We felt seen, cared for, and hopeful that the current conditions could

(continued on page 17)

and would improve. We loaded up and made the four-hour journey home. We stopped for a rare treat to celebrate. A Wendy's Frosty. Little things like that seem so wonderful when you've been wandering in the wilderness searching for answers.

We made one more trip to the ER due to a choking episode, where the EMTs found us on the living room floor recovering. Her lips had turned blue, and her eyes rolled back in her head while I desperately tried all I could to save her. Once again, I'd thought I was going to lose her. My hypervigilance grew. I can't count how many times I'd lay in bed or have a quiet moment and feel that MG is such a bully. I'd wish it had attacked me instead of Anita. I'd take it all away from her if that were possible.



The future held appointments with her general physician, a neurologist, a pulmonologist, an optometrist, a dentist, and an ophthalmologist. High-dose Prednisone induced Glaucoma, spurted growth of cataracts, and created a macular crease. It also cracked a few of her teeth. A few surgeries later and weaning off of Prednisone, things were better. You're fighting one battle after another.

Life didn't stop while we played catch up. I dropped 70 pounds. Grandkids were being born, events we could no longer attend were still being held. We lost Anita's parents in a tragic car accident, and my mother passed away two weeks later. Talk about kicking you when you're down! The various stages of grief that were already evident in our lives were now amplified. Then a pandemic arrived. More hypervigilance and less getting out and about. We pressed on.

Today, Anita's MG is well managed. She is driving to her own appointments, she's active with all her crafty projects, and back to feeling good about being productive. I push her to achieve more than she thinks she can, and I understand when she just needs to stay in bed longer and let her batteries recharge.

She's remained the most wonderful human I've ever known.

I have not always made the best decisions for my own care. When Anita regained her independence, I let loose and used alcohol to relieve the hypervigilance that gripped me. This was not productive for me; it stressed Anita and is counter to my role. I reacted to this by beating myself up, having thoughts like, "I'm not a good caregiver," which I prided myself on being. I gained 50 pounds back.

Caregivers must be as willing to accept their own shortcomings as they are for their patient. You'll go through phases. You'll go from feeling incredibly determined to feeling completely defeated. From Energizer Bunny to complete exhaustion. But in time, I promise, determination and patience will prevail.

I try to find what I'm thankful for. We're thankful the kids have become compassionate adults and good parents. We're also thankful for organizations, groups, and individuals who seek to inform, treat, and support families that experience the monster of MG – MGFA and argenx to name just a couple.

Under great leadership they've pressured the system and made incredible, record progress with so many new treatments now available and in the pipeline as well as commercials on TV! MG is becoming a term people understand. It seemed relatively unheard of just a few short years ago.

Even with treatments that bring a tolerable sense of normalcy to the MG patient's life and the caregiver able to return to some activities that were sacrificed, I find that part of my psyche will entertain thoughts of impending doom in consideration of memories developed during the onset period of MG and now facing the long-term effects of immunosuppressant medications on my loved one's longevity. I try to stay present and celebrate the progress.

We try to give back. We've given our local EMTs literature on MG. We've shared with our friends and family what we've learned. We've found ways to make a difference.

Anita has volunteered for new treatment trials and is an MG Friend through MGFA. She gets assigned to individuals who have reached out wanting to be contacted and calls them as often as they desire. We wish we'd have found something like this in the early days. I am seeking to do similar for caregivers.

I donate plasma since so many MG patients use plasmapheresis as a treatment, and they even pay me for it! Did you know you can donate plasma twice a week? I highly recommend it if you're able. It's quite rewarding.

Today, life is good. We're thankful and closer than ever. Caregivers, please reach out. Find a support group near you. You need to be acknowledged, heard, understood, supported, and cared for.

This story first appeared on David and Anita's blog, Living Out Loud.

Mistakes Caregivers Make and How to Avoid Them

By Toni Claire Gitles, CEO of Heart of Caregiving

We are often thrust into a caregiving experience with a loved one. Often unprepared, overwhelmed feelings and stress can derail our life in an instant, while we use trial and error strategies to figure out how best to manage our new responsibilities.

Using my 40 years of professional experience in the healthcare industry and 14 years of lived experience caring for my mom, I gathered the mistakes and lessons learned. I compiled them in *21 Mistakes Caregivers Make & How to Avoid Them*. My book guides caregivers through common mistakes and empowers you to thrive in your roles with solutions, tips, and strategies to reduce stress and increase happiness. This overview will get you started transforming the mistakes into your success strategies.

1. You are Unprepared for a Health Crisis

You can expect to be a caregiver at some time in your life, but you haven't had the important conversations with a spouse, parent, or sibling before a health crisis occurs. You don't organize their health history, and you take your responsibilities as their caregiver for granted.

You can be blindsided by a diagnosis or a hospitalization that immediately becomes a medical crisis for the entire family, where emotions can run high. The stress you experience is compounded by your lack of confidence and fear of making a mistake or the wrong decision.

Take steps to prepare for a medical crisis by learning the medical history, medications your loved one takes, and physicians that care for your loved one so you can be a confident advocate and support person.

2. Everything Changes, and You Fail to Change

Maybe it's not an emergency. You may notice warning signs of a problem physically, mentally, or emotionally, but you ignore them. Don't wait. Have a calm and heartfelt conversation with your loved one about your concerns related to their health or abilities. Come from a place of love and support.

3. You Don't Prioritize Your Well-Being

You don't take care of yourself first, ask for help, or look for and find resources to support you and your loved one. When you begin helping a family member, your efforts may only require a few hours a week and you can balance competing priorities easily. As your duties intensify, you sacrifice your schedule for that of your loved one. Reclaim time, regain energy, and reset your priorities so your wellbeing rises to the top of the list. Locate help and resources to give you time to participate in the activities and family time that give your life meaning.

4. Ineffective Communication Skills

You fail to find out what your loved one needs and wants and how family and friends can help, and you settle for an incomplete understanding of doctor's orders and explanations. You may need to learn new interpersonal skills and ways of communicating with friends, family members, and your loved one. Communication with doctors and healthcare professionals takes a new level of preparation and finesse. Lead with love and curiosity, make direct requests, and find your voice. You will learn to confidently advocate for your family member.

5. Not Planning for an Uncertain Future

Your loved one doesn't have legal documents in order, and you are unaware of your loved one's financial information. While sensitive, start the conversation to understand your family member's current financial and legal situation and their wishes for the future. Always consult with professionals to understand the options, make better choices, and be empowered to advocate for your loved one.

6. Dismissing Happiness and Celebrating Life

You put your life on hold and cease or question your connection and guidance with a higher power. Unknowingly, you undervalue giving and receiving love in your relationships. With intention and strategy, you can be happy even during some of the most challenging circumstances. Look for new ways to receive and give love and celebrate life and your loved one each day.

Using the solutions to these mistakes, create your own dynamic caregiving plan, which will relieve stress and some uncertainty. Take control of the things you actually can control. In caregiving, as in life, things don't always go as planned. Your reaction and attitude influence your experience.

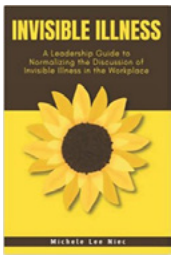
For more information, visit heartofcaregiving.com. Toni's #1 international best-selling book, 21 Mistakes Caregivers Make & How to Avoid Them: Strategies and Solutions to Reduce Stress and Increase Happiness, is available on Amazon.com.

Advice for the Accommodations and Education in the Workplace

Tips for ensuring you are seen, heard, and accommodated.

An interview with Michele Lee Niec

An invisible illness is one that you can't see from the outside. Someone may not "look" or "seem" sick, but, in fact, every day is a struggle.



Inspired by her own myasthenia gravis journey, Michele Lee Niec began researching the experience of others with invisible illness. She eventually wrote the book *A Leadership Guide to Normalizing the Discussion of Invisible Illness in the Workplace* (second edition out this year).

This reference guide defines invisible disability and offers initial steps employers and employees can take to create dialogue, foster understanding, and help ensure staff members with an invisible disability are comfortable and effective at work.

In honor of Disability Employment Awareness Month, Michele shared some best practices to ensure that people with invisible illness feel seen and heard at work.

How does an invisible illness like MG impact your ability to work?

The challenge is going to be that no two myasthenics are the same. Some might not be able to stare at a monitor all day because of their double vision. Some may need a certain temperature regulation. Some, depending on how they react to their treatment, may need flexible sick time. Some may struggle to communicate effectively if their voice muscles get fatigued. Some may need a certain chair that lets them rest their arms, even if no one else has a chair with armrests.

With any chronic illness, the experience will be unique to each person, but especially so with MG – there's a reason it's called the snowflake disease.

What advice do you have for requesting accommodations at work?

Meet with your employer and let them know it's ok to talk about your MG. Tell them what you need today and what you may need down the road. Accommodations can be ongoing or episodic -- who

I am today and who I might be, what I might need later. Having that conversation up front makes a difference.

You have to advocate for yourself and know what's going to work best for you. There are myasthenics in wheelchairs, and they'll need different accommodations than I would need. Use the My MG mobile app to track your good and bad times. When you start noticing trends, you have data to back up your requests.

Legally, what are people with an invisible disability entitled to per the Americans with Disabilities Act?

The ADA exists to protect employer and employee. Your employer doesn't have to provide accommodation that would put them in financial hardship, but they do need to provide "reasonable" accommodation. Employers also cannot discriminate in the hiring process (MG qualifies as a disability, as it's a physical impairment for most people). Of note, the ADA applies to companies with more than 15 employees.

When you onboard, you have the option to self-disclose that you have a disability, and you will have a legal right to workplace accommodations. If you are diagnosed after you're hired or decide that your symptoms are worse and you need support at work, you can still ask for ADA-mandated accommodation if you disclose to your employer at that time.

What advice do you have for self-advocacy in these situations?

For me, I've taken upon myself to be an educator for MG. I'm sure everyone's had that experience of, "Why are you parked in the handicapped spot? You look great." You need to become your own champion. You need to say, "I want you to know about this." By educating, you're not asking for sympathy, you're asking for empathy. We could all use more empathy. Starting with that educational approach really helps open up a conversation. Be self-aware of your needs and don't be afraid to advocate for yourself.

(continued on page 20)

What can employers do to better support employees with MG?
I do think employers should be proactive. In their handbooks they can share that if you have the need, we're here to support you. I think they have to speak as a global unit – "We as an organization believe in diversity, equity, and inclusion, and part of being inclusive and accessible is knowing that you have a place here and we want to work with you."

Then live it – don't just put it in the handbook and forget about it. Share stories with your employees about people going through invisible illness, then let them know, if you have challenges, my door is open. Leaders need to show they're open to two-way conversations.

What advice do you have for coworkers who want to support their colleagues with MG?
Support them by listening and not judging. That's the hardest part. Those who don't disclose their invisible illness feel they're lying, but when they do disclose, they feel judged. How do you live in that grey area between those two? As a coworker, peer, friend, you just have to ask questions, not make assumptions. "Hey, you look tired today, are you ok?" I guarantee that the person with a chronic illness will feel a weight lifted off their chest just to be asked that question.

Tips for a Successful Dentist Appointment

Practical advice from Dr. Cassagrande

Here are some tips from dentist and MG patient Dr. Gene Cassagrande on having a successful dentist visit when you have myasthenia gravis.

- Communication with your care team is vital. Make sure everyone in the office – from the receptionist to the hygienist and dentist – knows you have MG.
- Share the MGFA brochure, "Dental Treatment: Considerations for the Dental Care Team," found at myasthenia.org.
- Some modest accommodations to ensure you are safe and comfortable include:
  - Tip the chair back just to your comfort level.
  - Ask to use a rubber mouth prop to help keep your mouth open and relaxed.
  - A rubber dental dam can be helpful for restorative procedures. It prevents water and debris (i.e. from a filling) from going down your throat and can help prevent choking.
- Be sure to carry a list of cautionary drugs (find one at myasthenia.org) and share with your dentist and hygienist before any procedures. You can also email them the link to add to your chart.
- Any time you need major oral surgery, make sure you have a dentist-anesthesiologist, not just the oral surgeon. People with MG must take special care when under general anesthesia.
- Tools are available for MG patients if traditional flossing and brushing are difficult due to muscle weakness. Try an electric toothbrush, a water pick, floss holders, and mouthwash.

Watch Dr. Cassagrande's webinar for more advice on dental health for myasthenia gravis patients.

YouTube

View our full library of educational webinars at:
www.youtube.com/@myastheniagravisfoundation8053

Scan to watch Dr. Cassagrande's webinar

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.

ALEXION®

Seronegative MG Resource Center

Provides Answers for Patients

Most people diagnosed with myasthenia gravis have acetylcholine receptor (AChR) or muscle-specific receptor tyrosine kinase (MuSK) antibodies in their blood. A small minority of others have a different antibody, low density lipoprotein receptor-related protein 4 (LRP4).

If your blood does not contain these antibodies, you can still have MG if you meet certain diagnostic criteria. This is called seronegative myasthenia gravis (SNMG). Approximately 10% of MG patients are seronegative. The actual number could be higher, as many seronegative MG patients may go undiagnosed.

In those patients who have no detectable antibodies, the diagnosis is based on clinical presentation, which includes a thorough review of the medical history and an exam by a qualified physician, electrodiagnostic findings (which may also be negative in some cases), and response to typical MG treatments such as cholinesterase inhibitors.

Seronegative MG is poorly understood, but more is being done to research and develop better treatments for this "rare-of-the-rare" disease.

Seronegative MG is likely caused by the same mechanism as other types of MG – autoantibodies formed by your immune system attach the receptor sites between nerves and muscles, resulting in fewer nerve signals reaching the muscles and muscle weakness. In SNMG, however, the antibodies are not detectable with currently available testing, or there are different antibodies present that have not yet been discovered.

A new, more sensitive type of blood test called a cell-based assay may help seronegative patients find answers. This test, which is becoming more commercially available, may be able to detect AChR antibodies in patients who were previously thought to be seronegative. In a 2022 study published in the Journal of Neuroimmunology, 18.2% of seronegative patients tested positive for AChR antibodies using cell-based assay testing.

In addition, scientists around the world continue to investigate the mechanisms of MG, opening the door for the discovery of additional antibodies that may cause the disease.

You may have questions about what seronegative MG is, how to diagnose it, and how treatment might differ from antibody-positive MG. To help, the MGFA has created a Seronegative MG Resource Center online at myasthenia.org. This resource center is a helpful, high-level overview for patients and caregivers, and provides diagnostic and treatment resources for medical providers. The references section provides detailed information from academic sources about the topics discussed.

We will continue to add resources, articles, information, and patient stories to provide a robust set of materials. Thank you to contributors Cheri Heitman-Higgason, Zachary McCallum, and Leslie Edwards for their work on this resource.

Visit myasthenia.org/Newly-Diagnosed/Seronegative-MG-Resource-Center or scan the QR code.

MGFA Shares Expertise during Hawaii Symposium

Devastating wildfires tore through west Maui, Hawaii in August 2023 - destroying homes and taking nearly 100 lives. We have been saddened by this incredible loss of life, livelihood, and property. Our hearts continue to go out to our community members on Maui and our partner, Hawaii Pacific Neuroscience.

In support of MG patients in Hawaii and across the Pacific Islands, the MGFA co-hosted the 2023 Hawaii MG Symposium with the Hawaii Pacific Neuroscience Center for Neuroscience Diversity on June 17, 2023. The symposium's participants discussed health care disparities and improving MG care in Hawaii and the Pacific Islands.

Meridith O'Connor, assistant vice president of patient engagement, advocacy, and policy at the MGFA and Dr. Richard Nowak, chief medical advisor for the MGFA and a neuromuscular expert and faculty member in the Department of Neurology at Yale University School of Medicine, virtually presented about the MGFA's resources and advances in MG treatment and research, with an emphasis on precision medicine.

Meridith, an MG patient, highlighted our work in convening partnerships with patient advocacy organizations and industry partners. She discussed globally accessible educational materials and

resources as well as new developments in research. In addition, she expressed the value of our many support groups and how they greatly help patients manage and learn more about their MG.

Dr. Nowak discussed new developments in the field of MG and biomarkers and data that are resulting in new outcomes. His exciting recap of targeted treatments and new, groundbreaking treatment options helped the audience to better understand the classes of methods for alleviating symptoms and helping patients live a better quality of life.

You can view this informative virtual conference on the MGFA's YouTube channel by scanning the QR code.

Find an MG Friend

Caregivers Need Care, Too

If you take care of someone with a chronic illness, you may put your own needs second. But have you thought about the support **you** need to live your best life?

Being a caregiver comes with its challenges and stresses. Many caregivers find they need support, guidance, and kinship with others in similar circumstances.

MGFA's MG Friends program now offers support for caregivers, by caregivers. Volunteers are spouses, children, or parents of someone with MG. They provide one-to-one support via text, email, or phone call. Caregivers can ask questions or just talk. Request a friend – or volunteer to be one – at myasthenia.org/MG-Community/MG-Friends-Program.

The Caregivers Support Group offers a group setting to learn and chat with others. The group meets virtually on the third Saturday of the month at 11 a.m. Eastern Time. Register on the MGFA website at myasthenia.org/MG-Community/Find-MG-Support-Groups.

MGFA Provides Support for Young Adult MG Patients Everywhere

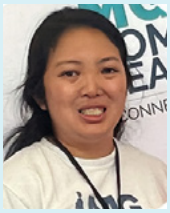
Led by volunteers who saw a need to support young people diagnosed with myasthenia gravis, MGFA started MAYA, or Myasthenia Advocacy for Young Adults. This group aims to foster authentic connections for young adults living with MG.

More than a support group, MAYA helps adults under 40 take action to make life better for young people with MG. MAYA members take the lead on community fundraisers and are active advocates in their communities.

Over 800 people are active in the MAYA online group, while a smaller group of members meet regularly over Zoom. They call in from places as diverse as Louisiana, Indiana, California, the District of Columbia, and even Belgium, Nigeria, and Saudi Arabia.

MAYA is a perfect example of the MGFA's mission in action – creating connections to enhance lives!

To learn more or join MAYA, email mgfamaya@gmail.com. For more information about our new support group for children and adolescents, visit the Support Groups page on the MGFA website or email moconnor@myasthenia.org.



"MAYA has given me the opportunity to connect with MGers my age that I would not have been able to connect with otherwise. It's so healing to talk with people who completely understand and can empathize with everything I've gone through in my MG journey. The group gives me so much hope and reassurance that I'm not alone in my fight with MG!"
- Jessica M., Support Group Leader

Find Patient Resources and Assistance

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

Financial Assistance

The Assistance Fund
(855) 845-7608 | tafcares.org
Helps cover FDA-approved medications that treat myasthenia gravis.

RareCare, NORD's Patient Assistance Program
(203) 571.3167 | MG@rarediseases.org
Rarediseases.org/patient-assistance-programs/financial-assistance
Helps cover health insurance premiums, deductibles, coinsurance, and copayments.

PAN Foundation
(866) 316-7263 | Panfoundation.org/disease-funds/myasthenia-gravis
Provides financial assistance for out-of-pocket treatment costs.

Other Resources

Patients Rising
(800) 685-2654 | HELP@patientsrising.org
Call or email the patient helpline to find a navigator who can help you self-advocate or find the care and treatments you need.

EveryLife Foundation
(202) 697-7273 | Everylifefoundation.org
Learn how to advocate at the state and federal level for legislation and policy that advances the needs of people with rare diseases, including MG.

JAN: Job Accommodation Network
(800) 526-7234 | Askjan.org
Ask questions about workplace accommodations and the Americans with Disabilities Act.

MGFA Opens West Campus in Online Community

New Buildings include a Pediatric Center, Urgent Care Center, and International Center

MGFA continues to expand its one-of-a-kind Online Community. In this unique virtual neighborhood, 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!

The Grand Opening for the West Campus took place in June to coincide with MG Awareness Month. The campus includes three new buildings – an Urgent Care Center, Pediatrics Center, and Multinational Center. We have also created a new MG Caregiver Room in the Town Hall on the Main Campus, a new chat area in the Industry Center, and a pediatric support group.

Caregiver Room – Navigate to the Town Hall on the main campus and check out materials and resources for caregivers, including a chat area to discuss challenges and perceptions and ask questions.

Urgent Care Center – On the new West Campus, the Urgent Care Center includes resources and materials to help patients and caregivers manage MG emergency and crisis situations. Always call 911 if there is an immediate emergency.

Pediatric Center – Educational resources on the West Campus for parents, children, and adolescents who need to talk about, manage, and learn more about myasthenia.

International Center – Soon to be fully open on the West Campus, this building will include materials and resources translated into several different languages.

New Pediatric Support Group – This video-conference space inside the Pediatric Center will host meetings with parents of MG patients as well as special "rooms" for young MG patients to connect and talk.

Check out these new spaces today. You can access the online community at myasthenia.org/MG-Community/MGFA-Online-Community.

If you are not a member of the MGFA Online Community, you can register and access resources for free.

2024

MGFA National Patient CONFERENCE

TAMPA, FL

April 28-30, 2024
Tampa, Florida

Join patients, caregivers, researchers, and medical professionals at the beautiful Westin Tampa Waterside for the largest annual gathering of the MG Community. We can't wait to see you!

- Learn more about managing myasthenia gravis
- Ask experts your questions
- Hear about MG treatment research and development
- Connect with peers
- Build community

Registration opens in December
Myasthenia.org/National-Patient-Conference

MGFA COMMUNITY HEALTH FAIRS

CONNECT • LEARN • SUPPORT

Join Us in 2024
Get the Answers You Need

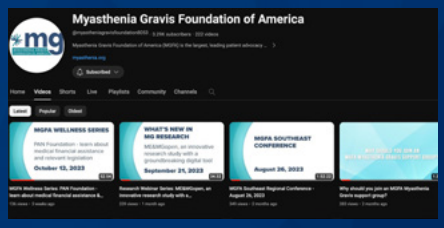
We will be expanding our Community Health Fairs in 2024, adding two new locations, bringing our total to 10! After receiving feedback from our attendees this year, we will be adding lecture series to all Community Health Fairs.

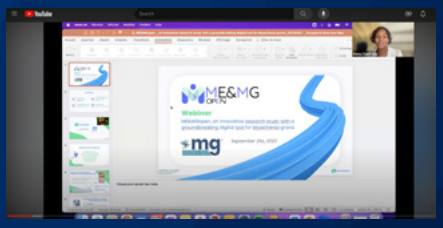
MORE information, MORE education, MORE community!

Myasthenia.org/Community-Health-Fairs

Watch All MGFA Webinars

Access our full library on YouTube





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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www.myasthenia.org

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...to all of our wonderful donors!
your generosity brings us closer to a world without MG.

Support the MGFA and Make an Impact on the MG Community

MGFA relies on your generosity and support to fund groundbreaking MG research that leads to new treatments, offer educational resources to help those individuals diagnosed with MG manage their disease, and provide opportunities to bring the MG Community together. Please consider making a monetary gift to the MGFA this holiday season. **Go to myasthenia.org/donatenow to donate today.**