MYASTHENIA GRAVIS FOUNDATION OF AMERICA

mg™ NEWS

Support • Education • Awareness • Research

FOUNDATION NEWS

MG Awareness Month Goes Virtual and Global!

June is MG Awareness Month and it’s upon us! We're looking forward to honoring this important occasion with you all (while also practicing social distancing). This year, MGFA is encouraging folks to find safe, creative ways to raise awareness about MG — and will then be displaying these efforts on a **digital world map that will light up in teal.**

To get started now, we encourage you to brainstorm creative ways to show your support, tell your story, or educate others about MG in your own community. For example, you might host a virtual fundraiser, create an **#MGStrong** mural in sidewalk chalk in your driveway or neighborhood (like the one pictured here), create signs that can be displayed outside your home, or light up your home with blue lights!

Eager to add your name to the map? Stories and photos can be submitted starting June 1. Stay tuned for more info! We hope that you will help us light up the world with this **Virtual Victory**!!

MGFA Welcomes New Team Member

MGFA is pleased to announce that Craig Strenger has joined the team as the organization's Vice President of Development. Craig brings over 30 years in the non-profit sector, and has served as an executive leader with Muscular Dystrophy Association, American Diabetes Association, and National Brain Tumor Society. His deep development knowledge and experience in the areas of donor stewardship, field operations, and corporate engagement will greatly benefit MGFA and help to shape its future as we embark on our new strategic plan. Welcome, Craig, to the MGFA Family!!

MG Walks Become Virtual Victories

The health and safety of our Community is *paramount* and is our top concern. With this said, MGFA has made the decision to transition all of our Fall walks to **ONE big, global virtual Celebration**. This virtual victory will be **LIVE** and will take place in October. We will continue to keep our community updated and there is much, much more to come on this front!

Please understand that MGFA's priority is the health of our patients, family members, and friends, and this has not been an easy decision to make but it has been made with your health, safety, and general well-being in mind.

RESEARCH

argenx Announces Positive Topline Results from Phase 3 ADAPT Trial for gMG

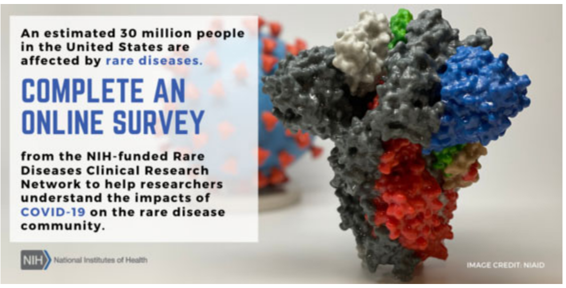
ADAPT met its primary endpoint defined as percentage of responders on the Myasthenia Gravis Activities of Daily Living (MG-ADL) score among acetylcholine receptor (AChR)-antibody positive generalized myasthenia gravis (gMG) patients. Responders are defined as having at least a two-point improvement on the MG-ADL score for at least four consecutive weeks.

To see the full press release, please see **here**.

Research Survey for Rare Disease Patients and their Families about Impacts of COVID-19

Rare disease patients or their caregivers are invited to complete a 20-minute online survey from home about the ways the novel coronavirus pandemic is impacting people with rare diseases and their families.

Impacts can be related to physical health, emotional health, availability of supplies, access to care, or other problems. Your responses may help researchers understand the impacts of COVID-19 on the rare disease community.



An estimated 30 million people in the United States are affected by rare diseases.

COMPLETE AN ONLINE SURVEY

from the NIH-funded Rare Diseases Clinical Research Network to help researchers understand the impacts of COVID-19 on the rare disease community.

The **Rare Diseases Clinical Research Network** (RDCRN) is conducting this study. The network is funded by the National Institutes of Health. It includes 23 research teams working to advance diagnosis and treatment of groups of rare diseases.

The Myasthenia Gravis Foundation of America and **Conquer MG** partners with RDCRN through its work with the Myasthenia Gravis Rare Disease Network (MGNet).

To complete the survey or learn more, **visit the study page here**. Questions? Email the study team at **rd.covid19@cchmc.org**.

Call for Abstracts Now Open for MGFA's 2020 Scientific Session

The Scientific Session is an annual meeting that provides medical professionals the opportunity to learn about, and share work on current, pre-publication research related to disorders of the neuromuscular junction.

To submit an abstract on research related to myasthenia gravis or other disorders of the neuromuscular junction see **here**. The deadline for abstract submissions is June 11, 2020.

To view the full call for abstracts, see additional information on our website **here**.

Strengthen MG Research By Joining the MG Patient Registry Today!

Subscribe to our email list.

As the MGFA community continues to grow, we ask each and every one of you that resides in the U.S., 18 years of age or older, to think about joining the MG Patient Registry. The registry has already made a huge difference for so many people with MG. The information you provide allows researchers to start and continue clinical trials, which leads to increased treatment options. The MG Patient Registry is an active database of individuals with myasthenia gravis (MG), developed for the purposes of research, treatment, and patient information. The registry is free to join and all data is protected by federal privacy laws.

More than 3,000 patients strong, the MG Patient Registry is the largest database to help propel research for MG. We ask you to help strengthen research and understanding about MG by joining now.

Join the MG Registry here

ADVOCACY

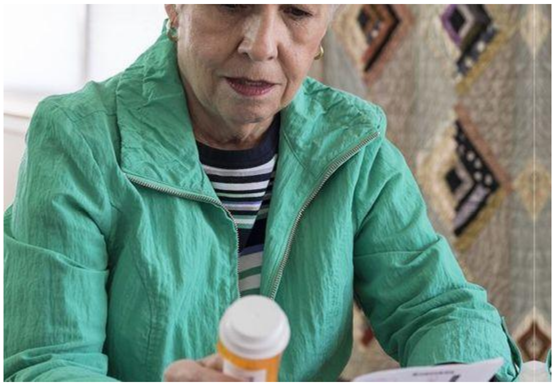
National Health Council Recommendations Aim to Expand Access to Treatments

The National Health Council (NHC), in partnership with 26 national patient organizations, submitted comments to the **Centers for Medicare and Medicaid Services (CMS)** in response to their COVID-19 Interim Final Rule. The NHC recommendations would enhance access to care while maintaining patient health and safety for those with chronic conditions that have a higher risk of contracting COVID-19. The recommendations propose increased flexibility for patients to expanded definition of “homebound” for those that may have contracted COVID-19.

To read the full recommendations, please visit the NHC website **here**.

AWARENESS & ALERTS

Cautionary Drugs Information Now Updated



Given the recent attention around antimalarial drugs, chloroquine and hydroxychloroquine, as potential treatments for COVID-19, we have recently updated the “Cautionary Drugs” information on our website and digital materials. To see complete information, please visit our website **here**. You can also download our “Cautionary Drugs” handout **here**.

Thank you to our Medical & Scientific Advisory Board and the International MG/COVID Working Group for their steadfast and swift guidance on this as new developments and information arise about COVID-19.

COMMUNITY & PROGRAMMING

MGFA Support Groups Stay #MGStrong through Virtual Meetings

In these challenging times, staying connected to your support system is more important than ever. Through virtual meeting technology, community leadership and local expert speakers, our MGFA Support Groups continue to stay connected and welcome new members.

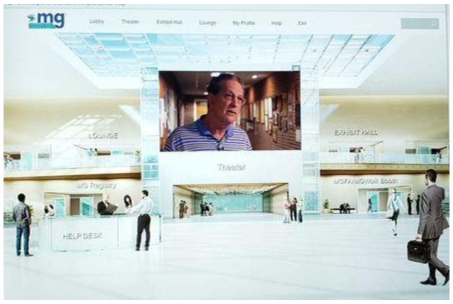
To view the recently updated Virtual Support Groups meetings schedule, please visit our website **here**. You can download the updated schedule **here**.

UCB Features MGFA Virtual Conference in its online company magazine!

UCB, a generous sponsor of our MGFA Virtual Conference in early April, included a great feature about going virtual to support the MG community during uncertain and unprecedented times. We are thankful to UCB for spreading the word and hope that we can inspire and aid other organizations as they navigate unchartered waters in staying connected to their communities.

To see the full article, please visit UCB's website **here**.

You can still access presentations, sponsor information and more by visiting the MGFA Virtual Conference **here** (a brief, FREE, registration is all that is required!)



The **National Organization for Rare Disorders (NORD)** is going virtual with its annual patient and family forum this year, which will take place on July 18th and July 19th. The forum will provide program tracks for newly diagnosed patients, long-term patients, caregivers as well as medical professionals and students.

To learn more about the forum and to register, please visit NORD's website **here.**

Myasthenia Gravis Foundation of America
myasthenia.org
1-800-541-5454 | mgfa@myasthenia.org