

## FOR IMMEDIATE RELEASE

## Myasthenia Gravis Foundation of America (MGFA) Kicks off Annual National MG Patient Conference With Program Announcements

Leading myasthenia gravis patient advocacy organization convenes more than 400 individuals diagnosed with MG as well as medical professionals and researchers, clinicians, caregivers, and industry.

**TAMPA BAY, FL – April 29, 2024** – More than 400 members of the myasthenia gravis (MG) rare disease community will come together this week at the MGFA National Patient Conference for support and a better understanding of how to manage their disease while learning about the latest in treatments and clinical studies.

Myasthenia Gravis Foundation of America (MGFA<sup>TM</sup>), the largest, leading patient advocacy organization solely dedicated to the myasthenia gravis community kicked off its annual conference today with a volunteer awards dinner and new program announcements. The conference features patient stories and individuals diagnosed with myasthenia gravis as well as presentations and discussions from patients, caregivers, researchers, MG expert clinicians, and pharmaceutical and industry partners. This is the largest gathering of MG Community members each year and will focus on the state of MG across treatments, medical and quality of life guidance, and research.

"We are so proud and excited to host this extremely influential, inspiring event each year. Bringing together MG patients and other members of the community to learn from and support each other is so powerful," said Samantha Masterson, president and CEO of the Myasthenia Gravis Foundation of America. "We have a record attendance in 2024 with many more individuals viewing the event virtually. I deeply hope that the MG community's experience at the conference helps patients and caregivers better navigate their own unique MG journey so that they have an improved quality of life."

MGFA is making a series of announcements at the event (See event program) while highlighting new information and programs to help individuals living with MG:

**MG Patient Helpline** - MGFA will launch a new MG Patient "Help Line" that will provide patients and caregivers with support, wellness strategies, and guidance for managing MG. This phone line will be covered by trained social work and medical provider professionals - not to give medical or treatment advice - but to help community members better navigate their MG journey and help direct patients to the information and resources they need. Look to a launch in May 2024.

**Translation of select educational resources** – MGFA has committed to translating select educational materials - including most of myasthenia.org and the MGFA Online Community - into a variety of international languages to help patients and caregivers who do not speak English as their first language.

**MG Walks** – MGFA is so proud to re-launch its signature MG Walks fundraising events this year. The organization has established three walks this year - in Boston, New York, and Tampa Bay in 2024. The MG Walks help fund and support the critical work of the MGFA through its programs, materials, resources.

**MGFA Global MG patient Registry** – The MGFA Global MG Patient Registry gives the MG community a loud voice in ensuring that research studies and clinical trials are built to evaluate the most promising MG research. By joining the MG

Registry, MG patients will be providing the live, self-reported patient health data that research professionals need to find better treatments.

**MyMG Mobile App** – The MyMG Mobile App helps patients track treatments, find support groups and medical professionals, and access educational resources, webinars, and materials. Later in May 2024, the mobile app will offer an automated MG-ADL symptom tracking scale. Patients will be able to track daily MG symptoms - twice a day - in the universally recognized MG-ADL scale to share with doctors and neurologists.

**15**<sup>th</sup> **Myasthenia Gravis International Conference** – This medical and researcher conference, held every three years, will be hosted by the MGFA in May 2025 at the Postillion Hotel and Conference Center in The Hague, Netherlands. MG researchers and experts from around the world will convene to present the latest studies, data, and outcomes from MG research trials across a variety of countries.

Approximately 70,000 to 90,000 are diagnosed and living with MG in the United States alone. MG patients suffer with debilitating physical symptoms such as extreme fatigue and muscle weakness that impact a person's ability to see, swallow, smile, walk or breathe.

MGFA focuses on funding promising research discoveries for better treatments while providing impactful programs, guidance, and education to support members of the MG Community. There has been extremely important progress in myasthenia research recently with four new FDA-approved treatments and many new disease management resources and educational materials.

## **About MGFA**

Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding better treatments and a cure for the rare neuromuscular disease myasthenia gravis (MG). We fund the most promising critical research discoveries and provide patient-centric programs and educational materials to connect members of the global MG Community and improve the lives of those living with MG. You can visit MGFA at myasthenia.org.

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