mg NEWS
MYASTHENIA GRAVIS FOUNDATION OF AMERICA
Support • Education • Awareness • Research

October 2020

Brought to you by the Myasthenia Gravis Foundation of America

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MGFA NEWS TOP STORY

MGFA Expresses Gratitude to Caregivers: November is National Family Caregivers Month

Submit a Photo of your Caregiver and Express Your Thanks to Those Who Support Us

November is **National Family Caregivers Month** and we wish to express our deepest gratitude to all of our community's amazing caregivers. Thank you to all the caregivers in our myasthenia community who serve as a source of strength, safety, and support for all those living with MG. The relationship between an MG patient and a caregiver is a sacred, powerful bond that is extremely strong but can also be as delicate as two intertwined snowflakes. We want to show our support and gratitude to all the caregivers out there for your time, dedication, and commitment to those with MG. With your help, we will continue to move closer to a world without MG.

We invite you to submit a photo of an MG patient with their caregiver, or your favorite photo of your caregiver and tell us why they mean so much to you. Go to the following weblink and submit a photo to see it displayed in our wonderful shifting photo gallery. This lovely program spotlights the love we have for our caregivers.

Learn More»

From the Desk of the CEO

MGFA President & CEO Samantha Masterson takes the opportunity to thank the entire MG Community in a personal letter that highlights our volunteers and those with MG, caregivers, medical professionals, and our critical partners.
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AWARENESS & ALERTS

MGFA Leads Patient Effort to Oppose Changes in CMS Coverage Policy

Newly proposed changes to the **Centers for Medicare & Medicaid Services (CMS)** Physician Fee Schedule (PFS) may have a significant negative impact on access to care for people living with myasthenia gravis. The **Myasthenia Gravis Foundation of America opposes** the CMS's recent proposal to retire the existing plasmapheresis coverage policy. If this policy is retired, therapeutic apheresis procedures coverage will be at the discretion of each region or state as opposed to the national coverage that is currently in place. Lack of formal national coverage for plasmapheresis could create widespread procedure access issues for patients.

MGFA led an extensive online petition effort and submitted more than 4,000 signatures and comments from across the MG Community. We hope our efforts result in decisions by CMS that will benefit the MG community and beyond. More to come.

MG Documentary Premiere “A Mystery To Me” to Feature MGFA

A new documentary film series called **“A Mystery to Me”** is sponsored by MGFA industry partner **argenx**. The international premier of this film will take place on Thursday, November 17, 2020, and will feature MGFA executives as part of an exciting online event to showcase the series. Based on three people living with myasthenia, the docu-series focuses on their initial diagnosis and subsequent lives having to navigate their unique instances of the disease.
Watch the Trailer»
Sign Up for the Premier»

IMPACTFUL RESEARCH

Participate in the MG Registry to Drive Improved MG Treatments

Please consider joining the **MG Patient Registry** by adding your unique set of MG information in our online survey. Patient information is compiled into a broad, aggregated database – Your survey responses are NOT directly applied to you. When many patients provide their accurate data as part of the survey, researchers and clinicians literally design their studies and clinical trials based on this data to test the right ideas and theories. Without patient data, these studies or trials are designed incorrectly or with the wrong outcome goals. The studies would be on the wrong path and if research is on the wrong path, then a potential cure is further away. You are truly, directly helping to find better treatments and a cure!

Join the MG Patient Registry»

MGFA Partner argenx Offers Two Year MG Study called MyRealWorld MG

Be part of this meaningful argenx-sponsored research study to better understand the lives of people living with MG. MyRealWorld MG is an international two-year study assessing the impact of Myasthenia Gravis on patients' lives. Working with patient organizations from 9 countries (US, Japan, Germany, UK, France, Italy, Spain, Canada, Belgium), biotechnology company argenx sponsors this innovative study and is inviting MG patients from around the world to participate and share information. You can download and use the MyRealWorld mobile app to enter data

Read More»

Short Term Survey Invites Patients to Share Intravenous Infusion Experiences

Suttons Creek is carrying out a patient market research study on auto-injectors for patients who have been diagnosed with generalized Myasthenia Gravis and have been treated with infusions. Today, many people with Myasthenia Gravis visit a clinic to receive intravenous (IV) infusions. A new treatment under development may make it possible to stay home and use an auto-injector to deliver an injection at home yourself. An auto-injector is a device that allows someone to self-inject a medicine at home. We would like to speak with people that have received IV infusions to treat Myasthenia Gravis and want to hear your interests and concerns. Your feedback will ensure that the new therapy is as convenient and comfortable as possible. The researchers would like to talk to people that are:

- Diagnosed with Myasthenia Gravis
- At least 18 years of age
- Are currently receiving or have received infusion therapy or injections as treatment for your Myasthenia Gravis symptoms

Please click on the link below to complete a short survey. Based on your survey results, you may be invited to participate and share your feelings about using an auto-injector to treat your symptoms.
Help Us Change Lives»

“What’s New in MG Research” Webinar Series Kicks Off

Wondering about the most recent progress in Myasthenia Gravis treatments research and clinical trials? You are invited to join our **MGFA “What’s New in MG Research”** webinar to learn about the latest research results, key clinical trial phases, and current outcomes from top research trials taking place right now. MGFA is offering this online webinar program series to anyone interested in learning more about the future of more effective MG treatments. We hope you’ll register for the latest update.
Register Now»

Clinical Trials for the MG Community

MGFA is dedicated to driving research to better understand, treat, and cure myasthenia gravis for good. To achieve this goal, we are committed to creating awareness about clinical trials for those with myasthenia gravis and related neuromuscular joint disorders. There are a number of clinical trials in the process right now. Check out the partial list of trials on the MGFA website or see clinicaltrials.gov for more.
Learn More»

Get Involved Today – Support MGFA

There are so many ways for you to Get Involved with MGFA to help the MG Community. Start a community event, volunteer or join a support group, participate in an MG Walk, or become a patient advocate. Contact us to learn how you can dedicate your valuable time to support the MG Community.
Check out all the ways you can help»

Purchase MGFA Apparel and Face Coverings

So many friends across the MG Community have asked about MGFA-branded shirts or face coverings, so we set up our first-ever **MGFA Online Apparel Store** to meet those needs. We hope that you will check out the store and we will be building it out over time and offer more apparel options in the future.
Support MGFA»

Support all our programs, research funding, and our mission to achieve a world without MG.

DONATE TO MGFA

SPOTLIGHT ON THE MG COMMUNITY

MGFA Art Contest a Huge Success with Creative Works of Art

What does the MG Community mean to you? That is the question so many talented and artistic community members addressed in amazingly creative ways. As part of the **MGFA Together We Stand** broadcast event, we asked MG Community members to create works of art that showcase what the community means to them. And they came up with so many lovely works of art in so many mediums – oil paint, watercolor, sculpture, needlepoint, crayon, and even items you find around the house. Check out our wonderful gallery of beautiful works of art.

View the Gallery»

New England Regional Conference

This year at our **MGFA New England Regional Conference**, we will come together VIRTUALLY to celebrate the Power of the MG Community in our New England States. In light of the COVID-19 pandemic, we cannot see each other in person, but as always, we will highlight important research, celebrate milestones and progress, and connect in a way that ensures those living with MG have a support system to navigate their lives with this disease. Please register today to join us on October 31 and November 1 starting at 11:00 a.m. Eastern.

Register Today»

COMMUNITY & PROGRAMMING

MGFA Focus on MG Publication – Fall Issue

FOCUS on mg

FALL 2020

Join our MGFA TOGETHER WE STAND Virtual Event on October 10 at 12:00 p.m. EDT

New Wellness Webinars Helps MG Community Live Well

Highlights in This Issue:

Our Focus on MG newsletter is published each spring and fall, and we include so many great stories that spotlight members of the MG Community and outline key new programs and milestones in research. We hope you will read our Fall 2020 issue.

Read Focus on MG»

MGFA In the News

Myasthenia Gravis and MGFA have been in the news lately. More and more people are learning about our challenges and needs. Check out these recent articles that highlight new information in MG and even feature MGFA.

The Westerly Scholar»

The Morgan Hill Times»

Find a Virtual MG Support Group

Are you looking to connect with others who share common MG experiences? Our MGFA Virtual Support Groups can offer you support, resources, educational programming a well as social and recreational activities. Get together virtually and catch up with friends – or make new friends. Share your story, learn from medical professionals, and offer your support. Check the following link to find the upcoming virtual support meetings.
Learn More»

Remember to Vote on November 3, 2020

Happy Halloween

Is this monthly e-newsletter valuable for you and your family? Let us know. You can send comments directly to MGFA@myasthenia.org or contact Michael Antonellis at mantonellis@myasthenia.org.

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