

## FDA approves two new therapy options for myasthenia gravis

On back to back weeks in June, the U.S. Food and Drug Administration approved two new therapy options for the treatment of myasthenia gravis (MG).

On June 20, Vyvgart Hytrulo, which is a subcutaneous version of Vyvgart (efgartigimod) produced by argenx was approved for the treatment of individuals with generalized myasthenia gravis (gMG). Individuals approved will now be able to receive Vyvgart in a delivery form that allows greater freedom and independence.

The following week on June 26, UCB received approval for RYSTIGGO (rozanolixizumab BLA) for the treatment of MG in individuals who are anti-acetylcholine receptor AChR positive and anti- muscle- specific tyrosine kinase MuSK positive. This is the first therapy of its kind approved for the treatment of MuSK MG.

The approval of the two new therapies for the treatment of myasthenia gravis once again shows the landmark time we are living with strides in research and drug development. Between 1960 and 2017 there were no therapies approved by the FDA for the treatment of myasthenia gravis . Now within the last 5 1/2 years there have been 5 approved including Soliris, Vyvgart, Ultomiris, Vyvgart Hytrulo and RYSTIGGO which is exciting and brings hope to the myasthenia gravis community.

For more information on each therapy, the Myasthenia Gravis Association (MGA) recommends you visit the websites for both indications and discuss further with your Neurology team to see if it might be the right fit of treatment for you.

### Upcoming Virtual Monthly Meetups

Our Virtual Monthly Meetups are still going strong and offer an at your fingertips educational experience. Led by our Virtual Meet Up Host, Sarah Bolton, our Virtual Monthly Meetup generally meets the 4th Monday of the month from 6:30-7:30pm, you can also find recordings of most of them on our youtube channel ([www.youtube.com/mgakc](http://www.youtube.com/mgakc)) to watch at your leisure. We have some great topics coming up that we want to share with you!

Monday August 28, 2023— Learn the MG antibody types and how to read MG lab values presented by Ghazala Hayat, MD

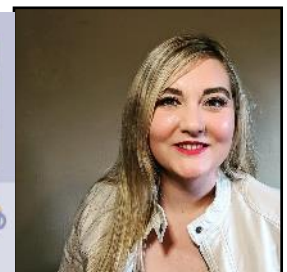
Monday September 25, 2023— Updates from Janssen

Monday October 23, 2023— What does STEP Therapy mean and how does it impact you? Presented by the Everylife for Rare Disease Foundation

Monday November 27, 2023— Come and share the best smart phone apps to manage your MG needs.

Monday December 18, 2023—Healthy holiday food ideas presented by Kristen Neusel, MS RD LD, CDCES, NASM CPT

To sign up for a session, watch your email for a link to register. You must have a Zoom account to participate in these webinars. If we do not have your email on file, email us at [info@mgakc.org](mailto:info@mgakc.org) to be added. Got a topic for a virtual monthly meetup you'd like to hear about? Let us know.



Sarah Bolton, Virtual Monthly Meetup Host



## 10 FOOD & MEAL IDEAS FOR SUMMERTIME



As most of us are in the midst of the dog days of summer, combating the heat and myasthenia gravis (MG) sometimes takes some creativity. We put together some summertime meal ideas for when it is hot, you don't feel like cooking *and* you may be dealing with swallowing issues.

1. Cottage cheese is having a moment. Such a moment that you can now buy it in individual containers with fruit on top. Now that might not be your jam, and thankfully you can still buy a plain container of cottage cheese, eat it plain or season with Everything but the Bagel seasoning!
2. Cold soups- did you know there was such a thing? A quick google search and you can find nearly any type of vegetable or fruit soup, made cold.
3. Scrambled eggs- scrambled eggs provide lots of protein and are generally easy to swallow. They can also offer a lot of variety by changing what ingredients you put in them.
4. Smoothies & Shakes- much like cold soups and scrambled eggs, the world is your oyster with smoothies and

shakes. Mix and match your preferred ingredients and for the amount of nutrition you are looking for.

5. Acai bowls- Acai is a purple berry from Central and South America that comes frozen, in powder or juiced. Acai bowls are also have a moment. Top the berries with granola, other fruit and coconut for a meal.
6. Chicken Salad/Egg Salad/Avocado Salad- Depending on your taste buds, there are many ways to make chicken salad, egg salad or avocado salad. And just to make the task easier, many grocery stores now offer rotisserie chicken already pulled and ready to eat!
7. Loose Meat Sandwiches- What is a maid rite you ask? It's a hamburger that instead of a patty is loose meat. If you are having trouble swallowing an actual hamburger patty, a maid rite is a great option. And even better is you don't have to stand outside and grill a hamburger patty. You can make a maid rite as easy as using 1lb of ground beef heated over a skilled while you add in a can of beef consommé and some onion powder.
8. Cold Pasta Salad- if you are hungry for pasta but feel like it's too hot for heavy lasagna or ziti, consider a cold pasta salad. Mix and match what you put in the salad for how strong your swallowing is. The dressing of a cold pasta salad can help soften some of the things you add if you are having difficulty chewing.
9. Corn OFF the cob- there is a tool that can help you get corn off the cob if it tires you out to have to chew corn on the cob.
10. Melons- Melons can be very refreshing and make a great snack or side in the summer. Customize how you cut your pieces based on how well you are swallowing.

Stay cool and stay safe!

Janssen



PHARMACEUTICAL COMPANIES OF

Johnson & Johnson



## MGA STAFF

### Executive Director

Allison Foss

### Community Program Coordinator

McKenna Fulton

## EXECUTIVE BOARD

### President

Michael Eagan

### Vice President

Brodie Beck

### Secretary

Stephanie Hubers

### Treasurer

Derek Haverkamp

## BOARD MEMBERS

Joe Bant

Jacquelyn Carroll, CMP

LaDonna Diller

Al Dimmitt

Lyndsey Flihs

Graham Naasz, DDS

Mamatha Pasnoor, MD,  
FAAN

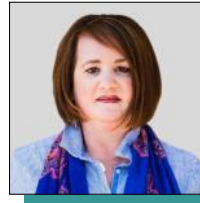
Tom Vansaghi, PhD

## CONTACT

816-256-4100

info@mgakc.org

# A Message from Allison



June has come and gone however, hopefully you saw via email and social media that June was Myasthenia Gravis Awareness Month. It's always a fun month to see the creativity of awareness ideas across the globe.

We want to keep the momentum going as we feel that it is important to raise awareness year-round. After all, we all know myasthenia gravis doesn't just go away so why should raising awareness!

On the following page, you'll note we've put together a facts about myasthenia gravis sheet. We hope that you'll consider printing this sheet and posting in a breakroom at work, your refrigerator at home, the bulletin board at a local coffee shop or attach into an email and send to family and friends. You can also save as a pdf or jpeg and post on social media. Want it emailed to you? Send us an email and we will send you a copy!

Got an awareness idea? Share it with us as we hope to keep the ball rolling!

In Hope & Gratitude,

Allison K. Foss | Executive Director | [allisonfoss@mgakc.org](mailto:allisonfoss@mgakc.org)

## Inside this Issue

- Page 4** MG Awareness Flier
- Page 4** Recap of MGA Triple Crown
- Page 6** Snowflake Shuffle recap
- Page 8** Clinical Trial Updates
- Page 9** Clinical Trial Updates continued
- Page 10-11** Support Group Updates
- Page 12** Annual Meeting & Educational Seminar
- Page 14** Membership Donations

## Submissions

Want to share your MG story or have a topic you would like to see covered? Email Allison at [allisonfoss@mgakc.org](mailto:allisonfoss@mgakc.org)

## Follow Us





# WHAT IS MYASTHENIA GRAVIS?

Myasthenia gravis (MG) is a chronic autoimmune neuromuscular disease that causes weakness in the skeletal muscles.

There is NO cure for MG.

**Impact of MG**  
chewing, swallowing, talking,  
facial expressions,  
eyes & eyelid movements



**2** types of MG  
ocular & generalized



Does not discriminate  
ethnicity, race or  
gender.  
Most commonly  
diagnosed in females  
under 40 and men  
over 60

- Signs & Symptoms
- \*shortness of breath
  - \*impaired speech
  - \*weakness in arms, fingers, hands, legs & feet
  - \*difficulty swallowing
  - \*blurred or double vision
  - \*changes in facial expression
  - \*drooping eye lids
  - \*weakness in eye muscles

myasthenia gravis association  
**MGA**  
of the heartland  
[www.mgakc.org](http://www.mgakc.org)

# Sun shines on the 12th Annual MGA Triple Crown Showdown

A beautiful sunny, spring morning provided the backdrop on the 12th Annual MGA Triple Crown Showdown on Sunday May 20, 2023 at Town Center Plaza in Leawood, KS. Over 500 participants, volunteers and vendors came together to raise awareness of myasthenia gravis by running, walking and tot trotting across the finish line. Thank you all for coming out and for our sponsors for making the morning possible! We hope to see you next year!



*Thank You to all of our Amazing Sponsors!*



CRAIG & BARB FOSS



GREG & JULIE HANSHAW



TIM & LORI PATTERSON  
CLINT FOSS & GRACE LIM  
JEFF & PAT PARADOCS



THE HOLT FAMILY  
DOUG BARKER  
THE GARDNER FAMILY  
TOM & CLARISA McMAHON  
JOHN & RHONDA HAMMES  
ALLISON FOSS



SALLY & STEVE JOHNSTON  
BRAD & GLORIA GASPER  
JERI & TOM KUNKLE  
TOM & MELINDA COOK

JULIE FOSS  
ARJ INFUSION SERVICES  
THE MATT FAMILY  
CHAD HARRIS  
OPTUM

Mike Wessel  
Jim & Nancy Horras  
People's Investment Professionals

SUSAN BAUER CREATIVE  
FOCUSED STORY FILMS  
CHRISTINA LUNDEEN  
BRYAN BOSCH  
F.I.T MUSCLE & JOINT CLINIC

TUFT & NEEDLE  
SUNSHINE AND SHADOWS PHOTOGRAPHY  
SWEET KISS BRIGADEIRO  
OVERLAND PARK AWARDS  
MELISSA'S SECOND CHANCES

AMAZING LASH BASH  
POWERLIFE YOGA  
FABLETICS  
SUPPLEMENT SUPERSTORE  
CHICKEN N PICKLE



## Steele joins MGA Board of Directors

Ashley Steele has joined the MGA Board of Directors. Ashley is the Assistant Marketing Events Manager at Polsinelli, based in Kansas City, MO. She earned her B.S. in Business Management and Marketing from Northwest Missouri State.



Born and raised in Independence, MO, Ashley is a big Chiefs fan! When she isn't traveling for work, she spends time with her 9 year old golden retriever, Bernie, her niece Molly and her nephews Mason and S.J. Ashley's dad was diagnosed with myasthenia gravis in 2020. We are thrilled to welcome Ashley to the Board of Directors.

For individuals with generalized myasthenia gravis (gMG) finding the strength to complete tasks in your daily life can seem impossible at times. The FLEX Study is investigating a drug called batoclimab for adults living with gMG to manage their symptoms. The second period of this research study may provide the opportunity for participants to self-administer the injectable study drug.

In this clinical research study, doctors want to evaluate the investigational drug to placebo, which looks like the investigational drug, but contains no active medication. The investigational drug has not been approved for the treatment of generalized myasthenia gravis or any other disease. It is considered experimental and can only be given to patients in clinical research studies. The results of this clinical research study will provide more information about batoclimab and its effect on mild to severe generalized myasthenia gravis.

**Who is eligible to participate in this clinical research study?**

**You may be eligible to participate if you:**

- Are 18 years of age or older
- Have been diagnosed with mild to severe generalized myasthenia gravis (gMG)
- Have been treated or are currently being treated with medication for gMG
- Meet additional study criteria.
- Study staff will determine eligibility based on additional study criteria



**FLEX**

To learn more about the clinical research study and to see if you may qualify, please visit our website at [www.flexMGtrial.com](http://www.flexMGtrial.com)



## Snowflake Shufflers raise awareness of myasthenia gravis

A great day was had at the 5th Annual Snowflake Shuffle 0.1K in Wichita, KS, on Saturday June 10, 2023. A huge thanks to organizers, Larry and Dana Paxson for their efforts and leadership to make this possible. Attendees enjoyed raffles, talking with sponsors & vendors, fellowship and a treat from the Kona Ice Truck!



THANK YOU TO OUR SPONSORS:



In Memory of Raymond Kent  
Dana and Larry Paxson  
Robert and Sue Fitzthum  
Bryan Bosh and Gingham Dragon







nufactor<sup>®</sup>  
A SPECIALTY INFUSION COMPANY

# Making a difference one patient at a time

Immune Globulin • Factor • Infiximab



Scan code to visit us  
at [nufactor.com](https://nufactor.com)

(800) 323-6832 | [nufactor.com](https://nufactor.com)



Nufactor Specialty Pharmacy has  
earned The Joint Commission Gold  
Seal of Approval

# Myasthenia Gravis Clinical Trial Updates

University of Kansas Medical Center

**Viala Bio** ClinicalTrials.gov identifier: **NCT04524273**

**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](mailto:lsaavedra2@kumc.edu)**

**Janssen** ClinicalTrials.gov Identifier: **NCT05265273**

**PI: Dr. Statland**

An Open-Label Uncontrolled Multicenter Study to Evaluate the Pharmacokinetics, Pharmacodynamics, Safety and Activity of Nipocalimab in Children Aged 2 to Less Than 18 Years With Generalized Myasthenia Gravis  
Experimental: Nipocalimab

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

Nipocalimab will be administered as an IV infusion

Total enrollment: 12 participants

**For more information contact: Katie Lillig [kjennens2@kumc.edu](mailto:kjennens2@kumc.edu)**

**Cabaletta Bio** Clinicaltrials.gov identifier: **NCT05451212**

**PI: Dr. Dimachkie**

A Phase 1, Open-label, Safety and Dose-finding Study of Autologous Muscle-specific Tyrosine Kinase Chimeric Autoantibody Receptor T Cells (MuSK-CAART) in Subjects With Anti-MuSK-antibody-positive **Myasthenia Gravis**

Experimental: MuSK-CAART

Cohort A: Infusion of MuSK-CAART at various dose levels with or without pre-treatment (6 groups planned).

Cohort B: Infusion of MuSK-CAART at the dose regimen selected from Part A

Total: 24 patients

**For more information contact:**

**Andrew Heim [aheim2@kumc.edu](mailto:aheim2@kumc.edu)**





# Myasthenia Gravis Clinical Trial Updates

**Immunovant MG**      **ClinicalTrials.gov Identifier: NCT05403541**

**PI: Dr. Pasnoor**

A Phase 3, Multi-center, Randomized, Quadruple-blind, Placebo-controlled Study to Assess the Efficacy and Safety of Batoclimab as Induction and Maintenance Therapy in Adult Participants With Generalized Myasthenia Gravis (gMG)

Experimental: Batoclimab

Period 1 arms:

Batoclimab 680 mg SC weekly

Batoclimab 340 mg SC weekly

Matching Placebo SC

Period 2 arms:

Batoclimab 340 mg SC weekly

Batoclimab 340 mg SC bi-weekly

Matching Placebo SC

Total enrollment: 210 participants

**For more information: Nick Staudenmier [nstaudenmier@kumc.edu](mailto:nstaudenmier@kumc.edu)**

**ALXN1720 – MG**      **ClinicalTrials.gov Identifier: NTC**

**PI: Dr. Dimachkie**

A Phase 3, Randomized, Double-blind, Placebo-controlled, Parallel, Multicenter Study to Evaluate the Safety and Efficacy of ALXN1720 in Adults With Generalized Myasthenia Gravis

Experimental: ALXN1720

Participants will receive a weight-based maintenance treatment with ALXN1720 on Day 1, followed by weight-based maintenance treatment of ALXN1720 on Week 1 (Day 8) and once every week (Q1W) thereafter for a total of 26 weeks. Following this randomized controlled treatment (RCT) period, all participants will receive ALXN1720 in an open-label extension (OLE) period of 96 weeks.

Placebo Comparator: Placebo

Participants will receive placebo during the 26-week RCT period, after which they will enter the OLE period of the study and receive ALXN1720.

Total Enrollment: 254 participants

**For more information:**

**Nick Staudenmier [nstaudenmier@kumc.edu](mailto:nstaudenmier@kumc.edu)**

**Cartesian**      **ClinicalTrials.gov Identifier: NCT04146051**

**PI: Dr. Pasnoor**

Autologous T-Cells Expressing A Chimeric Antigen Receptor Directed To B-Cell Maturation Antigen (BCMA) In Patients With Generalized **Myasthenia Gravis** (MG)

Phase 2 Trial

Experimental: Autologous T-cells expressing a chimeric antigen receptor directed to BCMA (Descartes-08)

Experimental: Phase 1b Dose-Escalation

Intervention: Descartes-08

Experimental: Phase IIa Expansion

Intervention: Descartes-08

Placebo Comparator: Phase IIb Randomized Control Trial

Intervention: Descartes-08

Total enrollment: 30 participants

**For more information contact:**

**Ali Ciersdorff [aciersdorff@kumc.edu](mailto:aciersdorff@kumc.edu)**

# The Skinny on MGA Support Groups

## Central Arkansas Group

**Next Meeting— September 14, 2023**

5:30-7:00 PM | Fletcher Library, 823 N. Buchanan St, Little Rock AR 72205

Open to individuals, caregivers & providers

RSVP: [info@mgakc.org](mailto:info@mgakc.org)

## Coffee with a Coordinator— St. Louis

**Next Meeting— July 27, 2023**

Monthly | 10:30-11:30 AM | St. Louis Bread Company, 10221 Manchester Rd, Kirkwood, MO

Coffee is Dutch treat | Open to individuals, caregivers & providers

RSVP: [info@mgakc.org](mailto:info@mgakc.org)

## Eastsiders Lunch Bunch

**Next Meeting— August 2, 2023**

1st Wednesday of the month | 11:30 AM-1:30 PM | Agape House 312 SW 19th Terrace Street, Blue Springs, MO

Bring your own lunch unless otherwise noted | Open to individuals, caregivers & providers

Hosted by Carol Hunt & Raymond Hankins, Volunteer Support Group Leaders

RSVP to [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)

## Greater Kansas City

**Next Meeting— October 21, 2023 (Annual Meeting)**

Quarterly on a Saturday | 10:00 AM-12:00 PM | Community Center D. at St. Joseph Medical Center, 1000 Carondelet Drive, Kansas City, MO

Light brunch is provided | Open to individuals, caregivers & providers

RSVP: [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)

## Kansas City Northland

**Next Meeting— September 14, 2023**

January-September, bi-monthly on a Thursday | 12:00-1:30 PM | Primrose Retirement Community, 8559 N. Line Creek Road, Kansas City, MO

Light lunch is provided | Open to individuals, caregivers & providers

Hosted by Sandy Gardner, Volunteer Support Group Leader

RSVP: [mckennafulton@mgakc.org](mailto:mckennafulton@mgakc.org)

## MG Pride Group

**Next Meeting— August 8, 2023**

Bi- Monthly on a Tuesday | 5:30-7:00 PM | Via Zoom

Open to individuals who identify as LGBTQ+ with MG, their allies and care partners

Hosted by Bryan Bosch, Volunteer Support Group Leader

RSVP: [btbosch81@gmail.com](mailto:btbosch81@gmail.com)

## Mid-Missouri Group

**Next Meeting— October 12, 2023**

Quarterly on a Thursday | 5:30-7:00 PM | Daniel Boone Regional Library, 100 W. Broadway, Columbia, MO

Open to individuals, caregivers & providers

Hosted by Jonni Jolliff, Volunteer Support Group Leader

RSVP: [info@mgakc.org](mailto:info@mgakc.org)

## NW Arkansas Support Group

**Next Meeting— September 17, 2023**

January-October, every other month on a Sunday | 2:30-4:30 PM | Springdale Public Library, 405 S. Pleasant Street, Springdale, AR

Open to individuals, 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](mailto:jrhuff1@cox.net)



# The Skinny on MGA Support Groups

## Springfield Support Group

### Next Meeting– July 25, 2023

Quarterly on a Tuesday | 5:30-7:00 PM | East Sunshine Church of Christ, 3721 E. Sunshine St , Springfield, MO 65809

Open to individuals, caregivers & providers

RSVP: info@mgakc.org

## St. Joseph Support Group

### Next Meeting– September 10, 2023

2:00-3:30 PM | Rolling Hills Library; Community Room, 1912 N Belt Hwy, St. Joseph, MO 64506

Open to individuals, caregivers & providers

RSVP: donnasjmo@yahoo.com

## St. Louis Support Group

### Next Meeting– October 28, 2023

Quarterly on a Saturday | 10:00-11:30 AM | Glendale City Hall, Glendale MO

Light brunch provided | Open to individuals, caregivers & providers

RSVP: info@mgakc.org

## Topeka Area Support Group

### Next Meeting– August 24, 2023

Quarterly on a Thursday | 6-7:30 PM | Topeka & Shawnee County Library 1515 SW 10th Ave, Topeka, KS

Open to individuals, caregivers & providers

RSVP: mckennafulton@mgakc.org

## Virtual Monthly Meet Up

### Next Meeting– August 28, 2023

4th Monday of the month | 6:30-7:30 PM via Zoom

Open to individuals, caregivers & providers

RSVP by registering for the webinar as posted

## Virtual Youth Group

### Next meeting– TBD

Meets quarterly on a Monday | 6:00 PM via Zoom

Open to youth who are diagnosed with myasthenia gravis and their parents

RSVP: allisonfoss@mgakc.org

## Wichita Support Group

### Next Meeting– TBD

Quarterly on a Saturday | 11:00-1:00 PM |

Open to individuals caregivers & providers

Hosted by Dana & Larry Paxson, Volunteer Support Group Leaders

RSVP: dkptiffany@gmail.com

## Young Friends of the MGA– Kansas City

### Next meeting– December 12, 2023

Quarterly at various locations in Kansas City | 6:00-8:00 PM |

Open to individuals who are generally in their 20s, 30s and 40s

RSVP: allisonfoss@mgakc.org

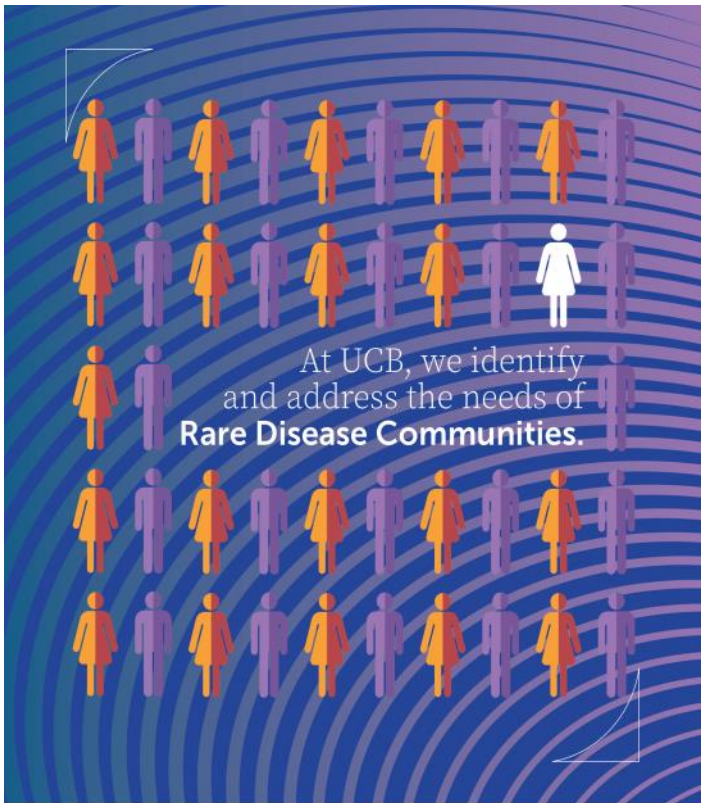
## Young Friends of the MGA– St. Louis

### Next Meeting– TBD

Quarterly at various locations in St. Louis | 6:00-8:00 PM |

Open to individuals who are generally in their 20s, 30s and 40s

RSVP: info@mgakc.org



UCB is committed to supporting rare disease communities. We will seek out scientific innovations that have the greatest impact on the lives of people living with severe diseases.

To learn more, visit [www.ucb-usa.com](http://www.ucb-usa.com)  
©2022 UCB, Inc. St. Dennis, GA 31686  
All rights reserved. US-PDA-2200132

 Inspired by patients.  
Driven by science.

# Date set for 63rd Annual Meeting & Educational Seminar

The 63rd Annual Meeting & Educational Seminar for the Myasthenia Gravis Association will take place on Saturday October 21, 2023 at St. Joseph Medical Center, in Kansas City, MO with registration beginning at 8:30am.

The MGA is proud to offer a hybrid meeting option this year. Attendees will be able to elect whether or not they want to attend in person or virtually. Virtual attendees will receive a meeting packet in the mail prior to the meeting.

The theme of this year's event is Empowerment through Advocacy and Education which will feature 2 well known patients who are active in their state and local advocacy efforts, Alexis Rodriguez and Glenda Thomas. Both Alexis and Glenda will share pieces of their MG story as well as how they are making waves in the community to raise awareness. Following their presentation, we will hear about therapy updates for the treatment of myasthenia gravis. As the MG space continues to evolve, we feel it is important to share another update. After all, lot has changed since last year's meeting.

In partnership with PromptCare, what is known to some as ARJ Infusion Services, the MGA will offer Nursing CEU's to nurses who attend the keynote sessions. This is applicable to both in person or virtual attendance.

Attendees will also enjoy the opportunity to meet with industry partners by stopping by their vendor tables. We'll have lunch and the day will conclude by 2pm. To register, go to [www.mgakc.org/events](http://www.mgakc.org/events) and click register for Annual Meeting.

**VIP OPTION SILENT & LIVE AUCTION**

JOIN US FOR OUR 6TH ANNUAL

# CROWN TOWN

FRIDAY AUGUST 25TH


# TRIVIA NIGHT

6:30PM START @

GEHA FIELD AT ARROWHEAD STADIUM, KANSAS CITY, MO

**TICKETS**  
**TABLE OF 10 - \$1000**  
**COUPLES - \$210**  
**INDIVIDUAL - \$115**  
Includes dinner and drinks

**RESERVE YOUR SPOT BY EMAILING**  
**ALLISONFOSS@MGAKC.ORG**






# NOW APPROVED

Ask about

VYVGART<sup>®</sup> Hytrulo

(efgartigimod alfa and  
hyaluronidase-qvfc)

Subcutaneous Injection  
180 mg/mL and 2000 U/mL vial



Scan to learn more

VYVGART is a registered trademark of argenx.  
VYVGART Hytrulo is a trademark of argenx.  
For U.S. audiences only.  
©2023 argenx US-ESC-22-00141 V1 06/2023

argenx 

## Membership Donations

Shannon Harris  
April Zobel  
Cindy Disque  
Glen Bartlett  
LaDonna Diller  
Jean White  
Marsha Naron  
James and Dianne Deckert  
Robert & Sandra Collard

thank you!

## Memorial Donations

### In memory of Howard Doctor

Joetta Kaaz

### In memory of Joan Stackhouse

Charles & Sarah Stackhouse  
William & Rebecca Stackhouse  
Barbara Bailey  
Mary Stebbins and the Schaller Family

### In Memory of Joan Petty

Scott & Lori Knoche

## Resources for Financial & Medication Assistance

Friends of Man— [www.friendsofman.org](http://www.friendsofman.org)  
GoodRX— [www.goodrx.com](http://www.goodrx.com)  
Needy Meds— [www.needy meds.org](http://www.needy meds.org)  
NORD— [www.rarediseases.org](http://www.rarediseases.org)  
PAN Foundation— [www.panfoundation.org](http://www.panfoundation.org)  
The Assistance Fund— [www.ta fcares.org](http://www.ta fcares.org)

Each of these websites has different criteria for different financial situations.



**A new oral investigational treatment option may help you manage your generalized myasthenia gravis symptoms.**

If you or a loved one has been diagnosed with generalized myasthenia gravis (gMG), the ExpanD Study may be an option. This clinical research study aims to evaluate the effects of an oral investigational medication in managing symptoms in adults with gMG.

### TO BE ELIGIBLE FOR THIS STUDY, YOU MUST:

- Be at least 18 years of age
- Have a confirmed diagnosis of gMG
- Be on a stable dose of gMG medication  
*(only applies to those currently on gMG treatment)*

To learn more, visit  
[ExpanDTrial.com](http://ExpanDTrial.com).

**ExpanD**  
A FORWARD STUDY

**ALEXION**<sup>®</sup>  
AstraZeneca Rare Disease



# Become a 2023 Member of the MYASTHENIA GRAVIS ASSOCIATION

*Help fund the tools  
to fight myasthenia  
gravis!*



-CONSIDER BECOMING  
A MEMBER TODAY-

*Your financial support  
helps to provide*

- new patient packets
- onsite clinic partnerships with neuromuscular specialists
- support & programming at one of our 16 support groups
- education & awareness events
- research
- 1-1 consultations

*programming that is  
100% free to patients*

*your support is appreciated  
beyond measure*



Myasthenia gravis (MG) has thrown a wrench into the lives of many.

Together, we can equip patients with the appropriate tools and resources they need on their journeys with MG.

Help the MGA nail down support for myasthenia gravis patients by becoming a member today!

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

I want to support the MGA by becoming a 2023 member or making a contribution:

- \$25.00 Basic Membership
- \$63.00 63rd Anniversary Membership
- \$100.00 Sustaining Membership
- \$500.00 Patron Membership
- \$1,000.00 Lifetime Membership

\$ \_\_\_\_\_ In memory of: \_\_\_\_\_

\$ \_\_\_\_\_ In honor of: \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

I am a:  MG PATIENT  RELATIVE  FRIEND  OTHER

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

-Contributions may be tax deductible  
-Make checks payable to:  
Myasthenia Gravis Association

## Myasthenia Gravis Association

2340 E. Meyer Blvd.  
Building 1, Suite 300A  
Kansas City, MO 64132  
Phone: (816) 256-4100  
Email: [info@mgakc.org](mailto:info@mgakc.org)  
[www.mgakc.org](http://www.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.



If you would like to be removed from or added to our mailing list, or if you have/will have an address change, please send a note to:

Myasthenia Gravis Association  
2340 E. Meyer Blvd.  
Building 1, Suite 300A  
Kansas City, MO 64132

- OR -

Call us at: (816)-256-4100  
Email us at: [info@mgakc.org](mailto:info@mgakc.org)