



**VOL. 65 ISSUE 2**

# MYASTHENIA GRAVIS ASSOCIATION NEWSLETTER

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## Myasthenia Gravis Association Annual Meeting 2025

Save the Date! Our annual meeting will be held on November 8th, 2025 at the St. Joseph Medical Center Kansas City, MO and, as in previous years, will be a hybrid event with the option to attend via Zoom.

The MGA Annual Meeting provides an opportunity for members and friends to gather and review the work of the association from the previous year and to welcome new Officers to the Board of Directors. With guest speakers presenting topics of interest to MGA members, their family, and friends, it also provides an educational experience that is unique to our area. The Annual Meeting also provides an opportunity to thank special people for their volunteer efforts to enhance the quality of life of those living with myasthenia gravis and for their support of our association. At this year's annual meeting, we have two keynote speakers ready to share their expertise and stories. You can learn more about our speakers, Dr. Al Freeman and Dr. Liz Plowman, on page 2.

## New In-Person Clinic Partnership at University of Missouri

On August 21<sup>st</sup>, the Myasthenia Gravis Association will begin our 5th clinic partnership with Dr. Vernita Hairston and Dr. Richard Barohn in Columbia, MO. We are excited to be working with Dr. Hairston and Dr. Barohn was an integral part of our very first clinic at the University of Kansas in KC and we are thrilled to be working with him again. Clinic will be held on the 3rd Thursday morning of each month. We are looking forward to the opportunity to support the MG community.



## 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



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<https://www.facebook.com/mgakc>



<https://www.youtube.com/user/mgakc>

# A MESSAGE FROM ALLISON

## There is Room for All, A Place for Everyone

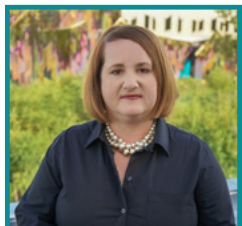
I shared a similar rendition of this recently at our 8<sup>th</sup> Annual Crown Town Trivia Night and thought it was a good message to share as our summer newsletter hits the press.

Apparently, August 1<sup>st</sup> is girlfriends' day and national friendship day is August 3<sup>rd</sup>. You know those silly little holidays made up probably to increase social media content. Our trivia night fell on August 1<sup>st</sup> and it had me reflecting on friendships and the tribes we build as we made preparations and table assignments.

In part, I think that is what we are working to create at the Myasthenia Gravis Association. We are working to create a tribe where each person feels seen, feels heard and has the encouragement to keep fighting the fight. Having a rare disease can be so isolating and leave you feeling so alone. Especially one with no cure.

Our support groups, our clinic partnerships and our education and awareness events are an integral part of tribe building. Our programming emails, newsletters, website and social media showcase all of the groups and opportunities we have going at any given time. We hope you'll check them out and see what interests you the most.

Girlfriends' day or friendship day or not, we hope you know you are welcome to be a part of our tribe at any time. There's room for all and a place for everybody, so we invite you to join one of our groups and find your place.



Looking forward to seeing you soon!

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



### MGA STAFF

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Allison Foss

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McKenna Fulton

**Event Coordinator**  
Halle Walker

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### CONTACT

816-256-4100  
[info@mgakc.org](mailto:info@mgakc.org)

# MGA ANNUAL MEETING

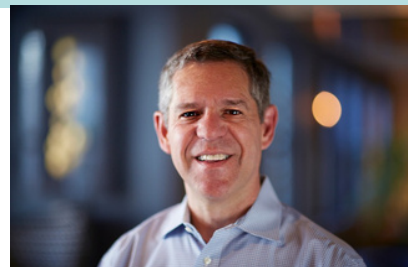
## Keynote Speakers 2025

**We are honored to welcome Dr. Al Freedman and Dr. Liz Plowman** as our keynote speakers at this year's Annual Meeting.

**Dr. Al Freedman – <https://www.rarecounseling.com/>  
Psychologist, Consultant, Rare Disease Advocate, and Rare Dad**

Al Freedman, PhD, is a psychologist, educator, and rare disease advocate with more than two decades of experience working with individuals and families affected by rare diseases and disabilities.

Dr. Al is inspired by his personal journey as the father of Jack, who lived with spinal muscular atrophy (SMA) for 26 years as well as his professional training and experience as an educator to provide counseling and consultation. He works with families, advocacy organizations, pharmaceutical companies, healthcare organizations, and schools to create meaningful support systems and impactful change within the rare disease and disability communities.



**Dr. Liz Plowman – <https://lizplowman.com/>  
Physical Therapist, Author, MG Advocate, and Rare Disease Researcher**

Elizabeth “Liz” Plowman, PT, DPT, M.Ed, LCDR, MSC, USN (Retired), is a licensed physical therapist and a retired U.S. Navy officer with over 15 years of clinical experience. After receiving her Doctor of Physical Therapy (DPT) degree from Texas Woman's University, she served in diverse settings including outpatient orthopedics, chronic pain, and telehealth—long before it became the norm. Diagnosed with Myasthenia Gravis (MG) herself in 2017, Liz brings a unique dual perspective as both clinician and patient.



She is the author of *Some Spoons Are Worth Spending: Practical Energy Conservation Strategies to Live Your Best Life With Myasthenia Gravis*, and a frequent speaker and educator on the intersection of MG and movement. Her work focuses on making life more livable for those with chronic fatigue and neuromuscular conditions through exercise, energy conservation, and patient empowerment.

A lifelong learner and advocate, Liz is passionate about improving the quality of life for people with MG through education, empathy, and practical strategies.

**Shaping what's next, together**

**MG is complex and unpredictable. While each person's experience is unique, managing MG – even while on treatment – can be challenging.**

A survey of 547 U.S. adults with MG showed that **more than 50% of respondents** reported a significant negative impact on their:

- Energy
- Physical activity
- Ability to work

At Immunovant, we're committed to helping to address the complex and variable needs of people living with MG. Your voice drives our work as we pursue a patient-focused approach to researching therapies across disease stage and severity.

**Tell us, what's your hope for what's next?** Share your perspective at: [tinyurl.com/yj2jkah3](https://tinyurl.com/yj2jkah3)

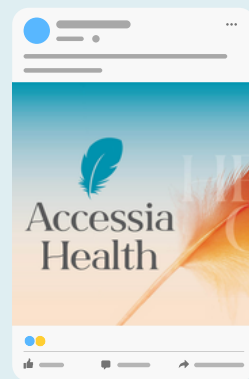


# BRIDGING THE GAP:

## EXPANDING ACCESS TO THE CARE YOU NEED

### Accessia Health: Patient Assistance Program

Accessia Health offers financial assistance programs designed to help patients manage the costs of chronic medical conditions, including rare diseases like myasthenia gravis. Their support includes help with insurance premiums, medication copays, travel expenses, and other essential health-related costs. The organization aims to reduce financial barriers and improve access to care by providing timely, compassionate support to qualified individuals.



Learn more or apply at [accessiahealth.org](https://accessiahealth.org).

### Muscular Dystrophy Association (MDA): Equipment Assistance Program

The Muscular Dystrophy Association (MDA) offers an Equipment Assistance Program to help individuals with neuromuscular diseases access medical equipment. This includes items like wheelchairs, hospital beds, and communication devices that may not be fully covered by insurance. MDA partners with supporters and manufacturers to provide gently used or donated equipment, helping ease financial burdens for families in need.



Learn more or apply at [mda.org](https://mda.org).

### Patient Advocate Foundation (PAF)

The Patient Advocate Foundation (PAF) provides free, professional case management services to help individuals facing chronic, life-threatening, or debilitating illnesses. Their team assists with navigating insurance denials, securing financial support for co-pays and out-of-pocket costs, and accessing necessary care and treatment. PAF also offers disease-specific support programs and educational resources to empower patients and their families.

Learn more at [patientadvocate.org](https://patientadvocate.org).



## CELEBRATING A MONTH OF IMPACT:

### MG AWARENESS MONTH JUNE 2025

This June, the MGA proudly marked Myasthenia Gravis Awareness Month with a blend of in-person events and online campaigns—uniting patients, caregivers, and supporters in our shared mission of education, awareness, and connection.



On Saturday, June 7th, we hosted three regional Snowflake Saturday Awareness Events in Des Moines, Iowa, Wichita, Kansas and Little Rock, Arkansas with more than 80 people in attendance.

These events brought our community together for educational presentations, support, and celebration and laid the foundation for future gatherings in each region.

Our digital outreach also soared to new heights. Through our “30 Days of MG,” “Light the Globe for MG,” and our awareness frame social media campaigns, we saw a 300% increase in views and engagement from May to June! This exceptional growth helps us reach more individuals affected by MG and raises crucial awareness about this rare disease.



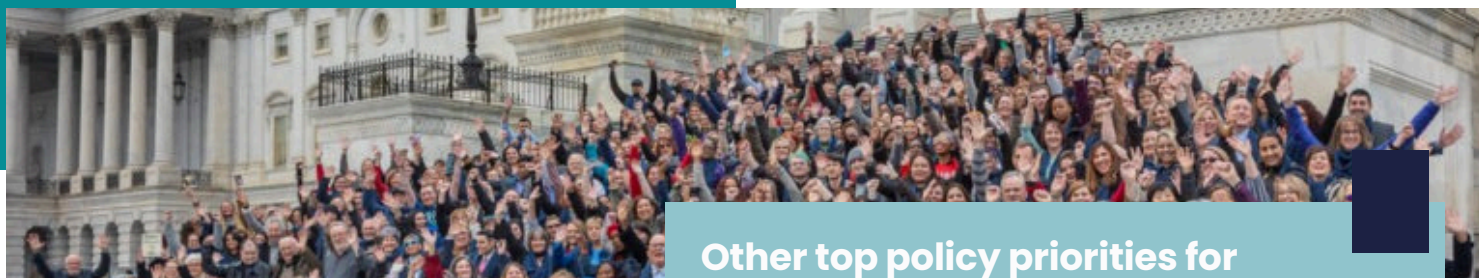
*Thank you to everyone who attended, shared, posted, and supported MG Awareness Month. Together, we're amplifying voices, spreading knowledge, and building a stronger MG community—one snowflake at a time.*

# YOUR VOICE, YOUR POWER

## VALUE IN POLICY

## Rare Disease Policy Watch: What's on the Horizon

As we enter the second half of 2025, rare disease patients and advocates are watching closely as key policy decisions take shape, decisions that will affect access to care, affordability of treatment, and the overall landscape for those living with conditions like myasthenia gravis (MG). That's why it's more important than ever to engage in advocacy, stay informed, and connect with lawmakers.



### Medicare drug price negotiations

Among the most anticipated changes are continued Medicare drug price negotiations, made possible by the Inflation Reduction Act. While these reforms aim to reduce out-of-pocket costs, they could unintentionally dampen innovation for rare disease treatments by reducing incentives for orphan drug development. The National Organization for Rare Disorders (NORD), along with over 100 rare disease groups, is advocating for clear protections to ensure these policies benefit rare disease individuals.

### Reauthorization of the Rare Pediatric Disease Priority Review Voucher (PRV) Program

The reauthorization of the Rare Pediatric Disease Priority Review Voucher (PRV) Program remains vital. This program helps encourage development of treatments for the nearly 50% of rare disease patients who are children. NORD and its partners are urging Congress to continue this program in its current form to support vulnerable pediatric populations, including Pediatric Myasthenia Gravis.

These evolving conversations around policy are more than just headlines, they are opportunities to influence real change. Whether it's sharing your MG story with your representative or supporting campaigns led by advocacy organizations like EveryLife Foundation and NORD, your voice matters. Let's keep pushing for equitable, safe, and affordable access for every rare disease patient.

### To learn more or take action, visit:

EveryLife Foundation for Rare Diseases | A 501(c)(3) nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.  
[everylifefoundation.org](https://everylifefoundation.org)

NORD | A 501(c)(3) nonprofit dedicated to Improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. [rarediseases.org](https://rarediseases.org)  
[congress.gov](https://congress.gov)

### Other top policy priorities for 2025 include:

- **Protecting the Orphan Drug Act and Supporting the Clinical Trials Modernization Act** ensuring robust funding for NIH and FDA rare disease programs and making rare disease research more inclusive and effective
- **Advancing newborn screening** while addressing concerns about the use and privacy of dried blood spot samples
- **Improving access to diagnostics** and telehealth, including genetic testing and out-of-state specialty care
- **Opposing the Promising Pathway Act**, which could fast-track unsafe treatments without sufficient clinical trials
- **Expanding Rare Disease Advisory Councils (RDACs)** at the state level to give rare patients a greater voice in local government decisions

# 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.**



# One Year Later

# CAR-T THERAPY

## Robin's Next Chapter

## From Relief to Reinforcement : A Follow-Up on MG Clinical Trial Participation

Last year, we introduced you to Robin, a member of the MGA community who courageously stepped into the unknown by enrolling in a CAR-T cell therapy clinical trial for myasthenia gravis (MG). At the time of our first article, Robin had completed her initial round of infusions and was beginning to experience a new level of freedom—free from biweekly IVIG treatments, on fewer medications, and seeing a dramatic drop in her MG-ADL score. While not without challenges, her experience was described as “life-changing,” and she was filled with hope for the future. Now, a year later and following a second round of CAR-T therapy, Robin sat down with us again to reflect on her continued progress, the reinfusion process, and the life she’s building post-trial.



### Day-to-Day Life After Reinfusion

Robin's results after her second round of CAR-T therapy were even more impressive. Although she completed five infusions instead of the originally planned six, she reported a much faster and more noticeable improvement than the first round. By January—just a few months after her last treatment—Robin traveled to Mexico for an extended stay and was walking up to five miles a day, symptom-free. Her most recent MG-ADL score dropped from a 10 to just 1. While she still occasionally experiences mild fatigue and weakness in the heat, her daily functioning has vastly improved. “It took a few months to fully kick in,” she shared, “but once it did, I felt like myself again.”

### Reinfusion Experience: Familiar, Yet Improved

Robin's second CAR-T experience came with a few hiccups—a missed dose and a longer-than-expected gap between infusions—but overall, the process was smoother than the first time. The apheresis was completed in-house at the hospital, and she was relieved not to need a port for this round. “I was determined not to have one, and so was the staff,” she said with a smile. The side effects were consistent with her initial experience: mild flu-like symptoms that were manageable with rest and over-the-counter medication.

### Continued Symptom Management

Now over a year post-reinfusion, Robin's MG-ADL score remains impressively low. Her reliance on medications like Mestinon and Imuran has significantly decreased. “If I miss a dose now, I don't really feel it,” she shared. She and her neurologist are now discussing plans to further reduce her MG medications. Follow-up appointments were scheduled regularly throughout the year, and Robin appreciated the continuity of care.

### Community & Support

Robin remains active in a Facebook group for trial participants and even connected with another member through a mutual friend. These ongoing relationships have provided her with encouragement, validation, and shared insight along the way.



One Year Later

# CAR-T THERAPY

Robin's Next Chapter

## From Relief to Reinforcement: A Follow-Up on MG Clinical Trial Participation (continued)

### Reflection and Advice

When asked what she'd tell others considering participation in the trial, Robin didn't hesitate: "Do it. It's so worth it." She described her past experience managing MG as a rollercoaster, with the unpredictable rise and fall of symptoms being both frustrating and unmanageable. She said she would choose the side effects of CAR-T therapy every time in exchange for the outcome of experiencing little to no symptoms over an extended period. Her reinfusion not only extended the improvements she had already experienced but also renewed her sense of purpose and advocacy. "It gave me something viable to share," she said. "I tell others—don't give up hope."

### Looking Forward

With better symptom management, Robin has resumed traveling and is focused on "getting the house in order." In the past year, she visited New York City, Washington, D.C., Michigan, and spent two months in Mexico. "I used to be afraid to leave the country," she admitted. "Now I'm planning trips again." Robin's biggest hope? That this trial is just the beginning. "It has the potential to be curative," she said.

### Conclusion

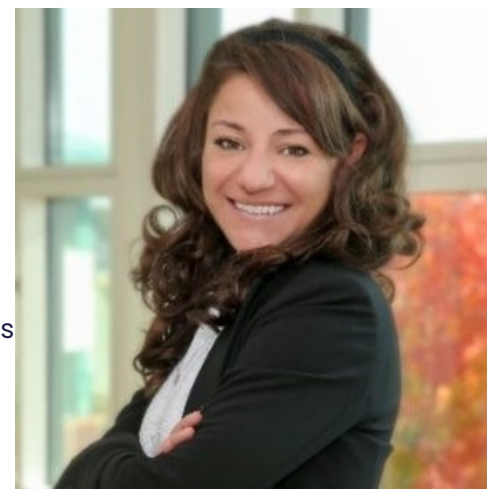
Robin's journey—from navigating the uncertainty of a clinical trial to experiencing lasting relief—illustrates the profound impact that innovation and perseverance can have in the lives of people with MG. Her story is a beacon for others considering the trial, showing that while the road may not be easy, it can lead to something truly transformative.

# REGENERON

## SCIENCE TO MEDICINE®

### About Regeneron

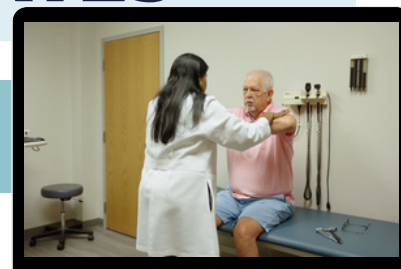
Regeneron is a leading biotechnology company that invents, develops and commercializes life-transforming medicines for serious diseases. Founded and led by physician-scientists, our unique ability to repeatedly translate science into medicine has led to numerous approved treatments and product candidates in development, most of which were homegrown in our laboratories. Regeneron accelerates drug development using our proprietary technologies, such as VelociSuite®, which produces optimized fully human and bispecific antibodies. We are shaping the next frontier of medicine with data-powered insights from the Regeneron Genetics Center® and pioneering genetic medicine platforms, enabling us to identify innovative targets and complementary approaches to potentially treat or cure diseases. Learn more at [www.Regeneron.com](http://www.Regeneron.com).





# MG CLINICAL TRIAL UPDATES

## University of Kansas Medical Center



Janssen PI: Dr. Farmakidis  
ClinicalTrials.gov Identifier: NCT05265273

An Open-Label Uncontrolled Multicenter Study to Evaluate the Pharmacokinetics, Pharmacodynamics, Safety and Activity of Nipocalimab in Children aged 2 to Less than 18 Years with Generalized Myasthenia Gravis

For more information contact: Samantha Colgan, scolgan@kumc.edu

DAS-MG PI: Dr. Dimachkie ClinicalTrials.gov Identifier: NCT04226170  
A Phase II, Study to Evaluate the Safety and Tolerability of Pyridostigmine When Given with Ondansetron to Subjects with anti-AchR positive Myasthenia Gravis

For more information contact: Nora Khalifa, 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

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

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

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

Cabaletta Bio PI: Dr. Dimachkie ClinicalTrials.gov identifier: NCT05451212  
A Phase 1, Open-label, Safety and Dose-finding Study of Autologous Muscle-specific Tyrosine Kinase Chimeric Autoantibody Receptor T Cells (MuSK-CAART) in Subjects with Anti-MuSK-antibody-positive Myasthenia Gravis.

For more information contact: Andrew Heim, aheim2@kumc.edu

# MG CLINICAL TRIAL UPDATES

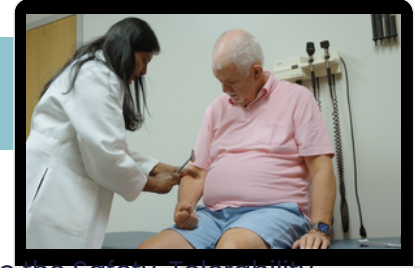
## University of Kansas Medical Center

COUR Pharma – MG 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)



## 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: Kristina Kelly, [kristina.kelly@health.missouri.edu](mailto:kristina.kelly@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: Kristina Kelly, [kristina.kelly@health.missouri.edu](mailto:kristina.kelly@health.missouri.edu)

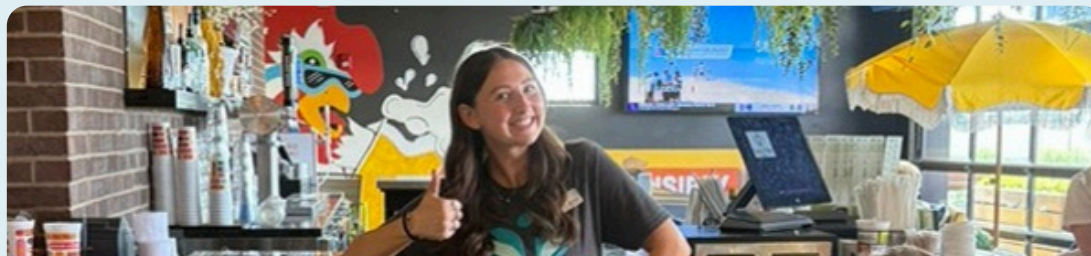


At Janssen, we are **relentlessly** focused, **actively** listening, and **expertly** helping to develop innovative solutions for those living with rare diseases, including generalized myasthenia gravis (gMG).



Learn more about gMG trials at [globaltrialfinder.janssen.com](https://globaltrialfinder.janssen.com)

# WHERE IN THE WORLD IS THE MGA?



## Wichita Snowflake Saturday

In June, Mckenna and Halle worked together to make our Wichita snowflake shuffle a success! It was an amazing time at Chicken N Pickle, supporting our community and spreading awareness.

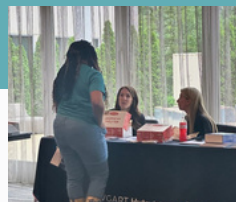


## 11th Congress of the European Academy of Neurology

Allison had the opportunity to go attend a conference in Helsinki, Finland put on by one of our industry partners, Alexion. It was an incredible opportunity to connect with patient organizations from across the globe as well as key leaders in the MG and rare disease community space.

## Little Rock Snowflake Saturday

In June, Kathryn was in Little Rock, Arkansas, celebrating Myasthenia Gravis Awareness Month with the community. Although a storm almost rained us out, it was a great time to meet new individuals with MG in Arkansas.



## Cartesian Therapeutics Awareness Month Event

In June, Allison was asked to speak to the team at Cartesian Therapeutics in Washington, DC, sharing her MG Journey. Cartesian, in celebration of Myasthenia Gravis Awareness Month, they have multiple individuals with MG come and share their journey to learn how they can better support the MG community.



## Iowa Snowflake Saturday

In June, Allison was in Iowa with our Iowa Support Group Leader, Katie, celebrating Myasthenia Gravis Awareness Month. Katie was able to share her MG Journey with the community.







# EXPLORE THE POSSIBILITIES

Ask your doctor about VYVGART Hytrulo (efgartigimod alfa and hyaluronidase-qvfc) and VYVGART (efgartigimod 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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argenx 

# See You There UPCOMING EVENTS At the MGA



## 65TH ANNUAL MEETING & EDUCATIONAL SEMINAR

**Date:** Saturday November 8, 2025

**Time:** TBA

**Locations:** Hybrid | Zoom or St. Joseph Medical Center | 1000 Carondelet Dr, Kansas City, MO 64114

The MGA Annual Meeting provides an opportunity for members and friends to gather and review the work of the association from the previous year. With guest speakers presenting topics of interest to MGA members, their family, and friends, it also provides an educational experience that is unique to our area. Participants attending via Zoom will receive a meeting packet in the mail. We are also offering 2 nursing CEU's through Promptcare.

At this year's annual meeting, we have two keynote speakers ready to share their expertise and stories.

- Dr. Al Freeman | Psychologist, Consultant, Rare Disease Advocate, and Rare Dad
- Dr. Liz Plowman | Physical Therapist, Author, MG Advocate, and Rare Disease Researcher

In addition to our speakers.

- Vendor fair where you can stop and visit with representatives from our pharmaceutical partners.
- Meet members of the MGA | staff, board members, members of our medical advisory committee, caregivers, family members, and individuals with myasthenia gravis.
- Nursing CEU's through Promptcare
- MGA Merchandise will be available for purchase



**Register Today!**

<https://lp.constantcontactpages.com/ev/reg/d22jcyg>

## SAVE THE DATE!

### 5K RUN/WALK & TOT TROT

**Date:** May 3, 2026

**Time:** TBA

**Location:** Town Center Plaza, Leawood, KS

Planning is already underway for our 15th Annual MGA Triple Crown Showdown at Town Center Plaza in Leawood, KS on Sunday May 3, 2026 and hope you'll join us! Select to participate in the 5K, Mile Mosey, Tot Trot or Stuck in Your Stall (Virtual). All funds raised through the MGA Triple Crown Showdown benefit services for the Myasthenia Gravis Association.



More details coming soon via email or stay up to date by following the runs Facebook and Instagram pages!

- Website: [www.mga5k.com](http://www.mga5k.com)
- Facebook: [@mga5k](https://www.facebook.com/mga5k)
- Instagram: [@mga5k](https://www.instagram.com/mga5k)



# Membership Donations

Dr. Nancy Roberge

Stephanie Hubers

Graham Naasz, DDS

Sara Bass

Janice and Steve Katz

Raymond and Angela

Hankins

Dorothy Steurer

Keith Asaeli

Erwin Clark

April Zobel

Shannon Harris, MD

Rusty Rabbit Foundation

Donnie Davis

Mike Nervig

Ron and Shirley Fearon

Camille Weiller

Robert and Sue Fitzthum

Stephen Gwiasda

In Memory of Larry Paxson

Dana Paxson



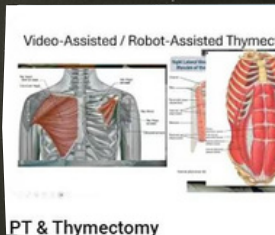
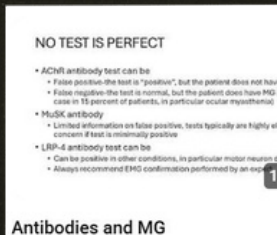
## Did you know we have a YouTube Channel?

### Have you visited MGA's YouTube channel lately?

It's packed with educational webinars, personal stories from the MG community, and updates on treatment options and advocacy efforts. Whether you're newly diagnosed or a long-time advocate, our video library is a great way to stay informed and connected. Don't forget to subscribe and share with others who may benefit!



<https://www.youtube.com/@mgakc>







# 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

Follow  
@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

## Missouri

### **Eastsiders Lunch Bunch – Blue Springs**

1st Wednesday of the month | 11:30 AM – 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 Meetings – September 3, 2025 | October 1, 2025 | November 3, 2025

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

### **Kansas City Coffee Club**

1st Thursday of the month | 9:30 AM – 10:30 AM | Location Varies

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

Next Meetings – August 7, 2025 | September 4, 2025 | October 2, 2025

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

### **Greater Kansas City Support Group**

Quarterly on a Saturday | 10:00 AM – 11:30 AM | St. Joseph

Medical Center, Kansas City, MO

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

Next Meeting – December 13, 2025 (Holiday BINGO!)

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

### **Kansas City Northland Support Group**

January–September, bi-monthly on a Thursday

12:00 PM – 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 Meetings – September 11, 2025 | November 13, 2025

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

### **Young Friends of the MGA– Kansas City**

Quarterly at various locations in Kansas City

6:00 PM – 8:00 PM

Open to individuals who are generally in their 20s, 30s and 40s

Next meeting – August 26, 2025 | TBA

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



**ASPIRING**

We're imagining the future of healthcare for those living with difficult-to-treat conditions like infertility, multiple sclerosis and cancer.

Passion fuels us on our mission to transform lives.

**#BeEMDSerono**

**EMD SerONO**

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# Find A **SUPPORT GROUP** Near you

## Missouri

### St. Joseph Support Group

Quarterly | 1:30 PM – 3:00 PM | Rolling Hills Library, 1912 N Belt Hwy St. Joseph, MO 64506

Open to individuals, caregivers & providers

Next Meeting – TBA

RSVP: donnasjmo@yahoo.com

### Springfield Support Group

Quarterly on a Thursday | 5:30 PM – 7:00 PM | The Library Station, 2535 N Kansas Expy, Springfield, MO 65803

Open to individuals, caregivers & providers

Next Meeting – October 2, 2025

RSVP: mckennafulton@mgakc.org

### Mid-Missouri Group

Quarterly on a Thursday | 5:30 PM – 7:00 PM | Daniel Boone Regional Library, 100 W. Broadway, Columbia, MO

Open to individuals, caregivers & providers

Hosted by Jonni Sutton, Volunteer Support Group Leader

Next Meeting – October 2, 2025

RSVP: 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 – August 28, 2025 | September 25, 2025 | October 23, 2025

RSVP: kathrynclemens@mgakc.org

### St. Louis Support Group

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

Light brunch provided | Open to individuals, caregivers & providers

Next Meeting – October 11, 2025

RSVP: kathrynclemens@mgakc.org

### Young Friends of the MGA – St. Louis

Quarterly at various locations in St. Louis | 6:00 PM – 8:00 PM |

Open to individuals who are generally in their 20s, 30s and 40s

Next Meeting – September 18, 2025

RSVP: info@mgakc.org





# Find A SUPPORT GROUP Near you

## Iowa

### Iowa Support Group

Bi-Monthly on the 2nd Wednesday | 7:00 PM – 8:00 PM | Kirkendall Public Library, 1250 SW District Dr, Ankeny IA  
Open to individuals, caregivers & providers  
Next Meeting – August 13, 2025  
RSVP: [info@mgakc.org](mailto:info@mgakc.org)



## Kansas

### Lawrence Support Group

Quarterly on a Thursday, rotates between Lawrence and Topeka, KS | 5:30 PM – 7:00 PM | Lawrence Public Library, 707 Vermont Street, Lawrence, KS  
Open to individuals, caregivers & providers  
Next Meeting – August 21, 2025  
RSVP: [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)

### Wichita Support Group

Quarterly on a Saturday | 11:00 AM – 1:00 PM | Wichita Public Library, Alford Branch 3447 S. Meridian St. Wichita, KS  
Open to individuals, caregivers & providers  
Hosted by Dana & Larry Paxson, Volunteer Support Group Leaders  
Next Meeting – September 20, 2025  
RSVP: [info@mgakc.org](mailto:info@mgakc.org)

## Arkansas

### Central Arkansas Group

Quarterly on a Thursday | 5:30 PM – 7:00 PM | Regen Med, 15300 Kanis Road, Little Rock, AR  
Open to individuals, caregivers & providers  
Next Meeting – November 20, 2025  
RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)

### NW Arkansas Support Group

Quarterly Saturday | 10:00 AM – 11:30 AM | Springdale Public Library, 405 S. Pleasant St. Springdale, AR 72764  
Open to individuals, caregivers & providers  
Next Meeting – August 23, 2025  
RSVP: [kathrynclemens@mgakc.org](mailto:kathrynclemens@mgakc.org)

## Newly LAUNCHED REGEN MED

THERAPEUTIC APHERESIS &  
MULTISPECIALTY INFUSION CENTER

15300 Kanis Road, Little Rock, AR 72223

501.246.5703



Dr. Tina S. Ipe, MD, MPH

Partial List of Therapies Offered

|           |              |
|-----------|--------------|
| Actemra   | Benflaxis    |
| Avsola    | Rituxan      |
| Benlysta  | Ruxience     |
| Cimzia    | Simponi Aria |
| Entyvio   | Soliris      |
| Inflectra | Stelara      |
| IVIG      | Tapeza       |
| Krystexxa | Truxima      |
| Ocrevus   | Tysabri      |
| Orencia   | Vyepti       |
| Remicade  | Xolair       |

Our **physician-operated medical home** offers a convenient alternative to the hospital for plasmapheresis and IV medications. We aim to provide customized treatments in a caring, professional, and relaxed environment. We offer **flexible scheduling** and work with you as the patient, physician, healthcare professional, and insurance provider to provide the treatments. **We manage the whole process after the referral is provided to us.**

We provide **therapeutic apheresis (plasmapheresis)** that treats 187 medical indications, including Myasthenia Gravis, Alzheimer's, and other autoimmune disorders. We also offer **therapeutic intravenous (IV) infusions** for, but not limited to:

- Hydration and electrolyte management
- Iron deficiency management
- Multispecialty medications

**Onsite amenities** include free parking, handicap access, private bays, wifi, snacks, and beverages. For more information, visit our website at <https://www.regenmed.vip/infusion>



# Find A **SUPPORT GROUP** Near you

## Virtual

### **Muscle Makers**

3rd Wednesday of the month | 2:00 PM – 3:00 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.

Next Meeting – August 20, 2025

Register at [mgakc.org](http://mgakc.org)

### **Virtual Monthly Meetup**

4th Monday of the month |

6:30 PM – 7:30 PM | Via Zoom

Open to individuals, caregivers & providers

Next Meeting – August 25, 2025

Register at [mgakc.org](http://mgakc.org)

### **MG Pride Group**

Bi- Monthly on a Tuesday |

5:30 PM – 6:30 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 – August 5, 2025

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

### **Young Friends of the MGA – Virtual Support Group**

Quarterly via zoom |

6:00 PM – 7:00 PM | Via Zoom

Open to individuals who are generally in their 20s, 30s and 40s

Next Meeting – September 2, 2025

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



# AMGEN

Amgen is proud to  
support the Myasthenia  
Gravis Association.

**Myasthenia Gravis Association**  
2340 E. Meyer Blvd. Building 1, Suite  
300A Kansas City, MO 64132  
Phone: (816) 256-4100  
Email: [info@mgakc.org](mailto:info@mgakc.org)  
[www.mgakc.org](http://www.mgakc.org)

**Become a 2025 Member of the  
MYASTHENIA GRAVIS  
ASSOCIATION**

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

|                                              |                                     |
|----------------------------------------------|-------------------------------------|
| I want to support the MGA by becoming a 2025 |                                     |
| Basic Member                                 | \$25.00 <input type="checkbox"/>    |
| 65th 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"/> |
| In memory of: _____ \$                       |                                     |
| In honor of: _____ \$                        |                                     |

|                                                        |                                   |                                 |                                |              |
|--------------------------------------------------------|-----------------------------------|---------------------------------|--------------------------------|--------------|
| Name: _____                                            | Address: _____                    | City, State, Zip: _____         | Phone: _____                   | Email: _____ |
| I am a: <input type="checkbox"/> MG PATIENT            | <input type="checkbox"/> RELATIVE | <input type="checkbox"/> FRIEND | <input type="checkbox"/> OTHER |              |
| -Contributions may be tax deductible                   |                                   |                                 |                                |              |
| -Make checks payable to: Myasthenia Gravis Association |                                   |                                 |                                |              |

MGA  
2340 E. Meyer Blvd, Bld. 1, Suite 300A  
Kansas City, MO, 64132