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myasthenia gravis association
MGA
of the heartland

Featuring keynote speakers

Alexis Rodriguez & Glenda Thomas

Both Alexis and Glenda are patient leaders in the MG space and have great stories to share regarding their journey and advocacy work.



Q & A Panel moderated by

Mazen Dimachkie, MD, FAAN, FANA, University of Kansas Medical Center

Featuring

John Eatman, MD, Advent Health

Nathan McGraw, MD, St. Luke's Health System

Mamatha Pasnoor, MD, FAAN, University of Kansas Medical Center



Q & A Panel will be an opportunity to ask questions, hear about treatment updates and get the latest info on all things myasthenia gravis

*virtual attendees
will receive a
packet in
the mail*



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Myasthenia Gravis

63rd Annual Meeting & Educational Seminar
Empowerment through Advocacy & Education
Saturday October 21, 2023

CHECK-IN STARTS
AT 8:30AM CST
PROGRAM 9:15-12:15
BREAKFAST & LUNCH
INCLUDED

**IN PERSON MEETING
TAKES PLACE AT
ST. JOSEPH MEDICAL
CENTER, COMMUNITY
CENTER D, 1000
CARONDELET DRIVE,
KANSAS CITY, MO**

**VIRTUAL MEETING ON
ZOOM**

6th Annual Crown Town Trivia Night raises over \$95,000 for the MGA

Over 335 attendees gathered on Friday August 25, 2023 at GEHA Field at Arrowhead Stadium for the 6th Annual Crown Town Trivia Night. Guests enjoyed a VIP hour where they had photo ops with Super Bowl LVII backdrops and meeting 6 time pro bowler, Tamba Hali followed by a silent and live auctions, fund-a-need and some fierce trivia competition. In the end, a tiebreaker handed the University of Kansas Health System the win! A huge thank you to Mike Kellar, emcee, our presenting sponsors, Alexion, argenx and Heritage Biologics, our attendees, donors, volunteers and table hosts. As well as a thank you and shout out to the Kansas City Iowa State Alumni Club for their assistance in hosting the event.

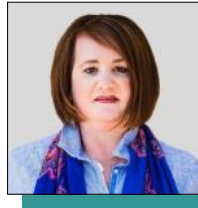


Flu before Boo

Did you know that the CDC recommends that you get your flu shot before Halloween? The flu vaccination is recommended for those over 6 months of age. If you have questions about the flu vaccination we recommend discussing with your medical team. As always we ask that if you are not feeling well that you refrain from attending a meeting in person.



A Message from Allison



Throughout the summer, you probably heard all the “era’s” talk as Taylor Swift took the country by storm with her tour. What followed were social media posts of people sharing what “era” they were in.

This brings me back to 2017 when I first started in my role at the Myasthenia Gravis Association (MGA). I will never forget in clinic one day at the University of Kansas Medical Center, Dr. Richard Barohn looking at

me and saying we were approaching the “golden era” for myasthenia gravis. I had no idea what this meant at the time.

But it’s clear to me now. This summer brought us the 5th FDA approved treatment for myasthenia gravis in 5 years. Prior to that the last FDA approved treatment for myasthenia gravis was in 1955 with pyridostigmine. Let us not stop there, there is more to come. There continue to be clinical trials and therapies in the pipeline. Research and more research. We continue to embark on a time of hope for each and every one of us.

It’s not lost on me the difficulties and challenges we face as we live with myasthenia gravis. But I can’t help but smile as I think about where we were and where we have come. We are truly living in the golden era.

Every day might not be good but there is good in every day!

PS. I started this post about a week before Taylor Swift took over Kansas City for the second time this year. Surely, you’ve heard.....

With hope & gratitude for whatever era you are in,

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

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McKenna Fulton

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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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@myastheniakc

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

Tips & Tricks for living with Myasthenia gravis—

We sought the advice of some in our community to share some of their tips and tricks. Question: What tips would you give somebody newly diagnosed with Myasthenia gravis?

1) Find an MG expert neurologist to treat you. "What's that," I asked? A neurologist who has worked or works with many MG patients and possibly one who also does research.

2) If the chosen neurologist doesn't pay attention, really "listen" (not just hear) or take time for to share EVERYTHING you need to say or ask, move on to another neurologist.

3) Advocating for yourself is the most important thing you can do for yourself. No one knows how you feel and/or what you are experiencing except you.

4) Reaching out to the Myasthenia Gravis Association is a great first step in order to start receiving information that will help you learn more about the disease. The organization also offers monthly meetings (small

and large group, in-person and virtual) and puts together yearly fundraisers involving the community where they will meet and get to know others who have MG. If they don't know the answer to something, they will find it and get back to them. They're a great resource!



Contributed by
Debbie Siemieniewski

"When I am struggling with MG, my swallowing goes downhill. Rather than cancelling out of dinner with friends, I explain my predicament. Then, I tell them I'll be there but won't be eating. I get my meal to go and then eat at home where I am more relaxed and not self-conscious. Then, I still get to see and visit friends, but not worry about struggling to eat in front of others."



Contributed by Janie Watts

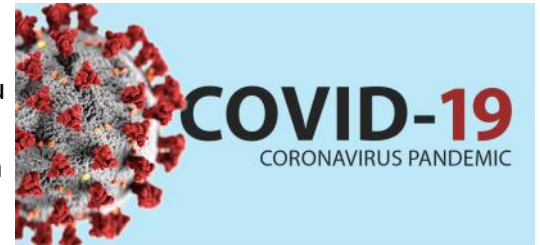


At Janssen, we are **relentlessly** focused, **actively** listening, and **expertly** helping to develop innovative solutions for those living with rare diseases, including generalized myasthenia gravis (gMG).



KU Neuromuscular Research team studying impact of COVID-19 on individuals with Myasthenia gravis

The University of Kansas Neuromuscular Research team invites you to participate in our survey to help them better understand the connection between Myasthenia Gravis (MG) and COVID-19. Given the ongoing pandemic, it is crucial to learn how MG patients are affected by COVID-19. Your insights are valuable and will contribute to their understanding. Your responses will remain confidential and anonymous. By sharing your experiences, you can help healthcare professionals and researchers improve support for MG patients during these challenging times.



Individuals diagnosed with MG and have had COVID-19 are eligible to complete this survey. The survey is a brief, multiple choice questionnaire regarding your MG history, vaccination status, COVID-19 severity, and how you were treated during the infection. To take the survey go to <https://redcap.kumc.edu/surveys/?s=4D4AJHFY7J73TNRR>



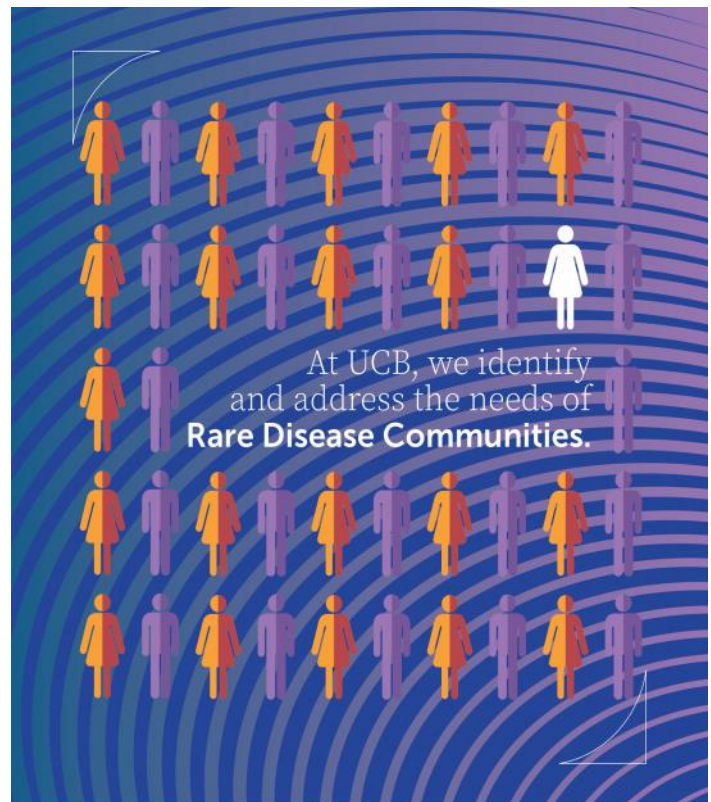
2023 marks the 40th Anniversary of the Orphan Drug Act

In 1983, the Orphan Drug Act was passed to increase the development of drugs to treat rare diseases. A rare disease is defined as affecting fewer than 200,000 people in the United States. Prior to 1983, only 38 drugs were approved to treat rare disease.

As part of the Orphan Drug Act, the Department of Health and Human Services and U.S. Food and Drug Administration (specifically the Office of Orphan Products Development) started working with stakeholders to generate interest in products associated with "orphan diseases." As part of the incentives for working on a therapy, over a seven-year period, pharmaceutical companies can receive market exclusivity for a drug approved to treat rare diseases as well as receive tax credits for research and development expenses.

By the numbers, 1 in 10 Americans have a rare disease. In addition, there are over 7,000 rare diseases of which only 700 have a drug approved for treatment. Over half living with rare diseases are children.

The Orphan Drug Act has not been without controversy however, it has paved the way to treatment options that were not previously available. As well as kept rare diseases in the forefront of research and development.



UCB is committed to supporting rare disease communities. We will seek out scientific innovations that have the greatest impact on the lives of people living with severe diseases.

To learn more, visit
www.ucb-usa.com
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 Inspired by patients.
Driven by science.

Anita's multi-year journey to diagnosis

I'm 47 years old. I have been having MG symptoms when I was about 4 years old, however I was not diagnosed until I was 45 years old. I went to doctor after doctor, specialist after specialist begging for help. In the end, MG was first suspected by an optometrist. He noticed my eyebrow was very arched and he said this often happens prior to ptosis. The muscle above the eyebrow is working hard to prevent the droop.

He then sent me to an ophthalmologist and my 41 year journey was over. I am triple AChR Seropositive. Currently, I am taking Pyridostigmine. I am doing "okay." MG is always filled with ups and downs. I think that is just a part of the disease course that one has to make peace with. My philosophy is to not go against the ups and downs, but to co-exist and work within the paradigm of the MG ups and downs.

By the time I was diagnosed I had been to 8 neurologists, 7 ophthalmologists, 1 neuro-ophthalmologist, hematologist, endocrinologist and immunologist. I passed every pulmonary function test. Nothing was found despite a very expensive overnight sleep study in a hospital setting. I passed every ophthalmologic evaluation and I was sent at various points to psychiatry. I went every time. I was open to anything that would help, but every psychiatrist was quick to realize I had a physiological problem, and they would encourage me to go to neurology etc. and try again.

I was given every diagnosis under the sun: When I was a juvenile - possible panic/anxiety attacks, smoke inhalation allergy - an overwhelmed kid basically or maybe an allergy. My complaints of difficulty breathing quickly turned into whether I was having sex and when I said I was not then I was asked about my home life etc.

As a young adult I was diagnosed with dry eyes for my blurry vision, I was also diagnosed with lateral strabismus and ocular migraines with or without aura.

My complaints of excessive fatigue were investigated, but nothing was found. At 23 years old my arms stopped working. But I thought it was due to a fall at my waitressing job. Doctors thought it was tendonitis due to overuse while waitressing. They then put me into PT and due to the fact my arms didn't work well, my records were often annotated that "patient does not put her full effort and says she "can't" do the exercises."



Anita Longoria shares her story with us. Have a story to share? Email info@mgakc.org

Have you ever been medically gaslit?

My complaints of nocturia and urinary incontinence went ignored. I had shortness of breath, difficulty breathing, and by my 30's I developed a very very deep cough. Almost all my life I woke up exhausted with booming head pain/headache and this got worse and worse. I had cognitive problems like processing issues, information retention (memory issues). I had brain fog, dizziness, lightheadedness...my list of symptoms go on and on.

The point is, I never had the "hallmark" symptoms. No ptosis, instead my eyebrow was arched. No double vision-except for a short period of time in 2016 and 2018. The third hallmark, muscle fatiguability well, I had it, but not in the way doctors expected.

Needless to say, over the years I suffered a countless amount of medical gaslighting that has left me deeply scarred. However, I am working hard to bring awareness to MG and to advocate for others with MG or struggling to get a diagnosis.

You can reach Anita at anita_longoria@yahoo.com

How long was your journey to diagnosis?



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Myasthenia Gravis Clinical Trial Updates

University of Kansas Medical Center

Janssen

ClinicalTrials.gov Identifier: NCT05265273

PI: Dr. Statland

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: Katie Lillig kjennens2@kumc.edu

Cabaletta Bio Clinicaltrials.gov identifier: NCT05451212

PI: Dr. Dimachkie

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

Viela Bio ClinicalTrials.gov identifier: NCT04524273

PI: Dr. Pasnoor

A 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

For more information contact:

Lilli Saavedra lsaavedra2@kumc.edu

Immunovant MG ClinicalTrials.gov Identifier: NCT05403541

PI: Dr. Pasnoor

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: Nick Staudenmier nstaudenmier@kumc.edu

Cartesian ClinicalTrials.gov Identifier: NCT04146051

PI: Dr. Pasnoor

Autologous T-Cells Expressing A Chimeric Antigen Receptor Directed To B-Cell Maturation Antigen (BCMA) In Patients With Generalized Myasthenia Gravis (MG)

Phase 2 Trial

For more information contact:

Ali Ciersdorff aciersdorff@kumc.edu

ALXN1720 – MG ClinicalTrials.gov Identifier: NCT

PI: Dr. Dimachkie

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:

Nick Staudenmier nstaudenmier@kumc.edu

Immunovant MG ClinicalTrials.gov Identifier: NCT05403541

PI: Dr. Pasnoor

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: Nick Staudenmier nstaudenmier@kumc.edu

At this time, there are no clinical trial updates at MU, SLU, or WashU.



Asaeli joins Board of Directors

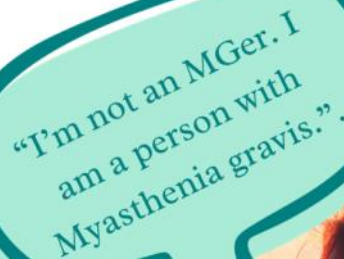
Longtime MGA volunteer, Keith Asaeli has joined the Board of Directors. Asaeli was named the Volunteer of the Year in 2022 after spending multiple years wearing many volunteer hats including on the committee for the MGA Triple Crown Showdown, an office volunteer and volunteer for trivia night. Asaeli became involved in the MGA as friend of former Executive Director, Danielle Kempker in 2016. Asaeli worked in IT for many years and recently pivoted his career to education working through the Belton Community School District. Asaeli and his family are active in their community, in their church and can often be found volunteering when not traveling or cheering on the San Francisco 49'ers, Giants or Warriors. Welcome Keith!



Person first language

All it takes is one search through Myasthenia gravis groups online to note that individuals with MG are often clumped into the term or phrase “Mgers”. You may also recall that last year we wrote a blog post about using **Person First Language**. As we continue to try to touch on this topic and lead an effort of change, we thought this would be a opportunity to provide a refresher.

Person first language emphasizes the person before the disability. Person first language was first written into the Americans with Disabilities Act in 1990. Much of the purpose of person first language is to help identify that individuals are people before their disability.



“I’m not an MGer. I am a person with Myasthenia gravis.”



Instead of saying, “I am an MGer.” say, “I am a individual with Myasthenia gravis.”

Instead of saying, “I’m getting together with some MGer’s.” say “I’m getting together with some individuals with myasthenia gravis.”

Instead of saying, “We are a bunch of MGer’s in this group.” say “We are a bunch of individuals who have Myasthenia gravis.”

Instead of saying, “Go ask the MGer’s” say “Go ask the individuals with Myasthenia gravis.”

Always remember you are a person before Myasthenia gravis!

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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to help spark awareness about vision impairment.



GO TO @MoreThanMG ON INSTAGRAM



TAP THE SPARKLES ICON



SELECT THE "SEE MG" FILTER



The Skinny on MGA Support Groups

Central Arkansas Group

Next Meeting– TBD

5:30-7:00 PM | Fletcher Library, 823 N. Buchanan St, Little Rock AR 72205

Open to individuals, caregivers & providers

RSVP: info@mgakc.org

Coffee Club– Kansas City

Next Meeting– November 2, 2023

Monthly | 9:30-10:30 AM | Another Broken Egg Café, 5358 W. 95th Street, Prairie Village

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

RSVP: info@mgakc.org

Coffee with a Coordinator– St. Louis

Next Meeting– October 26, 2023

Monthly | 10:30-11:30 AM | St. Louis Bread Company, 10221 Manchester Rd, Kirkwood, MO

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

RSVP: info@mgakc.org

Eastsiders Lunch Bunch

Next Meeting– November 1, 2023

1st Wednesday of the month | 11:30 AM-1:30 PM | Agape House 312 SW 19th Terrace Street, Blue Springs, MO

Light lunch provided | Open to individuals, caregivers & providers

Hosted by Carol Hunt & Raymond Hankins, Volunteer Support Group Leaders

RSVP to mckennafulton@mgakc.org

Greater Kansas City

Next Meeting— October 21, 2023 (Annual Meeting)

Quarterly on a Saturday | 10:00 AM-12:00 PM | Community Center D. at St. Joseph Medical Center, 1000 Carondelet Drive, Kansas City, MO

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

RSVP: mckennafulton@mgakc.org

Kansas City Northland

Next Meeting– November 9, 2023

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

RSVP: mckennafulton@mgakc.org

MG Pride Group

Next Meeting– October 10, 2023

Bi– Monthly on a Tuesday | 5:30-7:00 PM | Via Zoom

Open to individuals who identify as LGBTQ+ with MG, their allies and care partners

Hosted by Bryan Bosch, Volunteer Support Group Leader

RSVP: btbosch81@gmail.com

Mid-Missouri Group

Next Meeting– October 12, 2023

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 Jolliff, Volunteer Support Group Leader

RSVP: info@mgakc.org

The Skinny on MGA Support Groups

NW Arkansas Support Group

Next Meeting– January 2024

January-October, every other month on a Sunday | 2:30-4:30 PM | Springdale Public Library, 405 S. Pleasant Street, Springdale, AR

Open to individuals, caregivers & providers

Hosted by Roger & Jan Huff, Volunteer Support Group Leaders

RSVP not required, however; the Huff's can be reached at jrhuff1@cox.net

Springfield Support Group

Next Meeting– October 26, 2023

Quarterly on a Tuesday | 5:30-7:00 PM | East Sunshine Church of Christ, 3721 E. Sunshine St , Springfield, MO 65809

Open to individuals, caregivers & providers

RSVP: info@mgakc.org

St. Joseph Support Group

Next Meeting– November 12, 2023

2:00-3:30 PM | Rolling Hills Library; Community Room, 1912 N Belt Hwy, St. Joseph, MO 64506

Open to individuals, caregivers & providers

RSVP: donnasjmo@yahoo.com

St. Louis Support Group

Next Meeting– October 28, 2023

Quarterly on a Saturday | 10:00-11:30 AM | Glendale City Hall, Glendale MO

Light brunch provided | Open to individuals, caregivers & providers

RSVP: info@mgakc.org

Topeka Area Support Group

Next Meeting– November 9, 2023

Quarterly on a Thursday | 6-7:30 PM | Topeka & Shawnee County Library 1515 SW 10th Ave, Topeka, KS

Open to individuals, caregivers & providers

RSVP: mckennafulton@mgakc.org

Virtual Monthly Meetup

Next Meeting– October 23, 2023

4th Monday of the month | 6:30-7:30 PM via Zoom

Open to individuals, caregivers & providers

RSVP by registering for the webinar as posted

Wichita Support Group

Next Meeting– November 4, 2023

Quarterly on a Saturday | 11:00-1:00 PM |

Open to individuals caregivers & providers

Hosted by Dana & Larry Paxson, Volunteer Support Group Leaders

RSVP: dkptiffany@gmail.com

Young Friends of the MGA– Kansas City

Next meeting– December 12, 2023

Quarterly at various locations in Kansas City | 6:00-8:00 PM |

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

RSVP: allisonfoss@mgakc.org

Young Friends of the MGA– St. Louis

Next Meeting– TBD

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

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

RSVP: info@mgakc.org

Untold Stories

Life with Myasthenia Gravis



Now there is another way to hear from the myasthenia gravis (MG) community. You are invited to listen to **Untold Stories: Life with Myasthenia Gravis**, a special podcast series centered on the experiences of real people living with MG. In each episode, host Martine Hackett speaks with guests who will share their personal trials, tribulations, and triumphs from their MG journeys.



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

LISTEN NOW



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Virginia and Richard VonRueden

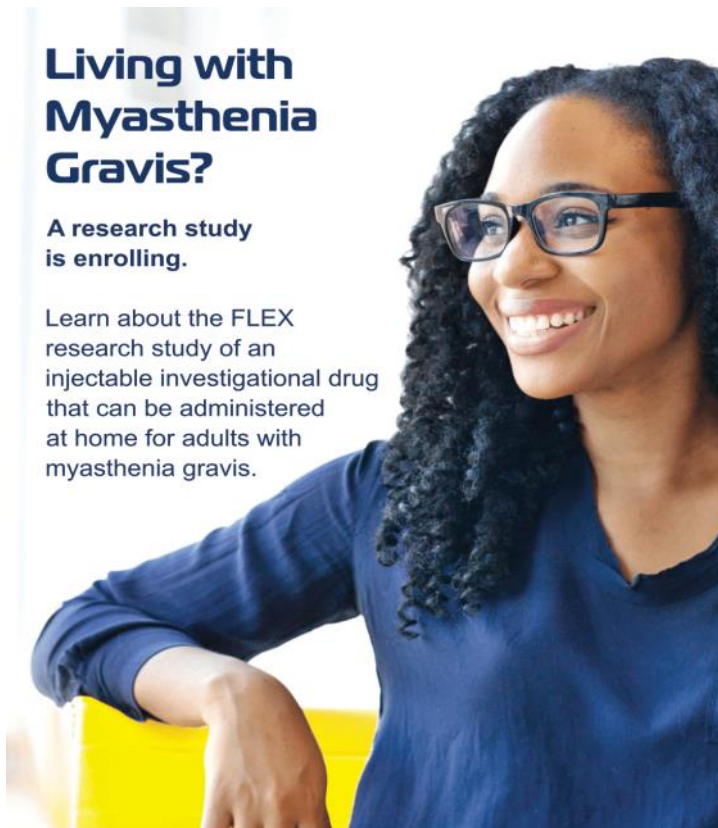


In August, Executive Director, Allison Foss joined Emily Stauffer and Dylan Simon from the Everylife for Rare Diseases Foundation at the National Conference for State Legislators in Indianapolis to share about the issues facing those with rare disease. This was an opportunity to connect and network with advocacy partners and industry from across the US. The Everylife Foundation will be presenting our October Virtual Monthly Meetup regarding STEP Therapy. Tune in on October 23rd to learn more about STEP Therapy and what you can do as a patient advocate.

Living with Myasthenia Gravis?

A research study is enrolling.

Learn about the FLEX research study of an injectable investigational drug that can be administered at home for adults with myasthenia gravis.



For more information, visit www.flexMGstudy.com

FLEX



Virtual Youth Group– We want your opinion!

We have hosted a Virtual Youth Group quarterly online for the past 2 years. We are trying to garner the best time for the group to meet as well as the preferences for delivery and concept. If you are a parent of a youth with myasthenia gravis, please send us a message with your preferences. info@mgakc.org



Become a 2023 Member of the MYASTHENIA GRAVIS ASSOCIATION

*Help fund the tools
to fight myasthenia
gravis!*



-CONSIDER BECOMING
A MEMBER TODAY-

*Your financial support
helps to provide*

- new patient packets
- onsite clinic partnerships with neuromuscular specialists
- support & programming at one of our 16 support groups
- education & awareness events
- research
- 1-1 consultations

*programming that is
100% free to patients*

*your support is appreciated
beyond measure*



Myasthenia gravis (MG) has thrown a wrench into the lives of many.

Together, we can equip patients with the appropriate tools and resources they need on their journeys with MG.

Help the MGA nail down support for myasthenia gravis patients by becoming a member today!

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

I want to support the MGA by becoming a 2023 member or making a contribution:

- \$25.00 Basic Membership
- \$63.00 63rd Anniversary Membership
- \$100.00 Sustaining Membership
- \$500.00 Patron Membership
- \$1,000.00 Lifetime Membership

\$ _____ 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

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.



If you would like to be removed from or added to our mailing list, or if you have/will have an address change, please send a note to:

Myasthenia Gravis Association
2340 E. Meyer Blvd.
Building 1, Suite 300A
Kansas City, MO 64132

- OR -

Call us at: (816)-256-4100
Email us at: info@mgakc.org