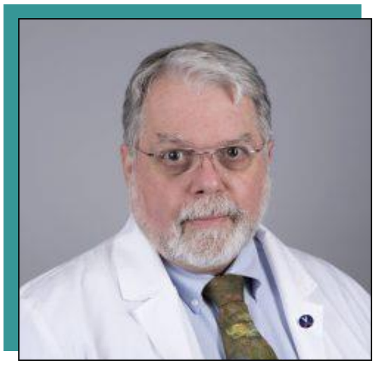
STRENGTH AND HOPE THROUGH
CONNECTIONS

myasthenia gravis association
MGA
of the heartland

MGA to Host Annual Meeting Mid-November

Mark your calendars for our 62nd Annual Meeting & Educational Seminar on Saturday, November 12th, 2022! For those who are not familiar, the Myasthenia Gravis Association (MGA) hosts this particular event every fall, providing stakeholders an opportunity to learn about organizational updates in addition to recognizing key partners that make our organization possible. Typically, there is an educational portion with a keynote speaker discussing a topic related to myasthenia gravis (MG).



We are excited to announce Dr. James "Chip" Howard will be speaking about the continued advances in MG treatments. Dr. Howard is Professor of Neurology, Medicine and Allied Health in the Department of Neurology at The University of North Carolina at Chapel Hill School of Medicine. He is the former *James F Howard Distinguished Professor of Neuromuscular Disease* and the prior Chief of the Neuromuscular Disorders Section at UNC. He received his medical degree from the Larner School of Medicine at the University of Vermont and his neurological training at the University of Virginia in Charlottesville. Dr. Howard is a practicing neurologist for over 43 years with a focus on myasthenia gravis and EMG. He currently directs the Myasthenia Gravis Clinical Trials and Translational Research Unit at UNC.

MYASTHENIA
GRAVIS

EMERGING THERAPEUTICS IN MYASTHENIA GRAVIS: HOPE FOR THE FUTURE

62ND ANNUAL MEETING & EDUCATIONAL SEMINAR

The topic for this year's presentation will be on emerging therapeutics in the treatment of myasthenia gravis. Over the last few years we have seen a drastic increase in the research and drug development of MG. In 2017, the FDA approved Soliris (eculizumab) as a treatment option for those living with generalized myasthenia gravis (gMG). Since then, the FDA has approved two additional drugs for gMG; Ultomiris (ravulizumab-cwvz) and Vyvgart, (efgartigimod). With numerous clinical trials taking place today, the MG community can most likely expect more treatment options on the horizon.

This is an incredibly exciting time for those living with myasthenia gravis and we want *everyone* to stay informed about the latest in this community. After hosting the meeting virtually for the last two years, we learned people were tuning in from all over the world! The educational will remain open to all those who wish to discover the latest advancements in myasthenia gravis. Thank you to our sponsors for making this event possible. To register for the event, head to our website at: www.mgakc.org

OUR GENEROUS SPONSORS:

argenx
Catalyst pharmaceuticals
ALEXION AstraZeneca Rare Disease
janssen
IMMUNOVANT
ucb Inspired by patients. Driven by science.
DMI
ARJ Infusion Services

The latest at the MYASTHENIA GRAVIS ASSOCIATION

10-year-old makes the most of her ocular MG

Lana Marie McManamor raised $2,105 for the MGA by selling hand-painted seashells! Lana was recently diagnosed with ocular myasthenia gravis but thankfully she has established a treatment plan that works for her.

Lana surpassed her $700.00 fundraising goal by a landslide! The local fire department and Knights of Columbus were some of her biggest fans, supporting her efforts with generous donations. Because of Lana's determination and creativity, she has created greater awareness around ocular MG and helped us all take one step closer to finding a cure for MG. Congratulations, Lana. We are so proud!

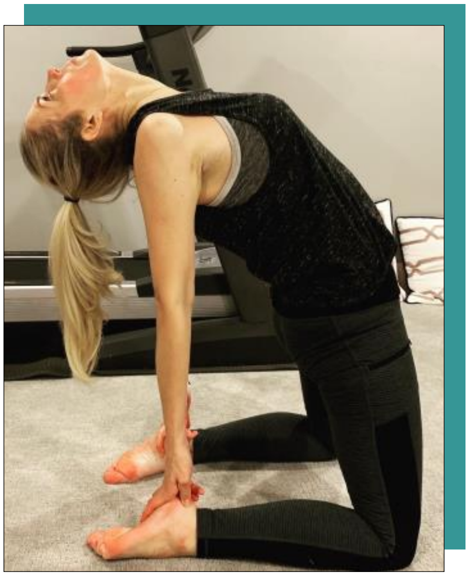
MGA community member reignites St. Joseph, MO group

Longtime MGA community member Donna Whittaker will be spearheading the reinstallation of our St. Joseph, MO support group come this November! Donna ran the St. Joseph group for many years and this year we are looking forward to having her lead the way for our friends in the St. Joseph area again. For details regarding this particular group, flip to our support group pages (12-13). Thanks for all your continued work in the MG community, Donna!

Breathing new life into the MGA

Catherine Singleton, our new Patient Care Specialist, recently hosted a virtual yoga session with our MGA youth group. During this session, we learned the true meaning of yoga and what it can offer. Read Catherine's perspective on the benefits of yoga, why it is practiced, and how it can be implemented in our daily living. --

Yoga is meant to be fun! Take the posture, Downward-Facing Dog for example; dogs don't compare themselves to one another and they don't care what their bodies look like. They just wag their tails as they feel joy and happiness. Yoga is the practice of accepting ourselves exactly as we are and sending love to every fiber of our being. Some days we may feel stronger than others, but yoga teaches us to acknowledge it, let it go, and give our bodies grace as we move and connect with our breath.



I love to practice Vinyasa Yoga. Vinyasa is the Sanskrit word, meaning, connection of postures, however; some people refer to it as Flow Yoga. In this practice you use an Ujjayi breath, which is a breath of fire that heats you up from the inside out. If you find yourself in a resting pose while still focusing on your breath for an entire class, this is still yoga! Yoga is about the connection of your mind, body, and breath. During yoga, you recognize your limitations and let go of them without judgment or comparisons. Like peeling back layers of an onion, yoga helps you connect with your most authentic self. Ultimately, it is about taking time to release preconceived notions like the stories we tell ourselves and the expectations we place on our lives.

myasthenia gravis association
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CONTACT
816-256-4100
info@mgakc.org

A Message from Meridith

Thank you to all those who had such nice things to say about the newsletter recently. The newsletter will have a fresh look that mirrors all the positive changes and advancements we have seen not only at the MGA, but within the myasthenia gravis community as a whole. The newsletter will continue to be comprised of informative articles as well as “friendly” pieces that invite our diverse group of readers to learn, engage, and connect.

No good thing is accomplished alone, and putting this newsletter together will always be a team effort. In the bulletin you may see guest writers, interviews, or even articles from other credible sources that are worth a read. Allison and I, as well as the rest of the staff have been tag-teaming it since day one, and I can assure you that their perspective and insight will always be incorporated within this publication.

I hope you enjoy the newsletter much as I have putting it together. Most importantly, my goal with this piece will always be for patients and community members alike to find strength and hope through connections.

With Gratitude,

Meridith O'Connor

Meridith O’Connor, MSW | St. Louis Program Coordinator
meridithoconnor@mgakc.org

Inside this Issue

Submissions

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

Follow Us

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https://www.facebook.com/mgakc

Noteworthy News

UCB currently researching multiple treatment options for MG

Global pharmaceutical company UCB has two, phase three studies that show promising findings for myasthenia gravis patients. Zilucoplan and rozanolixizumab are the two agents currently being researched. Although their mechanism of actions are different, both drugs are administered subcutaneously, potentially providing treatment options that offer flexibility for those living with MG. To learn more about these studies, head to https://clinicaltrials.gov/ or read this recent press release by UCB: https://www.ucb.com/stories-media/Press-Releases/article/UCB-presents-latest-data-from-generalized-myasthenia-gravis-portfolio-at-AANEM-meeting

ucb Inspired by patients.
Driven by science.

Survey findings released to further understand economic burden of MG patients

With the support of argenx, the Muscular Dystrophy Association recently published results from a survey developed to better understand the economic burden of myasthenia gravis patients and their families. According to the publication, claims-based studies have indicated high costs associated with MG, however; there is little evidence from the patient perspective. The goal behind this survey was not only to examine this burden from the people that experience it, but to utilize the findings to inform advocacy initiatives.

On page 6 you will find the poster that was distributed at the American Association of Neuromuscular & Electrodiagnostic Medicine Annual Meeting in September.

Nationwide launch for new mental health hotline

On July 16th, 2022, the 988 Suicide & Crisis Lifeline launched a new, 3-digit number for those who are experiencing a suicidal crisis or who are in need of mental health support. The public can call or text the hotline in which trained counselors will be on the other end to listen, assess, and provide resources, making mental health support more accessible for all. Community members will still be able to call the current Lifeline phone number (1-800-273-8255), yet; the 988 code offers those a fast, memorable number to utilize during time of need.

Xavier Becerra, Secretary of the federal Department of Health and Human Services, stated in a recent press briefing, “988 won't be a busy signal, and 988 won't put you on hold. You will get help." (Chatterjee, NPR, 2022). Not only confidential and free of charge, the 988 hotline is available twenty four hours a day, three hundred and sixty five days a year. Should you need an interpreter, call services are available in Spanish as well as 150 other languages.

988 SUICIDE & CRISIS HOTLINE
CALL , TEXT, CHAT
24/7

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

Picture your life in motion

Prescribing Information

GENERALIZED
MYASTHENIA
GRAVIS

doesn't get to make these plans

VYVGART is a first-of-its-kind, FDA-approved treatment for adults with anti-AChR antibody positive generalized myasthenia gravis (gMG)

AChR=acetylcholine receptor
Visit VYVGART.com/glossary for a glossary of terms.

Talk to your neurologist and **scan the QR code** to learn more or call **1-833-VYVGART (1-833-898-4278)**.

What is VYVGART™ (efgartigimod alfa-fcab)?

VYVGART is a prescription medicine used to treat a condition called generalized myasthenia gravis, which causes muscles to tire and weaken easily throughout the body, in adults who are positive for antibodies directed toward a protein called acetylcholine receptor (anti-AChR antibody positive).

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about VYVGART?

VYVGART may cause serious side effects, including:

- **Infection.** VYVGART may increase the risk of infection. In a clinical study, the most common infections were urinary tract and respiratory tract infections. More patients on VYVGART vs placebo had below normal levels for white blood cell counts, lymphocyte counts, and neutrophil counts. The majority of infections and blood side effects were mild to moderate in severity. Your health care provider should check you for infections before starting treatment, during treatment, and after treatment with VYVGART. Tell your health care provider if you have any history of infections. Tell your health care provider right away if you have signs or symptoms of an infection during treatment with VYVGART such as fever, chills, frequent and/or painful urination, cough, pain and blockage of nasal passages/sinus, wheezing, shortness of breath, fatigue, sore throat, excess phlegm, nasal discharge, back pain, and/or chest pain.
- **Undesirable immune reactions (hypersensitivity reactions).** VYVGART can cause the immune system to have undesirable reactions such as rashes, swelling under the skin, and shortness of breath. In clinical studies, the reactions were mild or moderate and occurred within 1 hour to 3 weeks of administration, and the reactions did not lead to VYVGART discontinuation. Your health care provider should monitor you during and after treatment and discontinue VYVGART if needed. Tell your health care provider immediately about any undesirable reactions.

Before taking VYVGART, tell your health care provider about all of your medical conditions, including if you:

- Have a history of infection or you think you have an infection
- Have received or are scheduled to receive a vaccine (immunization). Discuss with your health care provider whether you need to receive age-appropriate immunizations before initiation of a new treatment cycle with VYVGART. The use of vaccines during VYVGART treatment has not been studied, and the safety with live or live-attenuated vaccines is unknown. Administration of live or live-attenuated vaccines is not recommended during treatment with VYVGART.
- Are pregnant or plan to become pregnant and are breastfeeding or plan to breastfeed.

Tell your health care provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

What are the common side effects of VYVGART?

The most common side effects of VYVGART are respiratory tract infection, headache, and urinary tract infection.

These are not all the possible side effects of VYVGART. Call your doctor for medical advice about side effects. You may report side effects to the US Food and Drug Administration at 1-800-FDA-1088.

Please see the full Prescribing Information for VYVGART and talk to your doctor.

argenx

VYVGART is a registered trademark of argenx.

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MDA® Muscular Dystrophy Association

THE ECONOMIC BURDEN OF MYASTHENIA GRAVIS: A SURVEY OF AFFECTED PEOPLE AND THEIR FAMILIES

Yoder, K[1]; Gurunathan, S[2]; Phillips, G[3]; Perez, K[3]; Habib, A[4]; Narayanaswami, P[4]
[1]MDA [2]SG Science Writing Solutions [3]argenx pharmaceuticals [4]UC Irvine, [5]Beth Israel Deaconess Medical Center

CHALLENGE/ OPPORTUNITY

- Claims-based studies have demonstrated high costs associated with myasthenia gravis (MG)
- Evidence from the perspective of people with MG is limited

OBJECTIVE:

- To examine economic burden of MG by surveying people and their families living with the disease

KEY FINDINGS

- Total annual out-of-pocket costs (OOP): Mean, $15,961; median, $7,760
- Major drivers: Medications, medical care, health insurance (premium & deductible)
- People who received infusions paid higher OOP costs
- Disparities were noted by race/ethnicity, gender, income, and education
- Limitations: Respondents were self-selected; study lacked diversity (despite efforts to make survey broadly available)

SUMMARY/ NEXT STEPS

- The economic burden of MG is substantial, primarily driven by direct costs
- Study lacked diversity; broader outreach to people of color within the MG community is needed to better understand the MG burden in this population
- Results will be shared to educate the public and inform advocacy initiatives, with the goal of improving the lives of people with MG (manuscript in prep)

SURVEY DESIGN & DEMOGRAPHICS

A survey of the MG community to characterize economic burden of MG care


Developed with argenx MG Advocacy Leadership Council (MG-ALC)

Distributed online (Oct-Dec 2021)

1,058 respondents

815 (77%) people with MG

243 (23%) caregivers

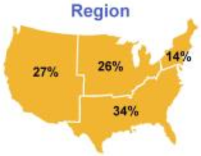
Themes
Direct & Indirect Costs
Employment & Losses
Financial Decisions
Quality of Life

Channels
E-mail
Facebook
Twitter
Instagram
Websites
Healthcare practitioners

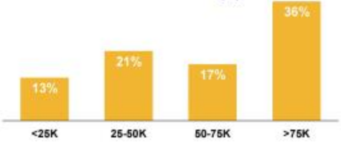
Advocacy Groups
Caregiver Action Network
Conquer MG
MDA
MGA
MGFA
MG Holistic Society
MG Patient & Caregiver Advocates
MG United
MGA WPA
The Merit Option

Respondents were personally living with MG or participated on behalf of someone with MG

Region



Annual Income ($)



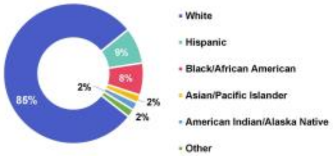
Gender

57% Female
42% Male
1% Other

Age

56 years (mean; SD 17)

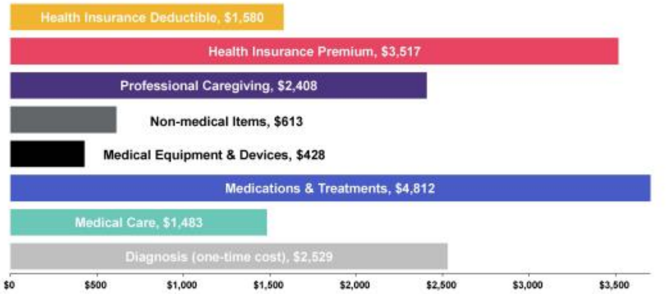
Race/ Ethnicity



ANNUAL OUT-OF-POCKET COSTS

Families paid an average of $15,962 total per year (median, $7,760)

Annual Costs Paid across MG Care Domains*



	Diagnosis	Medical Care	Medications & Treatments	Medical Equipment & Devices	Non-medical items	Caregiving	Insurance: Premium	Insurance: Deductible	TOTAL
n	957	935	977	968	880	1026	887	918	564
Mean (SD)	2,529 (3,073)	1,483 (5,604)	4,812 (10,079)	428 (906)	613 (1,374)	2,408 (7,886)	3,517 (5,742)	1,580 (1,879)	15,962 (21,372)
Median (Range)	1,942 (0-15,000)	917 (0-107,500)	2,288 (0-60,000)	414 (0-5,000)	607 (0-10,000)	513 (0-60,000)	2,959 (0-142,220)	1,249 (0-10,000)	7,760 (0-142,811)

*Among all who could provide a range and cost estimate

Cost Disparities

Higher OOP costs for select groups

People receiving infusions

Higher costs overall and in each domain

People of color

Female

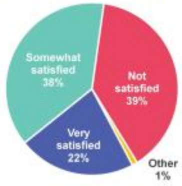
Lower income

Less educated

Higher costs in some domains

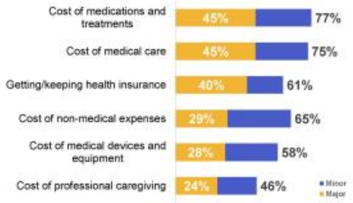
FINANCIAL HEALTH

Financial Health Satisfaction



39% NOT satisfied with their financial health

Top Economic Concerns



Concerns aligned with primary cost drivers

Financial Decisions

70% did at least one of the below to cover MG-related costs*

*Not shown: Received charity (17%), sold property (16%), delayed education (14%), sought rent/mortgage relief (9%), applied for grants/scholarships (9%), started a GoFundMe (7%)

Employment & Lost Wages

Work impacted:
- 75% of people with MG
- 79% of caregivers

Lost wages:
- 27% of people with MG
- 23% of caregivers

Disclosures: **KP and GP:** Employees of argenx (the study sponsor). **AH:** Research support: Alexion/AstraZeneca, argenx, UCB, Immunovant, Regeneron, CabalettaBio, VielaBio, Pfizer, Genentech. Honoraria: UCB, argenx, Alexion, Immunovant, Regeneron. PN (past 36 mos): Research payments (made to her institution): Astra-Zeneca/Alexion, Janssen/ Momenta, UCB, PCORI; Consultant: Astra-Zeneca/ Alexion, argenx, UCB, Janssen/Momenta. Honoraria: AANEM, AAN. Stock: Pfizer, Momenta, Dr Reddy's Laboratories, Viatris. Associate Editor of *Muscle and Nerve* and an unpaid member of the Board of Directors of AANEM.

Financial support provided by: argenx

Myasthenia Gravis Clinical Trial Updates

University of Kansas Medical Center

MOM-M281-011

PI: Dr. Farmakidis

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

Experimental: Nipocalimab Double-blind Placebo-controlled Phase:

Participants will receive nipocalimab intravenous (IV) infusions once every 2 weeks (q2w) up to 24 weeks during double-blind placebo-controlled phase.

Placebo Comparator: PlaceboDouble-blind Placebo-controlled Phase:

Participants will receive matching placebo of nipocalimab IV infusion q2w up to 24 weeks during double-blind placebo-controlled phase.

Open-label Extension (OLE) Phase:

Participants who complete the double-blind placebo-controlled phase will enter the OLE phase and continue to receive nipocalimab q2w IV infusion from OLE Day 1 to 24 weeks.

Participants who are stable on the q2w dosing regimen can be transitioned to a dosing regimen every 4 weeks (q4w) during OLE phase.

For more information contact:

Ali Ciersdorff aciersdorff@kumc.edu

Viela Bio

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

Experimental: Inebilizumab, (AChR-Ab+) MG

Participants will receive inebilizumab administered intravenously (IV) on Days 1, 15, and 183 of the randomized controlled period.

During the open-label period, participants will receive inebilizumab administered IV on Days 1 and 183.

Placebo Comparator: Placebo, (AChR-Ab+) MG

Participants will receive placebo administered IV on Days 1 and 15 and on Day 183 of the randomized controlled period.

During the open label period, participants will receive inebilizumab administered IV on Days 1, 15 and 183.

Experimental: Inebilizumab, (MuSK-Ab+) MG

Participants will receive inebilizumab administered IV on Days 1 and 15 of the randomized controlled period.

During the open-label period, participants will receive inebilizumab administered IV on Days 1 and 183

Placebo Comparator: Placebo, (MuSK-Ab+) MG

Participants will receive placebo administered IV on Days 1 and 15 of the randomized controlled period.

During the open label period, participants will receive inebilizumab administered IV on Days 1, 15 and 183

For more information contact:

Lilli Saavedra lsaavedra2@kumc.edu

Myasthenia Gravis Clinical Trial Updates

Janssen
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
Experimental: Nipocalimab

Participants aged 2 to less than [<] 18 years of age will receive nipocalimab once every two weeks for 24 weeks. After Week 24, all participants will have the option to enroll in long term extension (LTE).

Nipocalimab will be administered as an IV infusion

Total enrollment: 12 participants

For more information contact:
Katie Lillig kjennens2@kumc.edu

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

Making the Most of Telehealth Appointments

For our August virtual monthly meet-up, we focused on a very relevant topic: telehealth appointments. Chances are, you have had or someone you know has had an appointment with a healthcare provider utilizing some sort of technology. Whether it be a phone, email, or video chat, telehealth appointments are becoming the new normal.

It can sometimes feel overwhelming when you have so much to say to your care provider, but so little time. Generally speaking, an appointment is structured to learn if the patient has made any progress, to understand the current experience the patient is having, and to address concerns and goals. Below is an example of documentation you can bring to your telehealth appointment. Once you have a grasp around your physical symptoms, this will allow you to identify your lifestyle goals which in turn, will help you and your HCP make informed decisions about your treatment goals/considerations.

EXAMPLE

Overall, feeling well minus the unpredictable fatigue. I've noticed I am weaker in the afternoons and I typically need a 2 hour nap in the middle of the day. If I'm super tired or stressed, some of my other symptoms return like double vision. No more difficulty chewing/swallowing/breathing.

SYMPTOMS IMPROVED
-chewing/swallowing/breathing
-blurred vision
-general strength of muscles

SYMPTOMS STILL EXPERIENCING
-double vision in the evenings
-general fatigue, especially in the afternoons

NEW SYMPTOMS I'VE NOTICED
-gastrointestinal issues
-tingling on the right side of my arm

HELPS OR HINDERS MY MG?
-a nap in the afternoon
-the heat makes my MG worse

5th Annual Trivia Night Raises $75,000 for Myasthenia Gravis Association

by Allison Foss

For the last 5 years, the MGA has partnered with the Kansas City Iowa State Alumni Club to hold it's annual Trivia Night- Cy's Crown Town Trivia. Each year, it's grown a little bit more and the committee had to seek out a new location to accommodate the growth.

Planning the 5th Annual Cy's Crown Town Trivia started last spring and the group was quick to put down stakes at GEHA Field at Arrowhead Stadium for the August 26th event. While the group patiently waited for the NFL to release pre-season games, a huge sigh of relief was had when the Chiefs were slated to play the Green Bay Packers the night before at Arrowhead and trivia could go on as planned.

We had some special assistance in the planning; Jackie Carroll, who is on the MGA Board of Directors as well as an Iowa State Alumnae, holds the position of Director of Corporate Events at GEHA Field at Arrowhead Stadium. Without a doubt this contributed to the collaboration of one of the most memorable and epic events the MGA has held. Thank you, Jackie!

Over 300 guests game together, 157 of them VIP guests who enjoyed a private tour of the stadium prior to the festivities. Guests enjoyed cocktails, a popcorn bar, silent & live auctions, tacos & nachos, and 4 grueling rounds of trivia put together by Geeks Who Drink.

ALEXION
AstraZeneca Rare Disease
argenx
MONETA
DIEDERICH SIMMONS PEREZ TEAM
CarePartners
Specialty Infusion
Team Cocktail
IMMUNOVANT
janssen
ucb
CY'S CROWN TOWN TRIVIA NIGHT
HOWL AT THE MOON

This very spirited evening brought in a record breaking $75,000 for the MGA! The funds raised at Cy's Crown Town Trivia will ensure that we can continue to operate our clinics, support groups, be a resource hub, hold awareness events, and most of all, continue to do so at no cost to our patients.

We are so grateful for all who planned attended, supported, donated, gave right answers, gave the wrong answers, and just plain enjoyed themselves! Thank you for taking part in our historic evening!

The Skinny on MGA Support Groups

COVID-19 POLICY

COVID continues to plague many of our service areas, thus; the board has put a policy in place to protect the health and safety of our community. The following policy reflects our current decision-making process on in-person programming:

In areas where there is a high level of COVID-19 transmission per the CDC, in-person support group meetings will be suspended until the risk level returns to low or medium. The MGA will try to make decisions a week in advance when able. Please check the calendar online and your email for any updates.

Central Arkansas Group

Next Meeting– October 17th, 2022

5:30-7:00 PM | Courtyard by Marriott Little Rock West, 10900 Financial Centre Parkway, Little Rock AR 72211
Open to patients, caregivers & providers
RSVP: allison@mgakc.org

Coffee with a Coordinator– St. Louis

Next Meeting– October 27th. 2022

Monthly | 10:30-11:30 AM | Kaldi's Coffee Café, 120 Kirkwood Street, Kirkwood, MO
Coffee is Dutch treat | Open to patients, caregivers & providers
RSVP: meridithoconnor@mgakc.org

Eastsiders Lunch Bunch

Next Meeting– October 19th, 2022

3rd Wednesday of the month | 11:30 AM-1:30 PM | Agape House 312 SW 19th Terrace Street, Blue Springs, MO
Bring your own lunch unless otherwise noted | Open to patients, caregivers & providers
Hosted by Carol Hunt & Raymond Hankins, Volunteer Support Group Leaders
RSVP to info@mgakc.org

Greater Kansas City

Next Meeting— December 10th, 2022

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 patients, caregivers & providers
RSVP: info@mgakc.org

Kansas City Northland

Next Meeting– See you in January 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 patients, caregivers & providers
Hosted by Sandy Gardner, Volunteer Support Group Leader
RSVP: info@mgakc.org

Mid-Missouri Support Group

Next Meeting– November 3rd, 2022

Quarterly on a Thursday | 5:30-7:00 PM | Daniel Boone Regional Library, 100 W. Broadway, Columbia, MO
Open to patients, caregivers & providers
Hosted by Jonni Jolliff, Volunteer Support Group Leader
RSVP: allisonfoss@mgakc.org

NW Arkansas Support Group

Next Meeting– See you in January 2023!

January-October, every other month on a Sunday | 2:30-4:30 PM | Schmieding Center for Senior Health
Open to patients, 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

The Skinny on MGA Support Groups

Springfield Support Group

Next Meeting– October 18th, 2022

Quarterly on a Tuesday | 6:00-7:30 PM | Residence Inn by Marriott, 1303 SE. Kingsley, Springfield, MO
Open to patients, caregivers & providers
RSVP: allisonfoss@mgakc.org

St. Joseph Support Group

Next Meeting– November 5th, 2022

10:00-11:30 AM | Rolling Hills Library; Community Room, 1912 N Belt Hwy, St. Joseph, MO 64506
Open to patients, caregivers & providers
RSVP: donnasjmo@yahoo.com

St. Louis Support Group

Next Meeting– See you in 2023!

Quarterly on a Saturday | 10:00-11:30 AM | Glendale City Hall, Glendale MO
Light brunch provided | Open to patients, caregivers & providers
RSVP: meridithoconnor@mgakc.org

Topeka Area Support Group

Next Meeting– See you in 2023!

Quarterly on a Thursday | 5:30-7:00 PM | Topeka & Shawnee County Library 1515 SW 10th Ave, Topeka, KS
Open to patients, caregivers & providers
RSVP: info@mgakc.org

Virtual Monthly Meet Up

Next Meeting– October 17th, 2022

3rd Monday of the month | 6:30-7:30 PM via Zoom
Open to patients, caregivers & providers
RSVP by registering for the webinar

Virtual Youth Group

Next meeting– See you in 2023!

Meets quarterly on a Monday | 6:00 PM via Zoom
Open to youth who are diagnosed with myasthenia gravis and their parents
RSVP: allisonfoss@mgakc.org

Wichita Support Group

Next Meeting– November 5th, 2022

Quarterly on a Saturday | 11:00-1:00 PM | *new Location– Wichita Public Library, Alford Branch 3447 Meridian, Wichita, KS 67217
Open to patients, caregivers & providers
Hosted by Dana & Larry Paxson, Volunteer Support Group Leaders
RSVP: dkptiffany@gmail.com

Young Friends of the MGA– Kansas City

Next meeting– November 8th, 2022

Quarterly at various locations in Kansas City | 6:00-8:00 PM | Strang Hall, 7313 W 80th St., Overland park, KS
Open to patients who are generally in their 20s, 30s and 40s
RSVP: allisonfoss@mgakc.org

Young Friends of the MGA– St. Louis

Next Meeting– October 25th, 2022

Quarterly at various locations in St. Louis | 6:00-8:00 PM | LOCATION TBD
Open to patients who are generally in their 20s, 30s and 40s
RSVP: meridithoconnor@mgakc.org

Support the MGA

Your financial support enables the MGA to continue reaching patients impacted by myasthenia gravis every single day. We thank you for your continued support!

Amazon Smile

Did you know Amazon will donate .05% of the price of your eligible purchase to the MGA whenever you shop through Amazon Smile? Simply head to smile.amazon.com and select "Myasthenia Gravis Association of Kansas City" as your selected charity. If eligible, your purchase will help support our organization!

iGive.com

iGive.com is an online shopping portal where a portion of your purchase is donated to your favorite cause. iGive.com turns everyday shopping into donations for a worthy cause at no cost to shoppers or causes they support. Head to iGive.com to learn more!

Legacy Giving

There are multiple ways to make an impact at the MGA: include the MGA in your will or estate plan, become a member of the MGA, make a contribution toward the MGA, or volunteer!

Membership Donations

Glenn Bartlett
Cindy Disque
May Ellen Dowdy
Jimmie Harbour
Shannon Harris
Graham Naasz, DDS
Warren Swanson
April Zobel

Memorials

In Memory of Carol Leonard
Lisa Bureski
Mary Jo Campion
Alvin and Elizabeth Coleman
Christine DiPretore
Pauline and Marty Hunsberger
Cathy Kolongowski

In Memory of Monty Latham
Jennifer Garren
Carol and Lee Luck
Paine Tarwater & Bickers LLP

myasthenia gravis association
MGA
of the heartland

Rev. Bill Stackhouse Celebrates Milestone Birthday

We would like to wish a big happy birthday to Reverend Bill Stackhouse! Husband to founder of the MGA, Joan Stackhouse, Rev. Bill Stackhouse will celebrate his 100th birthday on October 23rd, 2022.

The Stackhouse family established the MGA in 1960 after Joan fell ill with the neuromuscular disease. Thanks to their innovation, determination, and passion, the MGA is able to continue their mission after 62 years.

Happy birthday, Bill! Thank you for having such a lasting impact on myasthenia gravis patients.

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

Making Connections

Education and support for
generalized myasthenia gravis

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

Register at **AlexiongMGEvents.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.

ALEXION

Consider becoming a 2022 Member of the
MYASTHENIA GRAVIS ASSOCIATION

Your financial support helps provide...

NEW PATIENT PACKETS
New Patient Packets (NPP) are sent directly to newly diagnosed MG patients, containing information and resources to support them as they start their journey with myasthenia gravis.

SUPPORT GROUPS
Support groups are a crucial part of our organization, allowing patients to connect and learn from one another. The MGA currently has 13 support groups across Kansas, Missouri, and NW Arkansas.

MG CLINICS
MG clinics are the key to establishing relationships with MG patients and providers. Our program coordinators manage 3 different clinics at various institutions including St. Louis University Hospital, St. Luke's Hospital, and University of Kansas Medical Center.

EDUCATION & AWARENESS EVENTS
The MGA hosts a variety of events that promote advocacy and awareness. Through these events, our organization is able to encourage community involvement, fund research, foster connections with patients, providers, and healthcare stakeholders.

LET YOUR LIGHT SHINE

You can make a difference in the lives of those with myasthenia gravis by becoming a member today!

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

I want to support the MGA by becoming a 2022 member or making a contribution:

☐ $25.00 Basic Membership
☐ $62.00 62nd 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____

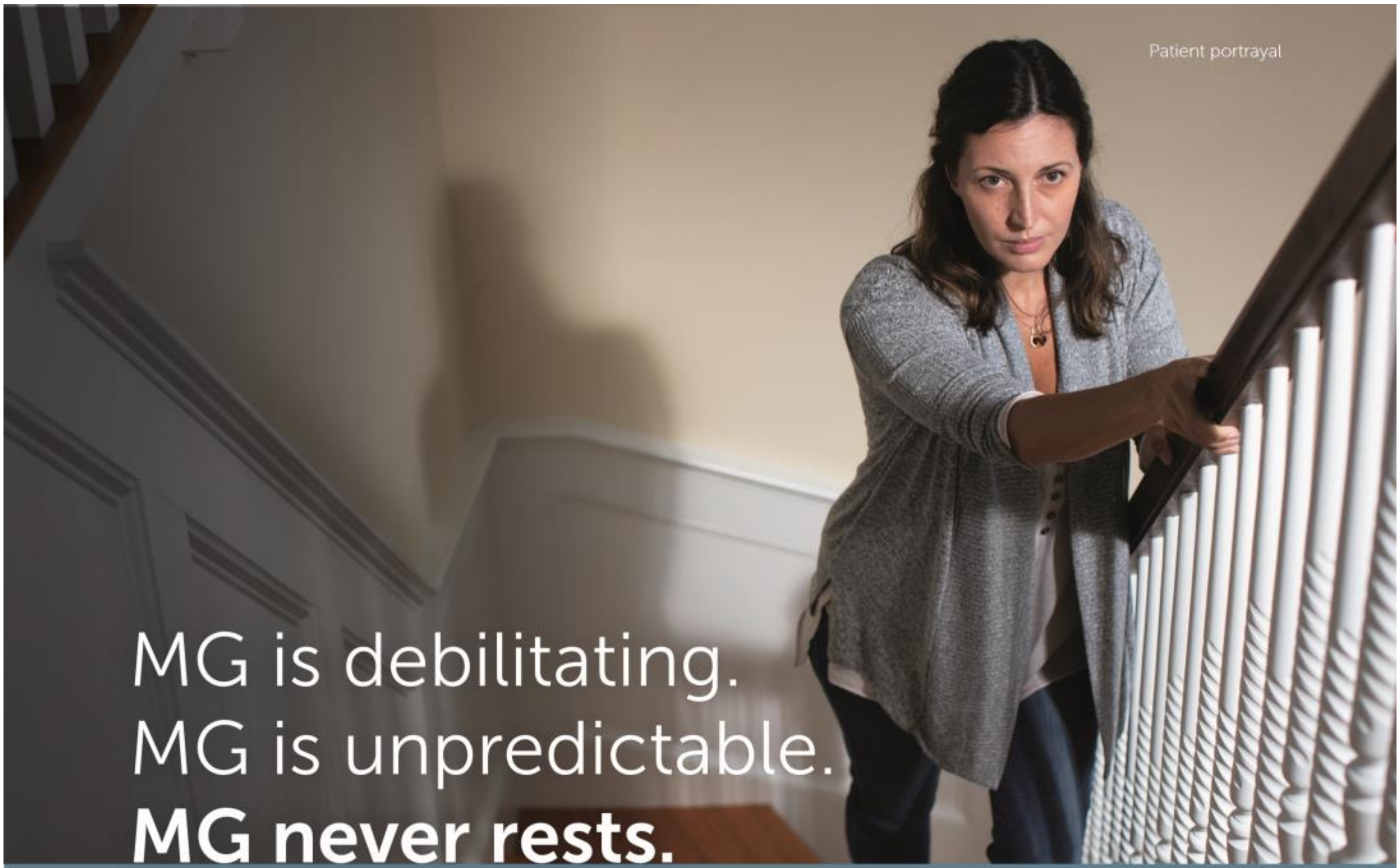
Phone ____

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


Patient portrayal

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

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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