Striving for a World without Myasthenia Gravis

#MGStrong
What is Myasthenia Gravis (MG)?

Myasthenia gravis (pronounced My-as-theen-ee-a Grav-us) comes from the Greek and Latin words meaning “grave muscular weakness.” The most common form of MG is a chronic autoimmune neuromuscular disorder that is characterized by fluctuating weakness of the voluntary muscle groups. Affecting both men, women, and children, MG can be diagnosed at any age. Symptoms can be mild or severe, and may vary considerably from one person to another. The disease can be ocular (causing double vision and drooping eyelids) or generalized, affecting the ability to speak, smile, swallow, use arms and legs, and, at its worst, even to breathe. Today, there are treatments, but presently no known cure.

Who Gets MG?

MG affects people of all races, genders and ages. Like snowflakes all MG cases are unique.

MGFA Can Help If you or someone you know is experiencing sudden or gradually increasing symptoms of muscle weakness, it could be a sign of MG or another serious condition. Talk to your doctor if you are short of breath, have difficulty smiling, talking or swallowing, or cannot walk any distance without having to rest.

www.Myasthenia.org
The Myasthenia Gravis Foundation of America (MGFA)

The Myasthenia Gravis Foundation of America (MGFA) is the only national voluntary health organization dedicated solely to myasthenia gravis and related disorders. The mission of the MGFA is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy and patient care. Our vision is a world without myasthenia gravis.

HISTORY: IT ALL BEGAN WITH A LITTLE GIRL NAMED PATRICIA

When her daughter, Patricia, showed symptoms of myasthenia gravis, Jane Dewey Ellsworth was determined to find out everything she could about this rare disease. She found very little information and few resources for help. In 1952, determined to change this, she founded the Myasthenia Gravis Foundation of America, Inc.

Today, the Foundation touches the lives of hundreds of thousands of patients, families, friends, and medical professionals across the country and around the world. Through scientific research, educational literature, website and social media, awareness campaigns, support groups, conferences, and more, the MGFA is moving closer to fulfilling our vision and mission.

Fulfilling the Mission

DRIVING RESEARCH TO FIND THE CAUSE, BETTER TREATMENTS, AND A CURE FOR MG:

- Funding transformational research grants that may lead to new treatment pathways.
- Funding post-doctoral fellowships to bring the brightest and best to the field of MG.
- Bringing top researchers together to exchange ideas at national and international scientific seminars.
- Advocating to legislators and the pharmaceutical industry for more MG research.
- Advancing understanding of the disease and promoting clinical trials by managing and growing the MG Patient Registry, www.MGRegistry.org.
THE MG PATIENT REGISTRY is owned and funded by MGFA. It is the only scientifically based longitudinal database on MG in the country. Launched in 2014, with new MG patients registering every month, the MG Registry is already yielding greater understanding of the patient experience, and has been used to support clinical trials. WE URGE EVERY PERSON WITH MG TO JOIN!

To get started go to www.MGRegistry.org. For more information see the MG Registry Brochure at www.Myasthenia.org.

Privacy Policy: The MGFA, MGFA Patient Registry Committee, and the University of Alabama at Birmingham’s Institutional Review Board for Research all provide oversight for operation of the MG Patient Registry. These work in parallel to ensure that the purposes and objectives of the Registry are supported and to ensure that the rights and welfare of those enrolled in the Registry are protected.

For a full text of the Privacy & Security Statement, visit the Registry Website at www.MGRegistry.org and choose the “Become a Participant” tab.

SERVING PEOPLE WITH MG AND THEIR FAMILIES:

- Providing accurate and timely information – through print, web, and social media.
- Connecting people living with MG to each other — through a growing network of support groups, MG Walks, trained peer support volunteers, and social media.
- Delivering educational programming – through webcasts, podcasts, and videos.
- Answering questions and connecting people to community resources and MG specialty care through a telephone help line service.
- Bringing together more than 200 members of the MG Community at an annual educational conference.
- Providing a mobile app to enhance doctor/patient communication.

The myMG app is a tool patients can use to help track their MG symptoms and employ when visiting their physician. Use the tool regularly. Then, when visiting your doctor, print a tracking report from your computer and discuss it with your doctor. www.myMG.Myasthenia.org
RAISING AWARENESS AND ADVOCATING FOR CHANGE:

Informing the public about MG through an annual MG Awareness Campaign.

Communicating news and information important to the MG Community through press releases, frequent e-blasts, social media, E-Updates, our website: www.Myasthenia.org and the semi-annual newsletter Focus on MG.

Connecting and empowering grassroots volunteers who are the heart of the MG Community to raise their voices on issues important to those living with the disease.

Advocating for key issues important to those affected by MG, such as increased funding for MG research, patients’ rights and access to care, disability rights, and family and caregiver support. Partners include: NORD – The National Organization for Rare Disorders, The National Health Council (NHC), Research!America and the American Autoimmune Related Diseases Association (AARDA).

EDUCATING HEALTH CARE PROFESSIONALS AND SCIENTISTS:

Providing information and resources for professionals who treat people with MG, including a handbook: Myasthenia Gravis – A Manual for the Health Care Provider.

Raising awareness of MG in the larger medical community, targeting primary care physicians, ophthalmologists and optometrists, and emergency care providers.

Hosting medical and scientific meetings and conferences:

• The MGFA Scientific Session, held in conjunction with the annual meeting of the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM). This half day program brings together as many as 200 clinicians and scientists to learn about current research and treatment pathways in MG.

• The International Conference on Myasthenia Gravis and Related Disorders, held once every 5 years in collaboration with the New York Academy of Sciences. This three-day meeting is the largest gathering in the world of clinicians and scientists focused on MG, drawing more than 300 participants from around the globe who connect to focus on the latest and most important scientific discoveries in MG.

• Educational meetings for nurses, held annually in conjunction with the MGFA National Conference.
YOU Can Help MGFA
Support People with MG
and Their Families!

EDUCATE, SHARE AND RAISE AWARENESS

❖ Educate others about MG and the challenges it brings, and how the MGFA can help.
   Visit local physicians’ offices and ask for permission to display brochures or promote your local support group.
   Staff an information table at a health fair or other venue. The MGFA can provide materials, banner, etc.
   Participate in *June is MG Awareness Month*. Contact the MGFA office for a toolkit.
   Spread information via the Internet and social media about MG and the support that the MGFA can provide. Use Facebook, Twitter, or Instagram, or start a blog.
   Become a peer support volunteer. Organize an *MG Support Group* in your area, volunteer to help with an existing group, or provide telephone support to others as part of the *MG Friends* program. Call the MGFA office to learn more.

❖ Join our growing network of MG advocates. Write or call your legislative representatives about issues that are important to people with chronic illnesses.
❖ Volunteer at an MG Walk or other special event.

DONATE & RAISE FUNDS

❖ Make a tax-deductible donation. Also encourage your employer, family, and friends to make matching contributions. For more information go to www.Myasthenia.org and click “Donate.”

❖ Join your local MG Walk! People with MG, families, professionals and others connected to myasthenia gravis can help by becoming MG Walk team captains, walkers and fundraisers in your local area.

❖ Become a Do It Yourself (DIY) fundraiser. Host an event inviting friends, family, colleagues, and neighbors to participate and donate the proceeds to the MGFA. Call the MGFA office at 1-800-541-5454 to talk about your idea and receive a toolkit.

❖ Make a bequest to the MGFA in your will. For more information go to http://www.legacy.vg/myasthenia.
The MG Walk Campaign continues to bring together people in the MG Community to talk about their experiences – many for the first time – and grow the resources and awareness desperately needed. While there are treatments, there is currently no cure for MG...and THAT is why we walk together toward the ultimate finish line...a world without myasthenia gravis!

If you are a local MG constituent, a member of the medical community, or a business that would be interested in supporting the MG Walk Campaign, please contact Info@MGWalk.org or 1-855-MGWalks (649-2557). For a listing of all local MG Walks throughout the country and to learn many more exciting details about the Campaign, please visit www.MGWalk.org. Together, we will be stronger!

Stay connected to the MG Walk Campaign
www.MGWalk.org
Financial Information and Stewardship

The MGFA meets all of the standards of BBB Wise Giving Alliance, Community Health Charities, and the National Health Council, and is a careful steward of donations received. Seventy-eight percent (78%) of every dollar donated in 2016 went to support the MGFA’s mission.

PUBLIC SUPPORT

The MGFA is generously supported by donations from individuals, walkers and walk Teams, trusts, corporations, charitable organizations, and others.

2016 EXPENSES

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Information You Can Trust

There is much information available today on the Internet on nearly every subject, but it is often hard to sort out truth from fiction. Information published by the MGFA has been reviewed (and often written) by top experts in MG. The organization’s Medical/Scientific Advisory Board is a collective of more than 150 of the top MG clinicians and scientists in the world. Twenty nurses also serve on the MGFA Nurses Advisory Board. Members of these groups volunteer their time unselfishly, writing and reviewing articles and brochures, organizing curricula and speaking at programs and conferences, and advising on research funding decisions. They are on call to help the MGFA staff respond to complex questions from the MG Community. The information you get from the MGFA is supported by the knowledge and expertise of these clinicians and scientists.

For more detailed financial information, please see the MGFA’s latest annual report, audit, and Form 990, go to the website at www.Myasthenia.org.
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