



Co– Founder Rev. Bill Stackhouse passes

On Thanksgiving Eve, one month after his 100th birthday, Rev. Bill Stackhouse, co-founder of the Myasthenia Gravis Association (MGA) passed away in Pasadena, CA.

Rev. Stackhouse and his wife Joan founded the MGA in 1960 as they landed in Kansas City post missionary work in West Africa. Joan had been diagnosed with

myasthenia gravis a year before and they found there was little support. Rev. Bill served as a part of Southminster Presbyterian Church in Prairie Village for 5 years prior to moving to the East Coast. During those 5 years, the Stackhouses built the foundation for the MGA. The Stackhouses retired to Pasadena over 25 years ago.

We are grateful for the work that Rev. Bill and Joan did and are thinking of their family during this difficult time.



Executive Director attends Rare Disease Connect in Neurology in Spain



In early December, Allison Foss, Executive Director of the MGA attended the Rare Disease Connect in Neurology Conference in Madrid, Spain sponsored by UCB Pharma.

Allison was able to provide input on a panel regarding patient experiences in the United States alongside Jude Kings, RN from the UK and Pushpa Narayanaswami, MD, Beth Israel Deaconess Medical Center. While an honor to be able to share what we are doing here in the USA it was also an honor to learn what organizations are doing across the globe to combat myasthenia gravis and to raise awareness.

One major takeaway from the conference for Allison was that while living in different time zones and regions and speaking different languages, many of the barriers patients face are the same no matter where they live. The other major take away

from the conference is the reinforcement of what an exciting time this continues to be for patients with myasthenia gravis and the therapies in development.

We have some new faces at the Myasthenia Gravis Association to share with you.

Hello to McKenna Fulton—Community Program Coordinator

McKenna Fulton has joined our team at the Myasthenia Gravis Association as our Community Program Coordinator. If you are in the Kansas City and surrounding area, McKenna will be in the clinics at both the University of Kansas and St. Luke's as well as supporting the Kansas City area support groups. We are excited to have her on board.

McKenna graduated from William Jewell College in 2022, earning a B.A. in Nonprofit Leadership and B.S. in Business Administration. Aside from meeting new patients and learning their stories, McKenna is eager to spread awareness about Myasthenia Gravis. In her free time, she likes painting and trying out different coffee shops in the Kansas City area. McKenna is from Camden Point, MO.



Tom Vansaghi, PhD has joined our Board of Directors.

For more than a quarter of a century, Dr. Tom Vansaghi has served in variety of senior-level positions in public service, higher education, and the nonprofit sector. He began his career as a volunteer on a gubernatorial campaign (Mel Carnahan in 1992) that led to a series of leadership roles in Jefferson City, Missouri where he worked in state government with the Office of the Governor and Missouri General Assembly. He was recruited to lead the government relations, fundraising, strategic planning, marketing, public and community relations for a regional state university (Northwest Missouri State University in 1999) and later an urban/suburban community college district (Metropolitan Community College in 2004). Later, he was appointed as the executive director of an international association of primary care physicians dedicated to promoting the triple healthcare aim of enhancing the patient experience, improving the



health of the population, and reducing costs (North American Primary Care Research Group in 2013). In 2015, Dr. Vansaghi became a tenured professor of nonprofit leadership at William Jewell College in Liberty, Missouri. At Jewell, he engages undergraduate students in critical thinking to prepare them to pursue meaningful lives leading nonprofit organizations. He also serves as the director of strategic planning for the college. He has served as a senior fellow at the Midwest Center for Nonprofit Leadership where he teaches graduate seminars and courses on nonprofit fundraising since 2010.

Dr. Vansaghi has been an advocate for social justice since the 1990s when he served as the chair of the Board of Directors for the National Conference of Christians and Jews (later the National Conference for Community Justice) in Kansas City. At William Jewell College, he has taught a required undergraduate course on identity, which he focuses on race since 2017. From August 2021 until June 2022, he served as an interim executive director to a diverse-by-design, urban charter school (Citizens of the World) in addition to teaching full time.

Vansaghi holds a bachelor's degree in government from Northwest Missouri State University, a Master of Public Administration degree from the University of Missouri-Columbia and a PhD in Political Science and Public Affairs from the University of Missouri-Kansas City. He lives in Brookside (Kansas City, Missouri) with his wife Lisa, and twin boys Jack and Ben.



MGA STAFF Executive Director Allison Foss

Community Program Coordinator McKenna Fulton

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CONTACT

816-256-4100 info@mgakc.org

A Message from Allison

2023 has started off with change for the MGA. We said goodbye to Meridith O'Connor, St. Louis Program Coordinator and Catherine Singleton, Patient Care Specialist. We are grateful for the work they did in their respective roles.

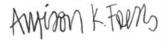
We also said goodbye to Dr. Tania Papsdorf and our Springfield Clinic partnership at Cox Health as she left the practice. We hope in the future we can hold a partnership there once again.

Goodbyes leave room for hellos. We are excited to say hello to McKenna Fulton, our Community Program Coordinator as well as Tom Vansaghi, PhD to our Board of Directors and to officially roll out our Central Arkansas Support Group on March 20th. We are working on some amazing programming for 2023 with a wide variety with we think many of you will enjoy.

If we missed you at a clinic during our transition, please do not hesitate to reach out as we are here to help.

As we have said many a time over the last few years, there is often silver linings to change and we look forward to the momentum that continues to connect us with many of our patients on the ground. See you soon!

With Gratitude,



Allison K. Foss | Executive Director | allisonfoss@mgakc.org

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Noteworthy News

argenx seeking approval on subcutaneous efgartigimod

argenx has sent a Biologics License Application to the U.S. Food and Drug Administration for under the skin, subcutaneous efgartigimod (Vygart) to treat generalized myasthenia gravis (gMG) in adults. The application was submitted in September and a decision is expected by the FDA in June 2023.



The submission was based on positive data from the Phase 3 ADAPT-SC trial demonstrating noninferiority of subcutaneous efgartigimod compared to intravenously administered VYVGART (efgartigimod alfa-fcab) based on total immunoglobulin G or IgG reduction at day 29.

Efgartigimod is an antibody fragment designed to reduce pathogenic immunoglobulin G (IgG) antibodies by binding to the neonatal Fc receptor and blocking the IgG recycling process. Efgartigimod is being investigated in several autoimmune diseases known to be mediated by disease-causing IgG antibodies, including neuromuscular disorders, blood disorders, and skin blistering diseases, in both an intravenous and subcutaneous



23andMe offers research study for patients with myasthenia gravis

23andMe, which is a genetics and ancestry biotech company is seeking individuals with myasthenia gravis to learn more about the genetics of people living with myasthenia gravis. This research study can be done from the comfort of your own home by providing your saliva and self reported data. They are looking for 1,000 people to assist with the study and all participants must be over 18 years old. To register go to https://enroll.23andme.com/research/rare-disease/identity/



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





To to learn more about the clinical research study and to see if you may qualify, please visit our website at www.flexMGtrial.com





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.





ALXN2050-MG-201_Half Page Ad_V1_03AUG2022

MGA holds 62nd Annual Meeting & Educational Seminar

On November 12, 2022, the 62nd Annual Meeting & Educational Seminar was held virtually with a record 259 registered participants including 80 nurses who received CEU's for their participation.

Participants received updates on research and clinical trials on current and potential therapies for myasthenia gravis from Dr. James "Chip" Howard of University of North Carolina— Chapel Hill. Some of the pending therapies that Dr. Howard addressed included Batoclimab, Descartes-08, Inebilizumab, Nipocalimab, Rozanolixizumab and Zilucoplan. Dr. Howard also addressed the ongoing issues for



patients with myasthenia which is showcased in the fact that while new therapies are coming out there are still barriers. Some of the barriers including the toxicity and side effects of the medications to transportation to treatments. Following Dr. Howard's presentation, Dr. Mazen Dimachkie, University of Kansas Medical Center moderated a Q&A session.

In addition to the keynote, the MGA was able to honor some very special people with awards including the Diana Wilmoth "Sunflower" Award given to Dr. John Sand, the Stackhouse Award to Sandy and Gary Gardner and the Volunteer of the Year Award to Keith Asaeli.

Thank you to all who attended and tuned in to the meeting. We are looking forward to the 2023 meeting being back in person with a virtual option for those who prefer the comfort of their home on October 21, 2023.



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Myasthenia Gravis Clinical Trial Updates

University of Kansas Medical Center

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

Myasthenia Gravis Clinical Trial Updates

Janssen

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

Immunovant MG

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

Recruiting in Little Rock, AR & St. Louis, MO,

ALXN2050 expanD ClinicalTrials.gov Identifier: NCT05218096

The study consists of a blinded 8-week Primary Evaluation Period (PEP) and a blinded 26-week Extended Treatment Period (ETP). After completion of 34 weeks of treatment, participants will enter an Open-label Extension (OLE) Pe-riod for up to 1.5 years.



The Skinny on MGA Support Groups

COVID-19 POLICY

COVID continues to plague many of our service areas, thus; the board has put a policy in place to protect the health and safety of our community. The following policy reflects our current decision-making process on in-person programming:

In areas where there is a high level of COVID-19 transmission per the CDC, in-person support group meetings will be suspended until the risk level returns to low or medium. The MGA will try to make decisions a week in advance when able. Please check the calendar online and your email for any updates.

Central Arkansas Group

Next Meeting- March 20, 2023

5:30-7:00 PM | Fletcher Library, 823 N. Buchanan St, Little Rock AR 72205 Open to patients, caregivers & providers RSVP: info@mgakc.org

Coffee with a Coordinator-St. Louis

Next Meeting-February 23, 2023

Monthly | 10:30-11:30 AM | St. Louis Bread Company, 10221 Manchester Rd, Kirkwood, MO Coffee is Dutch treat | Open to patients, caregivers & providers RSVP: info@mgakc.org

Eastsiders Lunch Bunch

Next Meeting-March 1, 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 patients, caregivers & providers Hosted by Carol Hunt & Raymond Hankins, Volunteer Support Group Leaders RSVP to mckennafulton@mgakc.org

Greater Kansas City

Next Meeting— April 15, 2023

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 patients, caregivers & providers

RSVP: mckennafulton@mgakc.org

Kansas City Northland

Next Meeting-March 9, 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 patients, caregivers & providers

Hosted by Sandy Gardner, Volunteer Support Group Leader

RSVP: mckennafulton@mgakc.org

Mid-Missouri Support Group

Next Meeting-February 16, 2023

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

Open to patients, caregivers & providers

Hosted by Jonni Jolliff, Volunteer Support Group Leader

RSVP: info@mgakc.org

NW Arkansas Support Group

Next Meeting- March 19, 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 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

The Skinny on MGA Support Groups

Springfield Support Group

Next Meeting-February 23, 2023

Quarterly on a Tuesday | 6:00-7:30 PM | The Library Center, 4653 S. Campbell, Springfield, MO 65810 Open to patients, caregivers & providers

RSVP: info@mgakc.org

St. Joseph Support Group

Next Meeting-March 12, 2023

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

Open to patients, caregivers & providers

RSVP: donnasjmo@yahoo.com

St. Louis Support Group

Next Meeting- April 1, 2023

Quarterly on a Saturday | 10:00-11:30 AM | Glendale City Hall, Glendale MO Light brunch provided | Open to patients, caregivers & providers

RSVP: info@mgakc.org

Topeka Area Support Group

Next Meeting- April 13, 2023

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

Open to patients, caregivers & providers

RSVP: mckennafulton@mgakc.org

Virtual Monthly Meet Up

Next Meeting-February 27, 2023

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

Open to patients, 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- March 1, 2023 | WSU Health Fair

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

Open to patients, caregivers & providers

Hosted by Dana & Larry Paxson, Volunteer Support Group Leaders

RSVP: dkptiffany@gmail.com

Young Friends of the MGA- Kansas City

Next meeting-TBD

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

Open to patients 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 | LOCATION TBD

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

RSVP: info@mgakc.org

First dosing of CAR-T Therapy has begun

(information shared from UCI Health publication 11/2022)

Carteisan Therapeutics has begun the first dosing of its placebo controlled, Descartes-08.

Descartes-08, is an mRNA-modified, autologous CAR T-cell product designed to attack B-cell maturation antigen. It is the first clinical trial using CAR T-cell therapy to treat an autoimmune disease.

CAR T-cell therapies have been a huge success in treating some cancers, but their use of integrated DNA carries a long-term risk for severe complications. RNA-based CAR T-cell therapies minimize that risk and offer the potential of significant long-term benefit with minimal side effects. Descartes-08, unlike other available therapies, specifically targets the production of disease-causing antibodies by addressing the role of plasma cells, which are the antibody-producing cells that cause generalized myasthenia gravis.

In 2021, Cartesian Therapeutics released results from the first cohort of the ongoing phase 1/2a clinical trial of Descartes-08, which showed that the therapy was well tolerated, with no evidence of cytokine release syndrome or other serious product-related adverse events. According to Cartesian, all patients experienced at least a full class improvement on the Myasthenia Gravis Foundation of America (MGFA) Clinical Classification system. Patients also showed marked improvement on the Myasthenia Gravis Composite (MGC) scale, a standard measure of overall disease severity. Cartesian reported mean improvement on the MGC scale of more than 50% about three months after Descartes-08 therapy.

According to Cartesian, Descartes-08 uses a novel modality and mechanism of action for treating generalized myasthenia gravis and other autoimmune diseases. It differs from anti-B-cell agents, which do not address long-lived plasma cells, and differs from FcRn blockers or complement inhibitors, which try to intervene only after the autoantibodies are produced and pathogenic mediators are amplified. Descartes-08 is intended to halt production of autoantibodies by targeting pathogenic long-lived plasma cells that can survive for decades within the body.

Save the Dates





12th Annual MGA Triple
Crown Showdown
8am | Sunday May 21, 2023
Town Center Plaza,
Leawood, KS
Patients registration FREE—
contact info@mgakc.org for
code
www.mga5k.com
Patients can request a customized discount code to share with
family and friends!



5th Annual MGA Snowflake
Shuffle 0.1K
10:30am | Saturday June
10, 2023
Linwood Recreation Center,
Wichita, KS
Registration coming
soon!
Patients registration FREE!



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Your financial support enables the MGA to continue reaching patients impacted by myasthenia gravis every single day. We thank you for your continued support!

iGive.com

iGive.com is an online shopping portal where a portion of your purchase is donated to your favorite cause. iGive.com turns everyday shopping into donations for a worthy cause at no cost to shoppers or causes they support. Head to iGive.com to learn more!

Legacy Giving

There are multiple ways to make an impact at the MGA: include the MGA in your will or estate plan, become a member of the MGA, make a contribution toward the MGA, or volunteer!

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Jim Blaufuss Jeanette Cashatt
Steve Kays Joan Stackhouse

Gordon & Marie Nave Jimmie Harbour & Sharon East

Erwin Clark Marilyn Barrett
Donnie Davis Harold Wood
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Sandy & Gary Gardner

Janie Watts Lisa Gioia Judy Redmyer Dan Gifford

Richard DeGeorge Anita & Everett Jenkins

Janice Frazer Joann Andersen Charlene Vollmer Craig & Barb Foss

Jeff & Nancy Shniderman

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Richard and Jan McGuire in memory of Dr. Jacob McGuire

thank you!

Alpha Kappa Delta in honor of Betty

Clark

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- support & programming at one of our 16 support groups
- education & awareness events
- research
- 1-1 consultations

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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: | Name |
|---|---|
| | Address |
| \$25.00 Basic Membership | |
| \$63.00 63rd Anniversary Membership | City, State, Zip |
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| \$ In memory of: | I am a: MG PATIENT RELATIVE FRIEND OTHER |
| \$ In honor of: | 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 |



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

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- OВ -

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ADM of the MGA

through awareness, education and patient services. those who are affected by this autoimmune, neuromuscular disease, The Myasthenia Gravis Association (MGA) is dedicated to improving the quality of life for

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