

Strength and Hope Through CONNECTIONS

Volume 61 Issue I

Winter 2021

2020 Year in Review

2020 was a year like no other! Are you tired of hearing that? Words came into our lives like, "unprecedented, pandemic, masks, COVID-19, and Zoom." Are you wishing those words away? Despite all the chaos of 2020, the MGA achieved some great milestones and accomplishments that we are excited to recap with you!

JANUARY

- begins planning *Cheers to 60 Years* birthday celebration.
- launches *Cheers to 60 Years* video. (Head to our Youtube channel and check it out!)
- invites Dr. Govindarajan from the University of Missouri to speak to Springfield Support Group members about Soliris.
- establishes a clinic partnership with St. Louis University.
 Clinic takes place every Tuesday staffed by Meridith O'Connor, STL Program Coordinator.

FEBRUARY

- forms it's first Topeka Support Group with 17 patients in attendance!
- holds it's first Leap in and Learn Educational Forum in St. Louis on Rare Disease Day.

MARCH

- is represented by Wichita Support Group members at a health fair at Wichita State University.
- postpones the North Kansas City Support Group due to COVID-19. Shortly after, the MGA purchases a subscription to Zoom.
- suspends clinic visits at the University of Kansas, St. Luke's, and Saint Louis University due to COVID-19.

APRIL

- transfers to virtual programming. Tanya Renner, Kansas City Program Coordinator, organizes Zoom tutorials for patients and families.
- hosts 3 virtual support groups and 1st virtual board meeting.
- begins to shift the MGA Triple Crown Showdown to a virtual setting.
- postpones birthday celebration, 3rd Annual Snowflake Shuffle, and 4th Annual Cy's Crown Town Trivia Night.







MAY

raises more than \$38,000 for the virtual Triple Crown Showdown. A total of 337 participants were in attendance, all across the U.S. including Kansas, Texas, Colorado, and Washington!

JUNE

- rolls out new program, *Virtual Monthly Meet Up.* The virtual support group meets every 3rd Monday of the month from 6:30-7:30 pm.
- obtains a proclamation in Missouri, declaring it Myasthenia Gravis Awareness Month.
- celebrates MG Awareness Month with patients, families, and providers by participating in activities through an interactive awareness calendar.
- resumes clinic at the University of Kansas Medical Center.

JULY

- resumes clinic at St. Luke's Hospital on the Plaza in Kansas City and in Overland Park.
- rolls out new database in Salesforce for staff.
- provides patients, families, and providers with updates on COVID-19 with presentation by Dr. Fred Plapp.

AUGUST

- raises more than \$2,500 in a Facebook fundraiser for the Cy's Crown Town Trivia Night benefit which was cancelled for the year.
- invites patients and families to Aging and MG presentation by Dr. Jafar Kafaie of St. Louis University.









SEPTEMBER

- hosts 2nd joint virtual happy hour with the Young Friends of MGA KC & STL groups via Zoom.
- conducts Virtual Monthly Meet Up with presentation focused on MG Clinical Trials.

OCTOBER

- hosts the 2nd Annual Reel in MG Fishing Derby alongside the Warren & Macias families. 80
 attendees enjoyed a beautiful day socially distanced around the pond and competed for
 the largest catch!
- facilitates the Eastsiders Lunch Bunch to kick off their first group luncheon at Blue Springs Park.

NOVEMBER

 celebrates the 60th Annual Meeting virtually with 105 attendees participating, learning about mental health and self-care as well as getting a COVID-19 update.

DECEMBER

• makes contributions to MG research at the University of Kansas Medical Center, the University of Missouri, and St. Louis University.

A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

If you've just finished reading the first two pages of our newsletter, you've seen we had quite a year! The pandemic may have slowed down our in-person meetings, awareness activities, and fundraisers but we can all pat ourselves on the back for what we achieved and accomplished in 2020!

Whether you joined us via Zoom, saw staff in one of our clinics, gathered with us in person before COVID-19, ran virtually for the MGA Triple Crown Showdown, or got out your fishing pole for our Reel in MG Fishing Derby, we are so grateful that you were a part of our 60th year!

We've got lots of great programming in the works for 2021 and will be evaluating each support group area individually and on a case-by-case basis as the pandemic carries on. Our hope is that by the end of 2021 we will be back to all in-person groups and clinics as well as continuing to offer virtual programming to those who prefer connecting online.



I said this last newsletter, but the mission of the MGA is to work to improve the lives of those impacted by myasthenia gravis. That remains the same, pandemic or not. Have an idea or have a need? Please reach out! We'd love to hear from you!

Allison Foss, Executive Director allisonfoss@mgakc.org

MGA Board of Directors & Staff

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Tanya Renner

Plapp joins Medical Advisory Committee



We are excited to announce that Fred Plapp, MD, Medical Director of Laboratory Medicine, Vice Chair for Clinical Affairs and Clinical Professor in the Department of Pathology at the University of Kansas Medical Center, has joined our Medical Advisory Committee. If you've ever received a plasmapheresis treatment at the University of Kansas Medical Center you'll definitely recognize Dr. Plapp as he is one of the doctors overseeing inpatient treatments.

Dr. Plapp co-founded ClinLab Navigator, LLC and created the website, <u>ClinLabNavigator.com</u>, a comprehensive resource for healthcare professionals containing more than 900 laboratory test interpretations and guidelines. Welcome, Dr. Plapp!

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Follow Us







ARJ INFUSION SERVICES

COOD VIBES

PARE SARE

ARPs compassionate clinicians and care specialists help manage your myasthenia gravis through nursing care, streamlined deliveries, and valuable resources.

Sole Bull

Patients rely on ARJ ReadyPack^e shipments for thoughtfully organized infusion supplies and medication



We secured over \$6.5 million in financial assistance and lifestyle resources for patients and families last year



specialary infusion Free ARJ Level Up Fanny Pack!

arjinfusion.com/LevelUpMGA



MEMBERS OF THE MAC ISSUE STATEMENT REGARDING COVID-19 VACCINATION

Prior to the close of 2020, the FDA approved two vaccinations for COVID-19.

The MGA has compiled COVID-19 resources on our homepage in addition to releasing a statement in collaboration with several members of our Medical Advisory Committee. You can find the statement below. As always, be sure to discuss your specific medical situation with your medical team to determine what's best for you.



THE MYASTHENIA GRAVIS ASSOCIATION MGA MEDICAL ADVISORY COMMITTEE FEEDBACK REGARDING COVID-19 VACCINE AND MG

Dear Community Members of the MGA,

The following responses are meant for patients over the age of 16 or 18, dependent upon the Pfizer or Moderna type of vaccine.

As of December 18th, 2020:

- While there are some unknowns, the MGA Medical Advisory Committee (MAC) believes that a COVID-19 vaccine is generally a good idea for those living with myasthenia gravis (MG), immunosuppressed or not. There appears to be no known MG-specific contraindication to the novel mRNA-based COVID-19 vaccines.
- If you are given the option to choose a vaccine, we suggest getting the vaccine with
 the highest rate of protection. If you are not given a choice, we encourage getting one
 of the COVID-19 vaccines currently offered as we believe the benefits appear to
 outweigh the risks. The published data from the phase 1 preclinical studies for both
 vaccines (Pfizer-BioNTech & Moderna) suggests good safety and good tolerability.
- A concern for MG patients is that immunosuppressant drugs can reduce the
 effectiveness of the vaccine in generating an immune response against the virus that
 causes COVID19. Therefore, getting vaccinated while on lower doses of
 immunosuppressant drugs may be more effective. Nevertheless, if this is not possible
 due to ongoing MG treatment, immunization is still recommended.
- Should you have personal concerns drug allergies or other severe allergies or conditions that concern you, the MAC asks that you please consult with your doctor for a detailed risk-and-benefit discussion before receiving the COVID-19 vaccine.

In the future, we may have better validated antibody tests that help us determine who is protected and who could benefit from a booster shot. The above statement may change as other COVID-19 vaccines get introduced.

The medical advisory committee of the MGA is committed to supporting patients with myasthenia gravis. The following members of the committee have reviewed and approved this document:



We asked the neuromuscular team at the University of Kansas to provide an update of the current clinical trials involving MG. As you may recall, 2020 was a busy year of clinical trials and potential drug developments! The following is an update provided by Constantine Farmakidis, MD, Neuromuscular Division, University of Kansas Medical Center, cfarmakidis@kumc.edu.



ONGOING STUDIES

for more information about these clinical trials, contact Samantha Colgan, Research Coordinator, Department of Neurology at 913-945-9938 or scolgan@kumc.edu

A Phase 3 Clinical Trial of Rozanolixizumab in Adult Patients with Myasthenia Gravis (Clinicaltrials.gov study ID: NCT03971422)

Rozanolixizumab is a monoclonal antibody drug that does not yet have FDA approval for medical use. This drug binds to the neonatal Fc receptor and interferes with successful recycling of IgG antibodies. This aims to knock down the level of IgG antibodies including myasthenia graviscausing IgG antibodies. Rozanolixizumab is given though a self-administered injection into the fat tissue underneath the skin (subcutaneous injection).

This is a phase 3 clinical trial, which is the last phase of new drug development prior to possible FDA approval. This also effectively means that the drug has been previously successfully vetted for safety and tolerability in a previous phase 2 study (https://pubmed.ncbi.nlm.nih.gov/33219142/ published November 2020).

This ongoing phase 3 clinical trial has three treatment groups: lower dose of the drug, higher dose of the drug and placebo. As is typical for phase 3 clinical trials, along with a placebo group, there is random assignment of participants to a treatment group and blinding of patients and investigators to minimize the risk of bias. (Status: recruiting AChR and MuSK antibody patients)

A Phase 3 Clinical trial of Zilucoplan in Myasthenia Gravis (Clinicaltrials.gov study ID: NCT04115293)

Zilucoplan is another novel agent that is under clinical investigation and is not FDA approved for clinical practice. The drug's mechanism of action is terminal complement inhibition, which is the same as for eculizumab (Soliris). An important distinction between zilucoplan and eculizumab is that zilucoplan is self-administered through daily injections into the fat tissue under the skin (subcutaneous injections), while eculizumab is given through intravenous infusions every 2 weeks.

The complement system is a component of the human immune system that increases the effectiveness of antibodies in clearing bacterial invaders and particularly encapsulated bacteria. In fact, for eculizumab (the related drug to zilucoplan) there is a known increase in risk of meningococcal infection including meningitis from this bacterium. It is for this reason that study participants in the zilucoplan study must receive the 2 meningococcal vaccines prior to receiving study drug.

Again, as is typical for phase 3 clinical trials, there is a placebo group, random assignment of participants to a study treatment group and blinding of patients and study staff to minimize the risk of bias. (Status: recruiting AChR antibody patients)

ONGOING STUDIES (Continued)

A Phase 3 Clinical Trial of Inebilizumab in Myasthenia Gravis (Clinicaltrials.gov study ID: NCT04524273)

Inebilizumab is an FDA-approved medication for the treatment of a condition related to multiple sclerosis and known as neuromyelitis optica. The drug is approved to be started through 2 intravenous infusions, 2 weeks apart, with maintenance doses required once every 6 months thereafter. Inebilizumab is a monoclonal antibody drug designed to 1) bind cell surface markers specific to B-lymphocyte cells, 2) damage these cells that normally produce antibodies and 3) suppress the antibody-mediated portion of the immune system. Inebilizumab has a similar mechanism of action as rituximab (another B-cell depleting agent) that has been used in myasthenia gravis and particularly MuSK myasthenia gravis, where the evidence to supports its use is most compelling.

Again, as is typical for phase 3 clinical trials, there is a placebo group, random assignment of participants to the treatment group and blinding of patients and most study team members to treatment group to minimize the risk of bias. (Status: recruiting AChR and MuSK antibody patients)

A Phase 2, Clinical Trial of TAK-079 in Myasthenia Gravis (Clinicaltrials.gov study ID: NCT04159805)

TAK-079 is an investigational anti-CD38 monoclonal antibody drug that is not FDA-approved for clinical practice. The CD-38 immune cell surface marker is expressed on plasma and natural killer cells and can also appear in subsets of B and T lymphocytes when these cells are activated. Thus TAK-079 is designed to deplete a broader range of immune cells (natural killer, B, and T cells) possibly leading to more broad based suppression of the immune responses.

Like the other clinical trials on this list, this is a randomized, placebo-controlled study. A key distinction however is that it is a phase 2 trial (a study earlier in the drug development cycle) where the focus is on safety and tolerability. While drug effectiveness remains very closely monitored, this type of study is smaller (fewer participants) and the focus is initially on safety. There are three treatment groups in this study: lower level dose of TAK-079, higher-level dose of TAK-079 and placebo. Duration of the study period is 16 weeks. (Status: recruiting AChR and MuSK antibody patients)

RECENTLY COMPLETED STUDIES OF INTEREST

Efgartigimod phase 3 clinical trial in generalized myasthenia gravis

Efgartigimod is not approved as of this writing by the FDA for myasthenia or any other condition. But an approval could be forthcoming given the encouraging preliminary clinical trial results that have been made public thus far.

To understand how efgartigimod works, it is helpful to think back at the how myasthenia gravis is a disease mediated by autoantibodies. Autoantibodies are produced in error and recognize and attack normal parts of the human body. This is unlike typical antibodies that are produced by the immune system to identify invading microorganisms and to fight infections.

In myasthenia gravis, the autoantibodies that are best understood to cause the disease are against the acetylcholine receptor (also known as AChR receptor), the muscle-specific tyrosine kinase molecule (commonly referred to as MuSK) and the low-density lipoprotein receptor-related protein (commonly referred to as LRP4). What these autoantibodies have in common is a shared role in the communication between nerves that carry instructions for movement and muscles that receive these signals and contract to produce movement.

(Continued from Page 7)

Based on the mechanism of disease in myasthenia, it has long made intuitive sense that reducing the amount of disease-causing antibodies in a patient could lead to disease control. In fact, this is one of the ways that plasma exchange works. For those who are less familiar with plasma exchange, this is the procedure where blood is removed from the veins by a machine. The machine then separates the red and white blood cells and then returns them back to a vein. While at the same time, the machine removes the liquid portion of the blood that contains antibodies and replaces the fluid with specialized intravenous fluid to avoid dehydration. It is in the act of removing the liquid portion of blood that disease causing and other important immune mediators are rapidly cleared from the blood (and over several treatments) from the whole body.

So how is this all relevant to efgartigimod? Well, efgartigimod can be considered as a chemical form of plasma exchange (so plasma exchange but without getting IV lines and getting connected to the apheresis machine that does it). Specifically, the drug is designed to interfere with the human body's system for recycling and reusing the IgG group of antibodies. This is a very important category of antibodies because in addition to a long lifespan and high concentrations, AChR, MuSK and LRP4 myasthenia antibodies are all of the IgG subtype.

The target of efgartigimod is the neonatal Fc receptor of FcRN. This receptor binds IgG antibodies in circulation and protects them from destruction in the lysosome. In previous clinical trials it has already been demonstrated that efgartigimod, by interfering with IgG recycling, successfully knocks down IgG levels and myasthenia-specific antibody levels (https://pubmed.ncbi.nlm.nih.gov/31118245/ published May 2019)

The large phase 3 randomized and placebo-controlled trial of this drug has shown very promising results in myasthenia gravis. But these results are not yet peer reviewed, so more discussion of treatment effect will have to wait. A concern with any immunosuppressive drug is increased risk of infection. So far, the preliminary data reports suggest that the drug was well tolerated and with a safety profile similar to that of placebo. We will be reviewing information on this drug's effectiveness as it becomes available.

MGA Blog to Continue for 2021 Year



Our blog, MGA Digest, has proven to be a successful part of our programming and we are looking forward to offering you new MG content for the 2021 year! The goal of MGA Digest is to provide you with information that is educational yet personal. Much of what we do as a health nonprofit is to ensure patients are getting up-to-date news about MG, but our blog allows us to present material with your heart in mind.

What type of content will we be focusing on? Published every Friday, our weekly blog will contain various topics related to MG, people that are in the MG community, a review of past events, and a round-up of future programming for the upcoming month.

Do you have an idea for a blog post? Are you a writer who would like to guest-blog for one of our articles? Have an MG experience or story you are willing to share? We would love to hear from you!

I'm always eager to learn about the people, places, and things that are associated with myasthenia gravis. Please know I will continue to work hard and maintain this blog so that it is relevant, current, and thoughtful!

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

Current **Clinical Trials**







For Clinical Trials at the University of Missouri: Raghav Govindarajan, MD at govindarajanr@health.missouri.edu

KUMC & WUSTL

Safety & Efficacy Study of Ravulizumab in Adults with **Generalized Myasthenia Gravis**

The primary purpose of this study is to evaluate the safety | The purpose of the MycarinGstudy is to demonstrate the 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 randomizedcontrolled period, participants will enter the open-label extension period of the study and receive ravulizumab. *The following trial is now closed for enrollment.

Alexion Pharmaceuticals // ALXN1210-MG-306

Physicians

Dr. Mazen Dimachkie (KUMC) Dr. Muhammad Al-Lozi (WUSTL) Study Coordinator(s)

KUMC: Katie Jennens // kjennens2@kumc.edu WUSTL: June Smith // smith.june@wustl.edu

A Study to Test Efficacy and Safety of Rozanolixizumab in Adult Patients with Generalized Myasthenia Gravis

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.

> UCB Biopharma S.P.R.L. // UCB MG0003 **Physicians**

Dr. Mazen Dimachkie (KUMC) Dr. Muhammad Al-Lozi (WUSTL)

Study Coordinator(s)

KUMC: Ali Ciersdorff // aciersdorff@kumc.edu WUSTL: June Smith // smith.june@wustl.edu

SLU & KUMC

A Phase 3 Open-Label Study of Eculizumab in Pediatric Participants with Refractory Generalized Myasthenia Gravis (gMG)

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 Followup 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.

Alexion Pharmaceuticals // ECU-MG-303

Physician Dr. Jafar Kafaie

Study Coordinator

SLU: Jennifer Light // jennifer.light@health.slu.edu

Safety, Tolerability, and Efficacy of Zilucoplan in Subjects with Generalized Myasthenia Gravis

The RAISE study is a multicenter, randomized, doubleblind, 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.

Ra Pharmaceuticals // RA101495-02.301

Physician

Dr. Constantine Farmakidis

Study Coordinator

KUMC: Samantha Colgan // scolgan@kumc.edu

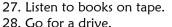
50 Ways to Beat the Winter Blues

We've hosted two virtual support groups in the last few months discussing the winter blues. After all, many of us have experienced 10 months of isolation and limited contact with the "real

If you've participated in the winter blues support group, you'll recall that it's interactive and we ask for suggestions from the group!

Check out our list, "50 Ways to Beat the Winter Blues" below!

- Start an indoor garden.
- 2. Draw a bath.
- 3. Try a new recipe.
- 4. Download Relax MD on your smart device.
- 5. Work on a puzzle.
- 6. Call an old friend.
- 7. Play a board game.
- 8. Join an online support group. (check out our online calendar for dates!)
- 9. Join one of our Facebook groups (www.facebook.com/ mgakc)
- 10. Learn a new hobby.
- 11. Start a gratitude jar.
- 12. Send a "just because" card to someone you love.
- 13. Go for a walk outside.
- 14. Have a car picnic
- 15. Drink more water.
- 16. Download a meal delivery app on your phone.
- 17. Rearrange your home.
- 18. Paint a room in your house.
- 19. Plan your next trip.
- 20. Write in a journal.
- 21. Watch a new TV series.
- 22. Watch old movies.
- 23. Look at old pictures.
- 24. Make freezer meals.
- 25. Text a friend or family member.



- 28. Go for a drive.
- 29. Go for a ride.
- 30. Use home exercise equipment.

26. Help a friend or family member.

- 31. Make cookies.
- 32. Plan a party.
- 33. Scrapbook.
- 34. Rediscover things that used to bring you joy.
- 35. Give yourself a manicure/pedicure.
- 36. Deep clean your house.
- 37. Find items to donate to charity.
- 38. Read a book.
- 39. Play video games.
- 40. Sew.
- 41. Draw.
- 42. Color
- 43. Knit
- 44. Take a nap.
- 45. Organize your junk drawer.
- 46. Bake food for others.
- 47. Practice yoga.
- 48. Join an online club (book club, history, crafts)
- 49. Find online volunteer opportunities.
- 50. Let sunshine in! Open your blinds and windows on warmer days.



SAVE THE DATE: MGA TRIPLE CROWN SHOWDOWN SET FOR MAY 16, 2021



The volunteer planning committee for the MGA Triple Crown Showdown has begun planning the 10th Annual MGA Triple Crown Showdown which is set for May 16, 2021 at Town Center Plaza in Leawood, KS. Plans are being made for participants to select an option to participate inperson or virtually. The MGA Triple Crown Showdown is the largest awareness and fundraising event for the MGA and features a 5K run, a mile walk and a kids tot trot! It's a lively morning complete with breakfast, vendors, and a kids activity area. 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 participants will receive a t-shirt and swag bag! Don't miss out and be sure to head to www.mga5k.com and register today!

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.

US-NON-20-00175 10/2020

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. App Store App Store Google Play Assembly Assembl











MG SUPPORT GROUPS

Area	Dates	Time	Location
Kansas City, MO	April 17th	10am- 12:00pm	Location— Zoom RSVP tanyarenner@mgakc.org or (816) 256-4100
KC Northland	March 2021	noon- 1:30pm	Location— TBD RSVP tanyarenner@mgakc.org or (816) 256-4100
Mid-Missouri	February 25th	6:30-8pm	Location— Zoom RSVP tanyarenner@mgakc.org or (816) 256-4100
Springfield, MO	February 4th	6-8pm	Location— Residence Inn by Marriott 1303 E. Kingsley, Springfield, MO RSVP tanyarenner@mgakc.org or (816) 256-4100
St. Louis	February 27th	10:00- 11:30am	Location— Courtyard by Marriott 8101 N. Dale Ave, Richmond Heights, MO RSVP tanyarenner@mgakc.org or 816-256-4100
Wichita, KS	TBD	1-3pm	Location— TBD 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	February 2nd	6pm	Location— Virtual RSVP to Allison Foss allisonfoss@mgakc.org
Young Persons with MG Group-STL	February 2nd	6pm	Location— Virtual RSVP to Meridith O'Connor meridithocon- nor@mgakc.org
Northwest, AR	March 14th	2:30- 4:30pm	Location-TBD Contact: Roger Huff for more info or to RSVP jrhuff1@cox.net or (479) 790-3022
Topeka, KS	TBD	6-8pm	Topeka & Shawnee County Library 1515 SW. 10th Ave Topeka, KS 66604 RSVP tanyarenner@mgakc.org or 816-256-4100
Eastsiders Lunch Bunch	3rd Wednes- day of the month	11am	Location— Virtual RSVP carolhunt04@yahoo.com
Virtual Monthly Meet Up	3rd Mon- day of the month	6:30pm	Meets via Zoom RSVP tanyarenner@mgakc.org or 816-256-4100



CHANGING PARADIGMS IN COMPLEMENT INHIBITION

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

MGA Connections



Are you newly diagnosed and looking for support or answers? Are you living with MG and wish to share your experience?

MGA Connections allows those impacted by MG to connect with one another.

Contact the MGA to learn about this program and we can get you in touch with the right people!



In Memoriam

Judy Mulhair
Richard Crimone
Robert & Julie Violette
Erin, Daniel, Danielle &
Rachel Tomley
Kathleen Mulhair
Bonnie Bacik
Rajesh Gopel
Mary Bradshaw
Kevin Kopach & Karen Cirra
Girish & Hansa Patel
Gautam, Prachi, Sudhir and
Neelam Patel
Kevin & KC Little
Pat Maher

Pat Maher
Peggy Myello
John Gregory
Joseph Rynn
Barbara Patterson
Sixty Plus Golf League
Michael Rynn
The Lewis Family
Theresa Kish

Dale & Judy Moore

Mary Ellen & Neil Evans Treehaven Garden Club Anne & Gerald Kopach Colleen & Robert Brown Dorothy & Kenneth Liuzzo

Donnie Mann

Steve & Patricia Mann William Penny Adrienne Mann

Norma Covington

David & Roxy Shipps Bobbie & Robert Stevenson

Howard Doctor

Wayne Greer Albert & Linda Kennett Caroline Helliker & Cairene Burks Frank Hollis

Ray Olsen

Nancy Hupp Anita & Everett Jenkins



WAYS TO SUPPORT THE MGA









SAVE THE DATE

June 12th: 3rd Annual Snowflake Shuffle | Wichita, KS

June 17th: Cheers to 60 Years | Kansas City, MO

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

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



Have an idea for a fundraiser in your community? Contact us today! allisonfoss@mgakc.org

Your financial support enables us to continue reaching patients across the heartland.

Did you know you can VENMO the MGA? Venmo Handle: @MGAKC



Membership Contributions

Danielle Kempker Lisa Gardner in memory of Todd Barnwell Cindy Disque Kerry & Dave Gordon CC & Karen Swarens Derek & Nina Haverkamp Brodie Beck Lisa & Jim Sackuvich Nancy & Ron Vinsant Ann Mowry Norma Covington Terre & Bruce Tepikian Carol & Linda Haverkamp Dr. Eric May Kerri & Gerald Mertens Jim Blaufuss Edsel Noland Ji & Sun Wei Vern Grothoff Donald Makoff Gene & Shirley Goode Janet Green Jeff & Cathy Schmeltz

Dorothy Canady

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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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