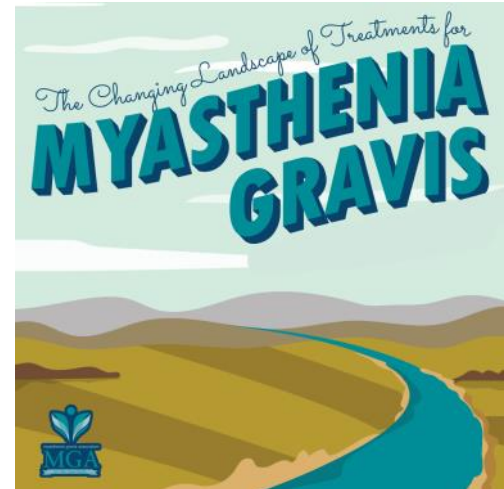


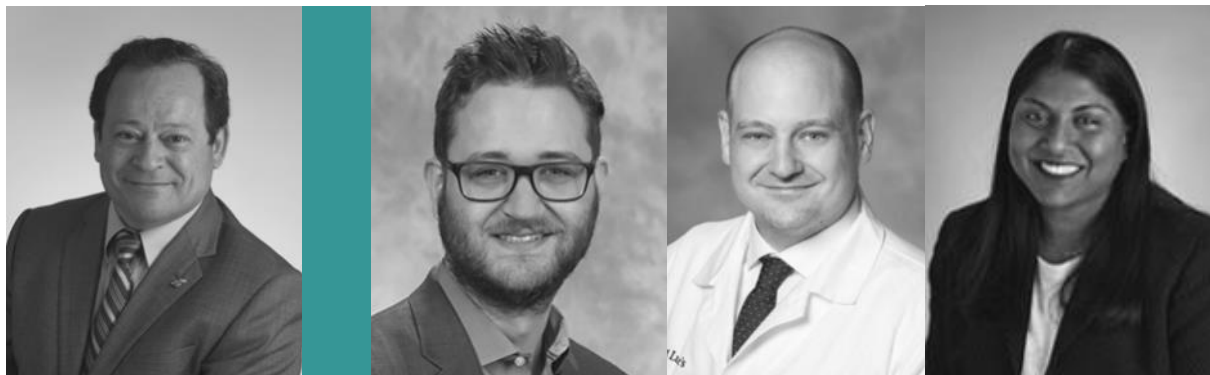
## The changing landscape of treatments for MG

Every fall, the Myasthenia Gravis Association hosts its annual meeting and educational seminar to keep constituents abreast of organizational developments and updates. This year's event, *The Changing Landscape of Treatment for Myasthenia Gravis*, will take place on Saturday October 30th. Due to the ongoing COVID-19 pandemic, the MGA will offer the seminar through a virtual platform.

Patients, families, and providers are invited to join the MGA from 8:30-11:30am via Zoom to receive these important updates and learn more about what is going on in the world of MG.



Mazen Dimachkie, MD, Professor and Executive Vice Chair of the Department of Neurology at the University of Kansas Medical Center will be the keynote speaker. His keynote will be followed by a panel of neurologists including Dr. John Eatman of North Kansas City Hospital, Dr. Nathan McGraw of St. Luke's Hospital and Dr. Mamatha Pasnoor of the University of Kansas Medical Center.



### Thank you to our sponsors



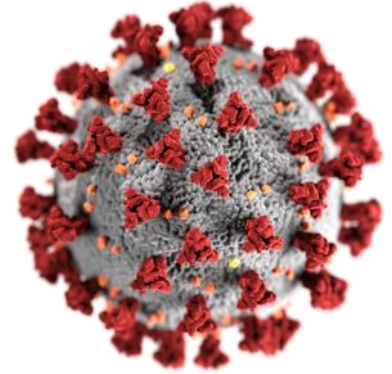
We are so grateful for our sponsors who have made this event possible this year. Thank you to argenx, ARJ Infusion Services, Alexion, UCB, Immunovant, Janssen, and Distinctive Meeting Group.

With partnership again this year from ARJ Infusion Services, we are able to offer 2 hours of CEU's for nurses. Please note that you will need a certificate in your RSVP.

To join the virtual MGA Educational Seminar and Annual Meeting, please RSVP to Tanya Renner [tanyarenner@mgakc.org](mailto:tanyarenner@mgakc.org) or 816-256-4100. Please RSVP by October 21, 2021 in order to receive a meeting packet mailed to you.

## Booster vaccinations become available for those who are immunocompromised

On August 12th, the FDA authorized a booster vaccination for individuals who are immunocompromised. Patients with myasthenia gravis taking immunosuppressant medications may fall under this category. There are several immunosuppressant drugs used in the treatment of myasthenia gravis including CellCept, Imuran, cyclosporine, prednisone and tacrolimus. The booster should be given at least 28 days after the second vaccination dose. Patients should discuss with their care team whether or not to get the booster vaccination. Many medical centers are offering the booster vaccination as are CVS, Walgreens, and other local pharmacies.



## St. Luke's clinic update: A message from MGA's Kansas City Program Coordinator, Tanya Renner



Have you been newly diagnosed with myasthenia gravis or are a returning patient at St. Luke's Hospital? Make sure to visit with MGA's Kansas City Program Coordinator, Tanya Renner at your appointment. We recently sat down with Tanya to discuss the latest happenings at our St. Luke's Clinic.

"The St. Luke's clinic is an important part of our organization," Tanya asserts. "Please know that I am here to provide education and support for every MG patient that walks through the door."

At some point during your clinic visit, Tanya will work with you to ensure you are receiving the proper resources and information to make the most out of your appointment.

"My favorite part about clinic is getting to know patients on a personal level. Doing so allows me to tailor resources that are most appropriate for you and your support system. Please feel free to ask me anything!"

Our program coordinators are there to inform you about support group meetings, clinical trials, community events, offer our latest newsletter, and if newly diagnosed, arrange for a new patient packet.

As a reminder, Tanya is at St. Luke's Plaza every 2<sup>nd</sup> Tuesday of the month and St. Luke's South every 4<sup>th</sup> Thursday.

"Do not hesitate to reach out to me with any questions or concerns you may have by calling the office or emailing me. Otherwise, I will see you at your appointment. I look forward to visiting with you!"

-Tanya Renner, MGA Kansas City Program Coordinator

## A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

No sooner than we hit print and packaged up the newsletters in July did all heck break loose on the delta variant. If you recall, my last column was about regaining some sort of normalcy.

It wasn't that I was upset about the printing of 500+ newsletters that now contained outdated information; I was upset to have digest this significant scale back.

You've read before, I love to plan, to organize, to keep a paper calendar and this last 20 months has basically been a prank on people like me. How many erasers does it take to tear the pages in your crisp new planner? How many pen scratch outs until you see it through on the other side?

Just like many of you, I crave normalcy. I crave people. I crave live interactions. We'll get there. It's just going to take some more time. Thank you for your patience and flexibility while we navigate these uncharted waters.

Be well,

Allison Foss, Executive Director  
allisonfoss@mgakc.org



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## Organization Announcement: MGA welcomes new member to board



The MGA is excited to announce our newest board member, Lyndsey Fliehs. Lyndsey was on the first planning committee for the Triple Crown Showdown and has been active with the MGA ever since.

Lyndsey is the Director of Awesomeness and co-owner of *Team Cocktail*, a local apparel and travel company. She graduated from Iowa State University with a Bachelor of Science in Marketing and Management. She loves bringing people together, traveling, and cheering on her favorite sports teams! Let's go Cyclones! Lyndsey lives in Blue Springs, MO.

## Inside this Issue

Medical card updates	5
Can you identify an MG crisis?	5
Clinical trials	6
Can you spot fake medical news?	7-8
Plasmapheresis coding update	8
Explaining MG using the battery theory	9
Trivia night success	10
YouTube channel updates	10
Support group calendar	13
Memberships & memorials	15





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# New and improved: MGA updates emergency medical card



ICYMI: Our emergency medical cards (EMCs) have been updated! Prior to this update we were working on other various resources within our new patient packets. The materials are now streamlined to fit with our organization specifically, and moreover, restructured with you and first responders in mind.

The new emergency medical card is organized into thirds, (front and back!) with each section containing important information in the event of an emergency.

Anyone who comes across this card will be able to quickly learn about MG and how to respond if you are in a respiratory or swallowing crisis. Additionally, first responders will have critical information at their fingertips such as current medications you are taking as well as identified cautionary drugs.

The card is helpful to have on hand when visiting doctor appointments as well. This document offers a space to identify other conditions you may have, known allergies, and relevant information such as your current insurance plan.

If you would like an updated MGA EMC, please contact Tanya Renner [tanyarenner@mgakc.org](mailto:tanyarenner@mgakc.org).

## Can you identify an MG Crisis?

**Medical emergencies (“crises”)** are rare but may occur when the muscles that support respirations are so weak that breathing or swallowing becomes very difficult. An MG patient may also have a “cholinergic crisis” as a result of anticholinesterase (i.e. Mestinon/pyridostigmine) overdose. The symptoms will be the same as an MG crisis. Respirations may be shallow and ineffective. The airway may become obstructed due to weakened throat muscles and accumulated secretions. Due to facial muscle weakness, a slurred speech pattern and/or an inability to respond normally, an individual who is severely weakened by MG may appear to be intoxicated. Check for a MedicAlert® bracelet or an MG Identification Card. For a list of “Medications to Use with Caution” with an MG patient go to <http://www.mgakc.org/new-resource-library.html> and scroll down to Medications/Treatments.



# MYASTHENIA GRAVIS CLINICAL TRIAL UPDATES

## KUMC CLINICAL TRIAL UPDATES



Contact: Samantha Colgan, CCRP  
scolgan@kumc.edu  
913-945-9938

- A Phase III, 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  
PI: Mamatha Pasnoor, M.D.
- A Phase II, Randomized, Placebo-Controlled Study to Evaluate Safety, Tolerability, and Efficacy of TAK-079 in Patients With Generalized Myasthenia Gravis  
PI: Mazen Dimachkie, M.D.

## MU CLINICAL TRIAL UPDATES



Currently, **there are no clinical trial updates for MU.**

For information regarding clinical trials:

Contact: Richard Barohn, MD  
rbarohn@health.missouri.edu  
573-882-3693

## SLU CLINICAL TRIAL UPDATES



Currently, **there are no clinical trial updates for SLU.**

For more information regarding clinical trials:

Contact: Rachel Grant  
rachel.grant@health.slu.edu

## WASHU CLINICAL TRIAL UPDATES



Contact: Oliver Doerr, oliver.doerr@wustl.edu

- 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

# Can you spot fake medical news online?

*Chances are you scroll through social media a time or two a week catching up on the whereabouts and life updates of friends and family. However, do you ever come across an article on your newsfeed and wonder whether or not it is legitimate?*

*This notion of “fake news” becomes particularly concerning when reading articles about medical information. Dr. Fred Plapp, MD, Clinical Professor and Medical Director of Laboratories at the University of Kansas Medical Center gave us practical and valuable tips on how to spot fake news, specifically pertaining to medical media.*



Fake news is broadly defined as false or misleading information masquerading as legitimate news. It is generated by outlets that seek to deceive the public with the goals of generating mass confusion, increasing political polarization, decreasing trust in public institutions, undermining democracy, and making money.

Fake news has become an insidious and widespread issue in the last five years, spreading beyond the realm of politics to science and medicine. Some recent polls suggested that 80 percent of Americans have encountered fake news regarding COVID19. Much of this fake news has attempted to cast doubt on the effectiveness or safety of public health measures such as vaccination, mask wearing, social distancing and quarantining. Other misinformation has sought to sell dubious preventive measures or phony cures.

The increasing pervasiveness of misinformation and disinformation makes it even more paramount that consumers can distinguish fake from real news. Below are some tips to detect fake news.

## ***How to Spot Fake News***

- Check out the source of the article. Is it from a reputable newspaper, website, or news organization? Fake news often uses domain names close to those of credible news outlets, such as WashingtonPosted.news and Ussanews.com to mimic washingtonpost.com and USNews.com. They may also use URLs such as .net or .co, instead of .com, .org or .edu. You can verify a URL by typing it into your internet browser.
- Look for red flags such as grammatical errors, misspellings, ALL CAPS, incorrect dates, and sensationalist images.
- Try to determine if the images have been photoshopped or repurposed by searching for the image to see if it appears in unrelated stories or in different forms. If so, be suspicious of its authenticity.
- Read beyond the headline. Does the content of the article support the headline? If content diverges greatly from the headline, it is most likely “click bait.”
- Look at the original publication date. Is this an outdated story that has been resurrected by social media?
- Does the article include at least one link to supporting data or studies published in a reputable scientific or medical journal?
- Is the author legitimate? Does the article include the author’s credentials or contact information? Are the author’s credentials accurately portrayed? Does the author have disingenuous motives? For example, America’s Frontline Doctors sounds credible but is an organization that has repeatedly peddled false information about vaccines and unproven treatments.
- Look for conspiracy angles. Does the article use language like, “here’s a reason why the authorities kept this quiet,” or, “this is a secret they didn’t want you to know.”
- Is the title of the article straightforward and factual or does it contain highly exaggerated language such as “scientific breakthrough,” “revolutionary,” or, “the first ever?” Ask yourself if the claim is too good to be true.

*Continued on the next page.*

### *How to Spot Fake News (Cont'd)*

- Remember that the number of likes, comments, and shares is not an indicator of truth.
- Use fact checking sites to confirm information and see whether other credible news outlets are reporting similar news.

#### Four Reliable Fact-Checking Sites

[FactCheck.org](https://factcheck.org)

[PolitiFact](https://politifact.org)

[Snopes.com](https://snopes.com)

[WP \[Washington Post\] Fact Checker](https://www.washingtonpost.com/fact-checker/)

To the right is an infographic provided by the International Federation of Library Associations and Institutions that nicely summarizes how to spot fake news.



## Plasmapheresis coverage decision follow up



In our last edition we shared information about how the Centers for Medicaid and Medicare were going to formally look at retiring the language for the usage of coverage on plasmapheresis. The physician fee schedule NCD 110.14 has been in place for nearly 30 years which ensures coverage of this lifesaving treatment for myasthenia gravis. In review, the decision on this policy was pushed back until 2022 which means the earliest changes could occur would be 2023. We'll keep you posted!

## Stock up on holiday gifts by shopping to support the MGA

Don't forget to buy your "Strength" blend coffee benefitting the Myasthenia Gravis Association. This special blend was created at the Roasterie, Kansas City's only air-roasted coffee company!

Additionally, our "Strength" blend has a beautiful label designed by our very own MGA community member, Kelsey Coleman. Coleman is a recent graphic design graduate from the University of Kansas living with myasthenia gravis.

To purchase a bag, head to <https://theroasterie.com/product/strength-blend/>





# Explaining MG using the battery theory



Have you ever tried to explain your experience with MG, but struggled to find the right words? Describing the MG experience can be a tricky matter. Saying, “I’m tired” or “weak” does not fully convey what those with MG feel. Some have used the spoon theory, which is a great start, but for me; I have always found it slightly complicated.

In our most recent children’s support group, I gave a presentation on how to explain your MG to your friends. Instead of using the spoon theory, I came up with my own and one that I feel is more relevant. Meet the battery theory.

In any case, at any age, the battery analogy is an appropriate way to illustrate what life is like with myasthenia gravis. Below is an excerpt of a piece I wrote for our blog, *MGA Digest*, about the analogy.

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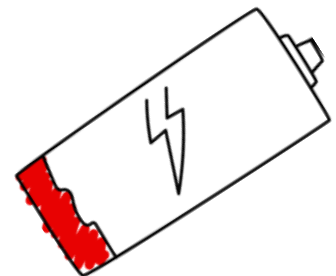
In this day in age, everyone, no matter what age, has some sort of device they use in their everyday life. Whether that is a computer, a cell phone, a tablet...we all interact with these things on a daily basis. But how is a battery like MG?

Think of our devices as a representation of our bodies. Our devices (bodies) need to be charged regularly in order for them to work efficiently and effectively. Similarly, humans, and moreover, those with MG, need to rest frequently and “recharge,” or sleep, to function.

But those with MG have somewhat of a faulty device. Somewhere along the line, an electrical signal or wire became faulty, and the battery (our energy) drains much faster compared to one in a healthy device.

What does one do with a faulty device? They charge it more and use it for a shorter period of time to conserve that battery. Additionally, a healthy device may be able to have tons of apps open and still work as it is supposed to. Yet, a faulty device can become overloaded by those apps. The device can get too hot or slow down, just like our bodies have to do when we overload ourselves with all that is required of us day after day. Sometimes our devices get so overloaded to the point where the battery is nearing it’s last bar, and we must choose how we want to use our device based on what is most important, kind of like how those with MG have to prioritize certain things over others because we do not have enough energy to do it all.

While we cannot trade our bodies in for new ones, we can feed off the energy of those who love us, the treatments that fuel us, and the positive outlook someone with MG can now expect.



--

Have you been keeping up with our blog, *MGA Digest*? Every Friday we publish an article discussing topics related to MG on a more personal level. To access our blog, head to <https://mgadigest.wixsite.com/mgac>

## What has been a success in 2021?



If you answered our 4th Annual Cy's Crown Town Trivia Night, you are correct! Partnering once again with the Kansas City Iowa State Alumni Club, the MGA held its trivia night on August 27, 2021 at the Vox Theatre. An indoor/outdoor setting allowed guests to play yard games outside while they sipped cool beverages before settling in for three rounds of lively trivia.

A pivot to an all virtual platform for our silent auction with our new Givergy software helped propel the success of the evening. Patrons could bid on items from their mo-

bile devices days leading up to the event, allowing for a competitive (but friendly!) bid war. The audience was fully engaged in our Fund-a-Need, so much so that an attempt to secure the live auction trip to Panama City Beach, Florida helped us raise more than \$51,000.00! With the funds raised, the MGA will be able to provide even more support and services to our support groups and clinics all throughout various cities including Topeka, St. Louis, Springfield, and Wichita. A true record-setting evening for the MGA!

Thank you to all who hosted guests at their tables, sponsored, volunteered, donated, and played to make it such a energizing evening. See you next year!



## Recent webinars available on Youtube Channel

If you've been participating in our Virtual Monthly Meet-Ups, you know we've done some recording of recent sessions for our Youtube channel.

On our channel you can find recent videos including information on getting a thymectomy, presented by Dr. Daon; anesthesiology, presented by Dr. May; MG medications and their side effects, presented by Dr. Hayat; and most recently, a COVID-19 antibody update, presented by Dr. Pasnoor.

To access these videos simply go to <https://www.youtube.com/user/mgakc>.





# We're plugged into the MG community



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# MG SUPPORT GROUPS

Area	Dates	Time	Location
Kansas City, MO	October 30th	8:30am-11:30am	<b>Virtual Annual Meeting &amp; Educational Seminar</b> RSVP Tanya Renner tanyarenner@mgakc.org or (816) 256-4100
KC Northland	Date TBD	noon-1:30pm	<b>Location– TBD</b> RSVP tanyarenner@mgakc.org or (816) 256-4100
Mid-Missouri	December 2nd	6:30-8pm	<b>Location– TBD</b> RSVP tanyarenner@mgakc.org or (816) 256-4100
Springfield, MO	October 19th	6-8pm	<b>Residence Inn by Marriott</b> <b>1303 E. Kingsley, Springfield, MO.</b> RSVP to tanyarenner@mgakc.org or (816) 256-4100
St. Louis	November 13th	10:00-11:30am	<b>Coutyard by Marriott</b> <b>8101 N. Dale Ave, Brentwood, MO</b> RSVP tanyarenner@mgakc.org or 816-256-4100
Wichita, KS	Date TBD	9:00-10:30am	<b>Location– TBD</b> RSVP Dana & Larry Paxson dkptiffany@gmail.com or (316) 269-9120
Young Friends of the MGA Group– Kansas City	November 30th	6pm	<b>Strang Hall</b> <b>7313 W. 80th Street, Overland Park, KS 66204</b> RSVP Allison Foss allisonfoss@mgakc.org
Young Friends of the MGA Group– STL	November 11th	6pm	<b>Location– TBD</b> RSVP Meridith O'Connor meridithoconnor@mgakc.org
Northwest, AR	October 10th	12:00-2:00pm	<b>Elm Springs City Park, Elm Springs, AR</b> RSVP Jan & Roger Huff jrhufl1@cox.net or (479) 790-3022
Topeka, KS	December 9th	6-8pm	<b>Location– TBD</b> RSVP tanyarenner@mgakc.org or 816-256-4100
Eastsiders Lunch Bunch	3rd Wednesday of the month	11am	<b>Location- Blue Springs Park</b> <b>2204 SW South Ave, Blue Springs, MO 64015</b> RSVP Carol Hunt carolhunt04@yahoo.com or 816-289-3523
Virtual Monthly Meet Up	3rd Monday of the month	6:30pm	Meets via Zoom RSVP tanyarenner@mgakc.org or 816-256-4100
Youth Group	December 7th	5:00pm	Meets via Zoom RSVP tanyarenner@mgakc.org or 816-256-4100

# Looking to connect with others

in the generalized myasthenia gravis (gMG) community?



Education and support for  
generalized myasthenia gravis

Register for a free webinar  
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link below\*



Register at [AlexionMGEvents.com](https://AlexionMGEvents.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.

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Amy & Sarah Bruns

Graham Naasz, DDS  
Kacy Becker



Have an idea for a fundraiser in your community? Contact us today at [allisonfoss@mgakc.org](mailto:allisonfoss@mgakc.org)! Your financial support enables us to continue reaching patients across the heartland.

## In Memoriam

### Susan Snell

Leanne Graves  
Rose Ley  
H and R Nordaas  
James and Claudia Copper

### Ronald Schaefer

Debbie and Steve Siemieniewski



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- ☐ \$ 61 (*61st Anniversary Membership*)
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 Email: [info@mgakc.org](mailto:info@mgakc.org)  
[www.mgakc.org](http://www.mgakc.org)  
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**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:  
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 2340 E. Meyer Blvd.  
 Building 1, Suite 300A  
 Kansas City, MO 64132  
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 Call us at: (816) 256-4100  
 E-mail us at: [info@mgakc.org](mailto:info@mgakc.org)

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**The MGA Digest**



Myasthenia Gravis Association