RESEARCH

GW Researchers Receive $7.8 Million to Establish Rare Disease Network for Myasthenia Gravis

MGFA is proud to represent the MG Community as a member of MG Net, and has committed $250,000 of funding ($50,000 for each year) to support the project. This commitment from MGFA, as well as that of Illinois-based Conquer MG, was instrumental in demonstrating the support of the MG Community for the project—an essential component of the criteria for funding established by the NIH.

The National Institutes of Health (NIH) has awarded a research team at the George Washington University (GW) $7.8 million to establish a rare disease...
network for myasthenia gravis. The network, which will be part of 25 established NIH Rare Diseases Clinical Research Network, will include basic and clinical investigators, patient advocacy groups and biotechnology and pharmaceutical companies working together to enhance therapeutic development for this rare disease. The team is led by former MGFA Medical and Scientific Advisory (MSAB) Chairs, Henry Kaminski, MD and Linda Kusner, PhD, and the steering committee members are all leaders of the MGFA MSAB as well.

Click here to read the official press release.

The grant will fund research into the underlying pathophysiology of the disease, provide fellowships in MG for young investigators, and fund pilot grants. This funding will also ensure that the serum bank created by the MGFA’s transformative grant will continue. To view the Research Funding Announcements, please see below:

- Clinical Research Funding Announcement: Pilot Grant Program for Myasthenia Gravis
- Myasthenia Gravis Network (MGNet) Scholar Program Research Funding Announcement

**Ra Pharmaceuticals Announces Dosing of First Patient in Phase 3 gMG study, RAISE**

Full Press Release here

Ra Pharmaceuticals, Inc. announced earlier this month the initiation of dosing in the RAISE study, its global Phase 3 clinical trial to evaluate zilucoplan for the treatment of generalized myasthenia gravis (gMG). For additional details about the trial via the National Institutes of Health, please see here.
Alexion Now Recruiting Patients for Phase 3 gMG study for Ravulizumab

Full Study details here

This interventional study is randomized, double-blind, placebo-controlled, multicenter Phase 3 study to evaluate the safety and efficacy of Ravulizumab in complement-inhibitor naïve adult patients with generalized myasthenia gravis. For additional details about the trial via the National Institutes of Health, please see here.

Immunovant Initiates Dosing in ASCEND-MG trial, Phase 2a clinical trial

Immunovant has initiated dosing in the ASCEND-MG trial, a Phase 2a clinical trial in patients with generalized myasthenia gravis. Immunovant plans to report top-line results from this trial in the first half of 2020. For more information about eligibility and study highlights, please see here. For additional details about the trial via the National Institutes of Health, please see here.

Strengthen MG Research By Joining the MG Patient Registry Today!

We are 3,000 patients strong, but we could still use your help!

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.

[Join the MG Registry here]

Cross-sectional Analysis of the MG Patient Registry Published in Muscle & Nerve

[Full Article available here]

This cross-sectional analysis of baseline records through July 2017 of the MG Patient Registry, focuses on disability and treatment.

Data analysis suggests that a large proportion of patients have a significant disease burden, as measured by two well-established, validated, disease-specific, and patient-reported measures—the MG-ADL and the MG-QOL15. These data highlight that MG remains a disease that may significantly affect the disease-specific quality of life of a large number of patients, despite current treatments.

ADVOCACY

Patient-Centered Outcomes Research Institute (PCORI) Re-Authorization Bill Released

On October 18, the Senate released a draft of bipartisan legislation to continue the work of the Patient-Centered Outcomes Research Institute (PCORI).
This legislation would authorize PCORI for the next ten years as well as change the way that data is gathered and used. Currently, PCORI funding is authorized to operate until mid-November. To ensure that funding continues beyond the deadline, the National Health Council is working on recommendations to strengthen patient engagement and outcomes. To view the complete letter, see here. To see the National Health Council’s priorities on the PCORI re-authorization, see here.

**Rare Disease Week Stipends Now Available from EveryLife Foundation!**

The EveryLife Foundation will offer a limited number of travel stipends to help more advocates to attend Rare Disease Week on Capitol Hill, which will take place from February 25-28th in Washington, DC. Please find the application here. The deadline for applications is December 2, 2019.

For more information on the week of events, please see here.
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!

- November 9, 2019: Houston, TX
- November 10, 2019: Manor, TX
- November 16, 2019: Santa Monica, CA
- November 17, 2019: San Diego, CA
- December 7, 2019: Scottsdale, AZ

If you are interested in volunteering for an MG Walk, please see here.
If you are in the Houston, TX area, the Houston Methodist Neurological Institute is holding its tenth annual conference on myasthenia gravis. The conference brings together physicians and MG patients for a day of MG education.

To learn more or register, please see here.

For those in the Durham, NC area, the MDA is hosting a day-long event on MG, featuring topics such as clinical trials and navigating community and federal resources. MGFA Board Member Dr. Katherine Ruzhansky and MGFA Medical & Scientific Advisory Board Member, Dr. James Howard will be speaking at this event.

To learn more or register, please see here.
Join Us at MGFA’s New England Regional Conference on November 3rd!

Registration for the MGFA New England Regional Conference is now open! The conference will take place on November 3rd at 10:30 am at The Verve Conference Center at the Crowne Plaza Hotel in Natick, Massachusetts. Meet with your fellow MG community and take part in talks with MG experts, physicians, researchers and pharmaceutical companies speaking on the latest discoveries and clinical trials.

Online registration is $10 in advance, $15 at the door. Brunch will be provided. Register here today!

Hotel reservations available online here or at 508-653-8800. Please use group code “MGN” when booking.

For more information, please contact Glenda Thomas or Pam Cerullo at mgfanegroup@gmail.com or 508-233-8211