myasthenia gravis association
MGA
of the heartland

STRENGTH AND CONNECTIONS HOPE THROUGH

VOL. 64 ISSUE 3

MYASTHENIA GRAVIS ASSOCIATION NEWSLETTER

INSIDE THIS ISSUE

What's New!

In-Person Clinic Partnership at Lake Regional
On June 17th, the Myasthenia Gravis Association began our clinic partnership with Dr. Tania Papsdorf at Lake Regional Hospital in Osage Beach, MO. You may recall the MGA had a clinic partnership with Dr. Papsdorf in 2022. We are excited to be working with Dr. Papsdorf again. Dr. Papsdorf will be taking individuals with myasthenia gravis in the MG clinic model one day a month.

If you are interested in being seen in Dr. Papsdorf's clinic at Lake Regional, please contact Allison Foss (allisonfoss@mgakc.org) for scheduling instructions.

Designing Our Life With MG
"Designing Our Life with MG" (DOLWMG) is a unique coaching group tailored for individuals living with Myasthenia Gravis (MG). The program aims to help participants acknowledge their diagnosis, develop healthy habits, and build confidence to thrive despite the challenges posed by MG. Led by Sarah Bolton, an ICF-credentialed life coach and fellow MG patient, the group offers a supportive, positive, and uplifting environment. Over six months, participants engage in live virtual sessions, asynchronous projects, and regular check-ins to foster continuous growth and connectivity. The program emphasizes self-advocacy, personal development, and practical tools to help members move forward with a sense of direction and purpose. Designed to be accessible and free of charge, it aligns with the Myasthenia Gravis Association's mission to provide meaningful support to individuals living with MG.

Check out our interview with Sarah Bolton, DOLWMG Coach, on page 10.

SUBMISSIONS

Want to share your MG story or have a topic you would like to see covered? Email Allison at allisonfoss@mgakc.org

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https://www.facebook.com/mgakc

A MESSAGE FROM ALLISON

Summer Thoughts

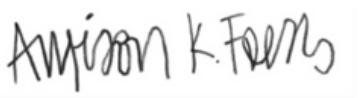
Years ago, when I first started in my role I went on a tour of Heritage Biologics, a specialty pharmacy. I was taken back by this display they had of shoes of individuals living with rare diseases. It set the scene as a reminder to those walking by about the journey those with rare disease are living. Each shoe tells a different story. A different set of circumstances. Such a powerful vision. I have never forgotten it and think of it often.

I always notice an uptick in the summer of a lot of "noise" in MG Facebook communities with people shaming others for how they are living their lives. Maybe because generally speaking summer can be a time of more freedom and in most places, the weather is warmer. The days are longer, and it appears more people are going out and about or taking vacations. However, it never fails that one person's post about a dream vacation or time spent with nature gets shamed by another individual. We had such a scenario on our own Facebook page several years ago and I think it's a good opportunity to share a gentle reminder that although we are each battling myasthenia gravis, we are each individuals and have a different set of circumstances.

What if we spent more time walking in each other's shoes and appreciating the differences we each have? What if we spent less time judging and did what was best for us? There is no doubt that having MG means there are things in life that you will have to tweak to be safe or doable, as I like to say. You'll likely have to make some adjustments to enjoy summer, however it is still possible!

It's so easy to want to tap your fingers on the keyboard with a response or an answer. In the words of Sarah Bolton, our Virtual Host, let's not "yuck on somebody else's yum!" Take a moment and try to walk in another's shoes. Be kind. Be gentle. You never know what somebody else is going through!

We'd love to hear your story! Send us a line at info@mgakc.org



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

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CAR-T Featuring ROBIN PETTYPIECE Personal Experience

Robin, a member of the MGA, participated in the Cartesian (Car-T) clinical trial over a year ago and is currently being reinfused after having positive results. Her experience provides a look into the challenges and triumphs faced by MG patients seeking new treatment avenues. This article captures Robin's journey, from her decision to participate in the trial to the impact it has had on her life.

Discovery and Motivation

Robin discovered the Car-T clinical trial through an email the same week that she was informed that her beloved neurologist of 14 years had passed away. While on the call, she recalled seeing the email and decided to take a second look at it. The clarity and comprehensiveness of the informational video attached to the email prompted her to consider this new direction. Robin weighed the pros and cons of participating in a clinical trial, because they do come with risks. The severe complications with her existing treatments were a strong persuader in her decision to participate. Robin was stable with IVIG and other medications but faced challenges such as loss of vein access, incorrect port placement, clotting issues, among other problems caused by repeated biweekly infusions. Her journey from 2010 to 2023 was marked by setbacks, including nonmelanoma skin cancer from Imuran and vascular disease. After her port failed and she had to undergo numerous angioplasty and stenting, she urgently needed an alternative. The trial offered a potential lifeline.

Enrolling in the Trial

Robin described the team as incredibly supportive and professional, ensuring she was well-informed and comfortable throughout the process. She does note that there have been some updates as the trial has progressed. For example, she is required to be within 15 miles of the clinical trial site for 24 hours after receiving the Car-T infusion. That was not required during the first round of infusions. Also, her initial trial included the chance of receiving a placebo. Her reinfusion is being done as an open label, which means no chance of placebo.

The enrollment process was thorough and manageable but has changed since she first applied. During the enrollment experience, Robin applied to all available clinical trial sites, ranging from Washington, California, and Florida. She ensured all her medical records were provided and met the trial's criteria. After a comprehensive physical exam and blood work in Florida, she qualified to be one of the participants at that site. Currently there is a central enrollment process with Cartesian directly, eliminating the need to apply to multiple sites

Treatment Experience

The process starts with collecting your blood cells via apheresis. They are then sent to the lab and re engineered to fight the MG antibodies. Once the cells were ready, Robin received one dose a week for six weeks. The infusion process involved 15 minutes of treatment, followed by 1 hour of observation before heading home. The consent form Robin signed prior to participating divulged numerous possible side effects, mostly flu like symptoms , such as fever, chills and nausea. Participants had 24/7 contact with the clinic and specific instructions for emergencies. She was to report any abnormal or unexpected symptoms to her care team via a 24-hour phone number. Robin compared the experience to what she imagines chemotherapy is like, with a range of side effects.

Robin experienced nausea, aches, fever and chills. The third hour post-infusion was particularly challenging, with severe chills and pain moving through different parts of her body. She described it as if the treatment was traveling through her body, fighting against her cells one section at a time. Despite the discomfort, she was able to manage these side effects with Tylenol and Benadryl. The side effects mostly subsided within 4-6 hours.

CAR-T FEATURING: ROBIN PETTYPIECE

Personal Experience Continued

Health and Symptoms

Robin's MG-ADL score improved dramatically from 12 to 1, indicating a significant positive response. While receiving treatment in the trial and the following months, Robin faced severe symptoms not related to the clinical trial. The symptoms presented to doctors as an allergic reaction, but Robin's intuition told her otherwise. She was finally diagnosed with a bacterial infection in her port. This would be triggered any time her port was accessed and used for various treatments. Although she saw great results from the Car-T therapy, she imagines that she would have had more positive and longer lasting results without having to fight a bacterial infection. The trial allowed her to avoid IVIG for 17 months, relying only on Imuran and Mestinon as needed. Despite the bacterial infection potentially impacting results, she experienced notable improvement. Robin was able to engage in social activities and travel after participating in the Car-T Trial. Her life no longer revolves around treatments, giving her a sense of normalcy and independence. This newfound freedom of not being confined to her treatment schedule was liberating. In addition to the side effects of IVIG, which left Robin with more bad days than good, she expressed that she would rather have a few weeks of bad from the Car-T therapy, in return for a solid year without repeated treatments. She is excited for what this next round will bring, hoping she will feel comfortable enough to plan a trip to Europe, which she had long ago given up on.

Monitoring and Follow-up

Follow-ups were meticulously scheduled at the same time each day. There were seven follow-ups, starting with the first three months of weekly appointments. Then they began to space out every two weeks, four weeks, eight weeks, her last appointment being at the one year mark. . Each followup appointment included regular blood work, physical exams, and evaluations of her MG symptoms. This information was collected and examined to monitor her progress and any side effects. Some preliminary results to this part of the trial have recently been published by the sponsor.

Challenges and Support

The primary challenge was the initial severe side effects and travel to and from the study site. During the immediate side effects post-treatment the trial coordinator and doctor provided support and guidance on managing these symptoms. The clinical trial coordinator was always available, offering support and resources as needed. Additionally, Robin connected with other participants for mutual support. Interacting with fellow participants provided Robin with a sense of community and shared experience, along with some symptom management tips, which was invaluable.

Overall Impression and Future Considerations

Robin is incredibly pleased with her progress. The improvement in her quality of life has been remarkable and she would recommend considering the trial to others that are also comfortable in taking that risk. Despite the challenges, the potential benefits far outweigh the difficulties, offering a chance at better management of MG symptoms. She hopes to continue seeing improvements and exceed her current level of symptom management. Robin's primary hope is that the trial results lead to broader availability of effective treatments for MG. She is optimistic about future advancements and improvements in managing this condition.

Conclusion

Robin's participation in the Cartesian clinical trial has been transformative. From overcoming severe medical challenges to achieving significant symptom relief, her journey offers renewed hope and a path toward a better quality of life for MG patients. For those considering this trial, Robin's experience underscores the potential benefits and the importance of exploring new treatment options.

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Remembering LARRY PAXSON
A True Myasthenia Gravis Warrior

Quiet, Supportive, Advocate

On Tuesday July 9, 2024, our Wichita Support Group Leader Larry Paxson died after a courageous 18 year battle with myasthenia gravis. Larry and his wife Dana have been leaders in the Wichita area for over 10 years.

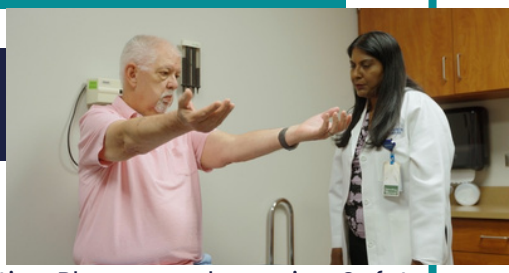
Larry was often soft spoken and could be observed taking it all in. He had a quiet, peaceful presence about him that attracted those who were newly diagnosed with myasthenia gravis to enlist in his help, support and advocacy. Larry was always willing to give his time to support those newly diagnosed as well as those who had been battling for years. Larry did radio interviews to help spread the word and raise awareness about myasthenia gravis. Larry and Dana were instrumental in finding ways to work with Wichita State University through their annual health fair. Additionally, Larry and Dana started a walk for awareness event in their community which today is known as the MGA Snowflake Shuffle 0.1K, an unwalk if you will where members of the MG community gather, celebrate and reflect on their journeys.

In addition to his own family and friends, Larry will be greatly missed by his MG family.

The Myasthenia Gravis Association

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: Ali Russo aciersdorff@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

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: Lilli 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

Cartesian MG-001 PI: Dr. Pasnoor ClinicalTrials.gov Identifier: NCT04146051
Autologous T-Cells Expressing A Chimeric Antigen Receptor Directed To B-Cell Maturation Antigen (BCMA) In Patients With Generalized Myasthenia Gravis (MG)

For more information contact: Ali Russo aciersdorff@kumc.edu

MG CLINICAL TRIAL UPDATES

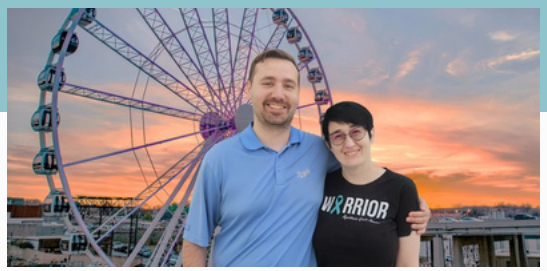
University of Missouri Medical Center

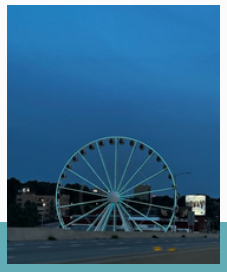
KATALYST MG PI: Kristina Kelly ClinicalTrials.gov Identifier: NCT06064695
Effects of Whole-body Electrical Muscle Stimulation Exercise on Adults With Myasthenia Gravis

To inquire about participating, contact the principal investigator, Kristina Kelly, PT, DPT, MS, EdM, NCS, CPT, PES: kristina.kelly@health.missouri.edu.

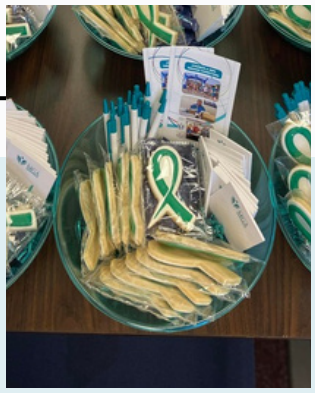



WHERE IN THE WORLD IS THE MGA?



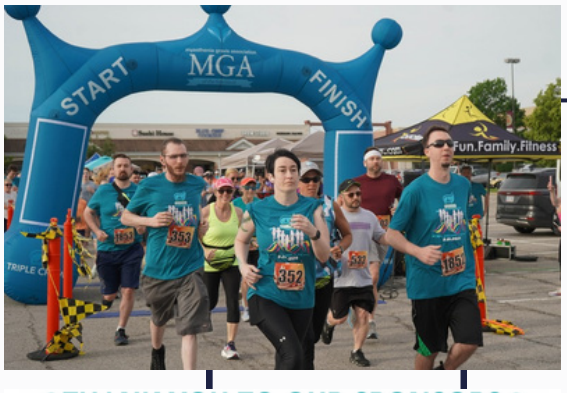


Light the World for MG Day
Sunday June 2nd was Light the Globe for MG Day. We were excited to have the support of Kansas City and St. Louis, who lit their Ferris Wheels teal for MG.



Neurology Outreach
We are committed to raising awareness year round! The MGA delivered baskets of information and sweet treats to Neurology offices in Kansas City, Columbia, Osage Beach and St. Louis.

Pickleball for a Purpose: STL
We wanted to extend our gratitude for such a great time Sunday at our first ever Pickleball for a Purpose! You helped us raise over $10,000 for the MGA!



Triple Crown Showdown
Thank you for helping us to make it an amazing day! We had 439 participants and over 100 volunteers. Of those, 68 of them were individuals living with MG! Your support has also helped us raise over $60,000!

6th Annual MGA Snowflake Shuffle 0.1K
Snowflake Shuffle attendees enjoyed time of fellowship, lunch, raffles, treats from the Kona Ice Truck and the opportunity to connect with industry partners to learn about the different therapy options.

EXPLORE THE POSSIBILITIES

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

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Subcutaneous Injection
180 mg/mL and 2000 U/mL vial

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

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

argenx

See WHAT'S NEW At the MGA

Designing our Lives with MG

The Myasthenia Gravis Association is excited to share that we received a grant for a virtual life coaching program through Alexion, argenx and UCB. Designing our Lives with MG is the brainchild of Sarah Bolton, ACC who proposed the idea to the MGA. We were able to come together and the program launched in June. Read below to learn more about Sarah and the program.

Personal and Professional Background

After graduating with a degree in journalism, I worked in hospitality and later explored a passion for cosmetology, opening my own skincare studio in 2019. However, as I started experiencing worsening symptoms of Myasthenia Gravis (MG), I had to rethink my career path. Diagnosed with MG after years of advocating for myself, I felt a mix of relief and fear. The support from my life coach, therapist, and MG community was crucial in helping me accept my condition and find a sustainable career. Drawing from my experience as a "hair-apist," I transitioned to becoming a life coach, earning my ACC credential in 2020. Inspired by my journey, I wanted to combine support group elements with coaching to help others navigate life with MG.

Living with MG has provided me with so much perspective. I've gained a greater sense of understanding and compassion for folks with disabilities and chronic illness(es). In coaching, I encourage my clients (and group participants) to show up just as they are. There's no need to "mask" how we are feeling or show up performatively. We can be ourselves, exactly as we are (even and especially when we are having a rough day).

Program Structure and Purpose

The primary goals of the "Designing Your Life with MG" coaching group are to help individuals with MG acknowledge and navigate their challenges, transform their relationship with their circumstances, and discover new possibilities for their lives. The intended outcomes include fostering a sense of empowerment, promoting resilience, and encouraging personal growth and positive action despite the limitations imposed by MG.

What sets this coaching group apart from traditional support groups or educational programs for MG patients is its focus on proactive, forward-thinking strategies rather than solely on the challenges and frustrations of living with MG. While traditional support groups often provide a space for venting and shared understanding, they can sometimes become mired in negative experiences. In contrast, "Designing Your Life with MG" emphasizes personal agency and the power of perspective. In this group I do not offer advice or solutions but instead use curiosity and questioning to help participants explore new ways of relating to their challenges and envisioning their futures. This approach helps participants shift their mindset, allowing them to see their circumstances differently and make intentional choices about how they respond to their condition.

Participant Engagement and Support

The coaching framework in "Designing Your Life with MG" encourages participants to find their own answers through a process of inquiry and self-discovery. Instead of offering advice or solutions, I ask open-ended questions that help participants reflect on their experiences, identify their values and goals, and explore new perspectives. This approach empowers participants to take ownership of their personal growth and find solutions that are authentic and meaningful to them.

To ensure a positive, safe, and uplifting environment within the group sessions, several key practices are implemented: Confidentiality, CommUNITY Agreements, Encouragement of Authenticity, Focus on Support and Acceptance. By combining these elements, "Designing Your Life with MG" creates a nurturing space where participants can engage in meaningful self-exploration and receive support from a community that understands their unique challenges and experiences.

UPCOMMING EVENTS

64TH ANNUAL MEETING & EDUCATIONAL SEMINAR

Date: Saturday October 26, 2024
Time: 8:30-1:00 PM CST
Location: St. Joseph Medical Center, Kansas City

FEATURING KEYNOTES

Living with Myasthenia Gravis, a personal testimony, Vickie Petz Kasper, MD

The Latest treatments for Myasthenia Gravis, Tania Beltran Papsdorf, MD

Registration is FREE. Nurses can receive 2 CEU's for attending. In person attendees will also enjoy vendor booths, breakfast and lunch. Virtual attendees will receive a meeting packet via US mail.

Register at www.mgakc.org

CROWN TOWN TRIVIA NIGHT

TRIVIA NIGHT

7TH ANNUAL CROWN TOWN TRIVIA

Date: August 16, 2024
Time: 6:30 pm - 10:00 pm
Location: GEHA Field at Arrowhead Stadium

Go to www.mgakc.org to register

General and VIP Tickets are available!

General Ticket Prices	**VIP Ticket Prices**
Table of 10 - $1000	VIP Table of 10 - $1650
Couples ticket - $210	VIP Couples ticket- $340
Individual ticket - $115	VIP Individual ticket- $180

PICKLEBALL FOR A PURPOSE | KC

A MGA EVENT

Date: November 3, 2024
Time: 4:00pm - 7:00pm
Location: Chicken N Pickle | Overland Park, KS

Grab a friend and join us for Pickleball for a Purpose as we raise funds to support the Myasthenia Gravis Association.

Cost: $150 per team

ERegister at www.mgakc.org

BOOZY BINGO | A MGA EVENT

Date: September 22, 2024
Time: 12:00 pm - 2:00 pm
Location: Craft Putt | Overland Park, KS

Cost: $2 per Bingo Card

Email info@mgakc.org to register.

Join us for a few hours of excitement, camaraderie, and the thrill of the win at Bingo Games! Mark your calendars for a Boozy Brunch filled with anticipation and fun all while raising funds for the Myasthenia Gravis Association.

MYASTHENIA GRAVIS ASSOCIATION SUPPORTS

NATIONAL CALL FOR OFFICE OF CAREGIVER HEALTH

The Myasthenia Gravis Association joined a handful of organizations in support for a critical initiative aimed at transforming the landscape for family caregivers across the United States. Recently, we joined 166 other organizations in signing a letter to President Biden, urging the establishment of an Office of Caregiver Health within the Department of Health and Human Services (HHS). This initiative is crucial for the millions of caregivers who provide essential care to aging, ill, or disabled individuals, often at great personal sacrifice.

The Importance of Family Caregivers

There are approximately 53 million family caregivers in the U.S., offering an estimated $600 billion in unpaid care annually. Despite their indispensable role, these caregivers frequently face significant physical, emotional, and financial challenges. As a longstanding advocate for caregivers, President Biden has made notable strides, including the Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers. However, as we move beyond the one-year anniversary of this landmark order, more comprehensive support is necessary.

Key Functions: Office of Caregiver Health

The proposed Office of Caregiver Health would have several pivotal roles:

- Recognizing caregivers as a population with specific needs.
- Integrating caregiver needs into all federal programs and policies.
- Coordinating research and program evaluation to inform policy and mitigate adverse outcomes.
- Streamlining access to caregiver resources through a centralized system.

ROSALYNN CARTER INSTITUTE FOR CAREGIVERS

NATIONAL CALL FOR OFFICE OF CAREGIVER HEALTH CONTINUED

A Unified Voice for Caregivers

The call for an Office of Caregiver Health stems from the recognition that caregivers are a distinct population with unique needs. This office would focus on elevating federal support, ensuring that caregivers are considered in health policy, regulation, program, and budget discussions. It would address the widespread fragmentation in caregiver support programs across federal agencies, making it easier for caregivers to access the resources they need.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 laid the groundwork for better caregiver support, but the sheer number of commitments across various agencies highlights the need for a dedicated office. The RAISE strategy offers momentum for this initiative, envisioning close collaboration with the Assistant Secretary for Aging and other federal entities.

A Call to Action

At the recent White House Caregiver Convening, Neera Tanden emphasized the critical juncture at which we stand: "We are so close to transforming our economy and transforming families and communities by finally stepping up and giving them the support they need but more importantly the support they deserve from their government." The Myasthenia Gravis Association wholeheartedly agrees and supports the establishment of an Office of Caregiver Health.

We look forward to President Biden's response to this important request and remain committed to advocating for the health and well-being of caregivers nationwide. For more information, please contact Diana Felner, Senior Director of Caregiver and Mental Health Policy at the Rosalynn Carter Institute for Caregivers, at diana@rosalynncarter.org.

Membership Donations

Raymond Phelps
Wesley and Helen Stillian
James and Ida Lake
Kenneth and Jill Koontz
Emma Hull

In Memoriam

Michael Barnwell
Lisa Gardner

Larry Paxson
Mazen Dimachkie, MD
Craig Bay
Lloyd McCune

SUPPORT FOR MYASTHENIA GRAVIS (MG)

Find what makes you More Than MG

Join the community of patients, caregivers, and other advocates

Whether you're looking to hear more about MG, find a friend with the same diagnosis, or receive some motivation, there's a place for you in the More Than MG community.

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

ALEXION AstraZeneca Rare Disease

Find A SUPPORT GROUP Near you

Missouri

Eastsiders Lunch Bunch - Blue Springs
1st Wednesday of the month | 11:30am - 1:00pm | 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 - August 7, 2024
RSVP to mckennafulton@mgakc.org

Kansas City Coffee Club
1st Thursday of the month | 9:30-10:30 AM | Location Varies
Coffee is Dutch treat | Open to individuals, caregivers & providers
Next Meeting – August 1, 2024
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 — December 14, 2024
RSVP: mckennafulton@mgakc.org

Kansas City Northland Support Group
January-September, 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 – September 12, 2024
RSVP: mckennafulton@mgakc.org

Young Friends of the MGA– Kansas City
Quarterly at various locations in Kansas City | 6:00-8:00 PM
Open to individuals who are generally in their 20s, 30s and 40s
Next meeting – November 19, 2024
Chicken N Pickle | 5901 W 135th St, Overland Park, KS
RSVP: allisonfoss@mgakc.org

St. Joe Support Group
Quarterly | Time TBA | Cabbage Roll, 2641 Lafayette St, St Joseph, MO 64507
Open to individuals, caregivers & providers
Next Meeting – October 7, 2024
RSVP: donnasjmo@yahoo.com

Find A SUPPORT GROUP Near you

Missouri

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 – October 17, 2024
RSVP: kathrynclemens@mgakc.org

Mid-Missouri Group
Quarterly on a Thursday | 5:30-7:00 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 10, 2024
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 22, 2024
RSVP: 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 – October 12, 2024
RSVP: kathrynclemens@mgakc.org

Young Friends of the MGA– St. Louis
Quarterly at various locations in St. Louis | 6:00-8:00 PM |
Open to individuals who are generally in their 20s, 30s and 40s
Next Meeting – September 12, 2024
RSVP: info@mgakc.org

Find A SUPPORT GROUP Near you

Kansas

Lawrence/Topeka Area Support Group
Quarterly on a Thursday, rotates between Lawrence and Topeka, KS| 6-7:30 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 – August 29, 2024
RSVP: mckennafulton@mgakc.org

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 Leader
Next Meeting – TBA
RSVP: dkptiffany@gmail.com

Arkansas

Central Arkansas Group
Quarterly on a Thursday | 5:30-7:00 PM | Fletcher Library, 823 N. Buchanan St, Little Rock, AR
Open to individuals, caregivers & providers
Hosted by Griselda Torres & Kelsey Sims, Volunteer Support Group Leaders
Next Meeting – November 7, 2024
RSVP: kathrynclemens@mgakc.org

NW Arkansas Support Group
Quarterly Saturday | 2:30-4:30 PM |Springdale Public Library, 405 S. Pleasant Street, Springdale, AR
Open to individuals, caregivers & providers
Next Meeting – November 9, 2024
RSVP: allisonfoss@mgakc.org

Find A SUPPORT GROUP Near you

Virtual

Virtual Monthly Meetup
4th Monday of the month | 6:30-7:30 PM via Zoom
Open to individuals, caregivers & providers
Next Meeting – August 26, 2024
Register at mgakc.org

MG Pride Group
Bi– Monthly on a Tuesday | 5:30-6:30 PM | Via Zoom
Open to individuals who identify as LGTBQ+ with MG, their allies and care partners
Hosted by Bryan Bosch, Volunteer Support Group Leader
Next Meeting – August 6, 2024
RSVP: btbosch81@gmail.com

Young Friends of the MGA– Virtual Support Group
Quarterly via zoom| 6:00-7:00 PM |
Open to individuals who are generally in their 20s, 30s and 40s
Next Meeting – October 1, 2024
RSVP: info@mgakc.org

Become a 2024 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 2024

- ☐ $25.00 Basic Member
- ☐ $64.00 64th Anniversary Member
- ☐ $100.00 Sustaining Member
- ☐ $500.00 Patron Member
- ☐ $1,000.00 Lifetime Member

$_____In memory of: _____

$_____In honor of: _____

Name :_____

Address: _____

City, State, Zip:_____

Phone:_____

Email: _____

I am a: ☐ MG PATIENT ☐ RELATIVE ☐ FRIEND ☐ OTHER

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

-Contributions may be tax deductible
-Make checks payable to:
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
www.mgakc.org