

MGA and The Roasterie brews up the “Strength” blend

Rise and shine, the “Strength” blend is here! The MGA is excited to announce our partnership with The Roasterie, Kansas City’s own air-roasted coffee company. A portion of the profits from the Strength blend will go directly to the MGA to benefit our organization.

The Strength blend comes in 12oz. or 5lb bags and can be purchased either ground or whole bean. Shipping is free for orders over \$30. To buy the Strength blend, head to The Roasterie website at: <https://theroasterie.com/product/strength-blend/>. Grab your cup of joe and support the MGA today!

The MGA would also like to recognize Kelsey Coleman, designer of our very own Strength blend graphic and logo! Kelsey is an individual living with myasthenia gravis who recently graduated from the University of Kansas with a degree in visual communications and graphic design. To learn more about Kelsey’s work you can go to www.kelseytoon.com.

Thanks a ‘latte’ for supporting the MGA!



Yokota Foundation provides generous support to the MGA



In February 2021, the MGA was honored to receive a \$50,000 donation from the Yokota Foundation. Tina and John Warren, sister and brother-in-law of St. Louis member, Mark Macias, are central to the Yokota Foundation and the integral link in this extremely generous gift. Their contribution to the MGA has allowed us to continue to meet the needs of patients and families impacted by myasthenia gravis.

The MGA experienced a financial shift in 2020, when funding was discontinued through the United Way. Donations such as the one we received from the Yokota Foundation have been

imperative to maintaining our promise to our MGA family and we are incredibly grateful for our continued partnership with Tina, John, Mark, and his girlfriend, Greta Rice. Thank you Yokota Foundation for making our mission possible!

Potential new therapy treating myasthenia gravis heads to the FDA

(Article sourced from *Practical Neurology* 3/2/2021)



The Food and Drug Administration (FDA) has accepted a Biologics License Application for intravenous (IV) efgartigimod (ARGX-113; Argenx, Breda, Netherlands) for treatment of generalized myasthenia gravis (gMG). The FDA has set a 10-month review process with a Prescription Drug User Fee Act (PDUFA) target action date of December 17, 2021.

The BLA is supported by results from the pivotal phase 3 ADAPT trial ([NCT03669588](#)), in which 67% of individuals with gMG who were positive for antibodies to the acetylcholine receptor (antiAChR+) responded to efgartigimod treatment as measured by the Myasthenia Gravis Activities of Daily Living (MG-ADL) scale. In comparison, 30% of participants treated with placebo had improvements on the MG-ADL ($P < .0001$). Minimal symptom expression, defined as a score of 0 on MG-ADL, was achieved by 40% of participants treated with efgartigimod vs 11% of those treated with placebo. For the open-label extension trial of efgartigimod, 90% of participants opted to continue or start treatment with efgartigimod.

“This is an important milestone for Argenx in our transition to a commercial-stage company and brings us closer to our mission to reach patients living with gMG, a debilitating neuromuscular disease,” said Tim Van Hauwermeiren, chief executive officer of Argenx. “We look forward to closely collaborating with the FDA through the BLA review process and to potentially making our first medicine available.”

Argenx has a preapproval access (PAA) program in the US, which will allow eligible people living with gMG to receive treatment with efgartigimod.

Measuring tools for myasthenia gravis

Have you heard your Neurologist mention the MG-ADL scale or ask you to grade your daily activity based on the Myasthenia Gravis– Activities of Daily Living (MG-ADL) scale?

Say what? The MG-ADL scale was developed in 1999 as a tool for patients to be able to self report their daily activity outcomes. The scale captures 8 categories including ocular function, speech, swallowing, respiratory function, chewing, strength of proximal upper and lower extremities. The higher the score, the more serious condition the patient is in. Self reporting of symptoms is reported in the range of 0 (normal) to 3 (most severe). The entire scale is rated with points from 0-24. Going up or down on the scale by 2 or more points is considered clinical movement.

Not only is the MG-ADL scale used at clinic appointments by patients so their Neurologist can get a pulse on one's condition and current impact, the MG-ADL is used for clinical trials to reflect movement and/or progression due to therapy.

Next time you visit the Neurologist, ask to grade yourself on the MG-ADL.



A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

At the start of our 60th Annual *Virtual* Meeting in November 2020, we played the song, "Here Comes the Sun." I've thought of those words so many times since then, and I can honestly say I'm starting to feel it which makes me smile.

As more and more people become vaccinated and the number of COVID-19 cases decrease, enabling us to get back into the communities we serve, actually seeing and being amongst people, I think, here comes the sun.

As we continue to plan this year's events, including our upcoming 10th Annual MGA Triple Crown Showdown, our Snowflake Shuffle 0.1K in Wichita, our Cheers to 60 Years, and our 4th Annual Cy's Crown Town Trivia commences, I think, here comes the sun.

As one more drug navigates its way through the pipeline on a journey to FDA approval and as more clinical trials pop up for drugs in development, I think here comes the sun.

It's been a hard, long year. The pandemic has changed us all but here comes the sun my friends. As a wise person once told me, "keep your face to the sunshine and you never see the shadows."

Allison Foss, Executive Director
allisonfoss@mgakc.org



MGA Board of Directors & Staff

President:
LaDonna Diller
Vice President:
Michael Eagan
Secretary:
John Sand, MD
Treasurer:
Derek Haverkamp

Joe Bant
Brodie Beck
Brett Henson
Stephanie Hubers
Lisa Sackuvich, RN
Nancy Vinsant
John Wilkinson

Executive Director:
Allison Foss
Program Coordinators:
Meridith O'Connor, MSW
Tanya Renner

SAVE THE DATE

May 16th: 10th Annual MGA Triple Crown Showdown

June 12th: 3rd Annual MGA Snowflake Shuffle 0.1K

June 17th: Cheers to 60 Years Birthday Celebration

August 27th: 4th Annual Cy's Crown Town Trivia Night

October 9th: NW Arkansas Annual Conference

October 30th 61st Annual Meeting

November 13th: St. Louis Educational Forum

*Keep up to date with all our activities and events by checking out our MGA calendar at www.mgakc.org

Inside this Issue

Give STL Day	5
MGA Triple Crown Showdown	5
Virtual Monthly Meet Up	6
Clinic Updates	7
Spring Cleaning	8
Clinical Trials	9
Snowflake Shuffle 0.1K	10
Support Group Calendar	12
Cheers to 60 Years	14
Memorials & Memberships	15





ULTRA-RARE HOME INFUSION CARE

Compassionate MG care across the heartland

Our team helps manage your myasthenia gravis through in-home nursing care, streamlined deliveries, and valuable resources.

TOP SPEED!

Rely on
ARJ ReadyPack®
deliveries for
thoughtfully
organized infusion
supplies and
medication



SUPER COOL!



We secured over
\$7 million in
financial assistance
and lifestyle
resources for
patients last year.

LEVEL UP WITH ARJ

Score a free Level Up
retro fanny pack!

arjinfusion.com/LevelUpMGA
866-451-8804



TOTALLY RAD!

ARJ ranks
nationally in the
top 10% for home
infusion patient
satisfaction



MGA participates in Give STL Day this May

The MGA is excited to partake in 8th Annual Give STL Day on May 6, 2021! Give STL Day allows 24 hours of giving in the St. Louis community as initiated by the St. Louis Community Foundation to strengthen community giving and partnerships. Nonprofits are able to showcase their needs to be connected to donors, new and old, and support them in their mission.

Last year during the pandemic, 4.5 million dollars were raised during Give STL Day. More than 17 million dollars have been raised for St. Louis area nonprofits since 2014. Between now and May 6, 2021, donors can go to www.givestlday.org and select their charity of choice to donate to. Donors can also fundraise for preferred charities by selecting the charity and creating their own fundraising page.

The MGA appreciates the support in advance for Give St. Louis Day. Be on the lookout for ways to support the MGA on Give STL Day!

MGA TRIPLE CROWN SHOWDOWN SET FOR MAY 16, 2021



Just a few short weeks remain before the 10th Annual MGA Triple Crown Showdown 5K, Mile Mosey and Tot Trot takes place at Town Center Plaza in Leawood, KS on Sunday May 16, 2021 at 8 AM! The MGA Triple Crown Showdown is the MGA's largest awareness event and brings together patients, their families, friends and providers alike. Over the past 10 years, the MGA Triple Crown Showdown has raised over a quarter of a million dollars for the MGA which allows us to continue providing supports and services across Kansas, Missouri and NW Arkansas.

Participants can elect to participate in this year's event either in person or virtually. **Those with myasthenia gravis can attend for free using the code MGA21** when they register at www.mga5k.com. **Friends and family can register for 20% off using code MGAfamily21.** All discount codes expire on 5/13/2021. All participants will receive a t-shirt and swag bag!

You won't want to miss out on this great morning of raising awareness! Not only will participants enjoy race festivities, but there will be a chance to commune with interactive vendors from Town Center merchants as well as specialty pharmacies and pharmaceutical companies providing options for myasthenia gravis care. There will also be photo-ops with Instafun KC, breakfast, and our special kids area!

We will be taking COVID-19 precautions. Masks will be required in the start and finish area. Participants are asked to bring your own water bottle. And if you are ill, we ask that you stay home and refrain from coming. Thank you for supporting our MGA family!

Upcoming Virtual Monthly Meet Ups

Have you been participating in our Virtual Monthly Meet Ups? Each meet-up takes place on the **3rd Monday of every month** from **6:30-7:30 pm on Zoom**. We've enjoyed connecting with so many of you virtually and are excited about upcoming programming that we have on the calendar!

Monday May 17, 2021— Chair Yoga and Meditation lead by SarahU Coach

come and learn how you can relax and center yourself all from the comfort of your own chair.

Monday June 21, 2021— Anesthesia and MG

hear from Eric May, MD, a member of our Medical Advisory Committee on how to prepare for your upcoming surgery

Monday July 19, 2021— Clinical Trial Partnership Update

Monday August 16, 2021— Medical IDs & Emergencies

There will be an emergency planning discussion as well as a focus on the importance of updating your medical ID tags by Lauren's Hope



MGA slowly rolls out in-person support groups

You've likely noticed that we have begun our slow roll out of in-person support groups across the region. This decision has not come lightly and our Board of Directors has evaluated each group monthly to determine next steps as we continue to cope with the pandemic. If a group is meeting in your area and you are on our mailing list, you should either receive an email or a physical mailer about the meeting. You'll note that at this time we are requiring masks to be worn at meetings, conducting pre-health questionnaires and temperature checks, and practicing social distancing.

As Spring has emerged, we are working to host some groups outdoors when locations are available to do so. At this time we are also not providing any refreshments at meetings. We are anxious to see all of you and reconnect in person but want to take the safety precautions to do so! If you aren't yet ready to meet in person, be sure to connect with us at one of our virtual offerings!

A call out for any interested youth with myasthenia gravis to form a virtual support group



We recently learned that there was an interest for a youth group to be formed! We are working to piece together a youth group that would meet via Zoom quarterly. If you are interested in being a part of this group or know someone that might be interested, please email Allison Foss allisonfoss@mgakc.org to be put on the interest list. More information will be forthcoming to those who express interest!

SLU clinic officially resumes in person at new facility

7

Same mission, new location. Meredith O'Connor, St. Louis Program Coordinator, officially returned to SLU clinic at their brand new, state-of-the-art facility this past March. Specifically, Meredith conducts clinic hours at the Center for Specialized Medicine (CSM), a collection of outpatient offices for SLUCare's primary care providers and specialists.

According to St. Louis University Hospital, the \$550 million dollar investment features 800,000+ square feet with over 300 private patient rooms, an expansive trauma center, robust ICUs, and additional areas for further expansion.

"The facility is pretty exceptional," Meredith states. "The old office building we were in at the beginning of 2020 was outdated, crowded, and wasn't conducive to neuromuscular patient needs. The CSM is truly impressive and as soon as you walk in the building you know that you are going to receive comprehensive care."

The CSM neurology clinic is an open-concept with banks of computers throughout, adorned with spacious consultation rooms, flat-screen TVs, and designated office space for internal staff. The Center for Specialized Medicine is located on 1225 S Grand Blvd., right beside the new SSM Health Saint Louis University Hospital.



(photo retrieved from SSM Health Saint Louis University Hospital website; photo by Garrett Canducci.)

MG clinic activity in Kansas City



It's been some 20 years since clinic partnerships began in Kansas City at the University of Kansas Medical Center and St. Luke's Hospital with the MGA. In early 2020, Tanya Renner, Kansas City Program Coordinator, began working in the University of Kansas Clinic on Tuesday and Thursday mornings. COVID-19 snagged the schedule for about 12 weeks and when clinic resumed in June 2020, Tanya was off and running to meet with patients two mornings a week. In fact, 67 clinics were held and 364 patients were seen in 2020 at KU!

Our St. Luke's Clinic partnership experienced significant change as we headed into 2020 with the retirement of founding clinic volunteer, Diana Wilmoth. COVID-19 stalled the clinic partnership at St. Luke's for nearly 4 months. While St. Luke's has also undergone staffing changes, the MGA team is working consistently with St. Luke's to resume the clinic schedule on the 2nd Tuesday at the Country Club Plaza and the 4th Thursday at St. Luke's South.

The purpose of MG clinics is to assist with wrap-around services for patients and ensure access to resources, lend a listening ear, and offer a hand of support. The MGA is proud to offer these services and knows they are invaluable to patients and their families. If we have missed you in clinic due to COVID-19 scheduling and you need something, please do not hesitate to reach out.

Spring cleaning tips with MG



Did you catch our blog post about spring cleaning with MG? Activities of daily living can be incredibly difficult for myasthenia gravis patients. Doing the laundry, putting away the dishes, and picking up groceries are responsibilities I tend to get overwhelmed with because I get fatigued so easily. Living with this disease for more than 15 years now, you learn what works best for you and make adaptations accordingly. Check out my 5 tips to spring clean with MG below:

Break it Down

Divide your spring cleaning into stages. Instead of trying to tackle it all at once, try taking on one project a day.. For instance, I will say, “I am going to clean out my junk drawer today,” or, “I am going to clean out my refrigerator today and then my freezer tomorrow,” or, “I am going to give myself one hour to straighten up the kitchen cabinets.” Splitting up responsibilities by time or task can help you conserve the energy we all need to get through the rest of the day.

Less is More

I live in a small apartment with not a lot of storage. I have tried to embrace a minimalist approach to my house. For instance, I replaced all my glass plates with just 4 plastic plates. The plastic plates are super lightweight and are easier for me to put away. With 4 plates, I know I will have enough when a friend or two stops by for dinner, and the dishes won’t be piling up in the sink on my weak days with MG.

At your Service

So now you have all this stuff to give away, but donating it is a whole other task in itself. Do yourself a favor and find a local charity that comes to your door for curbside donations. Another option is selling your clothes. If you’re like me, you may have pieces in your closet that still have the tag on them. There are different apps now that allow you to post, sell, and ship your clothing to people across the country. In recent years I have used a service called Thredup—it’s an online consignment shop where you can buy or sell clothes, but they do all of the “dirty work” for you! Something like Thredup is a great service that allows you to conserve your energy and bonus, make a profit.

Spring Cleaning: 21st Century Edition

Cell phones are basically another appendage. My phone is my calendar, photo album, mailbox, network, wallet, etc...Whenever you are resting after a long day with MG, maybe hop on your phone and delete unused apps or random screenshots/pictures that are taking over your storage. Also, invest in one of those UV sanitizing lights for electronics. In the era of COVID-19, I’ll take all the protection I can get!

Bottle it Up

I have a really cool collection that I keep. Want to know what it is? Pill bottles. Okay, maybe not the coolest but you get the point. I have a whole bag of empty pill bottles that sit in a bag just waiting to be repurposed. Rip and shred the label after you finish taking your prescription and find ways to reuse the containers. I may start throwing extra change in one of them and keep it in my car for when I park at a meter so I’m not scrambling for quarters at the bottom of my purse when the time comes.

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

KUMC & WUSTL

Safety & Efficacy Study of Ravulizumab in Adults with Generalized Myasthenia Gravis	A Study to Test Efficacy and Safety of Rozanolixizumab in Adult Patients with Generalized Myasthenia Gravis
<p>The primary purpose of this study is to evaluate the safety and efficacy of ravulizumab for the treatment of participants with generalized myasthenia gravis (gMG). All investigative site personnel, sponsor staff, sponsor designees, staff directly associated with the conduct of the study, and all participants will be blinded to treatment assignments. This is a randomized, control trial in which the patient will receive either the investigational drug or placebo drug through an IV infusion. After the 26-week randomized-controlled period, participants will enter the open-label extension period of the study and receive ravulizumab.</p> <p>*The following trial is now closed for enrollment.</p> <p><i>Alexion Pharmaceuticals // ALXN1210-MG-306</i></p> <p>Physicians Dr. Mazen Dimachkie (KUMC) Dr. Muhammad Al-Lozi (WUSTL)</p> <p>Study Coordinator(s) KUMC: Katie Jennens // kjennens2@kumc.edu WUSTL: June Smith // smith.june@wustl.edu</p>	<p>The purpose of the MycarinGstudy is to demonstrate the clinical efficacy and to assess safety and tolerability of rozanolixizumab in patients with generalized myasthenia gravis (gMG). This is a randomized, control trial in which the patient will receive either the investigational drug or placebo through subcutaneous infusion. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, please contact the appropriate study coordinator based on location and physician of interest.</p> <p><i>UCB Biopharma S.P.R.L. // UCB MG0003</i></p> <p>Physicians Dr. Mazen Dimachkie (KUMC) Dr. Muhammad Al-Lozi (WUSTL)</p> <p>Study Coordinator(s) KUMC: Ali Ciersdorff // aciersdorff@kumc.edu WUSTL: June Smith // smith.june@wustl.edu</p>

SLU & KUMC

A Phase 3 Open-Label Study of Eculizumab in Pediatric Participants with Refractory Generalized Myasthenia Gravis (gMG)	Safety, Tolerability, and Efficacy of Zilucoplan in Subjects with Generalized Myasthenia Gravis
<p>The purpose of this study is to evaluate the efficacy, safety, pharmacokinetics, and pharmacodynamics of eculizumab in the treatment of pediatric refractory gMG based on change from Baseline in the Quantitative Myasthenia Gravis (QMG) score for disease severity. The study will consist of an up to 4-week Screening Period, 26-week Primary Evaluation Treatment Period, an additional (up to) to 208-week Extension Period, and an 8-week Safety Follow-up Period. Eculizumab will be administered through an intravenous (IV) infusion. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, please contact the appropriate study coordinator based on location and physician.</p> <p><i>Alexion Pharmaceuticals // ECU-MG-303</i></p> <p>Physician Dr. Jafar Kafaie</p> <p>Study Coordinator SLU: Jennifer Light // jennifer.light@health.slu.edu</p>	<p>The RAISE study is a multicenter, randomized, double-blind, placebo-controlled study to confirm the efficacy, safety, and tolerability of zilucoplan in subjects with generalized myasthenia gravis. Subjects will be randomized in a 1:1 ratio to receive daily SC doses of 0.3 mg/kg zilucoplan or placebo for 12 weeks. Eligibility and inclusion criteria can be found in the clinical trial study record. If interested in this study, please contact the appropriate study coordinator based on location and physician.</p> <p><i>Ra Pharmaceuticals // RA101495-02.301</i></p> <p>Physician Dr. Constantine Farmakidis</p> <p>Study Coordinator KUMC: Samantha Colgan // scolgan@kumc.edu</p>

3rd Annual MGA Snowflake Shuffle 0.1K slated for June

In celebration of June as Myasthenia Gravis Awareness month, the Myasthenia Gravis Association is hosting our 3rd Annual MGA Snowflake Shuffle 0.1K in Wichita, KS at the Linwood Recreation Center from 10:30-1pm.

An event like no other, the 0.1K is an “un-run” where you don’t have to run anywhere and everybody earns a medal! Attendees will enjoy lots of great raffles, fellowship, vendors and a boxed lunch. Patient registration is free but you **MUST** be registered to attend. Family and friends can register for just \$25 by going to www.mgakc.org and clicking events and scrolling down to the Snowflake Shuffle.



All participants registered by May 29, 2021 will receive a t-shirt. Hope to see you there!

Join an MGA Facebook Group



The MGA has set up Facebook groups for each of its support group areas with the assistance of the different support group leaders. If you go to the MGA Facebook page (www.facebook.com/mgakc) and click groups up at the top header, you will be redirected to the “groups” page where you will find Support Groups for Kansas City, Wichita, Topeka, NW Arkansas, Mid Missouri, Springfield, St. Louis and then Young Friends pages for Kansas City and St. Louis. Eastsiders Lunch Bunch and Northland Kansas City are captured in the Kansas city Facebook page.

In order to join these Facebook groups you must respond to the membership questions. Requests to join the groups without a response to the questions will not be accepted. The purpose of these Facebook groups is so members can connect locally with patients they may see in group and to get local recommendations and support. We hope you find these helpful in your journey with MG.



In celebration of Volunteer Appreciation Week April 18-24th, the MGA would like to say thank you to all our volunteers! From support group leaders, to our Board of Directors to our MGA Triple Crown Showdown Committee to office volunteers, and many others, we know we would not be able to accomplish what we do without their support! Thank you!

You May Be Able To Help Researchers Understand More About MG

See if you are eligible to join this two-year-long **MyRealWorld™ MG** study.



MyRealWorld™ MG is a global research project focused on understanding myasthenia gravis. The study relies on anonymous data recorded in the **MyRealWorld™ MG** app by adult patients diagnosed with MG. The more information the study collects, the more researchers may be able to understand MG and how it shapes the lives of people who live with it every day.

Why you may want to participate:

- You may be able to help increase understanding by joining this international study of myasthenia gravis.
- You may be able to help researchers and the medical community better understand the lives of people living with MG.
- You may learn more about MG through educational content provided via the app.
- Your participation may support the larger MG community by increasing knowledge about the patient experience.

Once you download the **MyRealWorld™ MG** app, you'll be asked to set up a medical profile where you can record information about your MG experience and management. You'll also receive regular surveys about additional diagnoses, symptoms and your daily-life activities. Over a two-year period, the **MyRealWorld™ MG** app aims to capture more real-world evidence data of MG's effects than ever before.

HOW TO JOIN THE STUDY.



This app is available in Spanish.



US-NON-20-00175 10/2020

MyRealWorld™ MG | myrealworld.com

Sponsored by
argenx

In partnership with
mg
MYASTHENIA GRAVIS

Delivered to you by
vitaccess

MG SUPPORT GROUPS

Area	Dates	Time	Location
Kansas City, MO	July 17th	10am-12:00pm	Location- St. Joseph Medical Center Auditorium 1000 Carondelet Drive, Kansas City, MO 64114 RSVP tanyarenner@mgakc.org or (816) 256-4100
KC Northland	April 29th	noon-1:30pm	RSVP for location RSVP tanyarenner@mgakc.org or (816) 256-4100
Mid-Missouri	May 20th	6:30-8pm	Location- COSMO Park- Harris Shelter 1615 Business Loop 70 W, Columbia, MO 65202 RSVP tanyarenner@mgakc.org or (816) 256-4100
Springfield, MO	July 29th	6-8pm	Location- TBD RSVP tanyarenner@mgakc.org or (816) 256-4100
St. Louis	May 22nd	10:00-11:30am	Location- Deer Creek Park 3200 N. Laclede Station Road, Maplewood, MO 63143 RSVP tanyarenner@mgakc.org or 816-256-4100
Wichita, KS	May 8th	1-3pm	Location- Linwood Park South 1901 S. Kansas Ave, Wichita, KS Contact: Dana or Larry Paxson for more info or to RSVP dkptiffany@gmail.com or (316) 269-9120
Young Friends of the MGA Group- Kansas City	August 3rd	6pm	Location- Virtual RSVP to Allison Foss allisonfoss@mgakc.org
Young Persons with MG Group-STL	July 27th	6pm	Location- Virtual RSVP to Meridith O'Connor meridithoconnor@mgakc.org
Northwest, AR	May 16th	2:30-4:30pm	Location-TBD Contact: Roger Huff for more info or to RSVP jruffl@cox.net or (479) 790-3022
Topeka, KS	June 3rd	6-8pm	Location- Lake Shawnee Shelter #1 3137 SE 29th Street, Topeka, KS 66605 RSVP tanyarenner@mgakc.org or 816-256-4100
Eastsiders Lunch Bunch	3rd Wednesday of the month	11am	Location- Blue Springs Park 2204 SW South Ave, Blue Springs, MO 64015 RSVP carolhunt04@yahoo.com
Virtual Monthly Meet Up	3rd Monday of the month	6:30pm	Meets via Zoom RSVP tanyarenner@mgakc.org or 816-256-4100



ENROLLMENT IS COMPLETE

Thanks to the response from the MG community,
the CHAMPION MG study for adults with
generalized myasthenia gravis
has completed enrollment.

MM/GL/ULT/0010

Cheers to 60 Years! The MGA turns 60, *again*

Let's try this again! The MGA is turning 60! Well actually 61, but that's reason to celebrate don't you think?! We'll be celebrating on Thursday June 17, 2021 at Lidia's in Kansas City with a reception from 5-8pm. Join us for hors d'oeuvres and to toast our accomplishments! **Due to COVID-19, you must RSVP to allisonfoss@mgakc.org by June 10, 2021 to attend.**

Did you know that your 60th birthday is your "Diamond" birthday? In celebration, we are going to be raffling a "Diamond" Trip! Purchase a raffle ticket and one lucky winner will have the opportunity to select one of the below trips for 2 adults for 7 nights or a travel credit of \$4000 through Love to Travel. Raffle tickets are \$100 a piece with no limited to how many you can purchase. The winner will be drawn at the close of the 60th birthday celebration on June 17th and does not need to be present to win. For additional information and to purchase a raffle ticket head on over to www.mgakc.org.



Trip Option #1 Honolulu, Hawaii

Visit the beautiful Hilton Village Wai-kiki Beach resort, This amazing spot is a beachfront location with stunning views of the Pacific Ocean and Honolulu coastline including diamondhead. You will also have easy access to the beach, pool & lagoon on property and restaurants, shopping & entertainment in downtown Honolulu.



Trip Option #2 La Romana, Dominican Republic

Island lovers paradise with beautiful greenery & crystal clear water, this diamond in the rough will provide an amazing beach getaway. Once you arrive on the island, you'll be iwsked away in private transfers to the resort. Be treated amazing food & drinks (which are all included) at the 11 different restaurants and 10 bars on property. Enjoy snorkeling off the pier or sliding down one of the large slides at the waterpark or grabbing a cocktail at the swim up bar.



Trip Option #3 St. Lucia

Explore the beautiful rainforest island of St Lucia with this amazing package. Royalton St Lucia is a family resort offering sweeping views of the beach, fine dining and opportunities to explore one of our favorite islands. Go for a hike on the Piton mountains, snorkel off Jalousie beach or get a mud bath tour at Sulphur Springs. This island has everything! With your stay at the Royalton, you will have an ocean view to go along with your all inclusive experience.



WAYS TO SUPPORT THE MGA



Membership Donations

Norma Thomas
Stephanie & Jeremy Hubers
Gary Gronseth, MD
Richard & Janice McGuire *in memory of Dr. Jacob McGuire*

Sally Crowley
C.C. & Karen Swarens
Robert & Sandy Collard
Cindy Disque
Robert & Barb Riley

Floyd & Marjorie Gentry
Lucy Stinson
Larry Deaton
Steve Kaysx
Heather Rogers



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 across the heartland.

In Memoriam

Judy Mulhair
The Kaufman Family
Valerie & Jeff Valdemarco
Campbell & Philbin Medical Associates

Donnie Mann
Melissa Ruminiski



Consider becoming a 2021 member!

PLEASE PRINT

Cut & enclose in envelope & mail to: ➔

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____ Email _____

I want to help support the MGA by becoming a 2021 member or making a contribution:

- ☐ \$ 25 Basic Membership
- ☐ \$ 61 (*61st Anniversary Membership*)
- ☐ \$ 100 Sustaining Membership
- ☐ \$ 500 Patron Membership
- ☐ \$ 1,000 Lifetime Membership
- ☐ \$ _____ In Memory of:
- ☐ \$ _____ In Honor of:

Thank You!

MGA
2340 E. Meyer Blvd.
Bldg. 1, Suite 300A
KCMO 64132

PLEASE CHECK:

- ☐ MG Patient
- ☐ Relative
- ☐ Friend

*Make checks payable to the
Myasthenia Gravis Association:
CONTRIBUTIONS may be tax
deductible*

DONATE
NOW

www.mgakc.org

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
www.mga5k.com

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 or 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
 E-mail us at: info@mgakc.org

CHECK OUT OUR NEW BLOG!
[HTTP://WWW.MGAKC.ORG](http://WWW.MGAKC.ORG)
 INSIGHTS & UPDATES
 BLOG

The MGA Digest



Myasthenia Gravis Association