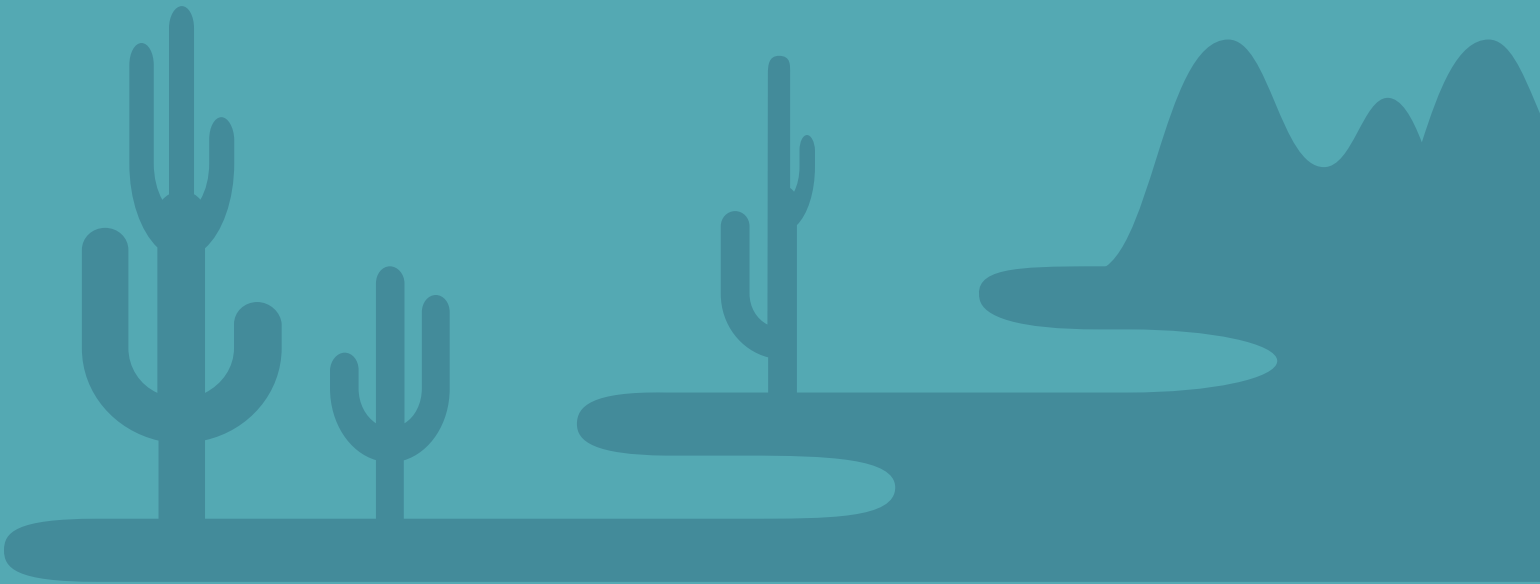


**2025**  
**MGFA National**  
**Patient**  
**Conference**  
**Phoenix, AZ**



**CONFERENCE PROGRAM • MARCH 30 – APRIL 1, 2025**

# WELCOME TO THE 2025 MGFA NATIONAL PATIENT CONFERENCE

The MGFA team, Board of Directors, and Conference Steering Committee are thrilled to welcome you to Phoenix for the MGFA National Patient Conference.

Creating community is a core part of the MGFA mission. There is something so special about sharing a smile and a conversation, seeing friends you know through a support group or social media, and forging new connections.

We hope you will use this time together to learn from one another and from our expert presenters. Each session has been designed to provide patients and care partners with guidance to enhance your

quality of life. Myasthenia gravis is an incredibly difficult disease, but you are not walking this journey alone. Please engage, ask questions, take notes, and let us know what you think of this year's presentations and activities.

Hosting you is our deep privilege. We hope you enjoy this time together as a community.

A special thank you to our Steering Committee for their guidance and to all our sponsors who make this event possible, especially our Presenting Partners, Alexion, Amgen, argenx, Johnson & Johnson Innovative Medicine, and UCB.

## Experience Rooms and Exhibit Hall

Don't forget to explore the Experience Rooms, full of interactive learning opportunities, and the Exhibit Hall, where you can engage with and learn from our partners. These spaces are open in the morning and during breaks between sessions and other activities. Find out more about the Experience Rooms at the end of the program booklet.

*Find the Experience Rooms and Exhibit Hall in the Sonoran Sky Ballroom.*



MGFA Conference attendees, present your gelato coupon for a free frozen treat at the...

## GELATO STATION

**SPECIAL THANKS TO OUR STRATEGIC PARTNER ALEXION**

# WHAT TO KNOW ABOUT THE CONFERENCE

## Ask Your Questions on Slido

This year, we are using the platform Slido for each session's Q&A. This tool will enable our virtual attendees to more easily participate.

- 1 Visit [Slido.com](https://www.slido.com) at the start of each session and enter **Event Code 3760443**.
- 2 Type in your question for that session's presenter(s) or vote for a question you would like answered.
- 3 Presenters will answer as many questions as time allows.



## Share your conference photos with us!

Tag the MGFA on Instagram or LinkedIn.

 @myastheniaorg

 [linkedin.com/company/myastheniagravisfoundationofamericainc](https://www.linkedin.com/company/myastheniagravisfoundationofamericainc)



## Did You Know?

Arizona was the last territory to become a state in the continental U.S., in 1912.

Just how hot is it here? In 2024, Phoenix had over 100 straight days of 100+ degree heat.



### Conference WiFi

Name: **ArizonaMeetingSpace**

Password: **MGFA25**

# AGENDA

SUNDAY, MARCH 30

**1:00 – 3:00 PM**

## MGFA Fair

Get to know the MGFA and resources available to people living with MG, care partners, and medical professionals. This is a great opportunity to learn more about MGFA's resources, discover ways to get involved, and build connections with the MG community.

Arizona Grand Ballroom

**3:00 – 5:00 PM**

## Exhibitor Booths and Experience Rooms

Sonoran Sky Ballroom

**5:30 – 7:30 PM**

## Welcome Reception and Dinner

Sponsored by argenx

Gather with other attendees for a sunset meal on the patio to kick off the conference.

Paseo Patio

### REMINDER

Use Slido to ask your questions during each session.

Slido.com: use code 3760443



## MONDAY, MARCH 31

**8:30 – 9:30 AM**

### Breakfast

Sponsored by Johnson & Johnson

Innovative Medicine

Paseo Patio

**8:30 – 9:30 AM**

## Exhibitor Booths and Experience Rooms

Sonoran Sky Ballroom

**9:30 – 9:45 AM**

### Welcome Remarks



**Samantha Masterson**

President and Chief Executive Officer,  
MGFA

Arizona Grand Ballroom

**9:45 – 10:30 AM**

## Keynote Address: Understanding the Disease Processes Driving the Subtypes of MG and Related Neuromuscular Junction Disorders



**Kevin O'Connor, PhD**

Professor of Neurology  
and Immunobiology,

Yale School of Medicine

Arizona Grand Ballroom

## Did You Know?

**150–200** out of every million people are living with myasthenia gravis globally.



**10:35 – 11:20 AM**

### Disease State and Treatment Options



**Suraj Muley, MD**  
Director of Neurology,  
Bob Bove Neuroscience Institute &  
Professor of Neurology, University of  
Arizona School of Medicine  
Arizona Grand Ballroom

**11:20 – 11:50 AM**

### Coffee Break / Mix & Mingle / Exhibitor Booths and Experience Rooms

Sonoran Sky Ballroom

**11:50 AM – 12:35 PM**

### The Changing Conversation



**Jeffrey Rosenfeld, PhD, MD**  
Loma Linda University  
Arizona Grand Ballroom

**12:35 – 1:35 PM**

### Lunch

Sponsored by Alexion

Paseo Patio

**1:40 – 2:20 PM**

### Empowered Voices: Navigating Legislative Advocacy and Self Advocacy for Lasting Change

**Melinda J. Burnworth, PharmD**



National Organization  
for Rare Disorders  
Arizona Grand Ballroom

**2:25 – 3:05 PM**

### Panel Discussion: The Path for You — Shared Decision Making



Led by **Kelly Graham Gwathmey, MD**  
Associate Professor of Neurology,  
Virginia Commonwealth University Health



Featuring **Randy Clough**  
and **Janel Worcester-Brown**  
Arizona Grand Ballroom

**3:10 – 5:00 PM**

### Exhibitor Booths and Experience Rooms

Sonoran Sky Ballroom

**5:45 – 9:00 PM**

### Restaurant Shuttles

#### Sponsored by Alexion

Transportation is provided to and from Rustler's Rooste for this evening's dinner. If you would like to use the shuttle, meet at the Conference Center on the lower level — NOT the resort lobby. Shuttles will run throughout the evening.

**6:20 – 9:00 PM**

### Dinner and Volunteer & Service Awards Ceremony

#### Sponsored by Johnson & Johnson

#### Innovative Medicine

Join us for a Western-themed dinner where we will also announce and celebrate our MGFA Volunteer and Service Award recipients.

Rustler's Rooste

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## TUESDAY, APRIL 1

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**8:30 – 9:30 AM**

### Breakfast

Paseo Patio

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**8:30 – 9:30 AM**

### Exhibitor Booths and Experience Rooms

Sonoran Sky Ballroom

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**9:35 – 10:20 AM**

### Unexpected Gifts: Transform Your Challenges and Rewrite Your Story



**Vickie Petz Kasper, MD**  
Author, Podcast Host, and  
Diplomate of the American Board  
of Lifestyle Medicine and Obstetrics  
and Gynecology  
Arizona Grand Ballroom

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**10:25 – 11:05 AM**

### #AskPatients: How Patient Engagement Shapes the Future of Care

Sponsored by Johnson & Johnson  
Innovative Medicine



**Jen Horoneff, PhD**  
CEO & Founder, Savvy Cooperative  
Arizona Grand Ballroom

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**11:10 – 11:40 AM**

### Coffee Break / Mix & Mingle / Exhibition Hall / Experience Rooms

Sonoran Sky Ballroom

## REMINDER

Use Slido to ask your questions during each session.

Slido.com: use code 3760443



**11:45 – 12:30 PM**

### Strength in Motion: Safe and Effective Exercise for Myasthenia Gravis



**Sarah Wright, DO, MS**  
Pediatric Neurologist,  
Children's National Hospital  
Arizona Grand Ballroom

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**12:35 – 12:40 PM**

### Closing Remarks



**Samantha Masterson**  
President and Chief Executive Officer,  
MGFA  
Arizona Grand Ballroom

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**12:45 – 1:45 PM**

### Lunch

Sponsored by UCB  
Paseo Patio

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**1:50 – 2:35 PM**

### Closing Plenary: Together We Rise



**David Jack**  
Motivational Speaker  
Arizona Grand Ballroom

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## Did You Know?

In 2024, the MGFA dedicated over  
**\$1 million** to research initiatives.





# EXPLORE THE EXPERIENCE ROOMS

Find the Experience Rooms in the Sonoran Sky Ballroom



The following activities are sponsored by Alexion Pharmaceuticals.

## Take on Your Tomorrow with gMG

Join Dr. Suraj Muley, MD, as he delves into how generalized myasthenia gravis (gMG) affects your body.

**Sunday, March 30 at 3:30 PM**

## Balancing Life with gMG — A Conversation with Patients and Caregivers

Join us for a heartfelt and intimate conversation with six gMG patients and their caregivers. They will discuss caregiver support, navigating treatment decisions, and the overall impact of gMG in their lives.

**Monday, March 31 at 3:00 PM**



## Go for Growth with argenx!

Nurture your growth, set meaningful goals, and rest and recharge. Hydrate and charge your phone while you take part in the Tree of Growth Mural and enjoy some takeaways, including a Plant Your Goal kit.

**Ongoing During the Conference**



## Junk Journaling Experience

Take a break, channel your creativity, and try a new hobby! Materials, guidance, and inspiration will be provided for anyone interested in starting a “junk journal.”

**Ongoing During the Conference**



## Breathe. Move. Thrive. Yoga for Every. Body.

Join Debroah Vick, an individual living with MG and NMD Pharma’s medical director, and yoga therapist Vera Kiyasova for an adaptive yoga session. Our program aims to provide an inclusive and safe environment for those looking to incorporate movement into their lives.

**Monday, March 31 at 9:00 – 9:30 AM  
and 3:30 – 4:00 PM**

## Meet a You, Me and MG Advocate

Stop by to hear from You, Me and MG advocate Megan about adapting — and prioritizing — your hobbies and interests to live your best life with MG.

**Sunday, March 30 at 3:30 PM**





The following activities are sponsored by Alexion Pharmaceuticals.

### Embracing Self-Care with MG — Free Mini Makeovers

Join the #MoreThanMG team and professional makeup artist Anton Khachaturian for self-care and makeup tips and complimentary 20-minute mini makeovers.

**Ongoing During the Conference**

### Pets & PEMs: A Pet Therapy Experience with Pets on Wheels

Enjoy quality time with our furry friends and discover the many benefits of pet therapy!

**Ongoing During the Conference**

### #MoreThanMG: A Digital Mosaic Wall Experience

Join us for a unique and inspiring digital photobooth experience designed to empower and unite the MG community.

**Ongoing During the Conference**



### Networking Time: Meet and Mingle with Others

Networking for individuals who live with MG

**Sunday, March 30 at 4:00 – 5:00 PM**

Networking for caregivers

**Monday, March 31 at 3:45 – 4:15 PM**

### Demonstration of a Self-administered, Targeted Therapy

Led by the UCB medical team, watch a step-by-step demonstration highlighting the preparation and administration of a self-administered targeted therapy, followed by Q&A with a UCB patient advocate.

**Monday, March 31 at 3:10 – 3:45 PM**

**Tuesday, April 1 at 12:45 – 1:20 PM**

### At Home Exercise with Vanetta Fenton — NASM Certified Personal Trainer

An interactive, resistance band exercise session with NASM Certified trainer, Vanetta Fenton. Learn basic strength training exercises that can be done in the comfort of your own home.

**Monday, March 31 at 4:15 – 5:00 PM**

### Healthy Eating and Food Demo with Registered Dietitian Kristin Neusel

At this interactive presentation on health and wellness, explore nutrition basics for gMG, label reading 101, helpful tools/apps for smart choices, recipe alterations, enjoying celebrations (without too many restrictions!), and more.

**Tuesday, April 1 at 1:20 – 1:50 PM**





# LET US KNOW WHAT YOU THOUGHT OF THIS YEAR'S CONFERENCE.



[forms.office.com/r/hj9ZMVkLcK](https://forms.office.com/r/hj9ZMVkLcK)

Take a short survey.

## THANK YOU TO OUR PARTNERS

We deeply thank our generous conference industry partners and sponsors. We appreciate your commitment to those living with myasthenia gravis.

### PRESENTING PARTNERS

