



**VOL. 66 ISSUE 1**

**MYASTHENIA GRAVIS ASSOCIATION  
NEWSLETTER**

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**FREE**

Myasthenia Gravis Association  
Snowflake Saturday + Rare Disease Day

**St. Louis Rare Disease Event**

Help us raise awareness for Myasthenia Gravis on Rare Disease Day! Join the Myasthenia Gravis Association in Clayton, Missouri for a morning of connection, education provided by Give an Hour touching on mental health and rare disease. Enjoy vendor booths, raffles, lunch, MGA merchandise for sale, and more!

**February 28th 2026**

**LOCATION:** THE CENTER OF CLAYTON | MEETING ROOMS A,B,C  
50 GAY AVENUE, CLAYTON, MO 63105  
**TIME:** 10:00AM - 1:00PM

**SCAN QR CODE TO REGISTER!**

Register to attend at [www.mgassociation.org](http://www.mgassociation.org)



*- with the generous support of -*



Including exhibitors - Show Me State Vital Care & Healix Infusion Care



HELP US SHARE YOUR MYASTHENIA GRAVIS JOURNEY  
**SHARE YOUR STORY**

**SUBMISSIONS**

Want to share your MG story or have a topic you would like to see covered? We have multiple ways for you to connect with the MG community! Email Kathryn at [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)

**FOLLOW US**

Follow us: @themgassociation  
Instagram | Facebook | YouTube



**[mgassociation.org](http://mgassociation.org)**

# A MESSAGE FROM ALLISON

## The Road that Brought Us Here



In December, I celebrated my 8th Anniversary with the Myasthenia Gravis Association. On the day of this milestone, I was up early, and on the road to our new clinic partnership at the University of Missouri in Columbia by about 5:45am.

The entire two-hour drive to Columbia it rained and was horribly windy in addition to still being dark out. The drive between Kansas City and Columbia on I-70 isn't for the faint of heart. I-70 is like the stepchild of all interstates as you dodge pothole after pothole, mixed in with road construction and always a lot of traffic. It wasn't the most fun drive I've ever taken. But I always take the time in the car to reflect and think, make plans, dream big dreams and somehow during all the chaos outside, I found time to reflect on the year we've had.

Let me just say, 2025 was an incredible year for the MGA. When I think of the last year, I smile. We have come so far, through so much darkness and storms and it finally feels like the wheels are on the bus and not off. I thought I'd take you through some of the milestones we have achieved over the past year.

### Quarter 1

We joined hands with the support group in Ankeny, Iowa and began supporting them. We also rolled out our newest support group, Muscle Makers. Muscle Makers is an online community where patients can gather and work on their hobby or craft. It's one of the coolest concepts I believe we offer which was born from an idea of one of our great community leaders, Bryan Bosch. McKenna Fulton, our Community Program Coordinator in Kansas City attended the Rare Disease Day events in Washington DC hosted by the Everylife Foundation for Rare Disease. Our 2nd Co-Hort of Designing our Lives with MG began with 49 applicants. Designing our Lives with MG, the mastermind of Sarah Bolton, life coach and individual living with MG, supported by our Diamond sponsors, Alexion, argenx and UCB. We attended the MDA Scientific Conference in Dallas where we engaged with key opinion leaders, patients, caregivers, industry partners and other patient advocacy groups. We held our first ever Corporate Advisory Council.

### Quarter 2

Our MGA team grew as we added Halle Walker as our first ever Event Coordinator. We attended the American Academy of Neurology Conference in San Diego as well as Kathryn attended the World Orphan Drug Congress in Boston. We held our 14th Annual MGA Triple Crown Showdown in which 504 participants participated in either the mile mosey, tot trot or 5K including over 70 individuals living with MG who volunteered or participated! We participated with 21 patient organizations from across the globe for Light the Globe for MG Day. We lit the wheel in Kansas City and the wheel in St. Louis teal for MG. We held 3 Snowflake Saturday events in Des Moines, IA, Little Rock, AR and Wichita, KS.



myasthenia gravis association

**MGA**

of the heartland

### MGA STAFF

Executive Director  
Allison Foss

### Community Program Coordinators

Kathryn Clemens  
McKenna Fulton

### Event Coordinator

Halle Walker

### EXECUTIVE BOARD

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### CONTACT

816-256-4100  
info@mgakc.org

# A message from Allison, continued



## Quarter 3

We partnered with Give an Hour and Patient Advocate Foundation to provide education to our community. In 2025, we held 14 webinars which achieved a 4.3 rating out of 5 stars! We held our 8th Annual Crown Town Trivia Night in partnership with the Iowa State Alumni Club of Kansas City which raised over \$150,000. Blaise Huck began her Capstone Project with the MGA as a Doctoral Student in Occupational Therapy at Rockhurst University. Additionally, our 5th clinic partnership began at the University of Missouri- Columbia which will be staffed by Jonni Sutton, MG Clinic Liaison. We held one of our largest webinars ever with James Howard, MD, University of North Carolina on the topic of Vaccines and MG.

## Quarter 4

We participated in the Late Onset Neurological Disease Consortium meeting ahead of AANEM in San Fransico where the committee is very close to revealing a tool to ease diagnosis of late onset neurological diseases. The MGA proudly announced its commitment to the MG Alliance, a national coalition of 6 MG organizations dedicated to raising awareness and advancing advocacy for those affected by Myasthenia Gravis. We held our 65th Annual Meeting and Educational Seminar where we had over 487 registrants from over 45 states and 23 countries. 20 nurses received CEU's from attending thru the support of Promptcare. Kristine Henson was awarded the Stackhouse Award and Raymond Clayton was awarded the Volunteer of the Year. We also rolled out a new website with the address of [www.mgassociation.org](http://www.mgassociation.org) to showcase our growth. We began our 6th clinic partnership at Advent Health with Dr. John Eatman in Overland Park, KS. Later in December, we began our 7th clinic partnership at SSM Health with Dr. Malo Bassam in St. Louis. We continued over \$75,000 to research for myasthenia gravis through a \$50,000 grant to the University of Kansas Medical Center and \$25,000 to the MGnet at George Washington University!

Whew. Are you as exhausted as I am just reading through that?

As I finished checking out the clinic in Columbia and started on the drive home, I realized that dark and stormy morning had turned into the most beautiful, mild, sunshine filled December day. A reminder to me, that when darkness fades, often sunshine escapes. We've got lots of great plans to execute in 2026 and are excited to have you along for the ride!

Allison K. Foss | Executive Director | [allisonfoss@mgakc.org](mailto:allisonfoss@mgakc.org)



**SERVED INDIVIDUALS IN OVER 45 STATES & 23 COUNTRIES**



**1419 ATTENDEES AT 108 SUPPORT GROUPS**



**255 NEW PATIENT PACKETS PROVIDED**




**\$75,000**  
donated to MG research efforts at the **University of Kansas Medical Center** and **George Washington University**




**518 INDIVIDUALS SEEN AT 150 CLINICS HELD**




**7 CLINIC PARTNERSHIPS**  
including 3 new partnerships in 2025

**39% INCREASE IN MGA DATABASE** \* 



**20 CEU'S**  
given to nurses who attended our 65<sup>th</sup> Annual Meeting & Educational Seminar



approval rating out of 11 webinars held in 2025

[www.mgassociation.org](http://www.mgassociation.org)

# Two targeted treatments for adults with generalized myasthenia gravis (gMG)

UCB is committed to making a difference for people living with gMG by providing two treatment options



## Is it time to rethink your current gMG therapy?

For people with gMG, symptoms present themselves differently in each diagnosed individual. While most people have fluctuating muscle weakness and fatigue, these symptoms vary from person to person and can range from mild to severe.

UCB offers two treatments that target different aspects of immune function related to gMG and have different methods of administration.



Scan to explore two distinct treatments that allow you and your doctor to choose the gMG treatment that fits your needs.

## UCB OFFERS TWO TREATMENTS THAT TARGET gMG DIFFERENTLY:

### An FcRn blocker

Harmful antibodies that cause gMG may stay in your body longer because of FcRn (neonatal Fc receptor).

### A C5 inhibitor

Harmful anti-AChR antibodies activate part of your immune system called "complement," which works to attack your muscle cells.

## Targeted treatments. More options.

Ask your doctor how a targeted therapy may help you meet your gMG treatment goals.

Learn more at [UCBforGMG.com](https://www.ucbforGMG.com)



Inspired by patients.  
Driven by science.

# What is **RARE DISEASE DAY** and Why it Matters



Each year, on the last day of February, people across the globe come together to recognize Rare Disease Day, an international awareness campaign dedicated to the millions of individuals and families affected by rare conditions. The purpose of the day is simple but powerful: to increase understanding of rare diseases and highlight the very real challenges faced by those living with them. Although each rare disease affects a relatively small number of individuals, collectively rare diseases impact an estimated 300 million people worldwide. These numbers remind us that while a condition may be considered “rare,” the community it represents is anything but small.

## **Why Rare Disease Day Is Important**

For many individuals and families, the rare disease journey can include delayed diagnosis, limited treatment options, and difficulty accessing specialized care. Rare Disease Day helps shine a light on these challenges while advocating for more equitable access to diagnosis, treatment, services, and social support.

Awareness leads to understanding and understanding leads to change. When communities, healthcare professionals, researchers, and policymakers recognize the impact of rare diseases, it becomes easier to advance research, improve care, and support policies that better serve those affected. Rare Disease Day is not only about awareness; it is also about building momentum for progress and ensuring that no one feels alone in their journey.

## **How Everyone Can Participate**

Rare Disease Day is designed so that anyone can take part. Participation can be as simple or as creative as you like. Many people share their stories or post messages of support on social media using the official hashtag #RareDiseaseDay to help amplify awareness. Others organize or attend local or virtual events, host educational programs, or partner with schools, workplaces, or community groups to start conversations about rare diseases. (Like our Snowflake Saturday + Rare Disease Day event. Learn more on page 12.)

## **How You Can Participate Year-Round with the MGA**

Rare Disease Day is a powerful moment of awareness, but advocacy and connection don't have to happen just once a year. The Myasthenia Gravis Association (MGA) offers meaningful opportunities throughout the year for individuals, patients, caregivers, and medical professionals to stay involved, share their voices, and help strengthen our community. One of the most impactful ways to participate is by sharing your story and experience. Personal perspectives—whether from someone living with myasthenia gravis, a caregiver, or a healthcare professional—help others feel less alone, increase understanding, and bring real-life insight to the challenges and victories within the rare disease journey.

We continue the conversation year-round through initiatives like Tuesday Truths and Wednesday Wins, where we share education, encouragement, and real stories from our community. These campaigns highlight both the realities and the resilience that define life with a chronic and rare condition. In addition, there are opportunities to share personal experiences through our blog features and newsletter stories, helping amplify patient and caregiver voices to a broader audience.



#RARE  
DISEASE  
DAY

**MORE THAN  
YOU CAN IMAGINE**

28 FEB  
2026



If you are interested in sharing your story, perspective, or expertise with the community, we would love to connect with you. Please email [info@mgakc.org](mailto:info@mgakc.org) to request more information about available opportunities.

# YOUR VOICE, YOUR POWER

## WHY PATIENT VOICES MATTER MORE THAN EVER

Living with myasthenia gravis means navigating more than symptoms, it means navigating systems. Insurance policies, medication approvals, research funding, and workplace protections are often shaped by decisions made far from the clinic room. That's where patient voices make the difference. Advocacy doesn't always look like standing at a podium. Sometimes it's sharing your story with a lawmaker, appealing an insurance denial, educating an employer, or participating in research.



## How Advocacy Shapes Care

### Insurance Coverage

When patients speak up about delays, denials, and the impact of high out-of-pocket costs, policymakers and insurers gain a clearer picture of the real-life consequences of access barriers. These stories help push for:

- Fairer prior authorization processes
- Broader treatment coverage
- Recognition of rare disease needs in policy decisions

### Drug Approvals

Patient-reported experiences are increasingly considered in the drug approval process. Regulatory agencies want to understand:

- How symptoms affect daily life
- What side effects are most burdensome
- What meaningful improvement actually looks like

Your lived experience helps shape how new treatments are evaluated.

### Research Funding

Funding priorities are influenced by community engagement. When patients and families raise awareness, participate in registries, or share their journeys, it highlights the urgency of continued research and innovation.

### Why This Matters

Rare disease communities are small, but our collective voice is powerful. Advocacy ensures that policies, research, and healthcare systems reflect the realities of those living with MG — not just statistics on a page. When you share your story, ask questions, or stand up for your care, you are not only advocating for yourself — you are helping shape a more informed, compassionate system for everyone who will come after you.

Your voice matters. Your experience is expertise. And your story has power.

## What Happens When Patients Share Their Stories?

When a patient speaks with a legislator, participates in an advocacy day, or submits a public comment, their story becomes more than personal — it becomes educational. Lawmakers may not fully understand rare diseases, but they understand people. Personal stories:

- Put a human face on policy issues
- Explain why timelines, access, and affordability matter
- Help decision-makers understand the daily realities of living with MG

One conversation can influence how a bill is written, how funding is allocated, or how a program is structured.

# YOUR VOICE, YOUR POWER

## POLICY WATCH

The EveryLife Foundation's Legislative Reference Guide highlights key federal policy areas that are shaping advocacy efforts for the rare disease community in 2026. These priorities reflect issues where the community's voice is needed most, from strengthening early detection programs to protecting access to care and treatment innovation.



## 2026 Federal Priorities

### Lead Initiatives

- Newborn Screening: Federal reauthorization & modernization efforts.
- Accelerated Approval Pathway: Protect early access to promising therapies.
- Orphan Drug Incentives & Tax Credits: Support continued development of treatments.
- Rare Pediatric Disease PRV Reauthorization: Give Kids a Chance Act (H.R. 1262 / S. 932).
- Orphan Drug Tax Credit: Cameron's Law (H.R. 1414).

### Research & Funding

- NIH & FDA Rare Disease Innovation Hub funding.
- Clinical trials & scientific collaboration: Scientific EXPERT Act (H.R. 1532 / S. 822).
- Engage BENEFIT Act for patient experience in FDA decision-making.

### Coverage & Access

- Medicaid coverage protections & prior authorization reform.
- Home infusion access: Joe Fiandra Access to Home Infusion Act.
- Genetic testing coverage & telehealth policies.
- Drug pricing & PBM reform.

### Other Key Policies

- Clinical trial diversity: ENABLE Act (H.R. 1436 / S. 627).
- Rare disease research & alternative funding programs.
- Ongoing monitoring: PASTEUR Act, RARE Act, PROTECT Rare Act, Safe Step Act, MINI Act.

## What Matters Most for Individuals with Myasthenia Gravis?

- **Early Access to Therapies:** Maintaining the Accelerated Approval Pathway ensures MG patients can access new treatments sooner.
- **Home Infusion Access:** IVIG and other infusions at home are critical — support for the Joe Fiandra Access to Home Infusion Act directly impacts MG care. Luckily, the recent funding package that ended the recent partial government shutdown included the Joe Fiandra Access to Home Infusion Act to begin coverage in 2027.
- **Orphan Drug Protections:** Preserving incentives and tax credits supports ongoing development of rare disease therapies, including MG medications.
- **Clinical Trials & Research Funding:** NIH support, the FDA Rare Disease Innovation Hub, and legislation like the Scientific EXPERT Act strengthen MG research and trial participation.
- **Coverage & Affordability:** Medicaid protections, prior authorization reform, and PBM/drug pricing policies help reduce barriers to essential MG treatments.

# MG CLINICAL TRIAL UPDATES

## University of Kansas Medical Center



MyClad PI: Dr. Mamatha Pasnoor  
ClinicalTrials.gov Identifier: NCT06463587

A Phase 3, Randomized, Double-Blind, Placebo-Controlled, 3-Arm, 3-Period Study to Assess the Efficacy and Safety of a New Formulation of Oral Cladribine Compared With Placebo in Participants With Generalized Myasthenia Gravis (MyClad)

For more information contact: Samantha Colgan, [scolgan@kumc.edu](mailto:scolgan@kumc.edu)

AURORA PI: Cartesian Therapeutics ClinicalTrials.gov Identifier: NCT06799247  
A Randomized, Double-Blind, Placebo-Controlled Phase 3 Trial of Descartes-08 in Patients With Generalized Myasthenia Gravis (MG)

For more information contact: Nora Khalifa, [nkhalifa@kumc.edu](mailto:nkhalifa@kumc.edu)

RemeMG PI: Dr. Pasnoor ClinicalTrials.gov Identifier: NCT06456580  
A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study with an Open-label Extension Period to Evaluate the Efficacy and Safety of Telitacicept in Patients with Generalized Myasthenia Gravis

For more information: Courtney Richardson, [c969r831@kumc.edu](mailto:c969r831@kumc.edu)

KATALYST MG PI: Dr. Pasnoor ClinicalTrials.gov Identifier: NCT06064695  
Effects of Whole-body Electrical Muscle Stimulation Exercise on Adults With Myasthenia Gravis

For more information for the KU trial location contact: Abby Davis, [adavis54@kumc.edu](mailto:adavis54@kumc.edu)

ARGX-113-2315 PI: Dr. Pasnoor ClinicalTrials.gov Identifier: NCT06298565  
A non-interventional, post-authorisation safety study of patients treated with efgartigimod alfa

For more information contact: Lilli Saavedra, [lsaavedra2@kumc.edu](mailto:lsaavedra2@kumc.edu)

Cabaletta Bio PI: Dr. Dimachkie ClinicalTrials.gov Identifier: NCT06359041  
A Phase 1/2, Open-Label Study to Evaluate the Safety and Efficacy of Autologous CD19-specific Chimeric Antigen Receptor T Cells (CABA-201) in Participants with Generalized Myasthenia Gravis

For more information: Lillian Saavedra, [lsaavedra2@kumc.edu](mailto:lsaavedra2@kumc.edu)

COUR Pharma PI: Dr. Dimachkie ClinicalTrials.gov Identifier: NCT06106672  
A Phase 1b/2a Double Blind, Randomized, Placebo Controlled Study to Evaluate the Safety, Tolerability, Pharmacodynamics, and Efficacy of CNP-106 in Subjects Ages 18-75 with Generalized Myasthenia Gravis  
Experimental: ALXN1720

For more information contact: Abby Davis, [adavis54@kumc.edu](mailto:adavis54@kumc.edu)



# MG CLINICAL TRIAL UPDATES

## University of Missouri



NMD Pharma PI: University of Missouri- Columbia  
ClinicalTrials.gov Identifier: NCT06414954

This Phase 2 proof-of-concept, dose range finding study aims to evaluate the safety and efficacy of 3 dose levels of NMD670 vs placebo in adult patients with MG with antibodies against AChR or MuSK, administered twice a day (BID) for 21 days.

For more information contact: Neetha Gali, [ngdcd@health.missouri.edu](mailto:ngdcd@health.missouri.edu)

COUR Pharma - MG PI: University of Missouri- Columbia ClinicalTrials.gov Identifier: NCT06106672  
A Phase 1b/2a Double Blind, Randomized, Placebo Controlled Study to Evaluate the Safety, Tolerability, Pharmacodynamics, and Efficacy of CNP-106 in Subjects Ages 18-75 with Generalized Myasthenia Gravis  
Experimental: ALXN1720

For more information contact: Neetha Gali, [ngdcd@health.missouri.edu](mailto:ngdcd@health.missouri.edu)

**Myasthenia gravis:  
Strength in unity**

**Join the Synergy-MG Study and see if your experience can make a difference**

The Synergy-MG Study is looking at an investigational medication for people with myasthenia gravis (MG) to see:

- how safe it is
- if there are any side effects
- what amount, or dose, works best
- whether it may help to improve symptoms of MG.

We are looking for people who:

- are 18-74 years old
- have been diagnosed with either generalized or ocular MG
- are on a stable dose of medication for the treatment of MG.



Want to know more? Contact us:



Amgen is proud to support the Myasthenia Gravis Association.

# See WHAT'S NEW At the MGA

## Meet Our New Board Members

### Tom Cook

Tom Cook is a retired communications major. He published business magazines for 19 years at Inter-tec Publishing, Overland Park, KS, followed by 19 years at Sprint/T-Mobile. In 2025, he funded an endowed journalism scholarship at the University of Kansas. He's also a former NCAA softball umpire.



### Kathy Perez

Kathy Perez brings over 30 years of leadership across BioPharma's commercial, R&D, and patient advocacy landscapes. Most recently, as VP and Head of Global Patient Advocacy at argenx, she led strategy across 15 rare autoimmune indications—translating patient insights into high-impact business outcomes. Under Kathy's leadership, biotechnology companies have launched groundbreaking Public/Private stakeholder collaborations and unique award winning podcast programs. But these efforts were never just about awareness—they were built to advance patient conversations, inform physician decision-



making, and support more inclusive care models.

Kathy now brings this model to biopharma clients—bridging advocacy and business with a unique combination of:

- Compliance Fluency – deep knowledge of regulatory safeguards in working with patient organizations and protecting ethical boundaries.
- Commercial Strategy – the ability to position advocacy within core business drivers: access, uptake, and market differentiation.
- Execution Rigor – a track record of delivering real programs that meet objectives, align internal teams, and drive measurable outcomes.

“Advocacy isn't a feel-good function—it's a strategic lever. When it's built right, it drives smarter science and stronger stakeholder trust.”

SPONSORED CONTENT

## CAN YOU MAKE AN IMPACT IN MYASTHENIA GRAVIS (MG) RESEARCH?

MYCLAD

**The MyClad Study is researching an investigational medication taken by mouth for generalized myasthenia gravis (gMG) and is now enrolling. Join us.**

The MyClad Study is looking to learn more about an investigational medication taken by mouth regarding its safety and ability to treat people with gMG. The investigational medication will be given as a capsule to be swallowed. We want to evaluate the ability to improve your gMG symptoms when using the investigational medication.

You may be eligible for this study if you:

- ▶ are an adult of at least 18 years of age or older
- ▶ have a confirmed diagnosis of MG with generalized muscle weakness.

Your doctor will review the study requirements and discuss your eligibility with you.

You will receive all study-related procedures and the investigational medication at no cost. Study participation will last for about 3 years.

This study has been designed with gMG patients' feedback and reviewed by an Institutional Review Board (IRB)/Ethics Committee (EC), which protects the rights, safety, and well-being of the participants.

To learn more, ask your doctor about the MyClad Study or scan the QR code.



[mycladstudy.com](https://mycladstudy.com)

# See WHAT'S NEW At the MGA

## Joining Hands to Strengthen Support in Nebraska

The Myasthenia Gravis Association (MGA) is proud to announce that we are joining hands with the Omaha MG Support Group to provide enhanced support, resources, and connection for individuals and families affected by myasthenia gravis in the Omaha area.

The Omaha Support Group meets every other month on the 2<sup>nd</sup> Saturday. The next and First Omaha MG Support Group Meeting with MGA Support will be:

Date: Saturday, February 14th  
Time: 10:00 AM – 11:30 AM  
Location: Moon Hollow Coffee  
5102 North 156th Street  
Omaha, NE 68116

We'd LOVE to meet you! Please join us for muffins and mingling.



myasthenia gravis  
**Omaha  
Support  
Group**

Please join us for  
muffins and mingling.

## Looking for Something to Read?

A community member, Johnny Jefferson, has sent us copies of their book, *OMG: Journeying Through Faith Through Troubling Times*. "This book is written to share my journey over a decade. I never thought I would have to stick a needle in my belly with a nurse in the room looking over my chart and recording my vitals and encouraging me to do so. I didn't think that I would fall down and not be able to get up although I was not intoxicated, had no broken bones, or over the age of 35."

If you are interested in receiving a complimentary copy, email us at [info@mgakc.org](mailto:info@mgakc.org).

**janssen** | PHARMACEUTICAL COMPANIES OF **Johnson & Johnson**

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





# EXPLORE THE POSSIBILITIES

Ask your doctor about VYVGART Hytrulo (efgartigamod alfa and hyaluronidase-qvfc) and VYVGART (efgartigamod alfa-fcab)

**VYVGART® Hytrulo**  
(efgartigimod alfa and hyaluronidase-qvfc)  
Subcutaneous Injection  
180 mg/mL and 2000 U/mL vial

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



Scan the QR code or visit [VYVGART.com](https://www.vyvgart.com) to learn more

Questions? Call 1-833-VYVGART (1-833-898-4278)

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# UPCOMING EVENTS



## MGA TRIPLE CROWN SHOWDOWN 2026

### 5K RUN/WALK & TOT TROT

**Date:** Sunday May 3, 2026  
**Time:** 8:00am, CST  
**Location:** Town Center Plaza, Leawood, KS

### PACKET PICK-UP

**Date:** Saturday May 2, 2026  
**Time:** 10:00am - 2:00pm  
**Location:** Town Center Plaza, Leawood, KS

**Date:** Sunday, May 3, 2026  
**Time:** Starting at 7am  
**Location:** Town Center Plaza, Leawood, KS

Packets will be mailed to those who registered for Stuck in the Stall after the run.

### CROWN TOWN TRIVIA NIGHT



**Date:** July 31, 2026  
**Time:** TBA  
**Location:** Sporting Park, Sporting KC | 1 Sporting Way, Kansas City, KS

For the first time ever, the FIFA World Cup is being held in Kansas City! To celebrate, we are excited to switch up our location for our annual Trivia Night.

Join us for a night like no other and discover opportunities on how to get involved! We are excited to switch up our location, bringing you a once in a lifetime experience following the FIFA World Cup in Kansas City!

More details coming soon via email!  
Stay informed: [www.mgassociation.org](http://www.mgassociation.org)

Register at [www.mga5k.com](http://www.mga5k.com)

All individuals living with MG register for FREE, email the MGA for the code at [info@mgakc.org](mailto:info@mgakc.org).



### Snowflake Saturday

### RARE DISEASE DAY EVENT | SAINT LOUIS

**Date:** February 28, 2026  
**Time:** 10:00am - 1:00pm  
**Location:** Center of Clayton, Clayton, MO

Help us raise awareness for MG on Rare Disease Day! Join the MGA for a morning of connection, education provided by Give an Hour touching on mental health and rare disease. Enjoy vendor booths, raffles, lunch, MGA merchandise for sale, and more!



Register here! 

# Membership Donations

Graham Naasz, DDS

BJ Fevold

Julie Foss

Janice and Steve Katz

Shannon Harris, MD

Janice and Richard McGuire in  
memory of Jacob McGuire, DDS

Sara Bass

April Zobel

Cindy Disque

Craig and Barb Foss

Terre Tepikan

Betty Banner

Camile Weiler

Blue Turtle Designs

Jeffrey and Cathy Schmeltz

Wes and Helen Stillian

Phyllis Peniston in honor of Pam  
Stucker

Susan Miletta

Kenneth and Diane Cummings

Warren Swanson

Ann Mowry

Faye Remollino Paez

Vern Grothoff

Daniel Turner

Chalas Bales

Gary & Sandy Gardner

Rick McGraw

Ralph & Dianna McCarty

Jon Patton

Gerald and Marcia Finke

May Ellen Dowdy

Roxie Drautz

Tim & Linda Rohr

Wei and Ji Sun

Marilyn Barrett

Florence Petrock

Steven Hartwich

Sally Wegman

Lisa Gioia

John and Cindy Wilkinson

Gene and Shirley Goode

Cheryl Powell

Aida Gurera

Charles & Nancy Curnell

Dr. Charles Stackhouse in memory  
of Joan & William Stackhouse

Douglas Dible

Winston Sommerfield

Greg & Kristen Shamburg

Dr. Mazen & Mary Dimachkie

Janet Grudman in memory of Helen  
Dasta

Navelle Grossman

Charles & Mary Haley

Alan & Gail Still

Richard & Ann Woody

Don & Marilyn Sisson

Ken & Lola Cook

Daniel & Donna Gifford

Dan Cogan

Marie Nave

Cheryl Hostinak

Glenda Thomas

Elana King

Susan Salnick

Ron Crumpler

Amanda Foster

Mark Barnes

Almar Abeson

Mike Seberger

Ann and Steve Mowry in memory of  
Norma Covington

## In Memoriam of Gordon Nave

Debra Litton

Jackie Marsh

Robert and Lois Moss

Martha Ward

Rhonda Bruns



Thank  
you



# 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.

## Visit More Than MG to explore:

- Patient stories shared through social media
- Tips for living life beyond an MG diagnosis
- Encouraging reminders and motivation
- Resources for you and your loved ones



MoreThanMG.com

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@MoreThanMG



Use our More Than MG Instagram filter  
to help spark awareness about vision impairment.



GO TO @MoreThanMG ON



INSTAGRAM TAP THE SPARKLES



ICON

SELECT THE "SEE MG" FILTER



# Find A SUPPORT GROUP Near you

## Arkansas

### Arkansas Support Group

Quarterly Saturday | 10:00 AM - 11:30 AM | Hybrid: Zoom or In-Person at Springdale Public Library, 405 S. Pleasant St. Springdale, AR

Open to individuals, caregivers & providers

Next Meeting - April 25, 2026

RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)



## Iowa

### Iowa Support Group

Bi-Monthly on the 2nd Wednesday | 6:00 PM - 7:00 PM | Kirkendall Public Library, 1250 SW District Dr, Ankeny IA

Open to individuals, caregivers & providers

Hosted by Katie Coffman, Volunteer Support Group Leader

Next Meeting - April 8, 2026

RSVP: [info@mgakc.org](mailto:info@mgakc.org)



## Kansas

### Kansas City Coffee Club

1st Thursday of the month | 9:30-10:30 AM

Urban Egg, 4921 W 119th St, Overland Park, KS

Coffee is Dutch treat | Open to individuals, caregivers & providers

Hosted by Janice Katz & Melissa Lathrop, Volunteer Support Group Leaders

Next Meeting - March 5, 2026

RSVP: [info@mgakc.org](mailto:info@mgakc.org)



### Lawrence Support Group

Quarterly on a Thursday | 6-7:30 PM | Lawrence Public Library, 707 Vermont Street, Lawrence, KS

Open to individuals, caregivers & providers

Next Meeting - March 5, 2026 | May 28, 2026

RSVP: [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)

# Find A SUPPORT GROUP Near you

## Kansas

### Wichita Support Group

Quarterly on a Saturday | 11:00–1:00 PM | Wichita Public Library, Alford Branch 3447 S. Meridian St. Wichita, KS

Open to individuals caregivers & providers

Hosted by Dana Paxson, Volunteer Support Group Leaders

Next Meeting – March 28, 2026

RSVP: [info@mgakc.org](mailto:info@mgakc.org)



## Missouri

### Eastsiders Lunch Bunch – Blue Springs

1st Wednesday of the month | 11:30 – 1:00 PM

312 SW 19th Terrace Street, Blue Springs, MO

Light lunch provided | Open to individuals, caregivers & providers

Hosted by Carol Hunt & Raymond Hankins, Volunteer Support Group Leaders

Next Meeting – March 4, 2026

RSVP to [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)



### Kansas City Coffee Club

1st Thursday of the month | 9:30–10:30 AM | Urban Egg, 4921 W 119th St, Overland Park, KS

Coffee is Dutch treat | Open to individuals, caregivers & providers

Hosted by Janice Katz & Melissa Lathrop, Volunteer Support Group Leaders

Next Meeting – March 5, 2026

RSVP: [info@mgakc.org](mailto:info@mgakc.org)

### Greater Kansas City Support Group

Quarterly on a Saturday | 10:00 –11:30 AM | Matt Ross Community Center

8101 Marty St, Overland Park, KS 66204 (Plaza Room)

Light brunch is provided | Open to individuals, caregivers & providers

Next Meeting – February 21, 2026

RSVP: [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)



### Kansas City Northland Support Group

Jan–Sept, bi-monthly on a Thursday | 12:00 –1:30 PM | Primrose Retirement Community, 8559 N. Line Creek Road, Kansas City, MO

Light lunch is provided | Open to individuals, caregivers & providers

Hosted by Sandy Gardner, Volunteer Support Group Leader

Next Meeting – March 12, 2026 | May 14, 2026

RSVP: [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)

# Find A SUPPORT GROUP

Near you

## Missouri

### St. Joseph Support Group

Bi-Monthly | 2:30 - 4:00 PM | Hazel's Coffee Roasting Company,  
3829 Frederick Ave, St Joseph, MO

Open to individuals, caregivers & providers | Coffee is Dutch treat  
Hosted by Donna Whittaker, Volunteer Support Group Leader

Next Meeting - April 2, 2026

RSVP: [info@mgakc.org](mailto:info@mgakc.org)



### Springfield Support Group

Quarterly on a Thursday | 5:30-7:00 PM | East Sunshine Church of Christ, 3721 E. Sunshine St, Springfield, MO

Open to individuals, caregivers & providers

Next Meeting - April 23, 2026

RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)

### Mid-Missouri Group

Quarterly on a Thursday | 5:30-7:00 PM | Shakespeare's Pizza - South, 3911 Peachtree Dr, Columbia, MO

Open to individuals, caregivers & providers

Hosted by Jonni Sutton, Volunteer Support Group Leader

Next Meeting - April 9, 2026

RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)

### St. Louis Coffee Club

4th Thursday of the month | 10:30-11:30 AM | St. Louis Bread  
Company, 10221 Manchester Rd, Kirkwood, MO

Coffee is Dutch treat | Open to individuals, caregivers &  
providers

Next Meeting - February 19, 2026

RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)



### St. Louis Support Group

Quarterly on a Saturday | 10:00-11:30 AM | Glendale City Hall Auditorium, St. Louis, MO

Light brunch provided | Open to individuals, caregivers & providers

Next Meeting - February 28, 2026

RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)

# Find A **SUPPORT GROUP** Near you

## Nebraska

### Omaha Support Group

Bi-Monthly | 2nd Saturday | 10:00 - 11:30 AM | Moon Hollow Coffee, 5102 North 156th Street, Omaha, NE  
Open to individuals, caregivers & providers | Coffee is Dutch treat  
Next Meeting - April 11, 2026  
RSVP: [info@mgakc.org](mailto:info@mgakc.org)

## Virtual

### Muscle Makers

3rd Wednesday of the month | 12:30 PM - 1:30 PM | Via Zoom  
A virtual community for individuals with MG to bring your hobbies to life. Bring your craft and creativity to your screen while connect with others.  
Hosted by Bryan Bosch, Volunteer Support Group Leader  
Next Meeting - February 18, 2026  
Register at [mgassociation.org](http://mgassociation.org)

### MG Pride Group

Bi-Monthly on a Tuesday | 6:00 PM - 7:00 PM | Via Zoom  
Open to individuals who identify as LGBTQ+ with MG, their allies and care partners  
Hosted by Bryan Bosch, Volunteer Support Group Leader  
Next Meeting - April 7, 2026  
RSVP: [info@mgakc.org](mailto:info@mgakc.org)

### Virtual Monthly Meetup

4th Monday of the month | 6:30-7:30 PM via Zoom  
Open to individuals, caregivers & providers  
Next Meeting - February 23, 2026  
Register at [www.mgassociation.org](http://www.mgassociation.org)

### Young Friends of the MGA- Virtual Support Group

Bi-Monthly via zoom | 5:30 PM - 6:30 PM | Via Zoom  
Open to individuals who are generally, in their 20s, 30s and 40s  
Next Meeting - March 24, 2026  
RSVP: [info@mgakc.org](mailto:info@mgakc.org)



## GENERALIZED MYASTHENIA GRAVIS (gMG)

A clinical study may offer a new option.

### Who Can Join

- We're helping families connect with a study for children living with gMG, a rare condition that causes muscle weakness.
- If your child is between 2 and less than 18 years old and has been diagnosed with generalized myasthenia gravis, they may be eligible to join a clinical trial exploring a study drug for gMG.

### Why Consider Participating

- Every participant receives the study drug
- Access to expert physicians with experience working with MG families

### See If Your Child Qualifies



[studies@patientwing.com](mailto:studies@patientwing.com)

[thymestudy.com/mga](http://thymestudy.com/mga)

213-459-2979

**Thyme** Pediatric gMG Study

**Myasthenia Gravis Association**

2340 E. Meyer Blvd. Building 1, Suite

300A Kansas City, MO 64132

Phone: (816) 256-4100

Email: info@mgakc.org

www.mgassociation.org

<p>Name: _____</p> <p>Address: _____</p> <p>City, State, zip: _____</p> <p>Phone: _____</p> <p>Email: _____</p> <p>I am a: <input type="checkbox"/> MG PATIENT <input type="checkbox"/> FRIEND <input type="checkbox"/> OTHER <input type="checkbox"/> RELATIVE <input type="checkbox"/></p> <p><small>-Contributions may be tax deductible -Make checks payable to: Myasthenia Gravis Association</small></p>		<p>I want to support the MGA by becoming a 2026</p> <table border="0"> <tr> <td>Basic Member</td> <td>\$25.00</td> <td><input type="checkbox"/></td> </tr> <tr> <td>64th Anniversary Member</td> <td>\$64.00</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Sustaining Member</td> <td>\$100.00</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Patron Member</td> <td>\$500.00</td> <td><input type="checkbox"/></td> </tr> <tr> <td>Lifetime Member</td> <td>\$1,000.00</td> <td><input type="checkbox"/></td> </tr> </table> <p>In memory of: _____ \$ _____</p> <p>In honor of: _____ \$ _____</p>		Basic Member	\$25.00	<input type="checkbox"/>	64th Anniversary Member	\$64.00	<input type="checkbox"/>	Sustaining Member	\$100.00	<input type="checkbox"/>	Patron Member	\$500.00	<input type="checkbox"/>	Lifetime Member	\$1,000.00	<input type="checkbox"/>
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Lifetime Member	\$1,000.00	<input type="checkbox"/>																

*Cut and enclose in envelope. Mail to MGA address below.*

# MYASTHENIA GRAVIS ASSOCIATION

## Become a 2026 Member of the