myasthenia gravis association MGA of the heartland

Strength and Hope Through
CONNECTIONS

Volume 62 Issue 3 Summer 2022

# MG Awareness Month: MG 101

This past June, we decided it would be best to get back to the basics in honor of myasthenia gravis awareness month. What is MG? How does it occur? What can one expect with a MG diagnosis? These questions can be answered (to some degree!) with a general understanding about the disease process and what is involved when someone is diagnosed with this rare disorder. Yet, we must not forget that MG is a snowflake disease; MG is unique to each person. The lived experience can vary greatly, and it is important to remember these differences. Nevertheless, below are some broad explanations, simplified to help educate others about the core concepts of this disease.

### *What is the process in which myasthenia gravis occurs?*

Myasthenia gravis is an autoimmune disorder. An autoimmune disorder occurs when the immune system, which usually protects the body from foreign invaders, mistakenly attacks itself.

Myasthenia gravis is a neuromuscular disorder as well. In a person with myasthenia gravis, there is a miscommunication between the nerve and muscle at the neuromuscular junction, the area in which nerve cells transmit signals to muscles to activate contraction. Messages are communicated through cells called neurotransmitters. These neurotransmitters typically bind to receptors for a muscle to contract, however; in a person with myasthenia, antibodies, which are produced by the body to usually protect it, will mistakenly either block, alter or destroy the receptor sites, preventing the muscle from contracting.

### *Myasthenia gravis affects what muscles?*

Myasthenia gravis affects the skeletal muscles of the body. Skeletal muscles are *voluntary muscles*, which are muscles that humans choose to move (i.e. raising your arm), whereas *involuntary* muscles are muscles that move automatically without conscious control (i.e. the heart).

### *What antibodies are associated with myasthenia gravis?*

There are various antibodies found in patients with myasthenia gravis. A healthcare provider such as a neurologist may order a blood test(s) to determine if there are elevated levels of specific antibodies to support an MG diagnosis. The following antibodies have been identified, however researchers suggest there are more antibodies to be discovered:

**AChR**: acetylcholine receptor antibody. The most common antibody associated with myasthenia gravis.
**MuSK**: muscle-specific tyrosine kinase. An even rarer subtype of myasthenia gravis.
**LRP4**: low-density lipoprotein receptor-related protein 4. Patients that test negative for both AChR and MuSk may test positive for LRP4.

Some patients test negative for antibodies associated with MG, however, they still may present with physical symptoms that align with an MG diagnosis. These patients are said to be "seronegative."

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*What other tests can patients undergo to confirm a myasthenia gravis diagnosis?*

There are various measures a healthcare provider may take in order to confirm or rule out a myasthenia gravis diagnosis. A healthcare provider will first conduct a physical and neurological examination. During this examination, the physician is assessing a person's muscle strength as well as coordination and things like muscle tone. Healthcare providers may also conduct a single fiber electromyography, or SFEMG. An SFEMG is a test that stimulates a person's nerves repeatedly with electricity to measure the muscle response. Other diagnostic measures include:

**CT Scan**: HCPs may order this type of imaging to examine the thymus gland. The thymus gland is considered an important part of the immune system that helps fight off infections. In patients with myasthenia gravis, the thymus gland may be enlarged (thymic hyperplasia) or even develop a tumor known as a thymoma.

**Ice Pack Test:** A HCP will place an ice pack on the patient's eyelid for a couple of minutes and then remove it to see if eyelid drooping has improved. Patients with MG typically struggle with droopy eyelids. When the muscle cools, weakness in MG patients is temporarily improved.

*What are some of the typical symptoms that myasthenia gravis patients have?*

In MG, a patient has muscle weakness which tends to worsen after activity and improves after rest. The severity of MG varies from patient to patient, however there are core symptoms that are involved with MG. Some of these symptoms include:

- Weakness in the eyes including drooping of one or both eyelids, blurred or double vision, and general weakness
- Change in facial expression such as an asymmetric smile
- Difficulty chewing and/or swallowing
- Trouble speaking; the muscles become impaired that are used in speech
- Weakness throughout the voluntary muscles including arms, hands, legs, and neck difficulty breathing

*How is myasthenia gravis treated?*

There are multiple treatment options for patients with MG. What works for one person may not work for the other, therefore it is important to discuss all options with your healthcare provider. The following is a general list of the current treatments for MG. There are many new emerging therapies on the horizon—talk to your physician about upcoming treatment options that are currently in the process of research and development.

- Anticholinesterase inhibitors; symptomatic treatment of MG
- Corticosteroids and other non-steroid immunosuppressants
- Monoclonal antibodies such as eculizumab (Soliris) and rituximab (Rituxan)
- Rapid acting immunotherapies including plasmapheresis and intravenous immunoglobulin
- Thymectomy; surgical removal of the thymus gland
- Newly FDA-approved drugs including Efgartigimod (Vyvgart) and Ravulizumab-cwvz (Ultomiris)

*Continue to page 4*

# A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

As the lights on Kansas City's Union Station turned to teal on Tuesday, June 7th, I couldn't help but smile. Contrary to popular belief, June for Awareness Month is something that causes me much angst. It sometimes feels as if everything is thrusted into one month of raising awareness and pulling out all the big stops, but as a patient, we know awareness never ends. MG never goes away; it never leaves us. When the month turns to July, we don't fold it all up and put it away until the next year. However, my smile may have been reflective of a few things. Working in our clinics during our staff transition, I am in awe of all the faces I am meeting and the stories I am hearing. We each come from different walks of life, intertwined because of this rare disease which is impacting us one way or another. We've had the highest of highs and the lowest of lows as we have fought through the challenge or living with MG. Or my smile may be reflective of the pride of the awareness and the work we are doing in America's heartland. To date, our outreach through clinics, social media, and the web to connect us with new patients through providing new patient packets has doubled since this time last year. Or my smile may have been because I have hope with the news of the second drug approved by the FDA within 6 months to treat generalized myasthenia gravis. My friends, keep smiling. There is hope. Better days are ahead and we will continue to raise awareness year round.

*Allison Foss, Executive Director*
allisonfoss@mgakc.org

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Todd Michael Barnwell
Given by Lisa & Steven Gardner

## Inside this Issue



## Support the MGA

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 impacted by myasthenia gravis.

***What is the outlook for someone with myasthenia gravis?***

Although the words "myasthenia gravis" mean "grave muscle weakness," the majority of MG patients can improve their symptoms and lead fulfilling lives with the right treatments.

If not treated properly, an MG patient can go into a "myasthenic crisis." A myasthenic crisis is a medical emergency that occurs when the muscles that control breathing weaken to the point where individuals require a ventilator to help them breathe. It may be triggered by infection, stress, surgery, or an adverse reaction to medication. It is important to maintain an understanding of MG symptoms and to listen to the body when there are signs of a crisis.

Finding the right treatment strategy can take some time, however; many MG patients are able to maintain a stable lifestyle and some even go into remission. The outlook for myasthenia gravis is a positive one.

# A Farewell to Fellow Board Members

The following board members will be transitioning off the board.

Secretary of the MGA, John Sand, MD has been a dedicated member of our board for over 25 years. Dr. Sand has taken on multiple roles on the board including president of the MGA. He has been the backbone of our organization and we are so grateful for all of the knowledge and guidance he has contributed over the past two decades. Stephanie Hubers, a longstanding board member of the MGA, has now fulfilled Dr. Sand's former position as Secretary.

Board member Brett Henson has supported the MGA since 2015. Before joining the board, Brett was involved with the MGA Triple Crown Showdown for many years.

Thank you all for your contributions and for supporting the MGA throughout the years. We wish you well on your next chapters ahead!

# SAVE THE DATE: 5th Annual Cy's Crown Town Trivia Night to take place on 8/26/22!

Join us on Friday, August 26th at GEHA Field at Arrowhead Stadium for this year's Annual Cy's Crown Town Trivia Night! If you have ever been to one of our trivia nights, you know a lot of fun is in store. In partnership with the Kansas City Iowa State Alumni Club, the MGA works towards raising awareness and financial support for various programming within the organization such as new patient packets, one-on-one consultations, and events. The event will take place from 6:30-10:00 PM. Bring your random-fact loving friends and join us for a fun night ahead! Tickets can be purchased on our website at www.mgakc.org.

*VIP ticket holders will have access to a special cocktail hour as well as a private tour of the stadium!

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400 mg/20 mL vial

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**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.

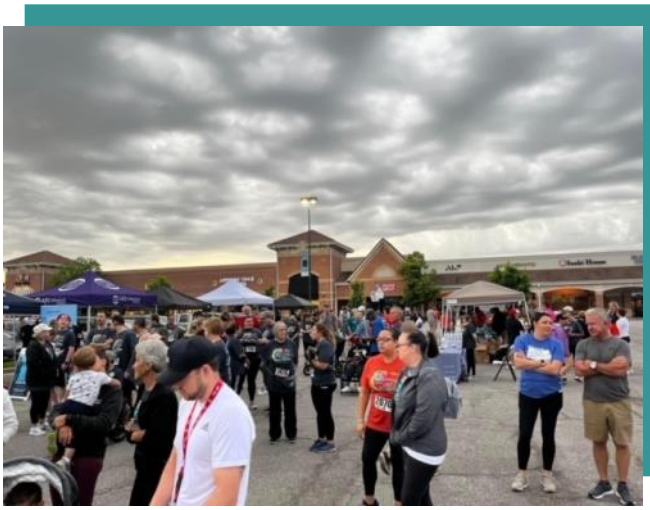
These are not all the possible side effects of VYVGART. Call your doctor for medical advice about side effects. You may report side effects to the US Food and Drug Administration at 1-800-FDA-1088.

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

argenx

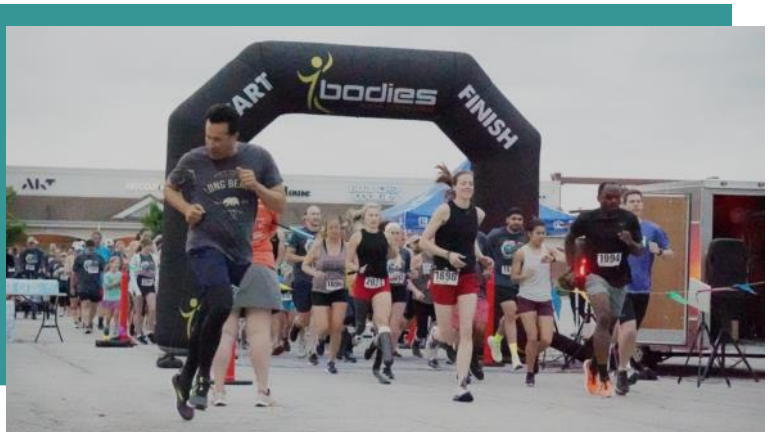
# MGA Triple Crown Showdown of 2022: A Recap

They say history repeats itself, and boy were they right. Before we knew it, our runners, walkers, and trotters were facing the downpouring rain. Sound familiar? For the past 2 years, the MGA Triple Crown Showdown has taken the stormy streets of Town Center Plaza and this year was no exception. With 422 registered participants, 95 volunteers, and 43 VIPs (MG patients), the 11th Annual Triple Crown Showdown was such a success. With over $60,000.00 raised, we were willing to brave any type of storm. Let's face it; that's what we as myasthenia gravis patients do, right?



Meridith O'Connor, St. Louis Program Coordinator stated, "This was my second showdown and needless to say I was humbled by all those who were up at the wee hours of the morning to set up with a smile on their face, eager to support the MGA, rain or shine." Vendors, sponsors, and partners came from all over the country to cheer on our racers and create even greater awareness for myasthenia gravis.

As Executive Director, Allison Foss, so eloquently put it, "[The] storm, it's so much like living with myasthenia gravis. One minute you are having a full-on conversation with somebody and then the clouds blow in and you are looking for shelter. It's unpredictable, it's beautiful, it's messy, it's chaotic, it's calm, it's hectic."




And it truly was. At the Triple Crown Showdown, we never know what to expect, but what we can bank on is a lovely morning comprised of hard workers, loyal supporters, and of course, a lot of fun.

If you want a rainbow, you have to put up with a little rain. We got our rainbow that day thanks to everyone that supported us near and far. A special thanks to our sponsors who made this event possible.

# Meet Catherine, Newest Member of the MGA Team!

We would like to officially welcome our newest member of the MGA team, Catherine Singleton!

Catherine joined the MGA as Patient Care Specialist in July 2022. She comes to the MGA with a magnitude of nonprofit experience and looks forward to cultivating relationships with MG patients, volunteers, and medical professionals. When she is not working at the MGA you can find her playing sand volleyball, playing board games with her 4 kids, or on a yoga mat.

Everyone, please give a warm welcome to Catherine—especially when you see her in clinic!

# MGA MG Clinics: An Overview

Over the course of the years, our organization has established multiple relationships with various healthcare institutions and professionals in the heartland area. Our primary goal with these partnerships is to provide additional support for myasthenia gravis patients, ensuring that each patient has someone they can connect with to help them along their disease journey. At the MGA, we refer to these established partnerships as MG Clinics.

If a patient is seen at an affiliated healthcare institution or is seen by a provider that has partnered with us, they will also be greeted by a member of the MGA team at the time of their outpatient appointment. During these visits, patients can expect to see not only a familiar face, but be provided with updates about MG research, MGA events including support groups, and resources relevant to them.

To date, we have maintained 5 MG clinics in Kansas City, Overland Park, St. Louis, and Springfield. The following providers work with us in our MG clinics:

- Dr. Swathy Chandrashekhar
- Dr. Mazen Dimachkie
- Dr. Constantine Farmakidis
- Dr. Duaa Jabari
- Dr. Omar Jawdat
- Dr. Mamatha Pasnoor
- Dr. Nathan McGraw
- Dr. Michael Schwartzman
- Dr. Ghazala Hayat
- Dr. Tania Papsdorf

Be sure to schedule your appointment on an MG clinic day. We look forward to seeing you at your next appointment!

# Ultomiris receives FDA approval for the treatment of generalized MG

Ultomiris (ravulizumab-cwvz) is the first and only long-acting C5 complement inhibitor for the treatment of gMG. The approval came after promising findings from the CHAMPION-MG Phase III trial. So, what does this exactly mean? Let's break it down.

We all have an immune system. The immune system protects our bodies from foreign substances and is our biggest defense mechanism against infection.

The immune system is made up of various parts, and one of those parts is called the terminal complement cascade. In short, the complement cascade is responsible for alerting the body of any pathogens and in turn, induces an inflammatory response to help fight infection off.
The complement cascade generates various proteins including the C5 protein, which plays a vital role in inflammation. Sometimes the C5 is overactivated, causing the cascade to over-respond, so much so that it attacks the body's own healthy cells.

Ultomiris, which is administered intravenously, inhibits the protein within the cascade.
In a recent press release, Dr. James F. Howard, JR. M.D. with the University of North Carolina School of Medicine, stated that the Ultomiris approval "offers patients, including those with milder symptoms, a long-acting C5 inhibitor with early onset and reliable efficacy."
Patients involved in the CHAMPION-MG Phase III trial reported side effects including respiratory tract infections and diarrhea.

Ultomiris was developed by Alexion Pharmaceuticals, a branch of AstraZeneca. Sound familiar? Alexion also developed Soliris (eculizumab), a treatment for gMG that was approved in 2017. Ultomiris is also FDA approved for other clinical indications including Paroxysmal Nocturnal Hemoglobinuria (PNH) and atypical Hemolytic Uremic Syndrome (aHUS).

To access the recent press release, head to https://www.astrazeneca.com/media-centre/press-releases/2022/ultomiris-approved-in-the-us-for-adults-with-generalised-myasthenia-gravis.html.

*If you want to learn more about Ultomiris, Kathy Logan with Alexion will be providing an educational about the drug on July 18th, 2022 for our virtual monthly meetup. The live viewing is scheduled from 6:30-7:30 PM CST and can be viewed later once the video recording is uploaded to our Youtube channel.

# MGA establishes Central Arkansas group


Our inaugural Central Arkansas meeting was set to roll out on July 18th at the Courtyard by Marriott in Little Rock. However at press time the COVID-19 level in Little Rock is categorized as high. Therefore the roll out will has been delayed. Stay tuned for a future date!

After learning about the need to support those in Little Rock, we decided to improve support with the assistance of our newly appointed volunteer support group leader, Kelsey Sims. If you or somebody you know would like to be attend, contact Allison Foss at allisonfoss@mgakc.org.

# Dr. Mamatha Pasnoor joins board

Please give a warm welcome to Dr. Mamatha Pasnoor, our newest member of the MGA board! You may recognize Dr. Pasnoor from serving on our medical advisory committee and is one of the neurologists we have continued to partner with within our MG clinics. Dr. Pasnoor is a renowned neurologist and professor at the University of Kansas Medical Center and we are looking forward to her perspective.

# 4th MGA Snowflake Shuffle 0.1K

Things were a bit frosty in Wichita, KS on Saturday, June 18th where we celebrated our 4th Annual MGA Snowflake Shuffle 0.1K. Patients and families enjoyed crafts, raffles, lunch, snow cones, and just being around each other after so much time apart with COVID-19. Thanks to all who came out and helped us raise over $10,000 for the MGA. Check out our photo collage of the event on page 12.

# Yokota Foundation gives generous gift

The Yokota Foundation which has so generously given to the MGA over the past 7 years has once again given a generous gift of $20,000 to the MGA. Comprised of MGA Member Mark Macias and his family, sister and brother-in-law Tina & John Warren, and girlfriend Greta Rice, they have been avid supporters in the connectivity and outreach of the mission of the MGA. We are so grateful for their support! Thank you!


4TH ANNUAL MYASTHENIA GRAVIS ASSOCIATION SNOWFLAKE SHUFFLE 0.1K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# The Skinny on MGA Support Groups

## Coffee with a Coordinator– St. Louis

Meets monthly from 10:30-11:30 AM at Kaldi's Coffee Café, 120 Kirkwood Street, Kirkwood, MO
Coffee is dutch treat
Open to patients, caregivers & providers
RSVP to meridithoconnor@mgakc.org to attend
**Next Meeting– July 28th**

## Eastsiders Lunch Bunch

Standing meeting the 3rd Wednesday of the month from 11:30-1:30 PM at the 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, Volunteer Support Group Leader
RSVP to info@mgakc.org to attend
**Next Meeting– July 20th**

## Greater Kansas City

Meets quarterly on a Saturday from 10 AM-12 PM at Community Center D. at St. Joseph Medical Center, 1000 Carondelet Drive, Kansas City, MO
Light brunch is provided
Open to patients, caregivers & providers
RSVP to info@mgakc.org to attend
**Next Meeting– July 16th**

## Kansas City Northland

Meets bimonthly January-September on a Thursday from 12-1:30 PM at Primrose Retirement Community, 8559 N. Line Creek Road, Kansas City, MO 64154
Light lunch is provided
Open to patients, caregivers & providers
Hosted by Sandy Gardner, Volunteer Support Group Leader
RSVP to info@mgakc.org to attend
**Next Meeting– August 11th**

## Mid Missouri Support Group

Meets quarterly on a Thursday from 5:30-7:00 PM at Daniel Boone Regional Library, 100 W. Broadway, Columbia, MO
Open to patients, caregivers & providers
Hosted by Jonni Jolliff, Volunteer Support Group Leader
RSVP to allisonfoss@mgakc.org to attend
**Next Meeting– TBD (July 21st meeting postponed due to high COVID-19 transmission level in Columbia)**

## NW Arkansas Support Group

Meets every other month from January to October on a Sunday from 2:30-4:30pm at the 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
**Next Meeting– September 18th**

## Springfield Support Group

Meets quarterly on a Tuesday from 6-7:30 at Residence Inn by Marriott, 1303 SE. Kingsley, Springfield, MO
Open to patients, caregivers & providers
RSVP to allisonfoss@mgakc.org to attend
**Next Meeting– July 26th**

# The Skinny on Our MGA Support Groups, Continued

## St. Louis Support Group
Meets quarterly on a Saturday from 10-11:30 at the Glendale City Hall, Glendale MO
Open to patients, caregivers & providers
Light brunch provided
RSVP to meridithoconnor@mgakc.org to attend
**Next Meeting– July 23rd**

## Topeka Area Support Group
Meets quarterly on a Thursday from 5:30-7 at the Topeka & Shawnee County Library 1515 SW 10th Ave, Topeka, KS
Open to patients, caregivers & providers
RSVP to info@mgakc.org to attend
**Next Meeting– September 8th**

## Virtual Monthly Meet Up
Meets on the 3rd Monday of the month from 6:30-7:30pm via Zoom
Open to patients, caregivers & providers
RSVP to info@mgakc.org to attend —-CHANGE
**Next Meeting– July 18th, 2022**

## Virtual Youth Group
Meets quarterly on a Monday at 6pm via Zoom
Open to youth who are diagnosed with myasthenia gravis and their parents
RSVP to allisonfoss@mgakc.org to attend
**Next meeting– TBD**

## Wichita Support Group
Meets quarterly on a Saturday from 1:30-3:30 at Ascension Via St. Francis, Wichita, KS
Open to patients, caregivers & providers
Hosted by Dana & Larry Paxson, Volunteer Support Group Leaders
RSVP to dkptiffany@gmail.com
**Next Meeting– TBD**

## Young Friends of the MGA– Kansas City
Meets quarterly at various locations in Kansas City
Open to patients who are generally in their 20s, 30s and 40s
RSVP to allisonfoss@mgakc.org to attend
**Next meeting– TBD**

## Young Friends of the MGA– St. Louis
Meets quarterly at various locations in St. Louis
Open to patients who are generally in their 20s, 30s and 40s
RSVP to meridithoconnor@mgakc.org to attend
**Next meeting– TBD**

*The MGA has adopted a policy of COVID-19 and Support Groups where any area that is going to be holding an in person support group must be categorized as a low-medium risk area in order for the meeting to be held in person. If the area is categorized as "high," the meeting will be postponed until the level recedes back to the low-medium risk. Safety continues to be a priority for the MGA as many of our patients are immune compromised.*

# MG CLINICAL TRIAL UPDATES

## KUMC

**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**

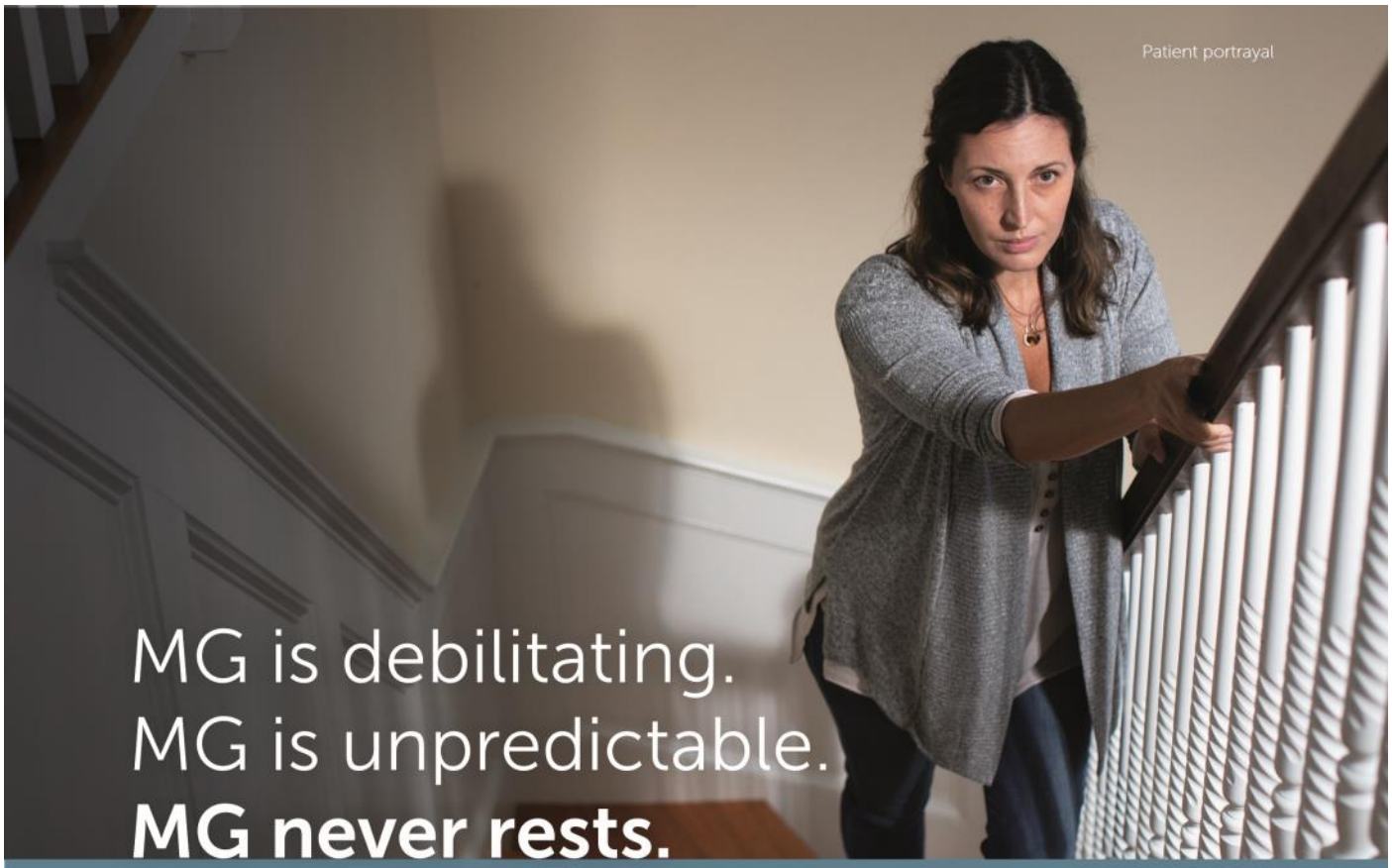
**PI: Dr. Pasnoor**

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

Currently, there are no clinical trial updates for MU, SLU or WashU.




# MG is debilitating.
# MG is unpredictable.
# **MG never rests.**

## And at UCB, neither will we.

**We're continuously working to understand the daily impact of myasthenia gravis (MG). So, we've made it our mission to help improve the lives of those in the community.**

That's why we support and work with advocacy organizations like the Myasthenia Gravis Association to help expand their reach and provide much-needed assistance. It's also why we're increasing awareness of MG through programs like gMG Never Rests and developing digital tools that reach beyond treatment to help people better manage their conditions. And it's why we're researching unique ways of solving the needs of the community. Our commitment won't end here. We're always striving to find more ways to support those impacted by MG.

Inspired by **patients.**
Driven by **science.**

**REFERENCES: 1.** Cutter G, et al. *Muscle Nerve*. 2019;60(6):707-715. **2.** Grob D, et al. *Muscle Nerve*. 2008;37(2):141-149. **3.** Xin H, et al. *J Clin Neurol*. 2019;15(3):376-385.



**DISCOVER WHY gMG NEVER RESTS.**

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!

**Consider becoming a 2022 member!**

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: _____

*Cut & enclose in envelope, and mail to:*

MGA
2340 E. Meyer Blvd., Bldg. 1, Suite 300A
Kansas City, MO, 64132

PLEASE PRINT

NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

PHONE _____ EMAIL _____

PLEASE CHECK: I am a ❒ MG Patient ❒ Relative ❒ Friend ❒ Other

**Make checks payable to the Myasthenia Gravis Association*
**Contributions may be tax deductible*
**Visit us at www.mgakc.org*

*Thank You!*

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


## 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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