myasthenia gravis association MGA of the heartland

STRENGTH AND CONNECTIONS HOPE THROUGH

VOL. 64 ISSUE 2

MYASTHENIA GRAVIS ASSOCIATION NEWSLETTER

INSIDE THIS ISSUE

Exciting News!

New In-Person Clinic Partnership at Lake Regional
On June 17th, the Myasthenia Gravis Association will begin a 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.

The MG clinic partnership at Lake Regional will mark the 4th MG clinic for the Myasthenia Gravis Association in addition to clinic partnerships at the University of Kansas Health Center, St. Luke's Hospital and St. Louis University. What the clinic model does is ensure that staff from the Myasthenia Gravis Association are available to meet with individuals with myasthenia gravis and their families to provide resources, lend a listening ear and helping hand as well as plugging the individual into the MG community.

Dr. Papsdorf graduated from the University of Kansas Medical School and did her residency at the University of North Carolina. During her fellowship and residency she wrote several MG research papers that she continues to work on. While at the University of North Carolina she trained under James Howard, MD who is well known in the myasthenia community. In her spare time, Dr. Papsdorf likes to bake fancy cakes, cupcakes, and cookies and run half marathons. She also enjoys spending time with her husband and two kids.

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

SUBMISSIONS

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

FOLLOW US

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@myastheniakc

https://www.facebook.com/mgakc

A MESSAGE FROM ALLISON

Happy Spring!

I hope this message finds you enjoying the blooms of flowers in your yard and the smell of freshly cut grass in your neighborhood. I love how spring helps remind us that a new chapter is beginning which brings me to share part of my MG story.

Nearly 15 1/2 years ago, I had a fistula placed in my left arm for monthly plasmapheresis treatments. The fistula has literally stuck out like a sore thumb or an egg in the crease of my arm, but it's been an element in saving my life as it allowed me to get my treatments.

Enter pulmonary and cardiac challenges about 2 years ago that I have worked with my medical team to figure out, only to have the cardiac issues continue to worsen. A few weeks ago, it was decided that my fistula was likely the culprit of my cardiac issues. So in early April, I went in and had my fistula surgically litigated or unhooked in hopes my heart won't have to work so hard. Luckily for me, I have been able to shift my treatment to one of the new therapies that the FDA approved for MG, and I haven't needed plasmapheresis since mid September 2023.

As I've been on the mend and moving a bit slow, I've been thinking a lot about how thankful I am for all those years I was able to get plasmapheresis but sometimes things run their course in life and we need to start anew. A fresh start, if you will. It's somewhat like when the seasons change. Time runs its course and one day we can turn over a new leaf or the calendar to something new!

I didn't anticipate how emotional I'd feel about getting my fistula unhooked, but on a few occasions when I told people about it, I got choked up. We had a good run, my fistula and I, but I am forever reminded that change is good. And now I'm grateful I'm responding to a new therapy and can see lighter, brighter days ahead!

New scars may mark up my arm right now, but it's just part of my story that is still being written!

Please know we are here if you need anything and we hope to connect with you soon!

Allison K. Foss

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

myasthenia gravis association
MGA
of the heartland

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Remembering ROGER HUFF

A Beloved Support Group Leader

Tremendous, Genuine, Advocate

Roger Huff was a valued leader of our Northwest Arkansas Support Group. Sadly, he passed away on March 17th, 2024, after a courageous 20-year battle with myasthenia gravis.

As we reflect on Roger's impact on our lives, we are reminded of how he spent his life caring for other people, in his career, in his personal life, and in his community involvement. It was through his own journey with myasthenia gravis, he found solace in working to build up a community right in his backyard of Northwest Arkansas. Roger was instrumental in bridging the gap between the medical community and resources for those battling rare diseases. He worked tirelessly after long days at his job at UAMS or after other volunteer gigs he was tied into, to make sure individuals with myasthenia gravis had questions answered, information in their toolboxes, and were equipped for another day. He and Jan initiated joining forces with the Myasthenia Gravis Association to bring our organization into Arkansas in 2015, and had been cheering us on as we extended our outreach to Central Arkansas. Roger Huff is why the Myasthenia Gravis Association exists in Arkansas, and for that, our entire community is thankful.

Roger shared his passions and hobbies, which spanned a wide spectrum of his life. He was knowledgeable about cooking, music, dogs, and caring for others.

We have big shoes to fill as we think about our support group moving forward without Roger, as he had the unique ability to wear many hats and play many different roles. On behalf of the Myasthenia Gravis Association, our heartfelt sympathy to all who had the pleasure of having Roger in their lives. May you feel the love from the community in the days, weeks, and months ahead.

The Myasthenia Gravis Association

BE IN THE KNOW!

THE JOE FIANDRA ACCESS TO HOME INFUSION ACT:

ADVOCATING FOR ACCESS

In the realm of healthcare advocacy, every legislative step forward holds the potential to profoundly impact the lives of individuals battling chronic conditions. For those with MG, maintaining access to vital treatments is not just a matter of convenience but often a lifeline. The recent emergence of the Joe Fiandra Access to Home Infusion Act has sparked significant interest and hope within the MG community.

Understanding the Act:

The Joe Fiandra Access to Home Infusion Act is a bipartisan effort aimed at expanding access to home infusion therapy under Medicare. Home infusion therapy is crucial for many MG patients who rely on intravenous immunoglobulin (IVIG) or other infusion-based treatments to manage their condition. However, accessing such treatments can often present logistical challenges, particularly for those with mobility issues or those living in remote areas.

The Act seeks to address these challenges by allowing Medicare coverage for professional services associated with home infusion therapy. This includes coverage for nursing services, patient education, and training necessary for administering infusion treatments at home. By facilitating access to these services, the Act aims to improve patient outcomes, reduce healthcare costs, and enhance overall quality of life for individuals with chronic conditions like MG.

Advocacy Strategies:

- Educate and Raise Awareness: By raising awareness about the Act and its potential impact on the MG community, individuals can garner support from fellow patients, healthcare professionals, and policymakers.
- Leverage Personal Stories: Sharing firsthand accounts of the challenges faced in accessing infusion therapy can humanize the issue and urgency of passing the Act.
- Engage with Legislators: Reach out to congressional representatives and senators to express support for the Joe Fiandra Access to Home Infusion Act.

The Joe Fiandra Access to Home Infusion Act holds immense promise for improving access to critical treatments for individuals living with Myasthenia Gravis and other chronic conditions. The MG community can play a pivotal role in advancing this legislation and ensuring that all patients have the opportunity to receive quality care in the comfort of their homes.

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Update on MYASTHENIA GRAVIS Research by Dr. Farmakidis, MD

Constantine Farmakidis, MD
Associate Professor of Neurology at the University of Kansas Medical Center
(disclosures: I have been involved as a site investigator for KU, and research study author for zilucoplan and nipocalimab)

The history of myasthenia gravis treatment could be divided in two: the pre-2017 and the post-2017 periods.

As many MGA members will know, pre-2017 the standard therapies for MG consisted of cholinesterase inhibitors like pyridostigmine (Mestinon); prednisone, which is a powerful suppressant of the immune system, surgical removal of the thymus gland, along with intravenous immunoglobulin G (IVIG) and plasma exchange which often have been reserved for patients with either severe myasthenia gravis exacerbation, or harder to control disease.

Since 2017 several new medications have been demonstrated to be effective in the treatment of MG. Considering that the last and only medication that was FDA-approved for myasthenia was pyridostigmine in 1955, and that since 2017 there have been 5 new medications approved for MG, it is not unreasonable to think that a new era has started for MG therapy.

So why this flurry of innovation and new treatments after all these years? The improved understanding of how myasthenia damages the nerve-muscle connection has been instrumental. For example, a new treatment for myasthenia, blocks a specific portion of the immune system that in patients with the acetylcholine receptor antibody, is activated, and punches small holes on the muscle-side of the nerve-muscle connection or neuromuscular junction. This part of the immune system is called the complement system, and its role in myasthenia was not established until the 1980s and 1990s. The drugs that block the complement system of the immune response are known as terminal complement inhibitors. Eculizumab, ravulizumab and zilucoplan are in this category of terminal complement inhibitor medications and are FDA approved for MG.

As described below, research is ongoing in the terminal complement category for MG. The focus is both on new compounds that target the complement system, as well as more user-friendly drug delivery systems, such as automatic injector mechanism for the drug.

Another reason for these advances in myasthenia treatment has been improved understanding of how the human immune system works in general. For example, the immune system has a way to recycle the all-important IgG antibodies, so that these antibodies survive longer in the human body. However, myasthenia gravis is a disease that is driven by disease causing IgG antibodies that damage the nerve-muscle connection. So, scientists used their understanding of this IgG recycling system, to try to block IgG recycling, lower levels of all antibodies, and in this way also lower the levels of myasthenia gravis-causing antibodies. These drugs are known as neonatal Fc receptor inhibitors, and to repeat, what they do is decrease all IgG antibody levels, including the antibodies that cause damage in myasthenia. The drugs in this category are efgartigimod and rozanolixizumab. Research is also ongoing for neonatal Fc receptor inhibitors in MG and is described further below.

Of course, there are more reasons for the flurry of successful drug development since 2017. An especially important reason are the advances in biotechnology that have allowed scientists to develop and manufacture drug molecules that can bind to their targets with high specificity (bind only to the correct target) and with high affinity (bind tightly enough). These molecules often mimic the design of human antibodies, sometimes the drug compound is an antibody fragment, and sometimes the drug can be a small molecule, with sophisticated ring-like features that give both chemical stability and binding specificity.

Update on MYASTHENIA GRAVIS Research (continued)

Constantine Farmakidis, MD
(disclosures: I have been involved as a site investigator for KU, and research study author for zilucoplan and nipocalimab)

Finally, the collective knowledge and infrastructure for completing complex clinical trials has expanded greatly in the last 20 years. This means that academic hospitals such as KU and pharmaceutical companies have developed much more sophisticated project management practices, improved data management tools, and meticulous auditing practices to monitor and protect data quality.

These large clinical trials for myasthenia for example, can span multiple continents and dozens of countries. They are an enormous undertaking. However, pharmaceutical companies are more comfortable with them, are doing more of them, and as a result there has been success in demonstrating effectiveness and bringing new drugs to patients.

Now a few comments on ongoing research in myasthenia in no order of preference, with an emphasis on studies recruiting at KU:

- Data shared at the American Academy of Meeting earlier this April 2024 indicated that a terminal complement inhibitor has ongoing treatment effect at about 2 years and that patients were able to decrease their prednisone use. Will need to see this in a journal publication format. Studies with this drug are likely to be recruiting for follow-up drug delivery studies at KU in 2024-2025
- Another late phase study of a terminal complement inhibitor drug for adult MG is ongoing. The drug is gefurulimab and is also known as ALX1720. Study enrollment at KU is ongoing
- Previous data indicated that using rituximab early in patients with myasthenia can make it more effective (Rinomax study) that when used later in the natural history of the disease (Beat MG trial which showed no treatment effect for rituximab in AChR antibody-positive MG). Early rituximab may be a treatment strategy in the future, if studies can confirm this early-treatment advantage for the drug
- Inebilizumab is another B-cell depleting therapy similar to rituximab. However, it targets a much broader group of B-cells than rituximab. For this reason, it is being studied in a large multicenter study, with the hope perhaps that this drug will be more broadly effective for MG patients than what has been seen so far with rituximab
- Nipocalimab is an intravenous neonatal Fc Receptor Inhibitor. This is being studied in children with MG at our center. There may further studies in adults as well at our center
- Batoclimab is a subcutaneous neonatal Fc Receptor Inhibitor drug that is being studied in adults at our center. Recruitment is ongoing at KU
- There are two CAR-T cell therapy clinical trials recruiting at our center: one for MuSK MG patients (Cabaletta Bio), and the Cartesian MG-001 trial, which has broader inclusion criteria. Both studies are currently open for enrollment at KU.
- KATALYST MG is a clinical trial that looks at the effects of whole-body electrical muscle stimulation exercise on adults with MG. This study has ongoing recruitment at KU
- ·And finally, the DAS-MG clinical trial looks to see if ondansetron can improve the tolerability of pyridostigmine (Mestinon) as pyridostigmine use is frequently limited by GI side effects

Please contact the KU research team with any questions. Ali Russo is the research lead for myasthenia studies. She can be reached at aciersdorff@kumc.edu

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

Immunovant MG PI: Dr. Pasnoor ClinicalTrials.gov Identifier: NCT05403541

A Phase 3, Multi-center, Randomized, Quadruple-blind, Placebo-controlled Study to Assess the Efficacy and Safety of Batoclimab as Induction and Maintenance Therapy in Adult Participants With Generalized Myasthenia Gravis (gMG).

For more information: Abby Davis adavis54@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

MG CLINICAL TRIAL UPDATES

University of Kansas Medical Center

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

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?

Members of our Wichita Support Group recently represented us, the Myasthenia Gravis Association, at the Wichita State University Wellness Expo on March 6th, 2024.

LaDonna Diller a member of our Board of Directors represented the Myasthenia Gravis Association, at the MDA Scientific Conference in Orlando, Florida March 3rd through March 6th, 2024.

Our Community Program Coordinator of Saint Louis, Kathryn Clemens, recently represented the MGA, at Washington University's 2nd annual Rare Disease Day Symposium in Saint Louis, MO on Leap Day 2024!

Untold Stories

Life with a Severe Autoimmune Condition

RUBY

ALL NEW UNTOLD STORIES!

The compelling podcast series, Untold Stories: Life with a Severe Autoimmune Condition, is back with a second season! Previously highlighting the experiences of real people living with MG, this season is expanding to share the stories of people living with other rare autoimmune conditions, such as CIDP. Host Martine Hackett continues to speak with a variety of guests, as they share their trials, tribulations, and triumphs.

MG=myasthenia gravis
CIDP=chronic inflammatory demyelinating polyneuropathy

LISTEN NOW

Host Martine Hackett
Associate Professor,
Director of Public Health Programs
Hofstra University

argenx

See WHAT'S NEW At the MGA

Meet Megan Choate our new Board Member

After years of watching my father wake at any hour to care for the most fragile newborns, a passion was born to help all people live at their best. Recognizing that writing was more of my gift than science, I left my hometown in Nebraska and headed to the University of Kansas, known for its journalism program and school spirit. Here, time was spent earning a Bachelor's of Science in Business Communications with a minor in psychology. After four years, countless campus jobs (orientation assistant still ranks as a top stop!) and forever friendships, I interned at the same place that enamored me from the start - Children's Mercy, a top-ranked pediatric hospital. It spoke to my soul to work with providers, hear and deliver on what families need, and see that even a marketing team can make an impact. Here, that spark that ties to purpose came alive with the chance to find answers for people's toughest health care concerns and give them hope about their potential.

When I'm not hustling, you will find me on sports fields cheering on my two boys, ages 11 and 14. Or at the newest restaurant in town, connecting with a friend. You may also catch me helping others decorate their homes, navigate their neurodiverse child's journey or taking the latest Peloton ride. While I'm a woman of many things, there's one that stays center: to bring awareness, education, research, inclusivity and support to help people live at their best.

-Megan Choate

UPCOMMING EVENTS

MGA
TRIPLE CROWN SHOWDOWN
2024

MYASTHENIA GRAVIS ASSOCIATION
TRIPLE CROWN
13th ANNIVERSARY
MAY 19, 2024

5K RUN/WALK & TOT TROT

Date: Sunday May 19, 2024
Time: 8:00am, CST
Location: Town Center Plaza, Leawood, KS

PACKET PICK-UP

Date: Saturday May 18, 2024
Time: 10:00am - 2:00pm
Location: Town Center Plaza, Leawood, KS

Date: Sunday, May 19, 2024
Time: Starting at 7am
Location: Town Center Plaza, Leawood, KS

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

Register at
www.mga5k.com

All individuals living with MG register for FREE, email the MGA for the code at info@mgakc.org.

MGA SNOWFLAKE SHUFFLE

0.1K WALK

Date: June 22, 2024
Time: 10:30am - 1:00pm
Location: 1901 S. Kansas Avenue
Wichita, KS 67211

Go to www.mgakc.org to register

All individuals living with MG register for FREE, just email the MGA for the code at info@mgakc.org.

PICKLEBALL FOR A CAUSE

A MGA EVENT

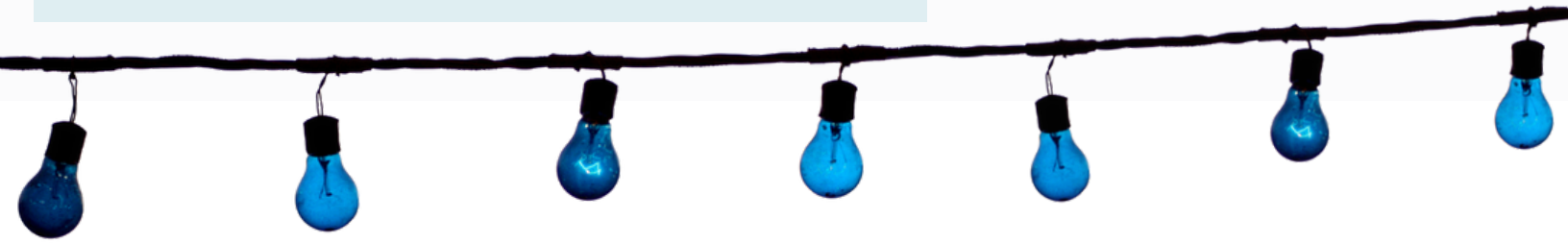
Date: June 2, 2024
Time: 4:00pm - 7:00pm
Location: Chicken N Pickle | Saint Charles, MO

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

Email info@mgakc.org to register.

DID YOU KNOW?
LIGHT THE WORLD JUNE 2ND

Did you know there are MG organizations that stretch across the globe? For the first time ever on June 2nd, MG organizations across the globe are going to come together for Light the World for MG Day. Take a time out on June 2nd and turn on your porch light for MG awareness or reach out to landmarks in your city or state and ask if they would light it up for MG. A special thanks to our partners at argenx, Alexion and UCB for their support of this project!



Membership Donations

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Al Dimmitt
Sally Marks

In Memoriam

Dr. Jake McGuire given by
Richard & Jan McGuire

James Roger Huff given by
Ron Crumpler
Randy Roberts

Yvette McLaughlin given by
Lucy Medugno
Yvette McLauaghlin given by Day Pitney, LLP

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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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 - May 1, 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 – May 2, 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 — July 13th, 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 – May 9, 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 – July 10, 2024, UP Down Kansas City 5:30pm
RSVP: allisonfoss@mgakc.org

Find A SUPPORT GROUP Near you

Missouri

St. Joe Support Group
Quarterly | Time TBA | Location TBA
Open to individuals, caregivers & providers
Next Meeting – TBA
RSVP: donnasjmo@yahoo.com

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 – July 18th, 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 – July 11, 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 – May 23, 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 – July 13, 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 – TBA
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 – May 2, 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 & Larry Paxson, Volunteer Support Group Leaders
Next Meeting – April 20, 2024
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 – May 2, 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 – August 3, 2024
RSVP: allisonfoss@mgakc.org

Find A SUPPORT GROUP Near you

Virtual

AMP Your Social Media Voice
5:00PM-6:00PM via Zoom
Open to individuals, caregivers & providers
Next Meeting – May 6, 2024
Register at mgakc.org

Virtual Monthly Meetup
4th Monday of the month | 6:30-7:30 PM via Zoom
Open to individuals, caregivers & providers
Next Meeting – May 28, 2024 *(due to Memorial Day)*
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 – June 11, 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 – June 18, 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
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