



VOL. 65 ISSUE 1

MYASTHENIA GRAVIS ASSOCIATION NEWSLETTER

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What's New?

In 2025, the Myasthenia Gravis Association is excited to expand our community outreach by introducing two new support groups. The first is the Iowa Support Group, led by our new volunteer leader, Katie Coffman. The second is Muscle Makers, a virtual meet-up designed for hobby enthusiasts to connect and share their interests, led by Bryan Bosch. We look forward to fostering these new opportunities! Continue to read for more information about the groups and their leaders.

Iowa Support Group

I'm Katie Coffman, and I was born and raised in Central Iowa, although I lived in Florida for about six months. I have two Australian Shepherd/Lab mixes: Cassiopeia, who's 9, and Andromeda, who's 4. I was diagnosed with Myasthenia Gravis in 2009, at the age of 19, after experiencing a bout of aggressive symptoms. The following year, a woman whose husband also had MG started a support group and asked me to be her co-leader. Shortly after, she decided to step down, and I've been the group leader ever since. I enjoy reading, cooking, hiking with my dogs, watching movies, and listening to music. Join us in welcoming Katie Coffman and the Central Iowa Support Group!

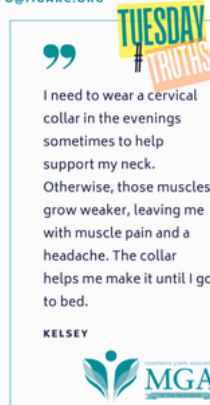


Muscle Makers

Bryan Bosh is a familiar face to the MGA by his leadership of MG Pride and his volunteerism within in the Greater KC area. Bryan approached us with the idea of leading an online craft community/support group. Now we have Muscle Makers on the 3rd Wednesday of each month, from 2-3pm! read more about the inspiration behind Muscle Makers on page 3.



INFO@MGAKC.ORG



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 Allison at allisonfoss@mgakc.org

FOLLOW US



@mga_heartland



@myastheniakc



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

A MESSAGE FROM ALLISON

Opening the Conversation

The Realities of Life with MG

A couple of weeks ago, we received several comments on social media that we were not sharing enough of the true picture of what it feels like to have myasthenia gravis. The feedback we received indicated that we were spending too much time sharing people's wins or celebrations as they journey through life with myasthenia gravis.

I spent a couple of sleepless nights thinking about this feedback. Knowing how hard our team works to share, support and provide services to all those with myasthenia gravis, I was upset to learn that some didn't feel we were listening to them. Out of this feedback, our team created the #tuesdaytruth social media campaign. We are currently looking for individuals who want to share their truth of living with myasthenia gravis. What does it feel like? What parts of your life has it impacted? What do your days look like as you navigate myasthenia gravis?

It's time I share my #tuesdaytruth on what living with myasthenia gravis looks like for me. Nearly 30 months ago, I began having to wear a non-invasive ventilator at night. It straps to my face and helps me breathe when I am too weak. My astral machine is an appendage that goes with me everywhere I go. It's a non-negotiable now in my life. And sometimes I hate it because it is a constant reminder of the fight I'm fighting. That's how MG looks for me.

Good days or bad, please know we are constantly asking for stories and feedback. Sometimes we have to dig deep to get people to provide stories about their life with myasthenia gravis. We want to hear your wins, celebrations, concerns, losses and frustrations. Please share them at info@mgakc.org

And because I do like to think of the jar half full in life, I want to end with this, "every day might not be good, but there is something good in every day...."

With gratitude,



Allison K. Foss | Executive Director | allisonfoss@mgakc.org



myasthenia gravis association

MGA
of the heartland

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816-256-4100
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Inspiration Behind **MUSCLE MAKERS** Virtual Support Group

The Creative Journey: Finding Joy Through Art with MG

Written by Bryan Bosch

I've always had a flair for artistic expression—sewing, acting, dining, dancing, sculpting, and more. Creating has always brought me immense joy, and being able to design and bring to life the ideas in my mind has been deeply fulfilling, especially knowing that they have brought happiness to others.

When I first started experiencing symptoms of MG, I noticed I could no longer fully engage in many of my creative outlets. Most of my activities had to take a back seat as I managed my symptoms. Minimal sewing projects were all I could manage, and even then, I had to take frequent breaks. It took me months to complete even small projects, like sewing a dragon or a blanket, until I stabilized on treatment.

During this time, I often wondered how others living with MG expressed their creativity. Did they have to adapt their methods or find new ways to pursue the joy of creating art? I rarely saw or heard stories about how others with MG continued to nurture their creative passions.

This led me to dream of creating a community where we could come together to share our accomplishments and inspire one another. A space where we could exchange creative ideas, collaborate on projects, and offer tips and tricks—both for the days when we feel strong and for the days when MG symptoms are more pronounced.

Inspiration Through Community

My inspiration comes from the passion, determination, dedication, and advocacy of others living with MG. Hearing their stories and exchanging ideas has motivated me to explore how we can support one another and improve our lives. While each of us experiences MG differently, we share a unique bond through the challenges we face, especially when it comes to expressing ourselves creatively.

I hope to build a creative, uplifting support system that focuses on the joys and passions that bring us fulfillment. I envision this community, called Muscle Makers, as a space where people can share their creative journeys, celebrate each other's talents, and collaborate on new projects.



Looking Ahead

My dream is for Muscle Makers to grow both nationally and internationally. I hope it will inspire others to find new and exciting ways to bring creativity into their lives, even in the face of challenges. A little bit of crafting, art, or creative expression can truly transform your mindset and bring light to your day.

Through Muscle Makers, I want to highlight the talents and artistic abilities of individuals living with MG because we are so much more than our diagnosis. Imagine a craft fair or talent spotlight showcasing the incredible skills and passions of our community—it could be a powerful way to inspire and connect with others.

We've all had to adapt and become new versions of ourselves, but that doesn't mean we have to give up creative fulfillment. Let's come together, share our journeys, and celebrate the beauty we can bring into the world.

BRIDGING THE GAP:

SCHOLARSHIPS FOR STUDENTS IMPACTED BY MG

UCB Myasthenia Gravis Scholarship

Due Date: Friday, February 28th, 2025



UCB
MYASTHENIA GRAVIS
SCHOLARSHIP™

Eligibility Requirements:

- Resident of the United States
- Physician-confirmed diagnosis of MG or be an immediate family member
- Seeking an associate's, undergraduate, or graduate degree, or certification from a trade school
- Be enrolled in or awaiting acceptance from an educational institution for the fall semester of 2025

More information: www.ucbmgscholarship.com

#RAREis Scholarship Fund

Due: March 18 through April 28, 2025



Eligibility Requirements:

- Applicants must be 17 years or older.
- Resident of the United States.
- Diagnosed by a physician with a rare disease, defined as affects fewer than 200,000 people in the US.
- Diagnosis Verification Form completed by a physician verifying the diagnosis.
- Plan to enroll full-time or part-time in undergraduate or graduate study at an accredited university or vocational-technical/trade school for the Fall 2025 semester.

More information:

www.everylifefoundation.org/rare-scholarship/

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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.



February 28

RARE DISEASE DAY

2025



What is Rare Disease Day?

Rare Disease Day is a globally coordinated movement dedicated to achieving equity in social opportunities, healthcare, and access to diagnoses and therapies for individuals living with rare diseases. Observed annually on February 28 (or February 29 in leap years—the rarest day), it unites a diverse community in raising awareness and advocating for change. Launched in 2008 and led by EURORDIS and over 65 national patient organization partners, Rare Disease Day serves as a powerful catalyst for advocacy efforts at local, national, and global levels.

RARE DISEASE DAY®

This day is for everyone—patients, families, caregivers, healthcare professionals, researchers, policymakers, and the general public—to take action. By sharing experiences, spreading awareness through social media, hosting events, illuminating landmarks, and engaging policymakers, we can shine a light on the 300 million people worldwide living with rare diseases. Together, Rare Disease Day aims to improve lives and foster inclusivity. Share your Rare Disease Day videos and photos on social media using #RareDiseaseDay and @rarediseaseday

Upcoming Rare Disease Day Events

- February 20: [Washington University School of Medicine Rare Disease Day](#) Virtual and in Saint Louis
- February 26: [CHOC & UCI Rare Disease Symposium & Family Conference](#) Virtual
- February 27–28: [2025 FDA–NIH Rare Disease Day](#) Virtually and in Maryland
- March 6: [Rare Disease Day 2025 at the University of Minnesota](#) Virtual and in-person



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

YOUR VOICE, YOUR POWER

VALUE IN POLICY

The MGA Supports Reauthorization of the Rare Pediatric Disease Priority Review Voucher Program



On December 4, 2024, the Myasthenia Gravis Association (MGA) joined 213 organizations in signing a community letter urging Congressional leaders to reauthorize the Rare Pediatric Disease Priority Review Voucher (PRV) program. This vital program, which expired on December 20, 2024, had been instrumental in advancing treatments for rare pediatric diseases.

The Importance of the Rare Pediatric Disease PRV Program

First established in 2012, the Rare Pediatric Disease PRV program incentivized pharmaceutical companies to develop treatments for rare childhood diseases. Through the program, companies that created FDA-approved therapies for rare pediatric conditions earned a transferable voucher for priority review of another drug application. These vouchers provided a faster FDA review timeline, potentially bringing life-saving therapies to market more quickly.

The program proved effective, supporting the development of therapies for 39 rare pediatric diseases. Notably, prior to the PRV program, only three of these conditions had FDA-approved treatments available.

Advocacy from the Rare Disease Community

The Creating Hope Reauthorization Act (H.R. 7384/S. 4583) had been introduced to extend the program for five years. The House of Representatives passed the measure unanimously in September as part of the amended Give Kids a Chance Act (H.R. 3433). However, the Senate did not take action before the program's expiration.

The letter MGA signed, addressed to Senate Leadership, emphasized the broad bipartisan support for reauthorization. It highlighted that the PRV program did not impact direct federal spending, as confirmed by the Congressional Budget Office. Instead, it served as an efficient mechanism to spur innovation in rare disease treatments.

The rare disease community rallied behind this reauthorization effort. The MGA's participation underscored its commitment to improving healthcare outcomes for individuals and families living with rare diseases, including those impacted by myasthenia gravis.

For more information or to support this initiative, visit everylifefoundation.org.

Consequences of Non-Reauthorization

With the program now expired, the incentives it provided to develop treatments for rare pediatric diseases are no longer available. This jeopardizes the pipeline of potential therapies for conditions with unmet medical needs. Developing treatments for rare pediatric diseases poses unique challenges, including small patient populations and the complexities of conducting pediatric clinical trials. Without the PRV program, pharmaceutical companies may lack the motivation to invest in these high-risk, high-cost endeavors. The failure to reauthorize the PRV program has profound implications, including:

- A slowdown in innovation for rare pediatric disease treatments.
- Reduced hope for families waiting for life-saving therapies.
- A missed opportunity to address significant unmet medical needs.

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.**

Big Changes **MEDICARE PART D** How Could it Affect Me?

What Does It Mean for People with Myasthenia Gravis?

Navigating the healthcare system can be challenging for anyone, but for individuals with Myasthenia Gravis (MG), the financial burden of medications can add an extra layer of stress. Fortunately, recent changes to Medicare Part D—thanks to the Inflation Reduction Act of 2022—are set to significantly impact how prescription drugs are paid for, offering both opportunities and challenges to those in the MG community.

A Brief History of Medicare Part D

The Medicare Modernization Act of 2003 introduced Medicare Part D, providing prescription drug coverage to seniors and those with disabilities. However, this came with the infamous "donut hole," a coverage gap that required beneficiaries to pay the full cost of medications after a certain spending threshold. This gap has long been a source of financial strain, particularly for those on high-cost medications often required by people with MG. In recent years, efforts have been made to close the donut hole and ease the burden on beneficiaries. With the Inflation Reduction Act, a three-year rollout of sweeping changes began in 2023:

- 2023: Adult vaccines became available with zero copays, and insulin costs were capped at \$35 per month.
- 2024: Low-income subsidies were expanded, and copays during the catastrophic stage of Part D were set to zero. Medicare was also granted the authority to negotiate drug prices directly with pharmaceutical companies, lowering costs for beneficiaries.

What's Coming in 2025?

For individuals managing MG, the most significant change arrives in 2025: a \$2,000 annual cap on out-of-pocket drug costs. Here's how the new structure will work:

- Drug Deductibles Stage: Deductibles will apply more broadly, even to tier 3, 4, and 5 specialty drugs often prescribed for MG. Those on Medicare Advantage plans may notice an increase in upfront costs.
- Initial Coverage Stage: After meeting the deductible, beneficiaries will pay their share of copays while Part D plans and drug manufacturers cover the rest.
- Catastrophic Stage: Once \$2,000 in out-of-pocket expenses is reached, beneficiaries will pay nothing for the rest of the year.

Additionally, a new Medicare Prescription Payment Plan will allow beneficiaries to spread their costs over monthly installments, reducing the immediate financial burden of high-cost prescriptions.

What This Means for People with MG

For individuals with MG, who may rely on high-cost treatments or other specialty drugs, these changes are a welcome relief. The \$2,000 annual cap means no more catastrophic out-of-pocket expenses that previously pushed many to make difficult decisions between medications and other necessities.

However, it's important to note that those who rely on lower-cost generic medications may face new deductibles on their prescriptions. It's crucial to review your plan in 2025 and evaluate how these changes might affect your overall healthcare costs.

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: Nora Khalifa nkhalifa@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

ALXN1720 – MG PI: Dr. Dimachkie ClinicalTrials.gov Identifier: NTC
A Phase 3, Randomized, Double-blind, Placebo-controlled, Parallel, Multicenter Study to Evaluate the Safety and Efficacy of ALXN1720 in Adults With Generalized Myasthenia Gravis.

For more information: Abby Davis adavis54@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

MOM-M281-011 PI: Dr. Farmakidis ClinicalTrials.gov Identifier: NCT04951622
Phase 3, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Efficacy, Safety, Pharmacokinetics, and Pharmacodynamics of Nipocalimab Administered to Adults with Generalized Myasthenia Gravis.

For more information contact: Ali Russo aciersdorff@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 Gravi

For more information: Lillian Saavedra Isaavedra2@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 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



COUR Pharmaceutical Development Company, Inc. PI: University of Missouri- Columbia
ClinicalTrials.gov Identifier: NCT06106672
This is a Phase 1b/2a First-in-Human (FIH) clinical trial to assess the safety, tolerability, pharmacodynamics (PD), and efficacy of multiple ascending doses of CNP-106. The clinical study lasts 222-days (up to 42 days for Screening, 180 Study Days). Subjects ages 18-75 with generalized myasthenia gravis (MG) will be screened up to 42 days prior to enrollment into the clinical study.

For more information contact: Kristina Kelly, kristina.kelly@health.missouri.edu



AMGEN

Amgen is proud to support the Myasthenia Gravis Association.

WHERE IN THE WORLD IS THE MGA?



Patient 360 Summit | Darmstadt, Germany

McKenna Fulton, Community Program Coordinator in Kansas City has been in Darmstadt, Germany attending the Patient 360 Summit alongside patient organizations from all over the globe. We are grateful to EMD Serono for the invitation to participate in this initiative.



Rare Disease Connect in Neurology Amsterdam

Rare Disease Connect in Neurology in Amsterdam. This initiative by UCB brings together patient organizations as well as health care providers to share and brainstorm on how to move the needle forward and best support those living with myasthenia gravis. An inspiring week and we are grateful for the opportunity to be there!



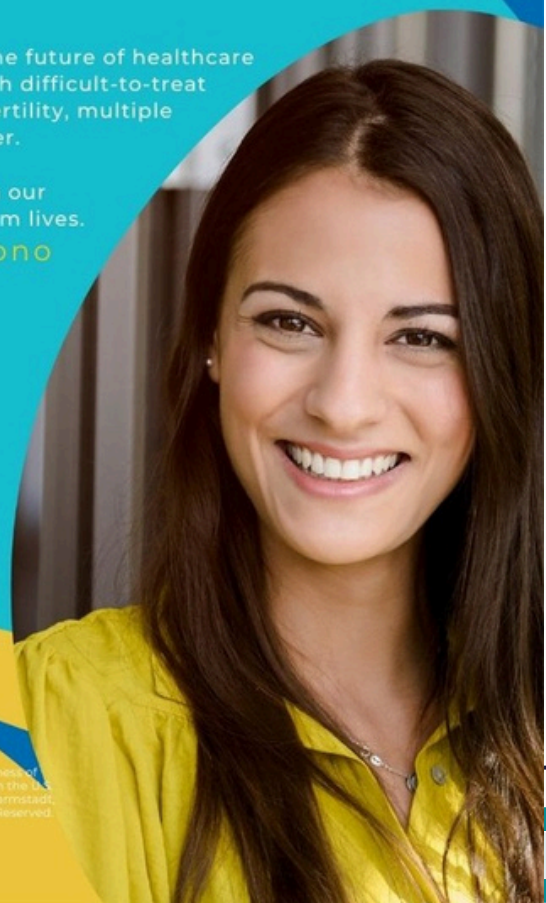
Holiday Bingo

Wichita and the Greater Kansas City Support groups came together for some holiday fun and BINGO! We had a total of 59 individuals.

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



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See You There UPCOMING EVENTS

At the MGA

CROWN TOWN TRIVIA NIGHT



Date: August 1, 2025

Time: TBA

Location: GEHA Field at Arrowhead Stadium, Kansas City, MO

For the last six years, the Iowa State Alumni of Kansas City has partnered with the MGA to present the annual Crown Town Trivia Night! One of our most popular events, the evening is filled with three rounds of exciting trivia surrounded by a live and silent auction. Join us for a night like no other and discover opportunities on how to get involved! We are excited to return to GEHA Field at Arrowhead for the 7th Annual Crown Town Trivia Night.

More details coming soon via email!

Stay informed:
www.mgac.org

5K RUN/WALK & TOT TROT

Date: May 18, 2025

Time: 8:00am

Location: Town Center Plaza, Leawood, KS



We are gearing up for the 14th Annual MGA Triple Crown Showdown at Town Center Plaza in Leawood, KS on Sunday May 18, 2025 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

Register is \$25 and free for individuals diagnosed with MG. Email info@mgac.org for a VIP code to use at checkout!

Website: www.mga5k.com

Facebook: [@mga5k](https://www.facebook.com/mga5k)

Instagram: [@mga5k](https://www.instagram.com/mga5k)

SNOWFLAKE SATURDAY JUNE AWARENESS EVENT

Date: Saturday June 7, 2025

Time: TBA

Locations: Des Moines, Iowa | Little Rock, Arkansas | Wichita, Kansas



We're excited to announce Snowflake Saturday, a new awareness event. This unique event will combine education, community, and fun to raise awareness for myasthenia gravis and support those affected.

- Vendor Tables: Sponsored by pharmaceutical companies and specialty pharmacies.
- Raffles & Merchandise: Raffle prizes and MGA merchandise will be available for purchase.
- Speaker/Program: An informative session featuring a guest speaker or program to educate and inspire attendees.

Snowflake Saturday will serve as a valuable opportunity to connect with the MG community, learn more about ongoing resources, and spread awareness. Stay tuned for dates, locations, and details—together, we'll make this a day to remember!

Membership Donations

Erwin Clark
Gordon & Marie Nave
Kacy Becker
Virgil Wiltz
Welsey & Helen Stillian
Susan Miletta
Richard DeGeorge
Ed Stambach
Stephen Nutt
Melinda and Tom Cook
Kenneth Cummings
Vern Grothoff
Don Sisson
Amanda & Justin Foster
John & Cindy Wilkinson
Mark & Diane Lindsay
Alan and Gail Still
Julie Foss
Judith Griffin
Mary Ann Gurera
Marilyn Barrett
May Ellen Dowdy
Jimmie Harbour
Dr. Eric May
Carl Hanfling
Scott & Karen Hazel
Madeleine Kohl
Navelle Gossman
Ji & Sun Wei
Muriel Cohen
Louis Padilla

Carol & David Jones
William Schwartz
Terre Tepikian
Mary Campbell
Steven Bricker
Tom & Barb Warrington
Greg & Terri Steele
Steve Hartwich
Janice & Steve Katz
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Betty Banner
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Karen Sims
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Marsha Naron
Gregory Spivy
Ashley Steele
Tom Vansaghi

Mamatha Pasnoor, MD
Jay Hurt
Mary Williams
Ron & Kala Coleman
Steve & Jane Triplett
Peggy Eagan Acosta
Becky Hainje
Laura Gotthelf
Cheryl Shoemake
Debbie & Steve Siemieniewski
Larry & Virginia Brinker
Kay Morrissey
Daniel and Denise Gifford
Warren Swanson
Janie Watts & John Rance
Michael & Dorothy Eagan

In Honor

Pamela Stucker

Phyllis Peniston
Patricia Scott

In Memoriam

Sheldon Hollub

Lynda Hireskorn

Patty Laughlin

Rose Parkeer & the 3rd
Thursday Basement Bunco
girls

Dr. Jacob McGuire

Richard & Janice McGuire





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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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 | Agape House 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 5, 2025
RSVP to 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 Meeting – March 6, 2025
RSVP: 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 – April 12, 2025
RSVP: 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 Meeting – February 13, 2025
RSVP: 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 – April 1, 2025 | TBA
RSVP: allisonfoss@mgakc.org



FLEX

Diagnosed with Generalized MG

Learn about the FLEX research study of an investigational injectable drug for adults with generalized myasthenia gravis.

Click the banner to learn more.



Find A **SUPPORT GROUP** Near you

Missouri

St. Joseph Support Group

Quarterly | Time TBA | Location TBA

Open to individuals, caregivers & providers

Next Meeting - TBA

RSVP: info@mgakc.org

Springfield Support Group

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

Open to individuals, caregivers & providers

Next Meeting - April 3, 2025

RSVP: kathrynclemens@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 - April 10, 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 - February 27, 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 - April 12, 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 - March 14, 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 – February 12, 2025
RSVP: info@mgakc.org

Kansas

Lawrence/Topeka Area 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 & Topeka & Shawnee County Library, 1515 SW 10th Ave, Topeka, KS
Open to individuals, caregivers & providers
Next Meeting – February 20, 2025
RSVP: 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 – TBA
RSVP: 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
Hosted by Griselda Torres & Kelsey Sims, Volunteer Support Group Leaders
Next Meeting – May 1, 2025
RSVP: 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 – May 3, 2025
RSVP: kathrynclemens@mgakc.org

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 – February 19, 2025
Register at 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 – February 24, 2025
Register at 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 – April 8, 2025
RSVP: 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 – June 3, 2025
RSVP: info@mgakc.org

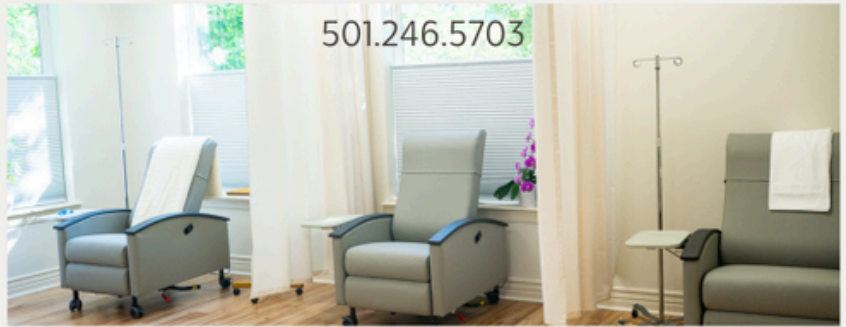
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REGEN MED

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	Renflexis
Avsola	Rituxan
Benlysta	Ruxience
Cimzia	Simponi Aria
Entyvio	Soliris
Inflectra	Stelara
IVIG	Tepezza
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>



Myasthenia Gravis Association
2340 E. Meyer Blvd. Building 1, Suite
300A Kansas City, MO 64132
Phone: (816) 256-4100
Email: info@mgakc.org
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 ☐
65th Anniversary Member	\$64.00 ☐
Sustaining Member	\$100.00 ☐
Patron Member	\$500.00 ☐
Lifetime Member	\$1,000.00 ☐
In memory of: _____ \$	
In honor of: _____ \$	

Name: _____	Address: _____	City, State, Zip: _____	Phone: _____	Email: _____
I am a: ☐ MG PATIENT	☐ RELATIVE	☐ FRIEND	☐ 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