Help Shape the Future of MGFA!

If you have not completed our MG Community Strategy Survey, this is your chance to be part of it now! The survey will close next week, so please make sure to share your input with us [here](#). 

Thank you to everyone who has participated so far- we are grateful for your time and insight!
Ra Pharma recently announced that they are officially recruiting patients for Phase 3 of their generalized myasthenia gravis (gMG) study of zilucoplan. The study, called “RAISE: Randomized Trial of Zilucoplan in Subjects with Myasthenia Gravis”, is a global, multi-center study. Similar to their Phase 2 study, it will be a placebo-controlled, 12-week study, but patients may continue their standard of care treatment and also receive the study drug. After the 12-week study, patients are given the option to continue to receive zilucoplan (no placebo arm) in an open label, long-term extension study called RAISE-XT.

To learn more or to participate in this trial, please contact trials@rapharma.com

Inform Research by Being Part of 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
Save the Date!

The 2019 Scientific Session will be held in conjunction with the AANEM Annual Meeting in Austin, Texas. For more details, see here.

ADVOCACY

The NORD Rare Diseases & Orphan Products Breakthrough Summit draws the rare disease community together for interactive discussions on topics such as: Addressing Affordability While Sustaining Innovation, Overcoming Gene Therapy Challenges for Patients and Manufacturers, How Technology is Advancing Rare Disease Diagnosis and Treatment and more!

To register, please see here.

Patients may access an unapproved drug through the U.S. Food and Drug Administration’s (FDA) expanded access program or via the 2018 federal Right-to-Try law, if the drug manufacturer agrees.

During GAO’s review of drug manufacturers, the majority stated that they would consider individual requests for access. To read additional highlights or the full report, see here.

AWARENESS & ALERTS

Assistive Technology Issue Brief from ACL

The Administration for Community Living (ACL) has released an Issue Brief on Assistive Technology. This brief discusses the important role of assistive technology in helping people of all ages with disabilities live full and independent lives. Information about ACL programs that help fund this technology is also included.
NIH Awards 20M to Neuroscience and Music Therapy Research

The National Institutes of Health has awarded $20 million over five years to support the first research projects of the Sound Health initiative to explore the potential of music for treating a wide range of conditions resulting from neurological and other disorders.

To read more, please see 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!

- October 6, 2019: Langhorne Pike, PA
- October 12, 2019: Springfield, VA
- October 20, 2019: Baltimore, MD
- October 26, 2019: Hamilton, MS
- 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.
The Pacific Northwest Regional Conference took place on September 21st at Bellevue College, with over 80 people in attendance. The morning speakers provided a wealth of information for attendees: Dr. Michael Weiss, a board certified neurologist at the Neurology Clinic at UW Medical Center, spoke about MG and the ongoing clinical trials available; Elaine DeLoach, a retired administrative law judge for the Social Security Administration, spoke about navigating the disability application and appeals process.

Afternoon speakers provided practical advice as well as industry insights. MaryPat O’Leary, an RN, spoke about living with an ongoing health issue. Pharmaceutical partners spoke about recent research developments for MG and clinical trials. The conference provided education and comradery between patients, speakers and sponsors. Kudos to Kathie Bibeau, Ray Bibeau and Sue Kenyon for all of their hard work and planning. Additional thanks to Zach McCallum for graphic design and to Pierre and Phyllis Clement for the help throughout the day.
Join Us at MGFA’s
New England Regional Conference
on Sunday, 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](mailto:mgfanegroup@gmail.com) or 508-233-8211