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

RESEARCH

MGFA Announces Multiple Research Funding Opportunities

We are pleased to announce the release of two Requests for Applications (RFAs) to spearhead promising research for myasthenia gravis. Our annual request for **High-Impact Clinical Research and Scientific Pilot Projects on Myasthenia Gravis and Related Neuromuscular Junction Disorders** is now open. This grant supports promising and innovative pilot studies with a clear plan leading to

new federal, pharmaceutical or private-supported investigations.

MGFA is also pleased to announce its first **targeted research opportunity to benefit the Seronegative MG community**. People diagnosed with seronegative myasthenia gravis – and their clinicians – face special challenges. Seronegative MG has been a relatively neglected area of research in the field, leading to uncertainty about patient outcomes and how to optimally manage patients. The MGFA requests submission of proposals that will lead to greater understanding of seronegative MG, particularly in determining treatment and disease management paradigms, and what may be most successful.

To learn more about our research priorities and funding, see **here**.

To learn more about our research grants, see **here**.

Ra Pharmaceutical's RAISE Study Enters Phase 3

The RAISE study is a multicenter, randomized, double-blind, placebo-controlled study to confirm the efficacy, safety and tolerability of zilucoplan in subjects with generalized myasthenia gravis. Subjects will be randomized in a 1:1 ratio to receive daily SC doses of 0.3 mg/kg zilucoplan or placebo for 12 weeks. After the 12-week treatment period, subjects will have the option to receive zilucoplan in a separate open-label extension study.

To learn more about eligibility, inclusion and exclusion criteria, visit the announcement on our website **here**. Additional details are also available via Ra Pharma's website **here** and on the National Institute of Health's Clinical Trials page **here**.

Strengthen MG Research By Joining the MG Patient Registry Today!

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

Join MGFA for Rare Disease Week on Capitol Hill This February!

You are invited to join MGFA, **EveryLife Foundation** and **Rare Disease Legislative Advocates**, MGFA and 800+ advocates for Rare Disease Week on Capitol Hill 2020 from February 25 to 28. Registration is now **open** for all of the events during this exciting and powerful week in Washington, DC.

If you are planning to attend and advocate for MG, please contact Nakeshia Betsill, MGFA's Director of Volunteer and Advocacy Programs at **nbetsill@myasthenia.org**

Please contact Shannon von Felden, RDLA Program Manager, with questions about the event at **svonfeldon@everylifefoundation.org**.

AWARENESS & ALERTS

Rural Healthcare in High Demand as Budgets are Stretched

The Health Resources and Services Administration of the U.S. Department of Health and Human Services reports a "global healthcare crunch", despite strong bi-partisan support of expanding the Health Center Program.

Learn more **here**.

Nursing Workforce Data & Trends Report Released by U.S. Health and Human Services

The Health Resources and Services Administration of the U.S. Department of Health and Human Services has released 2018 data and projected trends about the nursing workforce. Learn more **here**.

Join the Momentum of the MG Walk!

The MG Walk is dedicated to creating awareness, renewing hope, and generating a vast network of community and support, all while raising important funds for MGFA. The MG Walk puts the power directly into the hands of MG patients and allows everyone battling this illness to become the driving force behind funding for MG research, and ultimately, a cure.

Please see a list of upcoming MG Walks below. New MG Walks launch daily, so make sure to stay tuned via **MGWalk.org**!

- February 8, 2020: Coconut Creek, FL
- February 22, 2020: St. Petersburg, FL
- February 29, 2020: Tallahassee, FL
- March 14, 2020: Atlanta, GA
- March 14, 2020: New Orleans, LA
- April 4, 2020: Fort Worth, TX - **National MG Walk**
- May 9, 2020: Green Bay, WI
- May 17, 2020: Charlotte, NC

If you are interested in volunteering for an MG Walk, please see **here**.

COMMUNITY & PROGRAMMING

Register for MGFA's National Conference Today!

When: April 5-7, 2020 | Where: **Omni Fort Worth**

The National Conference is the largest gathering of the MG community in the U.S. We welcomed more than 300+ attendees to our conference in Atlanta in 2019. Let's make 2020 in Texas even bigger and better!

Presentations and breakout sessions cover all aspects of MG, from medical to personal to social. MG experts, MG community leaders, people with MG and family members come together to share their experience. Join us to gain knowledge, share resources and speak with others "who understand!"

To view the working program, social activities and more see **here**.

To register, see **here**.