

Recap on the MGA’s 63rd Annual Meeting & Educational Seminar

On Saturday October 21, 2023, over 175 individuals gathered via in person at St. Joseph Medical Center in Kansas City as well as online for the 63rd Annual Meeting & Educational Seminar including participants from 7 countries.

We first heard from keynotes, Alexis Rodriguez and Glenda Thomas on their journeys with myasthenia gravis. Both Alexis and Glenda are active in their communities of Atlanta and Boston respectively, as well as in their state with advocacy efforts. Following the keynote was a Q & A Panel facilitated by Mazen Dimachkie, MD, FAAN, FANA, University of Kansas Health System, featuring John Eatman, MD, Advent Health, Nathan McGraw, MD St. Luke’s Hospital and Mamatha Pasnoor, MD, FAAN, University of Kansas Health System. The Q & A Panel allowed an opportunity for an open floor of questions brewing in the community and touched on topics such as new treatments for myasthenia gravis to vaccines to antibody types and clinical trials. At the conclusion of the meeting, awards were given to the Bryan Bosch, Volunteer of the Year, Donna Whittaker, Stackhouse Award and Lisa Sackuvich, the Diana Wilmoth Sunflower Award.

The MGA would like to thank its sponsors of the event, Alexion, argenx, Catalayst, Janssen, UCB, Immuno-variant, and Distinctive Meeting Group. The MGA would like to thank Promptcare, formerly ARJ Infusion Services which assisted 11 nurses participating to get CEU’s. We are also grateful for the volunteers who helped with registration and ensuring the meeting went off without a hitch! We look forward to seeing everybody again next year if not before!

63rd Annual Meeting & Educational Seminar Award Winners



Bryan Bosch
Volunteer of the Year



Donna Whittaker
Stackhouse Award



Lisa Sackuvich
Diana Wilmoth
Sunflower Award



Myasthenia Gravis

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

What is STEP Therapy?

In October we hosted the Everylife Foundation for Rare Diseases at our Virtual Monthly Meetup to help educate and share more about STEP Therapy. The Everylife Foundation along with Perri W. from the Young Adult Rare Representatives (YARR) provided a recap for us for our blog and newsletter in case you missed the session.

What is step therapy?

Step therapy is a process where insurers limit coverage for a drug until the patient tries one or more alternative, often less expensive, medications. This is known as a “fail first” process because patients must “fail” on the cheaper medication before they can obtain the drug their provider initially prescribed. While it can cut costs for insurers, step therapy requirements interrupt care, divert resources from patients, and complicate [\[DS1\]](#) medical decision-making.

Why is step therapy a HUGE problem?

Step therapy increases time demands for patients and providers alike, burdening health systems and worsening health outcomes. In each step, providers prescribe a new medication, liaise with insurance companies, and complete paperwork, taking time away from medical decision-making. Step therapy requirements also delay access to proper and timely care. These delays are especially burdensome for patients with rapidly progressive conditions or limited life expectancies and who have waited months or years to receive a diagnosis. Some patients are unable to complete the many required steps set out by their insurance, in effect “falling down the staircase”.

Startling facts about step therapy:

- Patients can be required to try medications they have already tried under prior insurances.
- Patients can be required to try medications that are not FDA-approved for their condition (i.e. “off-label” use).
- Nearly 1 in 5 patients are unable to receive treatment at all due to step therapy (Alliance for Patient Access).

So, what can be done to help patients?

Elected officials, clinicians, and patients are working together to support legislation that will limit step therapy’s reach for those who need it most. In some states, for example, passed legislation has created processes to appeal step therapy denials and exemption guidelines so patients can avoid step therapy in cases of medical need. Some regulations would also require guidelines for step therapy to follow evidence from peer-reviewed journals to ensure clinical merit. Additionally, the federal SAFE Step Act, if passed, would ensure that group health plans offer exceptions to step therapy in specified cases, including when delaying effective treatment would lead to irreversible consequences.

An example of state advocacy

During RDLA’s 2022 Massachusetts State Advocacy Day, attendees advocated for state-level rare disease policies that would improve step therapy practices, increase access to genetic counselors, and lower patient out-of-pocket expenses. A few months later, H 4929 unanimously passed, increasing transparency and timeliness for step therapy practices for Massachusetts residents. This is just one example of patient voices leading legislative action.

So, what can YOU do to advocate?

Encourage your state and federal representatives to support step therapy reform. You can learn about how to engage in state advocacy by accessing the Rare Disease Legislative Advocate’s State Advocacy Hub, linked [here](#). You can also learn more about the federal SAFE Step Act [here](#).

[\[DS1\]](#) This section is good, but focuses a little too much on step therapy. It is a great example to cite and should for sure stay included, but I would use more broader prior auth language as well since it goes beyond step therapy



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A Message from Allison



One term that I've picked up from social media post COVID-19 is glimmer. What is a glimmer you ask? A glimmer is to shine faintly or unsteadily. A slight sign of hope.

We are in the dead of winter in Kansas City. We got smacked with two snowstorms and frigid temperatures that have last nearly two weeks. Did you happen to see Andy Reid's frozen mustache in the Chiefs wild-

card game last week? So as I sit snuggled on my couch next to my pooch, I'm looking for some glimmers.

Let's face it, winter is not my most favorite time of year. The boots, the winter coats, the dry skin. Not to mention, my recycling container blew over on trash day and spewed recycling down my icy street that I was trying to pick up in the below zero temps. So yep, I'm trying to find some glimmers.

However when I sit and reflect, I can't help but notice some of the glimmers, a warm, cozy home to be able to stay put in, a rescue dog who keeps me on my toes, friends & family that check in often, friends that offer to help shovel my driveway, the pure opportunity to have down time to rest, get good sleep and eat home cooked meals. A real glimmer of this weather has just been the opportunity to reset for me. I can't remember the last time I was homebound for so many days, probably COVID-19.

While the days can be long this time of year. Life is short and I hope you're finding the glimmers around you. We also know that environmental changes can be hard when you have a rare disease and we want you to know we are here for you. We hope to connect with you soon.

With gratitude,

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

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- Page 14** Membership Donations

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



Welcome Kathryn Clemens

We have a new face at the MGA! We are thrilled to welcome Kathryn Clemens to our team as the Community Program Coordinator in St. Louis. Our St. Louis University Clinic with Dr. Ghazala Hayat is set to resume later in January.

Kathryn graduated from Missouri State University with a Bachelors in Education and a Masters in Literacy. Kathryn is currently switching gears from teaching to supporting her community differently, through MGA. She is looking forward to building relationships within the community and learning how to better support those diagnosed with MG. In her free time, Kathryn enjoys connecting with nature through drawing, gardening, needle work, and exploring with her family.



Please join us in welcoming Kathryn!

Lasagna Love serves up dishes for those in need

We recently came across a cool resource we wanted to share, Lasagna Love. An idea sparked through the pandemic to leave lasagnas on the porches of those in need of a meal became the creation of a nonprofit called Lasagna Love. Individuals who are in need of a meal due to illness or life event can sign up at www.lasagnalove.org. Once registered, a volunteer request is made for a meal to be delivered at no cost with no judgement to the individual. Lasagna Love strives to feed families, spread kindness and strengthen communities.



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).



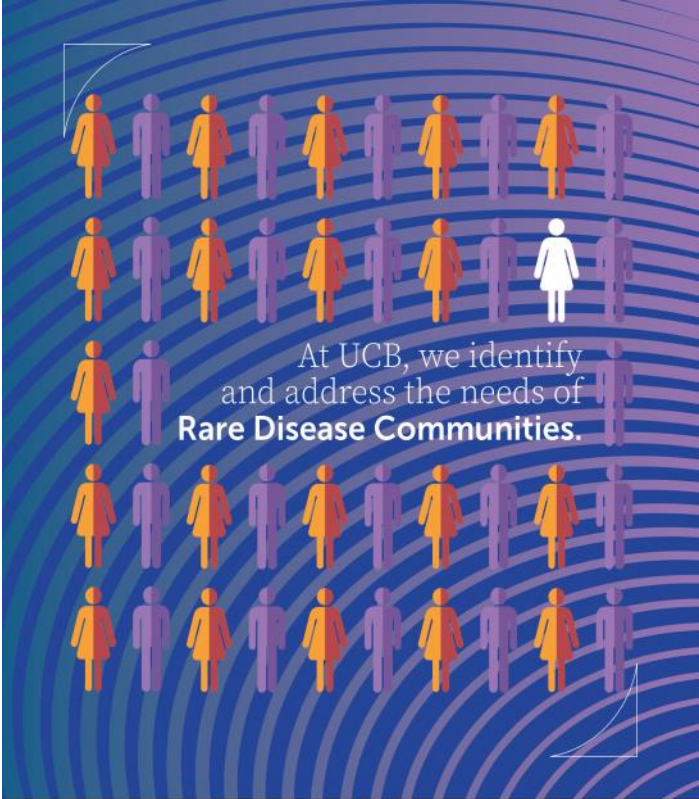


Members of the Greater Kansas City and Wichita Support Groups have a holiday tradition of playing BINGO! Members gathered in their respective cities on Saturday December 9th for some very spirited rounds of BINGO! In MGA BINGO, everybody leaves a winner!

Support Group Update



Exciting News! In 2024, we are conjoining a Lawrence/Topeka Support Group. We'll alternate between Lawrence and Topeka each quarter. **We'll meet February 8th in Lawrence! Stay tuned for more details.**



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.

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 Driven by science.



Rare Disease Day Symposium SECOND ANNUAL

Thursday, Feb. 29, 2024
EPNEC Auditorium
320 S. Euclid Avenue
St. Louis, MO 63110

Join us on Rare Day 2024 (Leap day!) for an event to talk about all things rare disease — advocacy and research, emerging science, networking and so much more.

Event agenda will include a continental breakfast, four speakers, a rare disease population parent and patient meet and greet, poster session, provided lunch and compelling abstract presentations.

For more information,
scan the QR code or visit
<https://wus.tl/rdd>



SPEAKERS



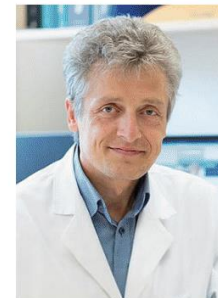
Kacie Craig, MEd
*Executive Director,
The Cute Syndrome
Foundation*



Sara Hamilton
*Clinic Manager,
Department of
Neurology*



Peter Marks, MD, PhD
*Director, Center for
Biologics Evaluation and
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Myasthenia Gravis Clinical Trial Updates

University of Kansas Medical Center

Janssen ClinicalTrials.gov Identifier: NCT05265273

PI: Dr. Farmakidis

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

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

ALXN1720 – MG ClinicalTrials.gov Identifier: NTC

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

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



The MuSK Myasthenia 1000 Study

This MuSK Myasthenia 1000 study seeks to collect a one time saliva sample from MuSK myasthenia gravis patients to help researchers identify genetic risk factors that cause this disease with hope to develop better treatments for patients. This study is funded by the National Institutes of Health's, Rare Disease Clinical Research Network for Myasthenia Gravis. This study is run at the George Washington University under the supervision of Henry Kaminski, MD, lead investigator of this project. Email musk1000@mfa.gwu.edu OR call 202-677-6205 for more information and to participate.

We thank you in advance for participating in this study.



A Rare Diseases
Clinical Research
Network Consortium





13th Annual MGA Triple Crown Showdown set for May 19, 2024

Save the date for the 13th Annual MGA Triple Crown Showdown 5K, Mile Mosey and Tot Trot on Sunday May 19, 2024 at 8am at Town Center Plaza in Leawood, KS!

We hope you'll join us for a fun morning of raising awareness of myasthenia gravis, mingling with others in the community and cheering on runners and walkers as they cross the finish line for a great cause!

Remember if you are living with myasthenia gravis, you register for no charge using the code VIP4MGA2024.

Don't live near Kansas City, virtually join us while being "Stuck in your stall." T-Shirts will be mailed to all "Stuck in your stall" participants following the event.

Want to make a greater impact, create your own fundraising page when you register.

For more information or to register head on over to www.mga5k.com

Executive Director attends Rare Disease Connect in Neurology in Berlin

Following Thanksgiving, our Executive Director, Allison Foss boarded a plane and headed to Berlin, Germany to take part in UCB Pharma's Rare Disease Connect in Neurology Conference.

Gathered in Berlin were 24 other patient organizations from across the globe including 14 other individuals with myasthenia gravis leading their organizations.

Allison spoke to health care providers and the group about what it is like to live having MuSK myasthenia gravis. As part of the presentation, Professor Amelia Evoli from Italy shared the distinguishing factors about MuSK+ individuals.

Pictured below are leaders from around the globe.



6th Annual Snowflake Shuffle set for June 22, 2024

The MGA will host its 6th Annual MGA Snowflake Shuffle 0.1K on Saturday June 22, 2024 at the Linwood Recreation Center in Wichita, KS. No running or walking is required! Just come out and connect with others impacted by myasthenia gravis. Visit with vendors and enjoy photo ops and lunch! We'll also have raffles you can take your chance at winning! Free for all individuals with myasthenia gravis. Registration coming soon!

MGA
SNOWFLAKE
SHUFFLE
0.1k *Run*

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The Skinny on MGA Support Groups

Central Arkansas Group

Next Meeting— February 8, 2024

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— February 1, 2024

Monthly | 9:30-10:30 AM | Billie's Grocery, 3614 W. 95th Street, Leawood, KS 66206

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

RSVP: info@mgakc.org

Coffee with a Coordinator— St. Louis

Next Meeting— January 31, 2024

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: kathrynclemens@mgakc.org

Eastsiders Lunch Bunch

Next Meeting— March 6, 2024

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— January 27, 2024 (Virtual)

Quarterly on a Saturday | 10:00 AM-11:30 AM

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

RSVP: mckennafulton@mgakc.org

Kansas City Northland

Next Meeting— March 14, 2024

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— February 13, 2024

Bi-Monthly on a Tuesday | 5:30-6:30 PM | Via Zoom

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

Hosted by Bryan Bosch, Volunteer Support Group Leader

RSVP: btbosch81@gmail.com

Mid-Missouri Group

Next Meeting— February 15, 2024

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: kathrynclemens@mgakc.org

The Skinny on MGA Support Groups

NW Arkansas Support Group

Next Meeting– March 23, 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– January 25, 2024

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– Spring 2024

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– January 27, 2024 (Virtual)

Quarterly on a Saturday | 10:00-11:30 AM |

Light brunch provided | Open to individuals, caregivers & providers

RSVP: kathrynclemens@mgakc.org

Lawrence/Topeka Area Support Group

Next Meeting– November 9, 2023

Quarterly on a Thursday, rotates between Lawrence and Topeka, KS| 6-7:30 PM | Lawrence Public Library, 707 Vermont Street, Lawrence, KS

Open to individuals, caregivers & providers

RSVP: mckennafulton@mgakc.org

Virtual Monthly Meetup

Next Meeting– January 22, 2024

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– Spring 2024

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– TBD

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

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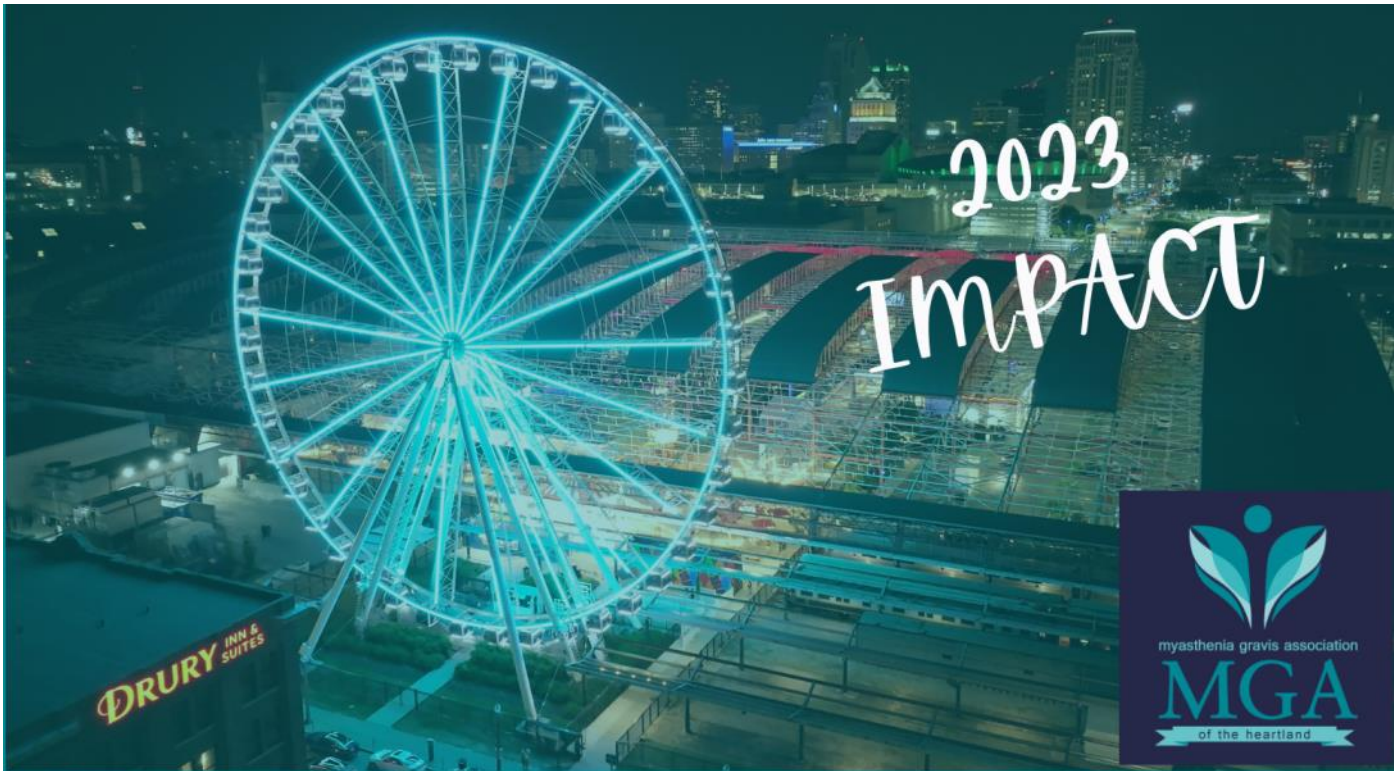
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Marilyn Barrett
In Memoriam
 Ronald Kohn given by Joanne Kohn




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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 

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<input type="checkbox"/>	\$100.00	Sustaining Membership
<input type="checkbox"/>	\$500.00	Patron Membership
<input type="checkbox"/>	\$1,000.00	Lifetime Membership

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Name _____

Address _____

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Phone _____

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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:

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Kansas City, MO 64132

- OR -

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Email us at: info@mgakc.org