FOCUS on mg

a publication of the MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Winter 2024/2025

Issue Highlights

Research Fuels the Future of MG Care

MGFA funds cutting-edge myasthenia gravis research

Strategic Plan Guides Our Work

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MG Walks are back! Sign up or volunteer today

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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.

FOCUS ON MG

Dear Readers and Supporters,

Access to high-quality educational materials and resources about myasthenia gravis has always been an important need for the MG community. We at the MGFA take great pride in serving as a proverbial "Educator-in-Chief," offering information that patients, caregivers, and medical professions rely on to learn more about MG and how to navigate this disease. As part of our 2024 – 2026 strategic plan, we are expanding our reach to audiences across the world — and we are doing this in a number of ways.

To help meet this global need for education, we have translated our website and other educational resources into six languages — with more to come. We hope MG patients and other stakeholders from around the world will begin to access and share these materials in their native languages.

This May, we are hosting the 15th International Conference on Myasthenia and Related Disorders in The Netherlands — the first time this prestigious research conference will take place outside of the United States. This location is extremely compelling for international researchers across Europe, the United States, and other regions to attend, learn from one another, and share the latest findings on the research horizon.

In addition, international investigators and researchers are now eligible to apply for MGFA grant funding. Our grants support promising scientific endeavors that may improve the quality of life for individuals diagnosed with MG. Just last fall, we awarded our first international research grant to Dr. Anna Punga at Uppsala University in Sweden. Dr. Punga's pioneering work focuses on investigating biomarkers in the blood that could predict MG development and treatment effectiveness.

MGFA experienced a monumental year of growth in 2024, with more growth on the horizon. Advances in science and technology make me both excited and hopeful for the future of MG care. Clinical trials are underway that could lead to new discoveries and treatments for those with MuSK or seronegative MG. We are on the brink of even greater discoveries to improve the lives of those living with MG — read about some of this work in this issue of Focus on MG.

I hope this magazine inspires and informs you — and, most of all, gives you hope.

Sincerely,

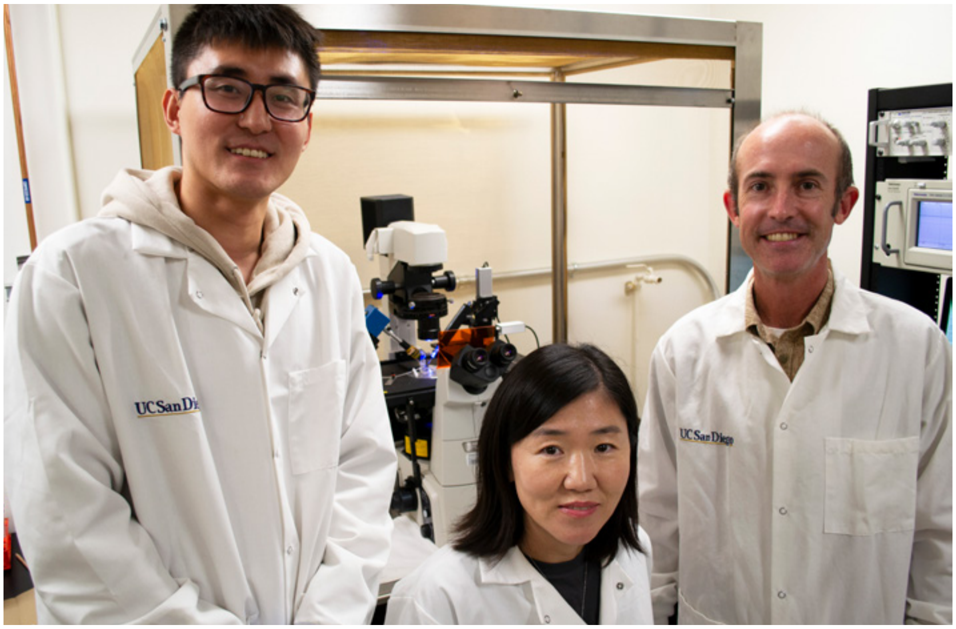
Samantha Masterson
President and CEO

Meeting Our Mission for the MG Community

UNRAVELING A KEY JUNCTION UNDERLYING MUSCLE CONTRACTION

Researchers capture the first 3-D images of the structure of a key muscle receptor, setting the stage for possible future treatments for muscular disorders

By Mario Aguilera, UC San Diego



Dr. Ryan Hibbs (right) with study first author Huanhuan Li, a postdoctoral scholar, and co-author Jinfeng Teng, a research data analyst. Photo credit: Mario Aguilera, UC San Diego School of Biological Sciences

The connections between the nervous system and muscles develop differently across the kingdom of life. It takes newborn humans roughly a year to develop the proper muscular systems that support the ability to walk, while cows can walk mere minutes after birth and run not long after.

University of California San Diego researchers, using powerful new visualization technologies, now have a clear picture of why these two scenarios develop so differently. The results offer new insight into understanding muscle contraction in humans that may help in developing future treatments for muscular diseases.

"In this study we set out to understand the molecular details involved in muscle contraction at the point of contact between motor neurons and skeletal muscles, which are the muscles we consciously control," said School of Biological Sciences Professor Ryan Hibbs, of the new study published in Nature. "We have discovered how the muscle protein changes in its composition during development, which is important in the context of diseases that cause progressive muscle weakness."

The ability of skeletal muscles to contract allows for our bodies to move — from walking and jumping to breathing and blinking our eyes. All skeletal muscle contractions originate at the junction between motor neurons, which originate in the spinal cord and brainstem, and muscle fibers. It's here that neurons release a transmitter chemical called acetylcholine. These molecules bind to a protein receptor on the cells of muscles, triggering an opening in the cell membrane. Electrical currents flow into the cell, which causes muscles to contract.

The way neurons release chemicals that communicate with muscles has been a model system studied for more than a century. But a missing piece of this system has been visual depictions of how the process works. What does the structure of the muscle receptor protein that opens up look like?

To find out, Hibbs, study first author Huanhuan Li, a postdoctoral scholar, and Jinfeng

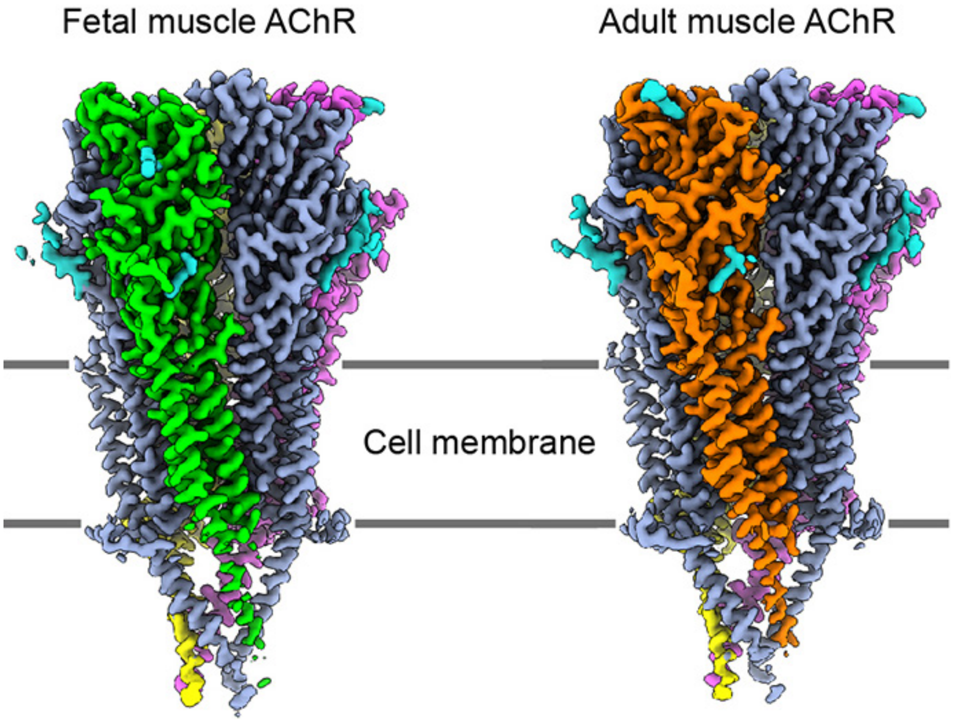
Teng, a research data analyst, tapped cryo-electron microscopy (cryo-EM) technology based at UC San Diego's new Goeddel Family Technology Sandbox, a hub for cutting-edge research instruments. Cryo-EM leverages ultra-powerful microscopes to capture images of molecules that are "frozen" in place.

The results featured the first visualizations of the 3-D structure of the muscle acetylcholine receptor. Since human tissue is difficult to obtain for such muscle contraction studies, the researchers accessed fetal tissue samples from cow skeletal muscles. In order to isolate the receptor in the samples, the researchers turned to an unlikely source: snake venom. A poisonous snake neurotoxin that paralyzes prey was used to latch onto the muscle receptors in the cow samples, allowing the researchers to isolate the receptors to study them. The cryo-EM visualizations then allowed the researchers to witness how the receptor development process unfolds.

Along with the new data came a serendipitous finding. The researchers discovered that they could see the structures of both fetal and adult receptors from the same fetal cow tissue samples.

"We hoped to see the structure of the receptor and we did see that, but we also saw that there were two different versions of it," said Hibbs. "That was a surprise."

In retrospect, the discovery of two receptor types makes sense, according to Hibbs. Since calves are developing in utero, the fetal receptors were expected. To walk like an adult shortly after birth, they start building adult nerve-muscle connections much earlier in development.



In a serendipitous discovery, UC San Diego researchers using cryo-EM technology captured the first visualizations of the 3-D structure of the muscle acetylcholine receptor in fetal and adult muscles. Credit: Hibbs Lab, UC San Diego

"This discovery explains how animals like cows that need to walk on the day they are born form mature neuromuscular junctions before birth, unlike humans, who have poor muscle coordination for months after birth," said Hibbs. "Being able to see the receptor details allows us to connect their differences to how one allows for nerve-muscle connection and the other allows for muscle contraction."

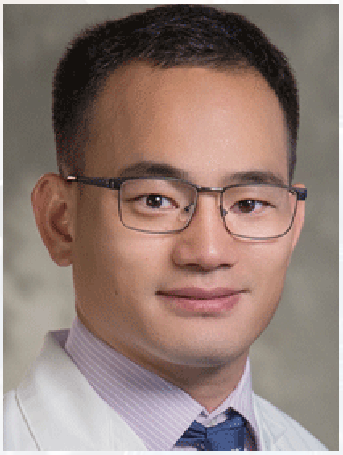
The findings of the study are already being applied to investigations of muscle-based disorders, such as congenital myasthenic syndromes (CMS) that result in muscle weakness. A common autoimmune disease known as myasthenia gravis involves antibodies that mistakenly attack the muscle acetylcholine receptor, causing weak skeletal muscles.

"This new level of insight into the muscle receptor will help researchers understand how mutations in its gene cause disease, and may facilitate personalized treatment for individual patients with different pathologies in the future," said lead author Li.

Funding for the study was provided by the Myasthenia Gravis Foundation of America and the National Institutes of Health (NS120496).

Dr. Ryan Hibbs's research into the architecture of the muscle acetylcholine receptor was funded in part by the MGFA's 2023 High Impact Pilot Project Award.

MGFA AWARDS $330,000 TO FUEL CUTTING-EDGE RESEARCH



Yingkai "Kevin" Li, PhD
Duke University

Gianvito Masi, MD
Yale University

Anna Punga, MD, PhD
Uppsala University

Each year, our grant program provides hundreds of thousands of dollars in funding to promising scientists. In the fall, MGFA announced another three High Impact Pilot Project Award recipients.

This grant supports early-stage research that will lead to new federal, pharmaceutical, or private foundation-supported investigations.

Learn more about these recipients and their work at myasthenia.org.

MG-ADL Helping Patients Track Symptoms in MyMG Mobile App

For many individuals diagnosed with MG, the MG-Active Daily Living (ADL) scale is a standardized and relatively easy method to evaluate and track the severity of MG symptoms. MG patients and their neurologists or doctors can complete the scale together during an office visit, or patients can track their symptoms on a regular basis.

When using the scale, most people print out an ADL and write in their symptom severity numbers. What if you could use your mobile phone to track your ADL on a daily and monthly basis to easily show your neurologist progress and a history of symptom severity?

Now you can via the MGFA MyMG mobile app.

The MGFA's app uses the MG-ADL in the symptom tracking section of the home screen. Tap in your symptom severity, and the app will store the data, enabling you to review the history of symptom severity over a period of weeks or months. You can even export the data to reports that can be shared with health professionals.

More and more, people living with MG are using technology to monitor and manage their MG, and the MGFA is now providing another well-received and tested evaluation process. We hope patients and caregivers realize a lot of value from this new feature.

Download the MGFA MyMG mobile app from the Apple Store or Google Play store, take a minute to create your profile, and start tracking your symptoms now.

MGFA My MG

Learn more

INDIVIDUALS WITH MG: WHY THEY ENROLLED IN THE MG PATIENT REGISTRY

mg™ MYASTHENIA GRAVIS FOUNDATION OF AMERICA
PATIENT REGISTRY

The MGFA Global MG Patient Registry is a longitudinal, ongoing research study that includes the largest set of self-reported MG patient health data in the world. More than 3,300 people diagnosed with generalized or ocular MG have added their health data to the registry since 2013.

People living with MG are the real experts on myasthenia gravis, and by adding their health data to the registry, they are helping guide new research and discoveries. There are many unknowns and questions about MG, and we do not have enough information about the disease to close those gaps. That's why patient-reported data is so important. Data in the MGFA Global MG Patient Registry can be used to discover and support treatments that could greatly improve the lives of those living with the disease.

Why Participate in the Registry?

Enrolling in the MGFA Global MG Patient Registry empowers you to take direct action that can lead to new treatments and, someday, even a cure.

The registry collects data through standardized surveys every six months. The data available to researchers is always anonymous and aggregated so no one can attribute your data directly to you.

Sign up today at
mgregistry.org

HEAR FROM PEOPLE WHO HAVE ADDED THEIR HEALTH DATA TO THE REGISTRY.

I signed up because it could get us closer to a world without MG. I live with seronegative MG, and I can join this study. I am not excluded as is the case with many other MG research studies. I can add my seronegative health data, and my MG experience can empower our whole MG community. The MG registry is safe, secure, and HIPAA and CDPR compliant, so your health data is protected and anonymized so that no one can attribute your data to you. You can trust that your health data will be confidential and analyzed by only true professionals.
— Anita Longoria

MG patients like me are the real experts of this disease. We understand how MG impacts our bodies more than anyone else, but sometimes, we feel ignored or not heard by those around us. When you enroll in the MGFA Global MG Patient Registry, you now have a loud voice.
— Kathi Timothy

Patient-reported data is the most valuable perspective on the disease. We need your expertise and experience with myasthenia to help guide researchers and MG experts to find better treatments and ways to manage MG. Research and discoveries will change the course of MG in the near future.
— Meridith O'Connor

Be Part of a Clinical Trial — *Help Yourself, Help Others*

Clinical trials move science forward, helping researchers develop new MG treatments for those who need them. If you are diagnosed with MG, we encourage you to learn about options and talk to your medical team. Several new studies are now recruiting individuals with specific criteria, such as pediatric patients and people with MuSK or seronegative MG. Participating in a study helps move the needle on treatment development and broader understanding of MG's impact on those affected.

Select Trials Now Recruiting

Evaluate the Safety, Tolerability, Pharmacodynamics and Efficacy of CNP-106 in Subjects with Myasthenia Gravis

This is a Phase 1b/2a First-in-Human (FIH) clinical trial to assess the safety, tolerability, pharmacodynamics, and efficacy of multiple ascending doses of CNP-106. Open to individuals ages 18-75 with generalized myasthenia gravis.

Sponsor: COUR

Efficacy and Safety of a New Formulation of Oral Cladribine Compared with Placebo in Participants with Generalized Myasthenia Gravis (MyClad)

The purpose of this clinical study is to determine the efficacy and safety of a new oral cladribine formulation in participants with generalized myasthenia gravis in comparison to placebo.

Sponsor: Merck Healthcare KGaA

MuSK Myasthenia 1000 Study

The purpose of this study is to collect saliva samples from 1,000 individuals diagnosed with laboratory-confirmed MuSK antibody-positive myasthenia.

Sponsor: Myasthenia Gravis Rare Disease Network (MGNet)

A Study of Efgartigimod PH20 SC in Children Between 2 and Less Than 18 Years of Age with Generalized Myasthenia Gravis

The purpose of this study is to measure the pharmacokinetics, pharmacodynamics, safety, tolerability, and immunogenicity of efgartigimod PH20 SC in pediatric participants with AChR generalized myasthenia gravis.

Sponsor: argenx

RESET-MGTM: A Phase 1/2 Study to Evaluate the Safety and Efficacy of CABA-201 in Participants with Generalized Myasthenia Gravis

The RESET-MG™ Study is a clinical research trial evaluating the effects of an investigational chimeric antigen receptor (CAR) T cell therapy, CABA-201, in patients with generalized myasthenia gravis.

Sponsor: Cabaletta Bio

Learn more about these trials at myasthenia.org or clinicaltrials.gov.

Hear from people with MG who have participated in a clinical trial

Danny DeBerry

"People say, 'This changed my life,' but this really has changed my life. It's hard to put into words."

Read his story

Kathalina Nguyen

"Being able to take part in this research trial fills me with gratitude and makes me optimistic. There are many treatment options out there — you just have to find the right one for you, even if it takes some trial and error. Never lose hope."

Read her story

RESEARCH FUELS THE FUTURE OF MG CARE

Myasthenia Gravis Foundation of America has a long history of fighting for people with MG — improving access to care, funding research, educating the community, and supporting patients and their families.

Having myasthenia gravis myself, I understand all too well the daily challenges that come from having a rare disease. As the national director of academic affairs and research initiatives at the MGFA, I have had a front row seat to the significant progress made in treatment development — and it gives hope that a cure is within our grasp.

At the MGFA, we fund the most promising research being conducted today. Through our grants, we support work that addresses basic patient rights, including a timely diagnosis, quality care, better treatment options and outcomes, and a patient voice in research.

The MGFA research agenda focuses on five priorities: identifying biomarkers, understanding disease mechanisms, developing targeted therapies, understanding patient outcomes, and strategizing pediatric treatment. Over the past five years, the MGFA has awarded more than $3.5 million to the best researchers in the MG field working towards those strategic priorities.

Our grant funding supports pioneering avenues of scientific exploration, moving the needle on the search for better therapies and a cure.

Dr. Aimee Payne received the 2022 Nancy Law Impact Award to pursue CAAR-T cell therapy research. She explains the power of an MGFA grant.

> **"It's often very difficult for researchers in this rare disease field to secure grant funding. The MGFA is invaluable because I don't think that this kind of research can be funded by traditional grant-funding mechanisms."**

Help us fuel critically important research like Dr. Payne's.

As an MGFA supporter, you understand the importance of the collective MG Community coming together to change the lives of all those affected by this difficult disease.

You can make a difference by making a gift to support our most critical work.

Support our work at **myasthenia.org/donatenow**.

Reach out to us at mgfa@myasthenia.org if you are interested in helping the MGFA plan for the future by including a gift in your estate.

Your support is a lifeline for those living with myasthenia gravis.

Laura Chandler
National Director of Academic Affairs and Research Initiatives

Make a Gift

MGFA OUTLINES NEW STRATEGIC PLAN

FOR TODAY AND INTO THE FUTURE

Every three years, the MGFA composes a detailed and comprehensive strategic plan that outlines key goals, objectives, and operational initiatives. A strategic plan functions like a rudder to help direct and navigate the MGFA toward growth and increased community engagement.

In 2023, the MGFA came off a broad set of extremely positive outcomes and results from its last strategic plan, and the MGFA team built on that success when creating its new plan.

The current MGFA strategic plan, officially launched earlier this year, formally outlines the organization's key priorities and growth opportunities for 2024 through 2026. This plan was thoughtfully and collaboratively developed by members of the MGFA staff and Board of Directors, with critical insights and feedback from the MG Community, including individuals diagnosed with MG, caregivers, medical professionals and researchers, industry and biotech companies, and a variety of additional stakeholders.

The strategic plan serves as the roadmap that directs the organization's operational work, goals, and planned outcomes through the end of 2026. The plan includes a set of key pillars or priorities, with proposed operational results and campaigns to achieve in the coming years.

These priorities include advancements in research and science, education and awareness, and revenue diversification — all set on a backdrop of expanded growth internationally that can position the MGFA to have an impact as a global leader in MG advocacy, education, and research.

01

Globalization and Impact

02

Education, Advocacy, and Awareness

03

Research

04

Revenue Growth to Expand Stakeholder Impact

Learn more about our strategic plan at **myasthenia.org/strategicplan**

LOOKING INTO THE FUTURE:
MGFA CRYSTAL BALL 2025

As we look ahead, what do we see in the forecast?

A new Board chair

Early in the year, we transitioned to a new chair, as Brian Gladden stepped down after three years in the role. Robert Thomas, our incoming chair (pictured), brings a wealth of experience on the Board — he previously served as vice chair — and in his professional life as an HR expert. Robert is committed to ensuring the MGFA meets its 2024 – 2026 strategic plan goals.

Fueling international service

As part of our strategic goal to play a leadership role in the MG space, the MGFA is developing strategies to support and educate those affected by MG around the world. This year, we will continue to translate educational materials, including the MGFA website. We are exploring partnerships with international patient advocacy organizations to determine the best way to work together to serve the MG Community. In May, the MGFA will host our first-ever event in Europe — the 15th International Conference on Myasthenia Gravis and Related Disorders. This prestigious research event will be held in The Netherlands to better engage scientists and researchers from around the world. We will also have time to gather with leaders from groups across Europe that serve the MG community.

More opportunities to connect

MGFA is expanding our localized Community Health Fair series, bringing you a total of 14 events this year, including our first international fair in Canada. (Check our website for a full list of locations and dates.) We are also expanding the MG Walk program to six locations. Creating connections is a key part of our mission, and we will continue to grow these programs as long as the community finds them valuable.

An improved digital experience

MGFA recently transitioned to a new platform for our website, which is an important resource for the MG Community. The new platform gives us the opportunity to refine what and how we share information. Look for a refreshed navigation, as well as a better experience when you use the site on your phone. In addition, the MGFA is exploring updates to our app, MyMG Mobile.

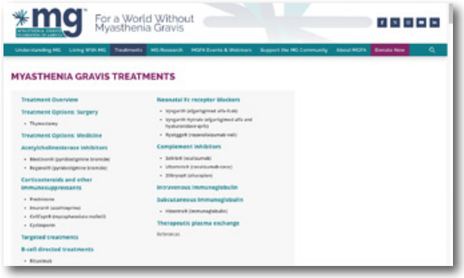
Making it Easier to Find MG Resources on Myasthenia.org

Individuals diagnosed with myasthenia gravis frequently tell us that the MGFA website (myasthenia.org) is their first choice for learning more about MG and the various options available to manage and navigate the disease. Our website includes educational materials, helpful resources, brochures and flyers, and a number of content pieces that can help patients and caregivers outline and establish a plan to manage their MG.

Recently, the MGFA has taken steps to reorganize content and make it easier and more efficient to find the information you need.

For example, we have organized MG-related educational information under the "Understanding MG" link on the homepage. This leads website visitors to glossaries and overviews of MG.

If you are "Living with MG" and need community support or brochures to help you manage your daily MG symptoms, check out our MGFA-sanctioned support groups, MG Friends program, and brochures. Or find MG experts in your area as part of our Partners in MG Care search function. We have organized "Treatments" as well as "MG Research" in easy-to-locate sections, and we have even outlined ways to get involved, fundraise, or donate. And our "MGFA Events & Webinars" link and "About MGFA" provide publications, educational live events and videos, and important financial information about our organization.



MYASTHENIA GRAVIS TREATMENTS

Treatment Overview
Treatment Options: Surgery
Treatment Options: Medicine
Acetylcholinesterase Inhibitors
Corticosteroids and other immunosuppressants
Targeted treatments
B-cell directed treatments
Neonatal Fc receptor blockers
Complement inhibitors
Intravenous immunoglobulin
Subcutaneous immunoglobulin
Therapeutic plasma exchange

Check out myasthenia.org and let us know your thoughts and opinions on these important changes.

MGFA Helpline Offers Guidance and Support

Whether you are newly diagnosed with MG or have been living with the disease for some time, you're likely to have questions about MG management from time to time. Having a reliable source of information is vital, which is why the MGFA is excited about offering our 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.

MGFA HELPLINE

1.833.647.8764

9:00 AM - 8:00 PM EST

While helpline operators cannot provide medical guidance (only a treating healthcare provider should do that), they can direct you to information and resources, including but not limited to:

- How to find a qualified neuromuscular specialist
- Finding support groups and other types of MG support
- Where to find treatment information
- Where to find MG emergency or general management assistance

"People often call the MGFA looking for resources," says Samantha Masterson, MGFA president and CEO. "The new MGFA Helpline will ensure we're ready to answer these questions in a very comprehensive and thoughtful way."

You can still call the MGFA's main phone number if you have a question about an MGFA program, want to get involved, need a specific MGFA resource, or would like to make a gift. Our office phone will continue to be answered from 9:00 a.m. – 4:00 p.m. EST, and you can email us any time at mgfa@myasthenia.org.

MGFA LAUNCHES FOUR NEW SUPPORT GROUPS

People living in Wyoming, San Diego, and Tennessee now have an MGFA support group to call their own. Last summer, volunteers in each area identified a need for support in their regions and offered to run the groups.

Kathi Timothy, community outreach coordinator for the MGFA, shared that support groups are critical for newly diagnosed patients but are also valuable resources for longer-term patients. She says that groups can help you build your network and learn more about MG, both of which can help your mental and physical health.

"Don't turn to a support group only when you're in crisis," she says. "Join the group before you are in a crisis state with your disease so that you are prepared and you have people who are in your corner, ready to help you and support you."

Myasthenia gravis affects people everywhere, says Samantha Masterson, MGFA's president and CEO. "We aim to have a presence wherever there is a need."

Volunteer Janel Worcester also approached the MGFA last summer interested in starting a support group, this one for people with MG who are raising children.

"Parenting is the most challenging and rewarding job that I have ever had," she says. "It can be difficult for the healthiest of parents. Myasthenia gravis adds another journey to navigate in the parenting realm, but it doesn't need to be in isolation."

The new group, Parenting with MG, is open to parents, pregnant people, and those who are considering parenthood.

"We'll learn from one another, share helpful hacks, hear from experts in the field and get the opportunity to be part of a positive, problem-solving community where you matter," says Janel.

Those interested in joining one of these new support groups — or any of our existing groups — can visit the support group page on myasthenia.org or email Kathi at mgfa@myasthenia.org.

FIND THE SUPPORT YOU NEED

Whether virtual, in person, or hybrid, MGFA support groups are a wonderful way to learn more about managing MG and to receive caring support. In addition to our location-based groups, the MGFA has several specialty support groups open to individuals around the world.

- Seronegative Myasthenia Gravis
- MAYA (Myasthenia Advocacy for Young Adults)
- Español (Spanish Language)
- Caregivers
- Pediatric (Children and Teens)
- Parenting with Myasthenia Gravis

Visit myasthenia.org to register.

SUPPORT FOR MYASTHENIA GRAVIS (MG)

MORE THAN MG

Find what makes you MORE THAN MG

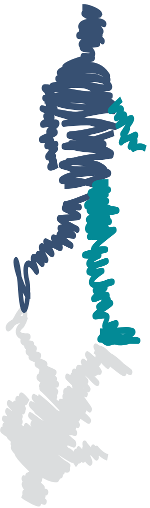
Join the community of patients, caregivers, and other advocates

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.

MORETHANMG.COM ↗

Follow
@MoreThanMG

ALEXION®
AstraZeneca Rare Disease



Walking for a World Without MG

Register for 2025 at myasthenia.org/MGWalk

In 2024, the MGFA relaunched our popular MG Walk program. If you participated in a walk in 2023 or before the pandemic, you know how fun and energizing it is to make a difference and connect with others in the MG Community. We were so excited to bring back the program in Boston, New York, and Tampa.

While hurricanes forced the postponement of our Tampa MG Walk, our walks raised over $50,000 to fuel our mission to create connections, enhance lives, improve care, and cure MG.

A huge thank you to our walkers and fundraisers for making the MG Walk a success! We look forward to seeing you in six cities in 2025.

2025
MGFA National Patient Conference
Phoenix, AZ

REGISTER TODAY

March 30 – April 1 | Arizona Grand Resort & Spa

myasthenia.org/events

Join hundreds of others from across the country as we build strong support community, learn more about myasthenia gravis management, and delve into the latest research and treatment options.

Over two days, you'll hear from myasthenia gravis experts, including doctors, researchers, patients, and caregivers with lived experience. Talk to others who know what you're going through and those who have new advice, wisdom, and expertise. Enjoy the beautiful Phoenix valley at a perfect time of year – arrive early and catch a spring training game, visit the Grand Canyon, or simply enjoy everything this area has to offer.

Registration is now open and again this year, there is no fee for patients and care partners!

MGFA EVENTS: LOOKING AHEAD TO 2025

EVENTS FOR PATIENTS AND FAMILIES

MGFA Community Health Fairs

MGFA's popular Community Health Fair series returns in 2025 with 14 locations, including two new cities. Dates and locations are available at myasthenia.org/events.

MG Walk

We are also expanding the MG Walk program, with six events around the country. More information and registration details are available at myasthenia.org/events. This program raised over $50,000 in 2024! All funds fuel our mission to create connections, enhance lives, improve care, and cure MG.

MGFA National Patient Conference

Our annual National Patient Conference returns, this time in Phoenix. Join us March 30 – April 1, 2025 for MG research information and updates, informative discussions with patients and community members in the MG space, news about MG treatments and discoveries, and many exciting educational topics to help you and your family better manage your MG journey. Registration is free again this year for those diagnosed with MG and their families.

Want to volunteer at an event?

Reach out to us at mgfa@myasthenia.org.

Volunteer roles include:

- Check-in desk
- Set up and break down
- MG Experience table
- MG Walk route guides
- Local event promotion

Virtual Programming

We will continue our research and wellness webinar series in 2025. Look for thoughtfully curated speakers who will discuss cutting-edge research, new MG treatments, and ways to care for your physical and mental health. If you missed a webinar, recordings are available on our YouTube channel.

RESEARCH EVENTS

15th MGFA International Conference on Myasthenia and Related Disorders

MGFA will host the 15th MGFA International Conference from May 13 – 15, 2025, in The Hague, The Netherlands. This prestigious scientific gathering is an opportunity for top researchers and clinicians to share their findings. For the first time, this conference will take place outside the United States to involve our partners in Europe and beyond.

MGFA Scientific Session

MGFA Scientific Session in October 2025 is another opportunity for researchers to share and discuss findings from recent studies and clinical trials. This annual gathering has grown in size and prestige over the last several years, illustrating the progress made in MG research and discovery. Review highlights from the 2024 session on our website.

Make sure you are on the MGFA's events email list to be informed if an event is coming to your area. Sign up at myasthenia.org/contact-us. You can also follow us on Facebook and Instagram to stay up to date.

Register for MGFA events at myasthenia.org/events

THE SNOWFLAKE DISEASE

By Greg Olsen

The "Snowflake Disease." That's what many people call myasthenia gravis. Just like a snowflake, the symptoms can appear one minute and be gone the next. If conditions are right, a snowflake will hang around for a while; perhaps minutes, or hours, or even days, but eventually it melts away.

Sometimes a person's experiences with myasthenia gravis are like snowflakes.

Symptoms can come and go at random. Sometimes the symptoms stick around for a few minutes, or a few hours, or a few days. They may vary in intensity, or they might just disappear altogether.... temporarily.

Have you ever heard a strange noise in your car and took it to the mechanic to find out what was wrong, only to have the noise disappear before you got there? That's what MG is like.

You may be experiencing symptoms at home and make an appointment with your doctor, but by the time you get there, the symptoms are gone.

Don't worry, just like the noise in your car, they'll be back sooner or later. That's why having a good doctor is so important. A good doctor will listen to you, believe in you, and provide you with the best care possible. Unlike the mechanic who will make you feel like it's all in your head, your doctor will get to the bottom of the problem and start the proper treatment.

Disappearing symptoms can be both a relief and a frustration.

It's a relief when the symptoms let up and allow you to return to normal life. At the same time, disappearing symptoms can also be frustrating, even embarrassing.

It's quite difficult for people to understand how you can display symptoms one moment and be absolutely fine the next. In fact, it may appear to them that the symptoms you were displaying are all in your head. I swear there was a snowflake there a minute ago.

Let me reassure you, if you have myasthenia gravis, the symptoms are real. Enjoy the moments when your snowflakes disappear, and don't give a second thought to anyone who doubts if your symptoms ever really existed. It doesn't matter what they think; it matters what you know.

Do you know what doesn't melt? The emotional toll MG takes on its victims. That never goes away. Those of us with MG have felt how people look at us when we suddenly start slurring our words. We've watched people stare at us as we drag our feet. We've witnessed how one eyebrow suddenly goes up, as they are surprised how quickly a symptom appears out of nowhere. We fear being judged by others as a fake, a liar, or a freak.

We're not faking. It's all real.

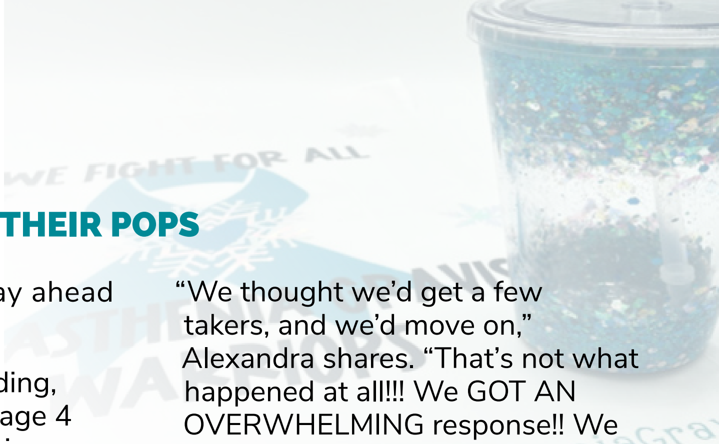
And while we can't control what people think, we can control how we react. It may not be easy to do, but let them think what they want. We know it's real.

Emotions also come into play from fear. On the outside we may appear tough as nails, but on the inside, each of us fears not knowing what's ahead for us. We fear ending up in a wheelchair or needing to have people help us. We're afraid that one day we will no longer be able to do the things we most enjoy doing. Most of all, we fear letting people down. Where we've always been there for them, one day we may need them to be there for us.

Myasthenia gravis is the Snowflake Disease, but while the visible symptoms often melt away, the invisible fears constantly remain inside of us.

We don't have to fight those physical or emotional demons alone. The Myasthenia Gravis Foundation of America is a great resource for those diagnosed with MG and their caregivers.

Follow Greg's MG journey on his blog, mglifebygreg.com.



THE STEHLIK SISTERS GIVE BACK IN MEMORY OF THEIR POPS

By Kate Stober

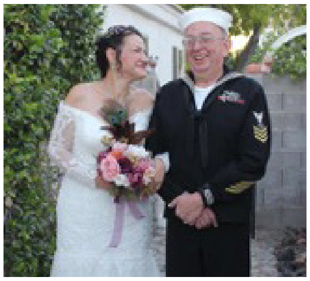
The way sisters Alexandra Hite and Amanda Coots describe it, Tom Stehlik was always destined to join the family, and his future health issues and myasthenia gravis diagnosis brought them even closer— helping them become a force for rare disease awareness.

A widower, Tom met the sisters' mom on a blind date in March 2015. For Tom, it was love at first sight.

Alexandra describes the meeting:

"Tom told me, 'The lilacs and orange blossoms were in bloom, and the breeze blew across my face. Then your mom came through the back door, and I said to myself, I'm going to marry that woman!'"

They were married on his birthday, June 4, 2015, just three months later.



Alexandra and her pops on her wedding day

Tom was elated that his new bride had children and grandchildren.

"He was the BEST pops and grandpops around. He loved us kids, but man did he love my mom. He fit into our family as if he was always a part of it," Alexandra shares.

Tom grew up in South Dakota, one of ten children on a small farm. Living with an abusive father showed him everything he didn't want to be. He left home to join the Navy at age 17 and served 21 years.

But his biggest battle lay ahead of him.

Five years after his wedding, Tom found out he had stage 4 metastatic renal cell carcinoma. While he recovered and was declared cancer-free, eight months later doctors discovered a cancerous tumor on his cerebellum. They decided to treat the cancer with immunotherapy.

Unfortunately, Tom experienced a very rare side effect. He was part of a small percentage of people — less than 1% in one study — who are diagnosed with myasthenia gravis subsequent to their treatment.

A day after his second infusion, Tom couldn't open his eyes, swallow, or breathe. He was taken to the ICU, where a doctor diagnosed him with MG.

Standard MG treatments didn't resolve Tom's symptoms, and he couldn't receive treatment for his cancer while his health was unstable.

"His frustrations grew daily, mom's heart broke more every day, and he wasn't getting any better at all," says Alexandra. "We spent more time in the ICU than at home."

After four heartbreaking months, Tom lost his battle with MG and cancer on January 22, 2022.

"Before Pops passed, he made us promise that we would do something to celebrate his life," says Alexandra. "So, we decided to honor him by raising awareness about myasthenia gravis."

That first June after his death, to align with Tom's birthday and his and their mother's wedding anniversary, Alexandra and Amanda decided to give away MG awareness decals.

"We thought we'd get a few takers, and we'd move on," Alexandra shares. "That's not what happened at all!!! We GOT AN OVERWHELMING response!! We sent out over 100 in the first round!

"We had to do something to make it easier on us, while also doing more for the MG warrior community, so Stehlik Sisters Against Myasthenia Gravis was born!"

Stehlik Sisters Against Myasthenia Gravis is a Facebook page and business dedicated to raising awareness about myasthenia gravis. The sisters sell MG merchandise like decals, koozies, t-shirts, and cups. On the 22nd of every month, they give away 50 teal MG awareness ribbon decals.

"It is our goal to create awareness and conversation that may someday lead to a cure. It worked for the red ribbon for AIDS awareness!"

They care passionately about supporting those living with MG, especially "some of the smallest warriors," says Alexandra. They've sent care packages to children as young as three who are battling the disease.

"We started this decal giveaway and then the Facebook page to not only celebrate Pops' life but also the many others fighting this awful diagnosis. We know that he is proud of the work we are doing. We hope for better treatments and a cure. It starts with awareness and education, and we hope we are headed in the right direction!"

Follow Stehlik Sisters against Myasthenia Gravis on Facebook or email them at anchor7seas@yahoo.com with SSAMG in the subject line to place an order.

mg™
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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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