FOUNDATION NEWS

2020 June Awareness:
We’re #MGStrong Around the Globe!

As MG Awareness Month draws to a close, we want to thank everyone across our global community for getting creative and helping people understand what myasthenia gravis is - and how it impacts those who live with this disease. From your backyards to city buildings – on your street and in your neighborhood, state, or country – you did everything you could to make MG Awareness Month the best ever – and it looks like you had so much fun too. So many volunteers and community members came out to post photos, create artwork, and tell stories about their unique experiences with MG. Thank you so much for being a critical part
of this year’s awareness month festivities. We couldn’t do this without you. Check out some of the images from the month and click here to see our global map of awareness activity.

MGFA Proud to Join MG United and MG Advocacy Groups Around the World

As we celebrate the end of MG Awareness Month, we’re proud to stand with key partners such as Argenx and its MG United campaign, Momenta, Alexion, and UCB as well as all MG advocacy groups, hospitals, and medical and academic institutions around the world.

We are all working together to improve the quality of life for people living with Myasthenia Gravis.

MGFA Introduces New MG Wellness Series

COVID-19 has created a new and unique set of challenges for the MG community. To meet this urgent need, MGFA has designed a video Wellness Series to connect, educate and empower the MG patients,
care partners and medical professionals. The Wellness Series will focus on four aspects of wellness: physical, social, emotional and psychological. The series provides patients with clear information in an accessible format. The information is broken out into “mini”-sessions which range from top-level wellness topics as well as more in-depth, detailed information for practicing specific areas of wellness.

Visit us here to learn more and stay tuned for our first video.

MGFA Welcomes New Team Members

MGFA continues to grow in order to establish more programming and global awareness that will help drive and fund new research, improve the quality of life for those living with MG, and drive education and guidance for our community. Please welcome new MGFA Team members and reach out to say, “Welcome!”

Michael Antonellis – Vice President, Marketing & Communications

Mike is a high-energy marketing and communications leader with more than 25 years of experience. As Vice President of Marketing & Communications for MGFA, he leads all awareness and promotions campaigns that drive development, programs, research, and patient support initiatives across a wide variety of audiences and channels. Prior to MGFA, he has served in leadership positions in non-profit organizations such as the National Brain Tumor Society as well as in for-profit organizations and marketing agencies. Mike graduated from Boston College with an A&S degree in Communications and concentration in Marketing.

Genna Mvalo – Director, Patient Advocacy and Community Engagement

Genna brings a wealth of experience in
nonprofit management and public health program implementation, most recently having served as the National Director of Development at the Patient Empowerment Network. Previously, Genna held development and management positions at prominent non-profit organizations including National Brain Tumor Society, Partners in Health, Accion International, Princeton University, and Delta Community Supports. She served as a US Peace Corps Community Health Volunteer in a rural village in Malawi where she focused her efforts on palliative care, youth education and empowerment, and HIV prevention. Throughout her career, Genna has focused her efforts on capitalizing on organizational strengths and empowering colleagues to achieve mission-driven goals. She graduated from Boston University with a Bachelor’s Degree in Biology and Public Health.

AWARENESS & ALERTS

COVID-19 Complicates Already Challenged FDA Foreign Inspection Program, as per the U.S. Government and Accountability Office (GAO) Report

The outbreak of COVID-19 has called greater attention to the United States’ reliance on foreign drug manufacturers. Much of the drug manufacturing for the U.S. market happens overseas—and drugs for treating COVID-19 are no exception.

Food and Drug Administration inspections of foreign and domestic drug manufacturers are critical to ensuring drug safety and effectiveness. But FDA began to postpone almost all inspections of foreign manufacturing establishments in March 2020 due to COVID-19. GAO testified that this
lack of foreign inspections removes a critical source of information about
the quality of drugs manufactured for the U.S. market.

To view the full report from GAO, please see their website here.

Plasma Donations Needed

Plasma saves lives and keeps our MG community #MGStrong. Making up 55
percent of human blood, plasma is essential for health — especially for patients
with MG who need plasma therapies. Medical professionals are forecasting a
shortage of plasma, so consider donating plasma if you can.

Find your local donation center here.

IMPACTFUL RESEARCH

MGFA Transformative Grant Generates New Paper on
Potential MG Biomarkers

Circulating Th1/17 cells serve as a biomarker of disease severity and target for early
intervention for MG patients.

Dr. Jeffrey Guptill and the research staff at
the Duke Early Phase Clinical Research Unit
at Duke University Medical Center has
submitted another new paper, accepted by the Journal of
Neuroimmunology. The research was the result of a transformative
grant provided by the Myasthenia Gravis Foundation of America.
This study focuses on a group of patients with myasthenia gravis (MG) who have anti-muscle-specific kinase antibodies (MuSK-MG). In summary, these results support a role for Tfh cell dysfunction in MuSK-MG. Highly specific treatment strategies to rebalance Tfh cells are a potential target for treating patients with MuSK-MG in the future.

Click [here](#) to read the summary or click [here](#) to read the full article.

**Momenta Pharmaceuticals Announces Positive Topline Results from phase 2 Study of nipocalimab**

Momenta announced positive topline results from their interim analysis of its Phase 2 *Vivacity-MG* study investigating nipocalimab (M281) in patients with generalized myasthenia gravis. As per the analysis, all four treatment arms showed efficacy in the myasthenia gravis activities of daily living (MG-ADL) score, the primary endpoint. Additionally, all dosing arms showed strong safety and tolerability profiles.

To see the full press release, please see [here](#).

**COMMUNITY & PROGRAMMING**

**Find an MG Support Group Near You**

Are you looking to connect with others who share common life experiences? Support Groups can offer you support, resources, educational programming as well as social and recreational activities.

- Share your story.
- Learn from local and international professionals.
• Offer support to your family & friends.
• Support Group meetings are an opportunity for your family, caregiver and / or friends to learn more about MG.

Click [here](#) to see virtual support groups and in-person groups in your area.

**National Institutes of Health All of Us Research Program Aims to Capture More Diverse Research Data**

The [National Institutes of Health (NIH) All of Us Research Program](#) is designed to advance individualized, research- and evidence-informed health care, and is committed to enrolling those who were previously underrepresented in health research. The All of Us program is inviting one million people across the U.S. to help build one of the most diverse health databases in history.

To learn more or to enroll, see the NIH All of Us program website [here](#).
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 Patient Registry here

NORD Living Rare, Living Stronger Forum Goes Virtual

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 see NORD’s website here. To register by July 19th, see NORD’s website here.