



Striving for a World without Myasthenia Gravis



What is Myasthenia Gravis?

A disorder causing extreme muscle weakness that can impact a person's ability to see, smile, walk, talk and breathe. In MG, the body's immune system attacks the connection between the nerves and the muscles, limiting the ability of the brain to control muscle movement.

MG affects people of all ages, genders, and races and is debilitating without treatment. Symptoms vary person to person, making each case unique which is why myasthenia is sometimes referred to as the "snowflake disease."

What is MGFA?

Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to the myasthenia community. MGFA touches the lives of MG patients and their families through research funding, patient education and support, and advocacy.

It all began with a little girl named Patricia. When Jane Dewey Ellsworth's daughter showed symptoms of myasthenia gravis, Ellsworth was determined to find out everything she could about this rare disease. She found very little information and few resources for help. Determined to change this, she founded the Myasthenia Gravis Foundation of America, Inc. in 1952.

Since then, the MGFA has become the largest leading patient advocacy organization dedicated to fighting for a world without myasthenia gravis.

Our Vision:

A World Without MG

Our Mission:

*Create Connections, Enhance Lives,
Improve Care, Cure MG*

Our Values:

RESPECT

EXCELLENCE

TRANSPARENCY

COLLABORATION

CONTINUOUS IMPROVEMENT

What We Do

As part of our mission to create connections, enhance lives, improve care and cure MG, we aim to:

Fund and Support Research: We lead the charge to fund and spearhead only the most promising MG research projects including a MGFA Global MG Patient Registry and academic or scientific clinical studies.

Educate the Community: We help those diagnosed with MG and their families understand their diagnosis and treatment options as well as how to achieve improved wellness through helpful resources, materials, webinars, and conferences.

Support Patients and Families: Through our MGFA support groups, online communities, and special events, we make sure community members don't feel alone as they navigate their MG journey.

Advocate for Patients: We come together with patients and medical providers to ensure our voices are heard clearly at all levels of government, across the medical and insurance communities, and around the world no matter where you live.

Raise Awareness: MGFA utilizes technology and communications to bring together MG experts, raise awareness about MG, and conduct events to improve time to diagnosis and ensure wider understanding of the challenges of MG.

RESEARCH



We have made great strides in treating MG, but today's treatment options still come with side effects and only partially address life-altering symptoms of MG. Our charge is clear: more work in this area is necessary to better understand MG, expand treatment options, and, ultimately, find a cure.

The MGFA engages with top researchers and clinicians to:

- Fund high-impact research with promising treatment pathways.
- Provide post-doctoral fellowships to bring the best and brightest to the field of MG.
- Foster collaboration and innovation through national and international conferences.
- Advocate for critical research funding.
- Advance understanding through the MGFA Global MG Patient Registry and clinical trials.

Funding for MG Research

We support research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. We prioritize five broad research priorities: Biomarkers, disease mechanisms, targeted therapies, patient outcomes and pediatric treatment.

Collaboration on MG Research

MGFA brings together the best medical and scientific minds in the world to focus on MG. Every three years we co-host the largest gathering of clinicians and scientists focused on MG in the world, and regularly organize symposia during major medical and scientific conferences.

MGFA Global MG Patient Registry

The MGFA Global MG Patient Registry was established in 2013 and is a longitudinal online registry that contains myasthenia gravis (MG) patient-reported health and symptom data. Patients from around the world safely and securely add their data, which is protected and private as part of a HIPAA and GDPR-compliant platform, powered by Alira Health. This actual, up-to-date MG patient data in the registry has directly helped researchers improve their understanding of the disease while developing new treatments to help patients manage their MG. The MG Global Patient Registry can be accessed at MGRegistry.org.

EDUCATION

Information You Can Trust

When it comes to your health, you need evidence-based advice. That's why any medical information published or curated by the MGFA undergoes a rigorous review by MG experts. Roughly 175 doctors, clinicians, scientists and nurses sit on our Medical/Scientific Advisory Board. These experts ensure we only share the latest, most rigorously reviewed research with you.

Members of these groups also volunteer their time to write articles, present and webinars and conferences, and advise on funding proposals. They are on call to help the MGFA staff respond to complex questions from the MG community.

Many resources, including publications, are available to read, watch or download at myasthenia.org.

MG Webinar Series

Our monthly webinars connect, educate and empower MG patients, care partners and medical professionals.

- **Wellness:** Nutritionists, yoga instructors, physical therapists, medical providers, and other experts share best practices for taking care of your mind, body, and spirit while living with MG.
- **What's New in MG Research:** Learn about the latest research results, key clinical trial phases, and current outcomes from top research trials taking place right now. Speakers include clinicians, neurologists and researchers from around the world.
- **Watch past webinars:** Go to the Myasthenia Gravis Foundation of America channel on YouTube and view past webinars, events, and patient videos.

Conferences and Events

Patients and caregivers can interact and learn together from experts at the annual MGFA National Patient Conference. At our Community Health Fairs and Regional Conferences, held around the country each year, the community can find local resources to help with MG. MGFA partners with volunteers around the country on walks, special events, and other fundraisers to support our work.

SUPPORT

Support Groups

Having a rare disease can feel isolating. But there are people all across the world who are living their best life with MG. Support groups offer much-needed connection, resources, educational programming, and social and recreational activities.



MGFA volunteers lead regional and thematic support groups, both in person and virtually, around the world. They include:

- **MAYA (Myasthenia Advocacy for Youth)**, a group guided by the desire to help young adults live a successful and positive MG lifestyle.
- **Spanish-Language Support Group**, which is offered virtually to make the group accessible to Spanish speakers everywhere.
- **Caregiver Support Group**, where spouses, parents and other caregivers can obtain guidance for navigating this disease as a family member of a patient.
- **Seronegative Support Group**, which is open to anyone who has this type of MG.
- **MG Friends Program**, provides peer-to-peer support services.

MyMG Mobile App

Our symptom tracker is a helpful tool for self-care and to share symptom progression with your doctor. Download the app at:

[Myasthenia.org/MyMG-Mobile](https://myasthenia.org/MyMG-Mobile)

ADVOCACY & RAISING AWARENESS

Our MG Voice

Through MGFA's ongoing patient advocacy program, patients get the support and know-how they need to take action. Volunteers write to Congress to ensure rights for rare disease patients, join efforts to influence insurance carriers to appropriately cover MG patients, drive awareness through their local media, and so much more.

MG Awareness Month

In June of each year, MG community members take action to create awareness and understanding of myasthenia gravis. We lobby federal, state and local government leaders, host the Dare to Care fundraiser, and organize media and social media campaigns. Together, we tell our collective story in hundreds of communities around the world.

Local Fundraising and Events

MG patients and advocates host local events and community fundraisers to create awareness and raise funds to support MGFA's mission. MGFA provides guidance and support to make these events a success.



MGFA Publications and Focus on MG

MGFA shares guidance, the latest research, patient stories, and stories of impact in several different digital and print publications. Our storytelling focuses on patient and caregiver needs.

MG News email newsletters are distributed monthly, and Focus on MG, our bi-annual magazine, highlights amazing work and people throughout the MG Community. The “MGFA Insiders” Blog shares important stories and videos of the people, programs, regions, and medical professionals that are driving change across the myasthenia community.

Notes



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