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
UCB MycarinGstudy is now recruiting in the U.S.!

Learn more about UCB here

MycarinGstudy is now recruiting study participants in the U.S. and UCB is excited to report that their first patient was enrolled on June 3rd. MycarinGstudy is a phase 3 clinical research study designed with myasthenia gravis (MG) patients to evaluate the efficacy and safety of a investigational drug product (rozanolixizumab), intended for subcutaneous (under the skin) administration for the treatment of MG. Study participants in MycarinGstudy should be living with generalized MG with a positive anti-AChR or anti-MUSK antibody test, and experience moderate to severe symptoms.

For more information, contact UCBCares@ucb.com or visit the Clinical Trials page of the National Institutes of Health here.

Inform Research by Being Part of the MG Patient Registry Today!

We’re almost 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

C-PATH and NORD to launch Rare Disease Data and Analytics Platform

The Critical Path Institute (C-Path) and the National Organization for Rare Disorders® (NORD) will be hosting a meeting to discuss the development of a new rare disease data and analytics platform. The goal of the platform is to accelerate the movement of therapies from bench to bedside for rare diseases. To learn more, or to register for the meeting, click here.

ADVOCACY

MGFA Releases Statement on IVIG Shortage

In response to the recent news and community reports of IVIG shortage, we released a statement for the MG Community, which can be found on our website here. We hope this statement provides more clarity around the specifics of the shortages and what to do if you are being affected. We take this matter seriously and will continue to keep you updated.
More information from the U.S. Food & Drug Administration about the shortage can be found [here](#).

**AWARENESS & ALERTS**

**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](http://MGWalk.org)!

- September 7, 2019: Louisville, KY
- September 14, 2019: Cleveland MG Walk
- September 14, 2019: Columbia, MO
- September 21, 2019: Southern IL MG Walk
- September 22, 2019: Chicagoland MG Walk
September 28, 2019: Portland MG Walk
September 28, 2019: Huntington, WV
September 29, 2019: Seattle MG Walk

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

Public Hearing and Comments on Advisory Guidelines for Aircraft Onboard Wheelchairs

The U.S. Access Board has released for public comment advisory guidelines for wheelchairs used on commercial passenger aircrafts during flight. These advisory guidelines will be used as technical assistance to air carriers and manufacturers of onboard wheelchairs by providing an example of how to meet the Department of Transportation’s planned performance standards.

Public hearing (via web and in-person) details will be available here.

Public comments are due October 21, 2019 and can be submitted here.
COMMUNITY & PROGRAMMING

MGFA’s Pacific Northwest Regional Conference
Taking Place on Saturday, September 21st!

Join us at the Pacific Northwest Regional Conference on Saturday, September 21st at Bellevue College in Bellevue, WA! Learn about the latest in MG research and connect with others who “understand”. We welcome all to attend, people with MG, caregivers, family members and friends. Lunch will be provided to attendees. Tickets to this event are free of charge. If you are able, we would appreciate any contribution you can make.

Registration will start at 9:00 am, the meeting will begin at 10:00 am. To register see here.

We are grateful to the MG community leaders that helped make this event possible. A special thanks to Kathy and Ray Bibeau for all of their work in bringing this program to the regional community!
Podcast on Managing Ig Shortages

Forecasting availability of Ig is complicated by the lengthy production cycle, volume of plasma donations, and product demand as well as regulatory or other manufacturing challenges.

Listen as Luba Sobolevsky (IgNS) and James Sheets (CSI Pharmacy) discuss the current Ig shortage and learn how nurses and care teams can help their patients.

Alexion Offers Live Educational Webinars

Alexion is offering live webinars and in-person educational events for patients with generalized myasthenia gravis (gMG).

To register for upcoming events, please see here.
If you’re in the D.C. area, the National Health Center is hosting a training session to introduce medical professional staff and members of patient and community organizations to the importance of the patient voice and use of value assessment findings. Interested in attending? Click here to learn more!

Houston Methodist Neurological Institute Holds 10th Annual MG Conference on November 2

If you are in the Houston, TX area, the Houston Methodist Neurological Institute is holding its 10th Annual Conference on myasthenia gravis. The conference brings together physicians and MG patients for a day full of MG education.

To learn more or register, please see here.