myasthenia gravis association
MGA
of the heartland

Strength and Hope Through
CONNECTIONS

Volume 62 Issue 2

Spring 2022

MGA Executive Director Meets MGA Founder

Sometime last fall, I was in my kitchen fixing dinner after a routine plasmapheresis treatment when I saw the message light blinking on the MGA phone system on my computer. I pressed play and was greeted with the sweetest voice of what I thought I heard them say, “My name is Joan Stackhouse.” I replayed the message once the hum of the microwave stopped and sure enough, it was Joan Stackhouse, otherwise known as the founder of our 62-year-old organization! I about dropped my dinner.

We had not had contact with Joan for many years as far as I was aware. Diagnosed with myasthenia gravis some 63ish years ago while doing mission work in Africa, Joan and her husband, Reverend William (Bill) Stackhouse, relocated to Kansas City to lead Southminster Presbyterian Church around the same time. Once they landed in Kansas City with two small children in tow and a diagnosis of a rare disease, they recognized they were going to need a little bit more support to navigate these new waters. Thus, the Myasthenia Gravis Association was born to support patients, their families, and friends as they too began to wander into the unknown.

Pictured: Allison Foss & Joan Stackhouse

Although the Stackhouse family left Kansas City five or so years later to continue their work within the church, they knew the organization was in good hands, providing the same quality of services as it had been during their leadership.

Nonetheless, touch was lost between Joan and the MGA, so when I heard that voice several months ago on the phone there was one thing that struck me—I have to meet this family! A few detours along the way as a result of COVID-19, I arrived last week at their nursing home in Pasadena, CA, only to find Joan sitting sweetly in her wheelchair at the entrance waiting for me. It was surreal that this moment was occurring.

Continue on page 4.

2022 MGA Triple Crown Showdown Race Ambassadors Help Gear Up for 11th Annual Run

In just a few short weeks, hundreds of participants will be taking to the streets of Leawood, KS, to help raise awareness for myasthenia gravis at the 11th Annual MGA Triple Crown Showdown; the MGA's largest awareness and fundraising event.

Participants are treated to swag, photo ops, breakfast, and opportunities to interact with vendors prior to and after the race. There are various participation levels from the 5K, to the Mile Mosey, and to the Tot Trot for the kids. For those unable to attend in-person, register for "Stuck in the Stall" and you will receive a t-shirt mailed to them following the event.

We are lucky enough to have the support of 6 Race Ambassadors (pictured above)! Each ambassador competes against one another to bring in the most participants. This is a fun challenge to get our community involved and create more awareness around MG! Thank you to our dedicated ambassadors! A huge thanks to argenx and Alexion for being presenting sponsors of our event.

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MGA Welcomes Two New MAC Members: Dr. Ghazala Hayat & Dr. Tania Papsdorf

Ghazala Hayat, MD, St. Louis University, and Tania Beltrain Papsdorf, MD, Cox Health Springfield, have joined the MGA's Medical Advisory Committee. Both physicians are respected neurologists throughout our service area, specifically with regard to myasthenia gravis. The MGA has established a clinic with each physician at the hospital they are affiliated with. Please give them a warm welcome to our MAC!

Dr. Ghazala Hayat

Dr. Ghazala Hayat is the Director of Neuromuscular Services and Clinical Neurophysiology and a professor of neuromuscular diseases in the Department of Neurology at Saint Louis University School of Medicine. She is also the Director of the ALS Center of Excellence. Dr. Hayat specializes in clinical neurophysiology, nerve conduction studies, electromyography, electroencephalograms, and spasticity and headaches.

Dr. Tania Papsdorf

Dr. Tania Papsdorf is a neuromuscular specialist at CoxHealth in Springfield, MO. After moving to Springfield, MO, she established the Myasthenia Gravis Clinic as well as the ALS Clinic of the Ozarks. Dr. Papsdorf earned her degree in biology and creative writing at Kansas State University, and later attended medical school at the University of Kansas School of Medicine. Her neurology residency and neuromuscular fellowship were completed at the University of North Carolina in Chapel Hill where she trained with Dr. James F. Howard Jr., a well-known neurologist in the myasthenia world.When not busy working, Dr. Papsdorf enjoys running, yoga, baking cakes, and spending time with her husband (also her high school sweetheart!) and two kids.

A MESSAGE FROM THE MGA'S EXECUTIVE DIRECTOR

Since the last publication of our Strength & Connections, I myself have experienced a myasthenic exacerbation. While frustrating as all get out, working with the various medical personnel and trying to get myself well, if I may add; this has been a very good reminder to me of why we are here and why we do what we do.

As I am a bit slower moving these days and trying to get back on my feet, I can't help but think this is going to be a positive for our organization. It's been several years since MG stopped me in my tracks. Most of the time I race from thing to thing forgetting I have a chronic rare disease but this not so gentle reminder is going to allow me to better see what many face on a day to day scale and how others utilize coping skills to get back on their feet. You're only as good as a true and tried experiment that you speak of.

So I as often say to others, "give yourself grace," "rest and recover," and I'm trying to do those things as I come out of this exacerbation with more care and concern for this rare disease that ties us all together. But my hope doesn't waiver. I know we are on the cutting edge of treatments that could change all of our lives. Until then, may we all see better days ahead.

Be well,

Allison Foss, Executive Director
allisonfoss@mgakc.org

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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.

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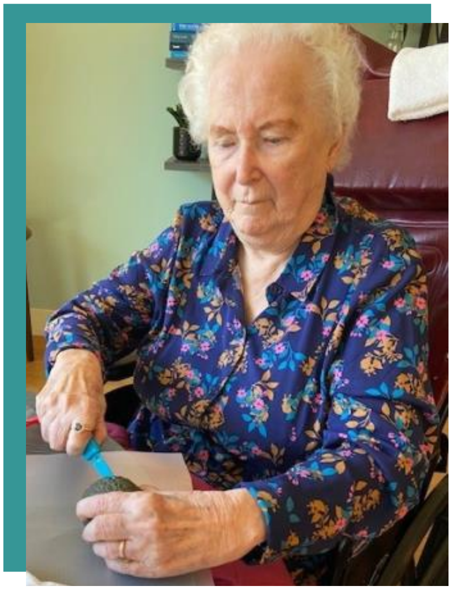


In chatting with Joan over the next several hours, I learned so many amazing things about her. When Joan's family transitioned to their chapter in the Pasadena Retirement Community, she started teaching art classes to other residents. Many of her pieces of art hang in the nursing home and they are beautiful. They are full of tiny little details and represent stories about the landscapes. As I watched her cut open a fresh avocado from her son's tree to share with me using a teal knife it made me smile as teal is the official color of MG awareness. I later learned teal is Joan's favorite color and that was long before she knew about the association. Joan and Bill have touched lives across the globe and it was obvious as I was there watching their interactions with other residents and staff, the kind of life they have lived. Nearly everyone we encountered knew who I was before Joan even introduced me as Joan had shared with them the purpose of my visit.

MG can rob you of many things in life, but I'll tell you what; one thing it doesn't rob you of is making connections with some of the most amazing gems on this planet. Late last year, we lead our annual campaign on the words, "let your light shine," and as I was flying home, I couldn't help but think how much the Stackhouse family has let their lights shine. In the face of adversity, they've embraced it and challenged themselves to be better and make a difference.

I'll leave you with this: Joan said to me, "I was determined if I was going to do anything, it was going to be first-class because we were not going to have a flimsy organization." I will remember that for as long as I live and work to improve awareness of myasthenia gravis. Never give up!

**The following article can be found on our blog, MGA Digest. Head to our blog to read the latest happenings at the MGA!*

SAVE THE DATE: 4th Annual Snowflake Shuffle 0.1K to take place on 6/18/22 in Wichita!

Our annual awareness 0.1K is coming up on **Saturday, June 18th, 2022**, at the Linwood Recreation Center in Wichita, KS from 10:30 AM-1:00 PM.

Join us for an uplifting morning, raising awareness for myasthenia gravis. We'll have boxed lunches, photo ops, vendors, raffles, and the best part; you don't have to run or walk anywhere! Head to www.mgakc.org, click events, and then click Snowflake Shuffle to register. Family and friends can register for just $25.

*Register by 5/31/22 to be guaranteed a t-shirt and swag bag!

VYVGART®
(efgartigimod alfa-fcab)
Injection for Intravenous Use
400 mg/20 mL vial

Picture your life in motion

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

The Skinny on Our MGA Support Groups

Coffee with a Coordinator– St. Louis

Meets monthly on the 4th Thursday from 10:30-11:30 @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– April 28th

Eastsiders Lunch Bunch

Standing meeting the 3rd Wednesday of the month from 11:30-1:30pm 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 kamibrendel@mgakc.org to attend.
Next Meeting– May 18th

Greater Kansas City

Meets quarterly on a Saturday from 10-12 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 kamibrendel@mgakc.org to attend
Next Meeting– July 16th

Kansas City Northland

Meets bimonthly January-September on a Thursday from 12-1:30 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 kamibrendel@mgakc.org to attend
Next Meeting– June 9th

Mid Missouri Support Group

Meets quarterly on a Thursday from 5:30-7 at the 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– April 28th

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– May 1st

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– May 3rd

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– April 30th

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 kamibrendel@mgakc.org to attend
Next Meeting– June 30th

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
Next Meeting– May 16, 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– June 6th

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– June 18th– 4th Annual Snowflake Shuffle 0.1K at Linwood Recreation Center, Wichita

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

Making Plans…

Kami Brendel, Patient Care Specialist

You know the saying, “Life is what happens while we’re busy making other plans?” Like many people I’ve known, the career I’ve grown to love is not the one I dreamed of as a child. In fact, I wasn’t even aware of it! As a kid, I wanted to follow in my mom’s theatrical footsteps. She was the drama teacher at our local high school. If you’d told me I would one day become a patient care specialist supporting people who live with chronic health conditions, I’d have been totally confused. But a magical aspect of life is that if you stay open-minded and say, “Yes” when opportunities arise, you often stumble into just the right scene with just the right players, at just the right time. I am thankful that I said, “Yes” to opportunities for work that inspires me on a daily basis. I’m grateful to be surrounded by people who not only live, but thrive, in the face of health challenges others can only imagine. These stories of strength and hope are both moving and motivational.

As for my story, connecting the dots from those early years of watching my mom direct plays on-stage to working in the rare disease arena may seem a long, disjointed trek, but it really wasn’t. I began my journey just as I had planned, working in theatre. That entailed many hours onstage becoming comfortable with the art of public speaking. Fast forward to Kansas City, 2016: I was newly married and looking for steady work where I could utilize my theatre training and hopefully make a positive impact. I had no idea what that would look like – but apparently the universe did. One day, I was digging through online job postings, and there was a listing screaming my name. (Okay, not literally – the sound was turned down on my computer…but I bet if I had it turned up, I’d have heard the ad shouting my name.) It was a job that checked all the right boxes. The next thing I knew I found myself working for a healthcare marketing company, training patient speakers to publicly share their stories of courage and perseverance living with rare chronic conditions. These patients had two things in common – they were grappling with rare disease states, and they were unbelievably inspiring. Many beautiful friendships were built, and many incredible stories of hope were told during my time there.

Then came the pandemic, and everyone’s world was turned upside down. Like many people, I took some time for self-reflection during the lockdown and decided I wanted to try something new. I was ready for a change. Again, life happened to me while I was making other plans because just as I was about to embark on an entrepreneurial pursuit from my home office, along came the Myasthenia Gravis Association. I believe everything happens for a reason. When I saw the position description for Patient Care Specialist, it just wouldn’t let me go. I’d worked with so many rare pathologies, but I had never heard of myasthenia gravis. The more I read and learned about the condition, the more I felt I wanted to know. When I saw the breadth of work being done by this tiny organization in Kansas City – my interest was definitely piqued. And when I met our Executive Director, Allison, and Program Coordinator, Meridith O’Connor, I was hooked. So far, we’ve had an amazing ride. I don’t know what the future holds, but I am going to try not to make any plans just in case… I mean, life is gonna happen and there’s no limit to what this dynamic agency of dedicated professionals and this determined patient population can achieve if we stay open to possibility, and just say “Yes” to opportunity. Life has taken me on some pretty great adventures so far, and I’m excited to see what’s next!

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

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

WASHU

MOM-M281-011, PI: Dr. Al-Lozi (see trial above)

A Phase 2, Randomized, Double-Blind, Placebo-Controlled Multicenter Study to Evaluate the Efficacy and Safety of ALXN2050 in Adult Participants with Generalized Myasthenia Gravis, PI: Dr. AL-Lozi

At the first visit, the study doctor will check if each person can take part. For those who can take part, participants will continue with their standard medicines for this condition during the study. Each participant will have a check-up by the study doctor. Then, the participants will have 1 of 3 treatments:

A low dose of ALXN2050
A high dose of ALXN2050
A placebo, however these participants will be randomized to receive medication after the first 8 weeks of the study.

Participants will not know which treatment they receive, nor will their study doctors. This is to help make sure the results are more reliable. After 26 weeks all patients are allowed to continue on a selected ALXN2050 dose for up 1.5 years while the Sponsor seeks drug approval.

A Study To Evaluate Efficacy, Safety, Pharmacokinetics, And Pharmacodynamics Of Satralizumab In Patients With Generalized Myasthenia Gravis, PI: Dr. Pestronk

At the first visit, the study doctor will check if each person can take part. For those who can take part, participants will continue with their standard medicines for this condition during the study. Each participant will have a check-up by the study doctor. Then, the participants will have 1 of 3 treatments:

A low dose of Satralizumab
A high dose of Satralizumab
A placebo, however these participants will be randomized to receive medication after the first 24 weeks of the study.

Participants will not know which treatment they receive, nor will their study doctors. This is to help make sure the results are more reliable. After 26 weeks all patients are allowed to continue on a Satralizumab dose based upon their weight for while the Sponsor seeks drug approval.

For more information regarding any of the following studies, contact Oliver Doerr: oliver.doerr@wustl.edu

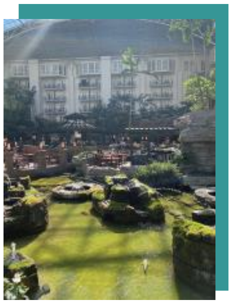
Currently, there are no updates for MU or SLU.

Transforming Healthcare Through Vulnerability

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

Before I knew it, I was standing at the entrance of the resort, in awe of my surroundings. Palm trees, coy ponds, little quaint villages…charmed by the idyllic accommodations. It felt as though I was in a totally different country. An exotic and foreign place where I was about to embark on new experiences. Then again, I was struck by how at home I felt. Like, this is where I was meant to be. All I could think of was, "I can't believe myasthenia gravis led me here."

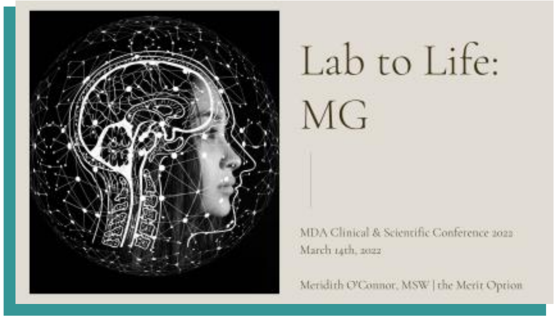
Diagnosed with a rare disease at such a young age, you have no idea how your life is going to look. Plans and priorities change, and the future becomes too overwhelming to think about because you are just attempting to survive the day. I've spent most of my life trying to keep my head above water, but in moments like the one I mentioned above, a wave of pride and true happiness came over me.



Around fall of 2021, I received an email from the Muscular Dystrophy Association, inviting me to serve as their guest speaker for the patient perspective of myasthenia gravis at the Clinical & Scientific Conference of 2022. The conference took place in mid-March at the Gaylord Opryland Resort & Convention Center in Nashville, TN. I had never attended a national medical conference, nor stayed at a beautiful resort such as this one. It was a pinch-me moment, to say the least.

MG, however, was less than impressed. In fact, it got a kick out of the some of the ironic situations I stumbled upon such as the map of the resort that was handed to me at check-in. Yes, you read correctly– a map. My room was over the river and through the woods so to speak; a trek for any person, but particularly a person with a neuromuscular disease. MG never fails to put me in my place either. The schedule was jam-packed and being the ambitious person that I am, I signed up for specific speaking engagements I was interested in attending. Amused by my enthusiasm, MG put me to bed and not in the presence of these speakers. I should have predicted that my unpredictable disease would act up! Nevertheless, these challenges I continue to face as a result of this disease are the reasons why I use my voice. In actuality, these obstacles help me in some twisted, paradoxical way.

The session I was a part of was called, "Lab to Life: MG." My co-panelists, all of whom which were researchers and clinicians, presented on the journey a drug takes from its inception to the hands of the consumer. I, the patient perspective, discussed my experience with MG, the experiences I see my fellow MG community members face, why these experiences matter, and how to utilize them constructively in healthcare.



Lab to Life:
MG

MDA Clinical & Scientific Conference 2022
March 14th, 2022

Meridith O'Connor, MSW | the Merit Option

The audience was comprised of providers, pharmaceutical company reps, and other affiliates in the HC industry. Dr. Kaminski, Chair of Neurology & Rehabilitation Medicine, and Professor of Neurology, Pharmacology, and Physiology at George Washington University, led the session followed by Linda Kusner, PhD, George Washington University; Petra Duda, MD, PhD, UCB Biopharma; and Sarah Jones, MD, Assistant Professor, UVA Neurology.

Continue to page 12.

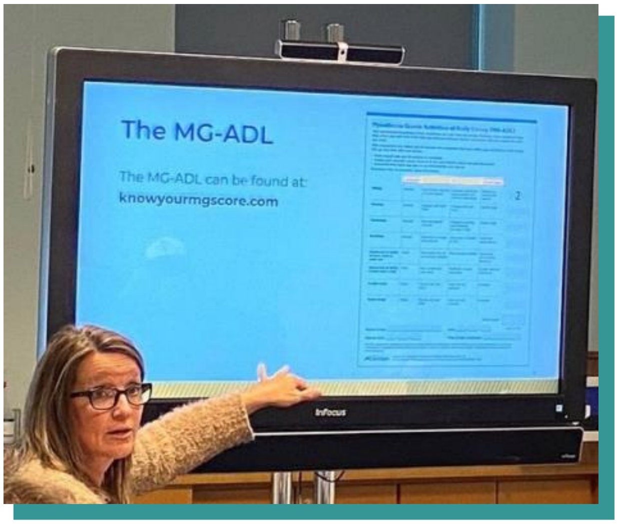
Being the youngest in the room is something I am quite used to with an MG diagnosis, so that was nothing new, but being surrounded by all of these incredibly intelligent people was slightly intimidating. My shoulders unstiffened and my mind was quickly put to ease when just before the presentation, my co-panelists and I were making small talk, chatting briefly about the MG landscape. The thing is, they were asking *me* questions about MG and wanted to know my take on certain topics. It was evident that my perspective was not only desired but valued. Their genuine interest in what I had to say made me feel like the work that I am doing in the MG community is actually creating positive change, and that's all I can really ask for.

I left Nashville with so many emotions, especially after reuniting with the neurologist that saved my life 17 years ago. My biggest takeaway was the reminder of my superpower. We all have various strengths and skills but when I was diagnosed with MG, I didn't know what I had anymore. I felt as though I had nothing. Although it took me awhile to find, I discovered my superpower: vulnerability. It's not always the most fun superpower but when I do use it, it is transformative.

The MG-ADL: What is it? What Does it Measure?

Are you familiar with the MG-ADL? The MG-ADL, otherwise known as the Myasthenia Gravis Activities of Daily Living Profile, is a scale healthcare providers use to assess the severity of MG symptoms a patient is experiencing. Much of what is measured are activities that you do in your day to day life such as talking, chewing/swallowing, the ability to do routine tasks such as brushing your teeth, combing your hair, etc. Neurologists are typically the ones that utilize this scale and will rate a patient's abilities based on their clinical judgment during or after a neurological exam. Once each task is rated, an MD-ADL score will be calculated. Your MG-ADL score will then help your doctor quantify your MG experience in conjunction with your personal account of your quality of life, helping them to make appropriate clinical recommendations to treat your myasthenia gravis.

If you are curious about the MG-ADL, give it a Google search and you will find that there are several different resources out there that show what exactly is being measured. During your appointment, you may not even know your doctor is using this tool. Regardless, a good way to better understand your own MG is to ask them what your MG-ADL score is. Furthermore, ask them what this score means clinically, and how they use to weigh treatment options.



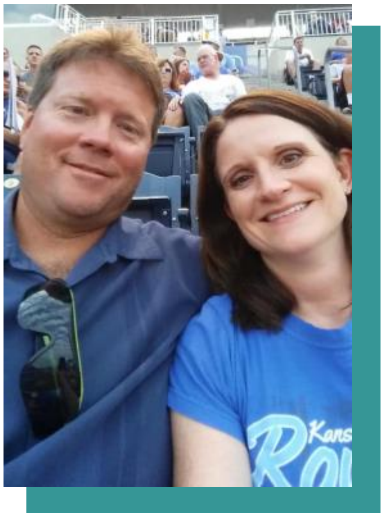
The MG-ADL

The MG-ADL can be found at:
knowyourmgscore.com

Lastly, thank you to Kathy Logan with Alexion who recently presented on the MG-ADL scale to multiple support groups for the MGA, educating patients both new and veteran.

Getting to know nurse Judy

The following interview was conducted by Kami Brendel.



Recently, I found myself sipping coffee and enjoying an incredible breakfast burrito in a diner in Lenexa. It was a relaxing Friday morning as I sat down for a one-on-one chat with University of Kansas Health System's very own, Nurse Judy – a familiar face to many MG patients. I asked her to join me for an interview so our readers could learn a bit more about multi-dimensional Judy: the mom, the wife, the volunteer, the destructor of walls (we'll get to that part, hang tight…) And I was greeted not only by our healthcare hero, but by a special guest star as well – her husband, David. Our meeting became a two-for-one interview that did not disappoint.

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MGA: "Tell me a little bit about your background and how that translated into a career in healthcare."
Judy: "I grew up on a farm, and I'm the first one in my family to have gone to college. I started working in a nursing home at age 14 in the kitchen and laundry. When I was 18, I got my certified nursing assistant license, and I loved it. I get very attached to all my patients."

At this point, Judy gets a bit emotional. It is evident how deeply she cares for others – not only for her patients, but for other people, full stop. It became crystal clear to me that Judy is, at heart, a true care-taker putting others first and foremost in her day-to-day life.

MGA: "So what got you started at a nursing home after growing up on a farm?"
Judy: Well, I had to work.

David chimes in here as he does a few times. He's obviously incredibly proud and supportive of Judy. We'll learn more about how they met soon, but suffice it to say, that this couple, married 32 years, shares an enviable bond of trust and mutual respect.

David: "Well, in a small town, there weren't a whole lot of options."
Judy: "I tried other things over the years, but I've always come back to healthcare. We got married when I was 17 and David was 18."
MGA: "Tell me about your young love story!"
Judy: "We both went to high school in Garnett, Kansas."
David: "We met Judy's freshman year when her family moved to Greely. We both went to high school in Garnett."
Judy: "And he liked me."
David: "So did a few others…"
MGA: "So, how did you meet?"
Judy: "He knew all the classes I took; he followed me around."
David: "Here we go…"

They go on to explain that they were at a dance with a group of friends and Judy was with another boy. Judy and the boy broke up that night because he noticed that she had more fun with David than she had with him! The rest, as they say, is history.

Judy: "It will be 33 years in June. We started out young, but he's always been my support."

That history entails Judy and David marrying and later welcoming two daughters, Samantha (Sam) and Erin. Judy found herself running a daycare out of her home when Erin, their youngest, was in first grade.

Judy: "I kept saying I wanted to be a nurse, but I was terrified to go back to school at 30. David kept encouraging me to do it. So, I finally got my LPN license, was hired as a temp at KU in neurology, and I loved it. I've been there ever since."

Judy told me that she started to go back to school at one point, but between family obligations and a battle with breast cancer, she chose to stay where she is, doing what she loves, where she is needed most.

MGA: "Who was your biggest influence in becoming a nurse?"
Judy: "My grandma. She taught me to do things like embroidery and sewing. She was always there for me.

Judy Cont'd: As she grew older, David and I were able to care for her and my grandfather during various health crises. Grandma saw everything as a learning experience, and her motto for me was, 'It'll make you a better nurse.'"

MGA: "What are some unexpected benefits of your profession?"

Judy: "Well, you have to be there for the people, it's not about the money. So, one of the benefits is the attitude of the patients. They are the most amazing people you will ever meet. I look at them and am inspired by the hope and positivity they bring. The connections you make as a nurse are incredible. You can get so much out of this job just by connecting with patients. You get out what you put in."

MGA: "How do you manage work/life balance with all the demands healthcare workers face?"

Judy: "I have to be careful. I don't check email or phone after hours except in emergency situations. When I get home, David is a great sounding board."

MGA: "How's that for you, David – living with a healthcare worker?"

David: "She does a great job – maybe a little venting now and then. Her career is tough and takes a lot of energy. I couldn't do it. I try to support her when she travels and go with her if I can. She volunteers me. I like to think when she gets home, I'm the one who gets her to stop."

Judy: "I'm a type A person; I go, go, go. David is a bit more relaxed, so we balance each other out."

MGA: "Speaking of type A people, I understand with everything else you have going on, you spend time volunteering, too. Tell us about some of your volunteer activities."

Judy: "I used to be a doula (birthing coach) for the Lighthouse which is a home for young first time mothers. I taught birthing classes, mentored the women, etc. Some of them would still contact me even 25 years later. And on a personal level, when our daughters were younger, our house was always open to their friends who needed a place to stay. Our home was just a safe hangout."

MGA: "And I know you're involved in the MGA's Triple Crown Showdown each year! What inspires you to go the extra mile (no excusing the pun)?"

Judy: "Well the MGA does so much in supporting our patients. I see the good that the MGA does. I may not have lots of free time, but I want to be there for my MG patients in any way I can."

MGA: "What are some fun things you'd like us to know about you?"

Judy: "Along with our incredible daughters, we are blessed with 2 great son-in-laws and now grandbabies, too. Sam and her husband, Max, just had our first grandbaby, Corbin, in December, and Erin and her husband, Matt, are expecting this September. We have two rescue dogs. We vowed not to have dogs, but when Erin brought home a dog, it took David two days to relent, and it took me four days. Then we adopted another one… We also love to travel, and I do woodwork, garden, and bake. I also love going to antique shops; for some reason I like wagon wheels and flow blue dishes. Antiquing is not at the top of David's list, but he goes for me."

At this point we veer off into a conversation about David being in construction, his being handy at home, and Judy discloses to me that she's not shy with a hammer either. Apparently, David walked into their kitchen one day to find Judy knocking down a wall…she wanted it gone…

David: "Yeah – we are both handy, and we love to travel. We have a tendency to just get in the car and drive. Judy doesn't like to have a plan. We'll have a destination in mind, but no concrete plan. We meander our way. And we don't do touristy things. We like some peace, we like wineries, and we like to stray from the beaten path."

MGA: "Last question, and it's an important one: There are two kinds of people in this world – Elvis or The Beatles. Without thinking, which kind are you?"

David and Judy (pretty much simultaneously): "Elvis."

MGA: "'Nuff said."

An update from Cartesian Therapeutics

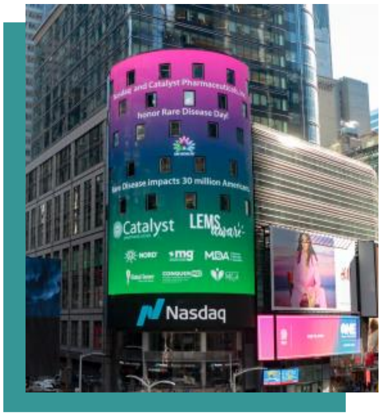
Cartesian Therapeutics, a fully integrated, clinical-stage biopharmaceutical company pioneering RNA cell therapy in and beyond oncology, will present late-breaking, interim data from its Phase 1/2a clinical trial of Descartes-08 in patients with generalized Myasthenia Gravis (gMG) at the 14th MGFA International Conference.

In the data to be presented, there were consistent, marked improvements in MG clinical status, evidenced by improvements on validated MG clinical scales including the MG Composite, MG-ADL and QMG scales. The depth of clinical response correlated with the dose of Descartes-08. On a case-report basis, investigators have characterized clinical responses to Descartes-08 as some of the most profound ever seen in their practices.

An oral presentation on Descartes-08 will be delivered on Tuesday, May 10, by Dr. Volkan Granit at 10:50 a.m. Eastern Time. A poster presentation will follow later the same day.

Cartesian's ongoing Phase 1b/2a study (NCT04146051) of Descartes-08 is a non-randomized, single group, open-label, multicenter study to determine the safety and preliminary efficacy of Descartes-08 in patients with gMG. Topline data from the trial's first cohort of the trial were announced in August 2021. For more information, visit https://www.cartesiantherapeutics.com/clinical-trials/. Descartes-08 is an mRNA-modified, autologous CAR T-cell product directed against B-Cell Maturation Antigen (BCMA), a specific marker for plasma cells. Descartes-08 is intended to halt production of gMG-mediating autoantibodies by targeting reservoirs of pathogenic long-lived plasma cells. Descartes-08 differs from anti-B-cell agents (which do not inhibit or kill long-lived plasma cells) and from FcRn blockers or complement inhibitors (which act only after autoantibodies are produced and pathogenic mediators are amplified). Given the encouraging results seen thus far in gMG, Cartesian is exploring the use of Descartes-08 for other autoantibody-mediated autoimmune diseases.

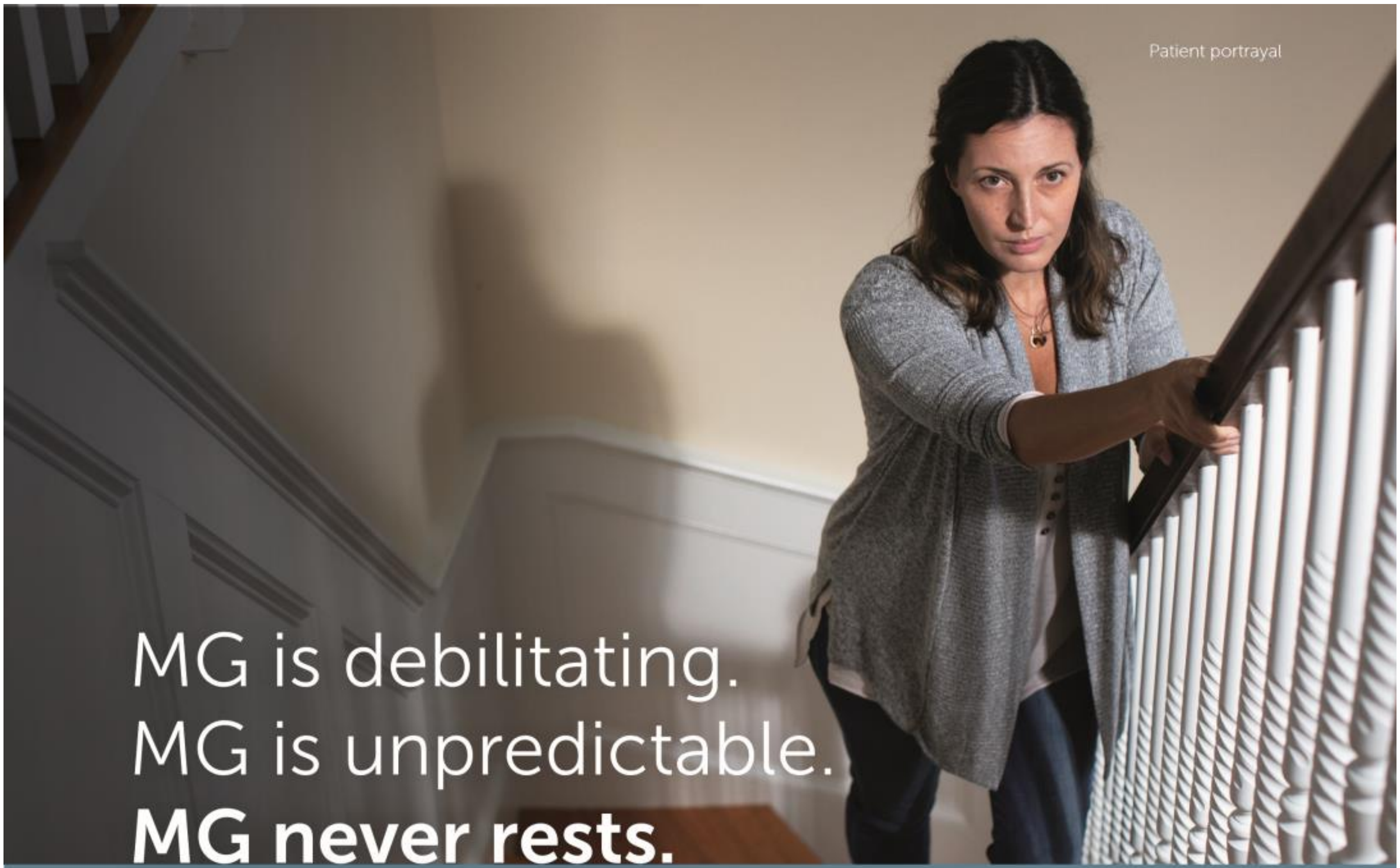
MGA gets representation on Rare Disease Day



A huge shout out to Catalyst Pharmaceuticals who helped the MGA get their name on the NASDAQ tower on February 28th for Rare Disease Day! We are incredibly grateful for the awareness opportunity through Catalyst and as you'll note in the picture, we were in very good company!

Connecting with the Myasthenia Gravis Foundation of California

In March while in California to meet the MGA Founders, Allison Foss took the opportunity to meet with Melissa Pangilinan of the Myasthenia Gravis Foundation of California (MGFC). Melissa has worked for the MGFC for 20 years and is a wealth of knowledge on all things myasthenia. Melissa shared resources that the MGFC offers to their patients including a book titled, "Myasthenia Gravis," which is an illustrated history that recounts a timeline of MG from 1879 to present day. Authored by John Carl Keesey, MD, the book is for sale by the organization for $25. You can learn more by going to their website, www.myasthenia-ca.org.


Patient portrayal

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: ______________________________

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Cut & enclose in envelope, and mail to:

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

PLEASE PRINT

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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!

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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.

Myasthenia Gravis Association
2340 E. Meyer Blvd.
Building 1, Suite 300A
Kansas City, MO 64132
Phone: (816) 256-4100
Email: info@mgakc.org
www.mgakc.org
www.mga5k.com