

## MGA Holds 61st Annual Meeting Virtually



This past October, the MGA held its 61<sup>st</sup> Annual Meeting & Educational Seminar virtually. The Annual Meeting & Educational Seminar provides our organization an opportunity to update its community members near and far about our achievements, partnering organizations, and topics related to MG. The event also allows the MGA to recognize the people that contribute to our efforts and make our organization possible.

The meeting began with an agenda overview followed by an examination of organizational finances. Allison Foss, Executive Director of the MGA, kicked off the meeting with an exciting statistic; more than 200 people were watching this virtual conference all across the country! One of the attendees happened to be Joan Stackhouse, founder of the MGA. Needless to say, it was a privilege to illustrate how far the MGA has come since its establishment!

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The MGA was delighted to have Dr. Mazen Dimachkie as their keynote speaker for the 2021 meeting. Dr. Dimachkie is Professor of Neurology & Chief of the Neuromuscular Division at The University of Kansas Health System and also serves as Executive Vice Chairman and Vice Chairmen for Research at the University of Kansas Medical Center. Throughout his presentation, Dr. Dimachkie touched on a variety of matters including the pathophysiology of MG, established MG therapies, and promising therapies on the horizon for MG patients.



Following Dr. Dimachkie's educational lecture, the MGA was fortunate to have a panel of MG experts weigh in on the changing landscape of treatment options for MG. In addition to Dr. Dimachkie, Dr. Mamatha Pasnoor, Dr. John Eatman, and Dr. Nathan McGraw offered their expertise on MG related issues in which attendees could submit questions to ask them directly. Attendees asked about an assortment of things including current MG treatments, antibodies associated with MG, COVID-19 issues, and more.



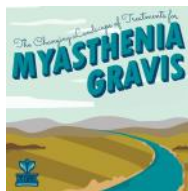
## 2 MGA 61st Annual Meeting— Awards & Recognition

The MGA wrapped up the educational piece of the Annual Meeting in October with the presentation of two awards; the Stackhouse Award and the Volunteer of the Year Award. The Stackhouse Award is given to a person or people who have made a lifelong difference to the MG Community by their dedication and leadership. The Yokota Foundation was the recipient of the Stackhouse Award. The Yokota Foundation has financially supported the MGA through generous grants the last 6 years as well as held the Reel in Fishing Derby twice at their home outside of St. Louis in 2019 and 2020. Thank you John and Tina Warren, Mark Macias and Greta Rice.



Dr. Constantine Farmakidis was the recipient for Volunteer of the Year Award. Recipients receive recognition as outstanding leaders dedicated and committed to the MGA. When COVID-19 began, Dr. Farmakidis was the first to reach out to the MGA and offer his services to assist with the education of patients on the pandemic. As the pandemic has carried on, he has continued to reach out and provide his time and support to assist with answering questions and providing information.

Thank you to The Yokota Foundation and Dr. Farmakidis for devoting your efforts to the MGA mission—we are incredibly grateful!



Thank you to our sponsors



Lastly, thank you to Distinctive Meeting Group and all of our participating sponsors for making this event possible.

### SAVE THE DATE: 11th Annual MGA Triple Crown Showdown to take place on 5/15/22!

Our annual 5K Run, Mile Mosey, and Tot Trot, otherwise known as the MGA Triple Crown Showdown, is scheduled for Sunday, May 15, 2022, at Town Center Plaza in Leawood, KS!

Join us for an uplifting morning, raising awareness for myasthenia gravis. Same place, better weather (hopefully!). Patients can register for free using code: MGA2022; friends & families can use code: MGAFAMILY2022 for \$5 off. Price increases on 2/28/2022, so don't delay! Head to [www.mga5kc.com](http://www.mga5kc.com) for more information.



## A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

I was recovering from a plasmapheresis treatment on a Friday night in late October at home when I glanced down at my laptop and saw we had a voice message at the MGA. I clicked to listen and to my ears delight, it was the voice of our founder, Joan Stackhouse! I immediately clicked the redial button and was greeted with a lovely hello.

To my excitement, Joan shared she wanted to participate in our 61<sup>st</sup> Annual Meeting since it was going to be virtual. I couldn't believe it! From that day in late October, I've had the privilege of having several conversations with Joan and her daughter, Ginny. While the uptick in COVID-19 cases paused a trip I had planned out to meet her last month, there is more to the story to come and I can't wait to see what unfolds.

So far, what I've learned from this is "expect the unexpected," and that pretty much rings true to the time we are living. Our best laid plans for 2022 stalled a bit due to the omicron variant or transitioned to a different format, an unexpected staffing change which has led to the development of a revised role, and the pending meeting of the founder of our 62 year old organization hanging in the forefront of 2022. It's going to be a great year and we are grateful you are all along for the ride! Stay tuned.....

Be well,

*Allison Foss, Executive Director*  
allisonfoss@mgakc.org



### MGA Board of Directors & Staff

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**Executive Director**  
Allison Foss  
**Program Coordinator**  
Meridith O'Connor, MSW

## Farewell & Best Wishes, Tanya!

This month, we say farewell and best wishes to Tanya Renner, our Kansas City Program Coordinator for the last 3 1/2 years. Tanya has been the friendly face that many have seen in our Kansas City clinics as well as behind the scenes at every event!

Thank you, from the bottom of our hearts, Tanya, and for all that you have done for the MGA. You will be missed!



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## FDA Approves New Treatment for Myasthenia Gravis

ICYMI: Argenx, a global immunology company, recently announced the FDA approval of VYVGART (efgartigimod alfa-fcab) for generalized myasthenia gravis patients. Tim Van Hauwermeiren, Chief Executive Officer of argenx stated in a recent press release that VYVGART is the “first and only FDA-approved neonatal Fc receptor blocker; and the first approved therapy designed to reduce pathogenic IgGs, an underlying driver of gMG.”

This is an exciting time for the myasthenia gravis community! Patients can now add this new medication to their treatment toolbox to help manage their disease. Myasthenia gravis patients have an array of treatment options including anti-acetylcholinesterase agents (Mestinon), corticosteroids and immunosuppressant agents such as Prednisone, complement inhibitors including Soliris, IgG therapy, plasma exchange, thymectomy, and now, VYVGART. VYVGART is an intravenous infusion and common side effects are respiratory tract infection, headache, and urinary tract infection. While VYVGART is indicated for patients who are anti-acetylcholine receptor antibody positive, it is important to remember that this type of research has the potential to open doors for other types of MG as well.

Thank you to argenx and everyone that provided their expertise to make another myasthenia gravis treatment possible. We are very excited to see how this will help MG patients in the future! Interested in learning more about VYVGART? Head to <https://www.argenx.com> and as always, please consult with your care provider to see if this medication is an appropriate option for you.



## MGA Expands Clinic Services



The MGA is excited to share that our clinic services have expanded south! In partnership with Dr. Tania Papsdorf, the MGA recently established a MG clinic at the Jared Neuroscience Center of Cox Health in Springfield, Missouri. Dr. Papsdorf sees patients with myasthenia gravis one morning out of every month. Staff from the MGA will meet with patients either before or after their appointment to provide support and resources. The MGA is anxious to get to know more patients in the southern Missouri region and be able to walk alongside them in their journey with MG.

Additionally, the MGA has expanded its clinic services with St. Luke's on the Country Club Plaza with Dr. Nathan McGraw. Dr. McGraw will see patients with MG one morning a month as well. Staff from the MGA will meet with patients of Dr. McGraw at that time to offer support and 1-1 consultation.



The MGA is grateful for the support of Dr. Papsdorf and Dr. McGraw, as well as the partnering facilities, Cox Health and St. Luke's. Collectively, we share a vision of providing wrap-around services to patients by making these clinics possible.

Thank you to our donors who have financially supported the MGA over the past years for also making these clinics possible. If you are not greeted by staff from the MGA or miss seeing one of us at your appointment, we are sorry we missed you! With COVID-19 things are very fluid and from time to time changes have to be made. Don't be shy, reach out and let us know we missed you so we can catch up!



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## MGA Adds Three New Board Members



### Al Dimmitt

Al Dimmitt lives in Kansas City, Missouri with his wife Kay and two small dogs. A retired community college teacher and administrator, he enjoys reading science, history, and fiction as well as keeping up with technology. He and Kay are baseball enthusiasts and Royals season ticket holders. Al was diagnosed with MG in 2018.



### Jacquelyn Luedtke, CMP

Raised in Omaha, Nebraska, and a graduate of Iowa State University (Go Cyclones!), Jacquelyn moved back to the Midwest after living in Colorado and Utah for a total of six years. A passionate, creative, and positive team player, with several years of event planning from inception to execution. Jacquelyn and her husband, Scott, reside in Overland Park with their two-year-old Pembroke Welsh Corgi named Clark. Jacquelyn is the Corporate Events Planner for the Kansas City Chiefs. If not enjoying a sporting event she can be found traveling, skiing in as many countries as possible, or hanging out with family and friends.



### Graham Naasz, DDS

Graham Naasz is a dentist from Overland Park, KS who became interested in treatment and research for myasthenia gravis from a close mentor from dental school. Born and raised in Kansas City, Graham is an avid Royals, Chiefs, and Jayhawk basketball fan. He is excited to bring another treatment facet to the multi-disciplinary treatment of myasthenia gravis. One of Graham's favorite activities is taking his Great Dane Cooper to Bark.

## Support the MGA



Have an idea for a fundraiser in your community?

Contact us today at:  
allisonfoss@mgakc.org

Your financial support enables us to continue reaching patients impacted by myasthenia gravis.

## In Memoriam

### James Lewis

Helen & James Hinshaw  
Margaret Martin  
Alan & Rosalind Crane

### William Webb

Thomas & Eileen Lundstrom

### Robert Bergeron

Robert & Patty Stapleton



## Brendel joins team at the MGA

Kami Brendel has joined the MGA as our new Patient Care Specialist and will be working in our Kansas City area clinics and support groups.

Kami is a communications professional with a deep commitment to healthcare. A graduate of Illinois Wesleyan University, she comes to the MGA with years of experience helping patients in the rare disease community write and share their stories of perseverance and strength to inspire newly diagnosed patients and their loved ones. Formerly Client Services Director and Training Specialist for VPR Patient Outreach Program in Kansas City, Kami is excited to join the MGA and looks forward to both raising awareness about myasthenia gravis and furthering the goals of the association.





# MYASTHENIA GRAVIS CLINICAL TRIAL UPDATES

## KUMC CLINICAL TRIAL UPDATES



Contact: Samantha Colgan, CCRP  
scolgan@kumc.edu  
913-945-9938

- A Phase III, Randomized, Double-blind, Multicenter, Placebo-controlled Phase 3 Study with Open-label Period to Evaluate the Efficacy and Safety of Inebilizumab in Adults with Myasthenia Gravis  
PI: Mamatha Pasnoor, M.D.
- A Phase II, Randomized, Placebo-Controlled Study to Evaluate Safety, Tolerability, and Efficacy of TAK-079 in Patients With Generalized Myasthenia Gravis  
PI: Mazen Dimachkie, M.D.

## MU CLINICAL TRIAL UPDATES



For information regarding clinical trials:  
Contact: Richard Barohn, MD  
rbarohn@health.missouri.edu  
573-882-3693

## SLU CLINICAL TRIAL UPDATES



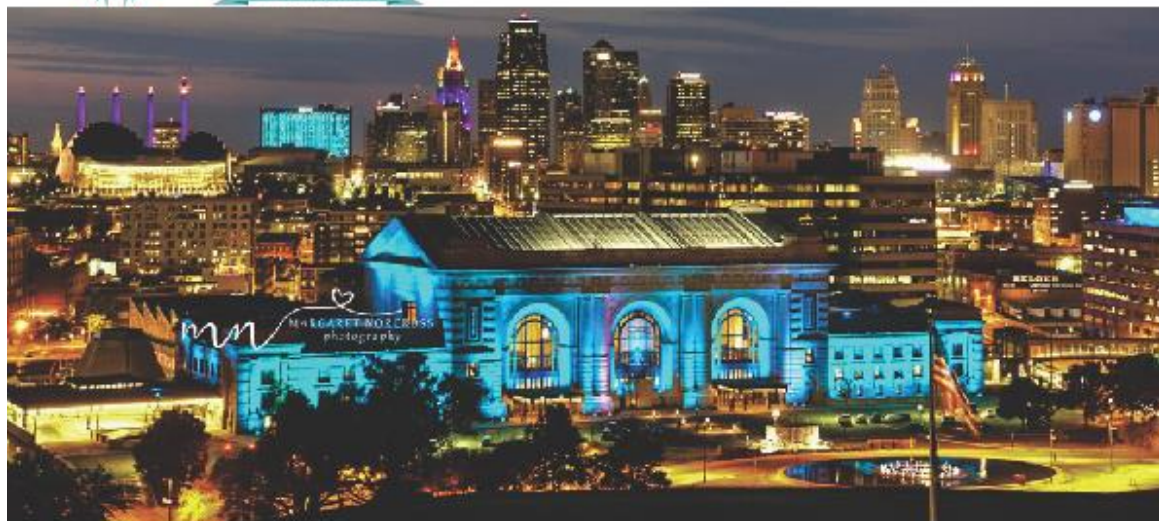
Currently, **there are no clinical trial updates for SLU.**  
For more information regarding clinical trials:  
Contact: Rachel Grant  
rachel.grant@health.slu.edu

## WASHU CLINICAL TRIAL UPDATES



Contact: Oliver Doerr, oliver.doerr@wustl.edu

- 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



## 2021 IMPACT

Working to improve the lives of those impacted by myasthenia gravis



### SUPPORT GROUPS

Support Groups meeting  
13 across Kansas  
Missouri & NW  
Arkansas  
members attending

632 53 meetings

6 webinars  
posted to MGA  
Youtube Channel

The MGA is  
patients,  
the



on the ground connecting with  
families & providers in



All services provided



### CLINICS

125 clinics held

clinic partnerships at  
KU Medical Center  
3 St. Luke's Hospital  
St. Louis University

555 patients seen



### OUTREACH

3000 contacts made thru  
phone, email,  
social media

48 blog posts written  
on the MGA Digest

880 attending  
awareness events

83 new patient  
packets provided  
registered

200 61st Annual Meeting



free!

**MYASTHENIA GRAVIS  
ASSOCIATION**  
[www.mgakkc.org](http://www.mgakkc.org)

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(efgartigimod alfa-icab)

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## Finding Your Motivation This Winter

It's cold, it's dreary, and we are still living in this pandemic— not necessarily a recipe for motivation. Like many of you, I have been struggling to see the light at the end of the tunnel with everything that's been going on with COVID, however; one thing I keep reminding myself to do is to keep moving!

The other day my best friend and I went for a walk. I cannot walk 6 miles like she does every day (her motivation is unreal!), but I am able to walk for the first part of her trail. To my own surprise, I walked over 2 miles! Given that I've been relatively sedentary lately, I was proud of myself for exceeding my own expectations and pushing myself in a healthy way. I have to say though, having someone to walk with helped distract me from noticing my fatigue. It is great when you get lost in conversation and aren't necessarily focused on how tired you are or how difficult that one hill is to climb.

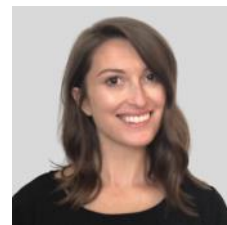
With myasthenia, it is a difficult line; knowing when to push yourself just a little bit more versus when to call it quits. What is the answer? I think it's a personal matter. Everyone's symptoms are different, and there is no one black and white solution. I have had this disease for 20 years

now, and every day is different. I may have been able to walk two miles the other day but I do not necessarily know if I'll be able to do that again today.

A partner to walk with helps, but you know what else keeps me motivated? That feeling I get after I exercise. I'm not talking about the physical feeling, because usually I'm pretty tired. Walking has done wonders for my mental health and sleep patterns. My anxiety decreases, my head is clear and I also just feel better about myself knowing that I have used my muscles.

I know it is easier said than done, and no; I am not suggesting you go out and walk two miles. What I am encouraging though is finding ways to stay motivated this winter, and to take care of your mind, body, and spirit in a way that is healthy and appropriate for you. There is a faint light ahead and I am going to keep walking towards it. Hang in there, everyone. We will get through this together!

**Meridith O'Connor, MSW**  
**St. Louis Program Coordinator**



## Calling all coffee lovers in the STL area!

We have a new program we are rolling out— Coffee with a Coordinator! On the last Thursday of every month from 10:30-11:30 AM at Kaldi's Coffee Café in Kirkwood, MO, Meridith, our St. Louis Program Coordinator, will be hosting a small gathering of MG friends to hang out and mingle over a warm cuppa' tea or coffee (or whatever you prefer!).

Sometimes it's nice to talk to people about your MG, and other times you don't feel like talking about it at all—and that's okay!! That's why we organized this new program. The MGA wants to support people with MG holistically. There are no age requirements, no specific MG types. Just bring yourself and come join us for a casual catch

-up session. If you are interested in joining Meridith and friends, please RSVP to [meridithoconnor@mgakc.org](mailto:meridithoconnor@mgakc.org).

meridithoconnor@mgakc.org or (816) 266-4100'."/>

**COFFEE**  
*with a*  
**COORDINATOR**

Coffee and friends make the perfect blend, don't you think? That's why the MGA is starting a new program called, Coffee with a Coordinator!

Join us for an informal opportunity to gather and visit with MG community members in the St. Louis area and meet with Meridith, our St. Louis program coordinator.

Mingle with others, get to know one another, and chat about anything (MG related or not)! Grab a coffee or drink of choice, support a local business, and foster meaningful connections.

Coffee with a Coordinator will take place on the last Thursday of each month from 10:30-11:30 AM unless otherwise noted.

Kaldi's Coffee Cafe | 120 S Kirkwood Rd, Kirkwood, MO 63122

RSVP to Meridith at [meridithoconnor@mgakc.org](mailto:meridithoconnor@mgakc.org) or (816) 266-4100

# <sup>10</sup> Positive clinical trial results shared from UCB on Ronzanolixizumab & Zilucoplan

Positive topline results from the Phase 3 MycarinG study<sup>1</sup> evaluating rozanolixizumab, a subcutaneously (SC) infused monoclonal antibody targeting the neonatal Fc receptor (FcRn), versus placebo in adults with generalized myasthenia gravis (gMG).

The trial met its primary endpoint, demonstrating a statistically significant and clinically meaningful change from baseline in the Myasthenia Gravis-Activities of Daily Living (MG-ADL) total score at Day 43. All secondary endpoints were also met with statistical significance.

Overall rozanolixizumab was well tolerated and no new safety signals were identified.

The safety and efficacy of rozanolixizumab have not been established, and it is not approved for use in any indication by any regulatory authority worldwide. The final Phase 3 data from the study and additional details will be presented at a forthcoming medical meeting in 2022.

Alongside rozanolixizumab, UCB is also investigating whether its developmental medicine zilucoplan, a peptide inhibitor of complement component 5 (C5 inhibitor), could deliver patient value to people living with gMG. Preliminary results from the company's RAISE study are expected in the coming weeks. The safety and efficacy of zilucoplan have not been established, and it is

not approved for use in any indication by any regulatory authority worldwide.

## **About the rozanolixizumab MycarinG study<sup>9</sup>**

The MycarinG study (NCT03971422) is a multi-center, Phase 3, randomized, double-blind, placebo-controlled study evaluating the efficacy and safety of rozanolixizumab in adult patients with gMG, with an open-label extension.

The primary endpoint for the MycarinG study is change in the Myasthenia Gravis-Activities of Daily Living Profile (MG-ADL) score, an eight-item patient-reported scale developed to assess MG symptoms and their effects on daily activities. Secondary endpoints include response rates, changes in the Myasthenia Gravis composite (MGC) score, the Quantitative MG (QMG) score, patient-reported outcomes and adverse events (AEs).

## **About the zilucoplan RAISE study<sup>10</sup>**

The RAISE study (NCT04115293) is a multi-center, Phase 3, randomized, double-blind, placebo-controlled study to confirm the efficacy, safety, and tolerability of zilucoplan in patients with gMG. Patients will be randomized in a 1:1 ratio to receive daily subcutaneous (SC) doses of zilucoplan or placebo for 12 weeks.

The primary endpoint for RAISE study is change from baseline to Week 12 in the Myasthenia Gravis-Activities of Daily Living

(MG-ADL) score. Secondary endpoints include change in the Quantitative Myasthenia Gravis (QMG) score, the Myasthenia Gravis Composite (MGC) and the Myasthenia Gravis Quality of Life 15 revised (MG-QoL15r) from baseline to Week 12; the proportion requiring rescue therapy; the proportion with minimum symptom expression (MSE) (defined as MG-ADL of 0 or 1), the proportion with a  $\geq 3$ -point reduction in MG-ADL and the proportion with a  $\geq 5$ -point reduction in QMG, all measured at Week 12.

## **About Rozanolixizumab**

Rozanolixizumab is a SC administered, humanized monoclonal antibody that specifically binds, with high affinity, to human neonatal Fc receptor (FcRn). It has been designed to block the interaction of FcRn and Immunoglobulin G (IgG), accelerating the catabolism of antibodies and reducing the concentration of pathogenic IgG autoantibodies.<sup>11,12</sup>

Rozanolixizumab is under clinical development with the aim of improving the lives of people with pathogenic IgG-autoantibody-driven autoimmune diseases, including gMG, primary immune thrombocytopenia (ITP), myelin oligodendrocyte glycoprotein antibody-associated disease (MOG-AD) and autoimmune encephalitis (AIE) by driving removal of pathogenic IgG autoantibodies.

The safety and efficacy of rozanolixizumab have not been established and it is not approved for use in any indication by any regulatory authority worldwide.

# Positive clinical trial results shared from UCB on Ronzaplixizumab & Zilucoplan, Continued

11

## About Zilucoplan

Zilucoplan is a once-daily self-administered SC peptide inhibitor of complement component 5 (C5 inhibitor) under clinical development by UCB in gMG. Topline results from the RAISE study, a multi-center, Phase 3, randomized, double-blind, placebo-controlled study to confirm the efficacy, safety, and tolerability of zilucoplan in subjects with gMG, are expected in H1 2022.

Further indications that are potentially addressable by zilucoplan include amyotrophic lateral sclerosis (ALS) and other tissue-based complement-mediated disorders with high unmet medical need. Zilucoplan was selected as one of the first drugs to be tested in a multi-center ALS platform study sponsored by the Sean M. Healey & AMG Center for ALS at Massachusetts General Hospital, Boston, MA.

The safety and efficacy of zilucoplan have not been established and it is not currently approved for use in any indication by any regulatory authority worldwide.

*Information taken from UCB Press release, December 2021*

## Financial Resources Available for patients with MG

The Assistance Fund– [www.tafcares.org](http://www.tafcares.org)

National Organization of Rare Disease–  
[www.rarediseases.org](http://www.rarediseases.org)

PAN Foundation– [www.panfoundation.org](http://www.panfoundation.org)

Needy Meds– [www.needymeds.org](http://www.needymeds.org)

Patient Advocate Foundation– Co Pay Relief– [patientadvocate.org/connect-with-services/copay-relief](http://patientadvocate.org/connect-with-services/copay-relief)

HealthWell Foundation– [healthwellfoundation.org](http://healthwellfoundation.org)

Save the Date

June 18, 2022

Wichita, KS

**MGA**  
**SNOWFLAKE**  
*shuffle 0.1K*

Registration details  
coming soon!

## MGA Virtual Youth Group to Host Authors at Upcoming Meeting

As you may be aware, the MGA established a virtual youth group late last summer. The group meets quarterly and offers children a safe space to live life fully with MG. On March 7th from 6-7 pm, the group will be joined by Evren and Kara Ayik, authors of *Extraordinary! A Book for Children with Rare Diseases*. Released in 2021, the book opens up conversation about identity, inclusion, and rare disease. Evren has been an advocate for acid sphingomyelinase deficiency (ASMD) and is currently attending California State University to become a special education teacher. Youth and their parents are both invited to tune into the group! To obtain the Zoom credentials, RSVP to [info@mgakc.org](mailto:info@mgakc.org).







# Re-thinking Possibilities

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# MG SUPPORT GROUPS

Area	Dates	Time	Location
Kansas City, MO	April 23rd	10-12pm	<b>TBD</b> RSVP info@mgakc.org or (816) 256-4100
KC Northland	March 10th	noon-1:30pm	<b>Primrose Retirement Center</b> RSVP info@mgakc.org or (816) 256-4100
Mid-Missouri	February 17th	6:30-7:30	<b>Virtual- Zoom</b> RSVP info@mgakc.org or (816) 256-4100
Springfield, MO	February 8th	6-8pm	<b>Virtual- Zoom</b> RSVP info@mgakc.org or (816) 256-4100
St. Louis	February 19th	10:00-11:30am	<b>Virtual- Zoom</b> RSVP info@mgakc.org or 816-256-4100
Wichita, KS	Date TBD	9:00-10:30am	<b>Location- TBD</b> RSVP Dana & Larry Paxson dkptiffany@gmail.com or (316) 269-9120
Young Friends of the MGA Group- Kansas City	March 1st	6pm	<b>Virtual- Zoom</b> RSVP meridithoconnor@mgakc.org
Young Friends of the MGA Group- STL	March 1st	6pm	<b>Virtual- Zoom</b> RSVP meridithoconnor@mgakc.org
Northwest, AR	March 13th	12:00-2:00pm	<b>Virtual- Zoom</b> RSVP Jan & Roger Huff jrhufl1@cox.net or (479) 790-3022
Topeka, KS	TBD	6-7:30pm	<b>Location- TBD</b> RSVP info@mgakc.org or 816-256-4100
Eastsiders Lunch Bunch	3rd Wednesday of the month	11am	<b>Location- Blue Springs Park</b> <b>2204 SW South Ave, Blue Springs, MO 64015</b> RSVP Carol Hunt carolhunt04@yahoo.com or 816-289-3523
Virtual Monthly Meet Up	3rd Monday of the month	6:30pm	Meets via Zoom RSVP info@mgakc.org or 816-256-4100
Virtual Youth Group	March 7th	6:00pm	Meets via Zoom RSVP info@mgakc.org or 816-256-4100

# Looking to connect with others in the generalized myasthenia gravis (gMG) community?



Education and support for  
**generalized myasthenia gravis**

Register for a free webinar  
or in-person event at the  
link below\*



Register at [AlexionMGEvents.com](https://AlexionMGEvents.com)

Based on the event you'd like to  
attend, you could receive information  
about one or more of the following:



Disease education  
from a physician



Stories from people  
living with gMG



Tips for managing  
symptoms

\*These events are open to gMG patients and caregivers in the United States.

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 Dale Shruben  
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**The Mission of the MGA**  
 The Myasthenia Gravis Association (MGA) is dedicated to improving the quality of life for those who are affected by this autoimmune, neuromuscular disease, through awareness, education and patient services.

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