

# MGFA National Patient Conference

Building Momentum for a Future Without Myasthenia Gravis

Tampa Westin Waterside Tampa, Fl April 28th - 30th, 2024

### Welcome to the MGFA's 2024 National Patient Conference

Dear Friends.

Welcome to our annual National Patient Conference! We are thrilled to welcome you to warm, beautiful Tampa to spend a few days together learning and sharing. This conference is always the highlight of our year as it is the largest gathering of the MG Community... there's nothing quite like coming together and having quality time with old and new friends alike.

On behalf of the MGFA, it is our privilege and absolute pleasure to welcome you to this event. We have a wonderful program planned for the next few days, filled with sessions that focus on the journeys of those living with MG... from learning MG basics, to enhancing one's quality of life, to the treatment landscape, to elevating the patient's voice, and caring for the caregiver. We will have many important discussions that will educate and inform, as well as motivate and inspire. Please feel free to participate, ask questions, and give feedback. We love to hear from our community members!

Thank you so much for your partnership, your insight, and your ongoing support. MGFA has a very deep history and is built on a foundation of collaboration with key stakeholders across our MG Community, including patients, caregivers, healthcare providers, researchers, and partners on so many different levels.

Again, we welcome you... we thank you and appreciate you... and we are so looking forward to this special time together.

Sincerely,



Samantha "Samm" Masterson President and CEO MGFA

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

A Special Thank You to











### **SUNDAY, APRIL 28**

### 1:30 - 3:00 PM MG 101 - THE BASICS OF MYASTHENIA GRAVIS



Michael Rosario-Prieto, MD BayCare Medical Group

This session is intended for new patients/caregivers or anyone who would like to learn about the basics of myasthenia gravis and how it affects patients.

Located in Oasis Ballroom (ideal for new patients, but all welcome)

### 2:30 - 4:30 PM NETWORKING OPPORTUNITIES Facilitated by UCB Representatives



2:30-3:00 PM - Caregivers

3:00-3:30 PM - Individuals Living with MG

3:30-4:00 PM - Young Adults Living with MG

4:00-4:30 PM - Working Professionals Living with MG

Join one of these opportunities to connect with others who may share your lived experiences.

Located in the Health & Wellness Room Sponsored by UCB (Sunset)

### 5:00 - 6:00 PM KEYNOTE - THE MG EXPERIENCE IN 2024



Tuan Vu, MD USF Health

What is the experience of being an MG patient in 2024? How have things changed over the years? Having more treatment options is always a positive thing but can also make a patient's treatment path unclear.

Located in Oasis Ballroom

### 6:00 - 9:00 PM WELCOME DINNER & AWARDS CEREMONY Sponsored by Alexion

Join us for a welcome dinner in the Oasis Ballroom for the MG Community.

MGFA will present the MGFA Volunteer Awards during dinner. All attendees welcome.

### **MONDAY, APRIL 29**

### 8:30 - 9:00 AM BREAKFAST Sponsored by argenx

Located in Oasis fover

### 9:00 - 10:00 AM MG ANTIBODIES & WHAT THEY MEAN TO YOU



Srikanth Muppidi, MD Stanford Health

Why is it important to know what your MG antibody status is? This session will explain how your antibody status can dictate your treatment options and your MG journey.

Located in Oasis Ballroom

### 10:00 - 10:30 AM BREAK / VISIT EXHIBIT BOOTHS / VISIT HEALTH & WELLNESS ROOM

Grab a coffee, mingle with friends, meet our vendors, or visit the health and wellness room for an at-home exercise session.



### AT HOME EXERCISE

**Cassie Guest** Physical Therapist

An interactive, resistance band exercise session with physical therapist Cassie Guest. Learn basic strength training exercises that can be done in the comfort of your own home.

Located in the Health & Wellness Room Sponsored by UCB (Sunset)

### 10:30 - 11:30 AM THE MG PATIENT-PROVIDER PERSPECTIVE: A MODERATED DISCUSSION



Allan Weiss, MD BayCare Medical Group Michael Rosario-Prieto, MD BayCare Medical Group Meridith O'Connor MGFA and MG Patient

**Kathleen Timothy** MGFA, Seronegative Support Group Leader, and MG Patient **Rakesh Nathwani** MG Patient and Seronegative Support Group Member

Hear from both patients and providers as they discuss their points of view on the various aspects of the MG patient journey.

Located in Oasis Ballroom

### 11:30 - 12:45 PM LUNCH & VISIT EXHIBIT BOOTHS Sponsored by Amgen

Located in Oasis foyer

### 12:45 - 1:00 PM THE VALUE OF COMMUNITY FUNDRAISING



Tom Bartlett MGFA Ambassador

A current MGFA volunteer will share his experience and perspective with fundraising in his community.

Located in the Oasis Ballroom

### 1:00 - 2:00 PM THE SERONEGATIVE EXPERIENCE



**Ali A. Habib, MD** University of California, Irvine Health What does it mean to be seronegative? Learn what seronegative MG patients face when searching for treatments.

Located in Oasis Ballroom

### 1:00 - 2:00 PM MYASTHENIA ADVOCACY FOR YOUNG ADULTS (MAYA)



Hannah Ensor MAYA Co-Leader Jessica Milanes MAYA Co-Leader Jerrica R. Farias, APRN USF Health

This session is for MAYA group members or those who are interested in joining. Topics discussed include issues and subjects that are exclusive to young adults. *Patients and caregivers only, please.* 

**Located in Conch Room** 

### 1:00 - 2:00 PM HEALTHY EATING PRESENTATION AND FOOD DEMO



Kristin Neusel Registered Dietitian, UCB

An interactive presentation on health and wellness, along with a food demo, for the MG community. Discussion will cover nutrition basics, label reading 101, enjoying celebrations (without too many restrictions!), smart choices & helpful tools/apps, and recipe alterations.

Located in the Health & Wellness Room Sponsored by UCB (Sunset)

### 2:00 - 2:30 PM BREAK / VISIT EXHIBIT BOOTHS / VISIT HEALTH & WELLNESS ROOM

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### 2:30 - 3:00 PM CARING FOR THE CARE PARTNER



**Lisa Bulot** Alexion

The Partners in Care series offers practical suggestions for supporting someone who is living with gMG. In this presentation we will cover common stressors care partners face, creating a self-care plan, and offer resources you may find helpful.

**Located in Oasis Ballroom** 

### 3:00 - 3:30 PM THE MG JOURNEY - MORE THAN MEDICINE



Judith Thompson, PharmD, MPH, CPHQ UCB

There are many factors that contribute to living well with chronic conditions - it's more than medicine alone. Join this session to learn how these factors may impact the MG journey.

Located in Oasis Ballroom

### 3:30 - 6:30 PM REST/BREAK/EXPLORE

6:30 - 9:30 PM TREASURE SEEKERS DINNER Sponsored by Alexion

Enjoy a themed dinner in the Oasis Ballroom for the MG Community.

### **TUESDAY, APRIL 30**

8:00 - 8:30 AM BREAKFAST Sponsored by argenx

Located in Oasis foyer

### 8:30 - 8:45 AM MGFA HORIZON IN 2024



Samantha Masterson President and CEO, MGFA

Priorities and the road ahead for the MGFA.

Located in Oasis Ballroom

## 8:45 - 9:30 AM ELEVATING THE PATIENT VOICE IN RESEARCH AND THE MGFA GLOBAL PATIENT REGISTRY



MGFA Registry Advisory Council
Moderated by Paul Strumph, MD MGFA Board Member

Learn why it is so important to participate in the MGFA Global MG Patient Registry and discover what types of research are being conducted thanks to patient-provided data.

Located in Oasis Ballroom

### 9:30 - 10:00 AM THE POWER OF DOG THERAPY



### **Alexion and GRRMF Hearts Of Gold Therapy Team**

Therapy dogs are a powerful calming force that can be used in various environments and situations. If you've ever spent time petting a dog and felt an immediate emotional boost, you experienced one of the mental health benefits of dog therapy. Join the Hearts of Gold presentation and discover the physiological processes influenced by interaction with therapy dogs.

Located in Oasis Ballroom

# 10:00 - 10:30 AM BREAK / VISIT EXHIBIT BOOTHS / VISIT HEALTH & WELLNESS ROOM HEALTHY EATING PRESENTATION AND FOOD DEMO



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Located in The Health & Wellness Room (Sunset)

### 10:30 - 11:00 AM THE LATEST UPDATES IN MG CLINICAL TRIALS



Tuan Vu. MD USF Health

This session will inform us of the latest developments in clinical trials for MG. Learn about new research and what we can expect in the future.

Located in Oasis Ballroom

# 11:00 - 11:30 AM CAPTURING THE VOICES OF PEOPLE LIVING WITH MG - INSIGHTS & PERSPECTIVES TO HELP DRIVE IMPROVEMENT IN THE MANAGEMENT OF MG



Nolan Campbell, MD Johnson & Johnson

To honor our credo, capturing patient insights and perspectives is of paramount importance, ensuring we keep patients at the center of everything we do. Here we discuss and provide example insights from two different approaches to elevate the patient voice: 1) creation of standing patient research councils enabling long-term relationships with patient and caregiver advisors, and 2) AI-enabled analyses of digital conversations to capture broader patient sentiments.

Located in Oasis Ballroom

### 11:30 - 12:00 PM TAKING CHARGE OF YOUR CARE: MG AND EMOTIONAL HEALTH



Lauren Jarman argenx

Your emotional health may be negatively affected by MG throughout your journey. We will show how your brain and body respond to stress and explore ways that may help to manage your emotional health and reduce stress.

Located in Oasis Ballroom

**12:00 PM LUNCH & CONCLUSION OF CONFERENCE** Sponsored by Amgen

Located in Oasis fover





# For a World Without Myasthenia Gravis



visit myasthenia.org

2024 **MGFA National Patient** Conference Tampa, FL



**View MGFA's Instagram** page and tag the MGFA @myastheniaorg

contact us at mgfa@myasthenia.org









