

MG NEWS



Dear Readers,

Welcome to MG News! We've changed our delivery and format slightly to ensure that we are sending you the latest news in the MG community, more frequently. We hope that you enjoy hearing from us more often and we thank you for reading!

*Best regards,
MGFA Communications Committee*

Registration for the 2019 MGFA National Conference is now open! We have 30+ sessions planned, along with social activities! To learn more or register, see [here](#).



RESEARCH

MGFA Announces 2019 Clinician-Scientist Development Award to Dr. Raja of Duke University



With funding support from the American Brain Foundation and MGFA, the Clinician-Scientist Development Award provides grant support to clinician-scientist's research related to myasthenia gravis. This award aims to recognize the importance of sound clinical research and encourage young investigators in clinical studies. This three-year award provides an annual salary of \$75,000 plus an annual \$5,000 for educational expenses. The grant will be awarded at the 2019 [American Academy of Neurology Annual Meeting](#) in Philadelphia, PA, this May.

Dr. Raja's project, titled, "*Real World Outcomes of Surgical and Medical Management in Myasthenia Gravis*", will analyze perioperative outcomes of myasthenia gravis patients who have undergone thymectomy. The project will focus on immunoglobulins, steroid use and real world outcomes of surgical and medical management of MG.

To learn more about Dr. Raja, please see [here](#).

Medication Reduction Research Project for People with MG

Dr. Michael Hehir is working hard on behalf of MGFA to secure funding from the [Patient Centered Outcomes Research Institute](#) (PCORI) for a project titled, "*REDUCE MG*". This project focuses on reducing MG medications for people who are stable. The survey takes less than five minutes to complete and will help further inform PCORI about the proposal. Anyone with MG complete the survey; you do not have to be stable to participate.

Survey Link: <https://redcap.med.uvm.edu/surveys/>
Code: F7JNMM8NH



We thank you in advance for sharing and helping inform MG research!

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



We're at 2,700 patients and counting, but we could still use your help!

As the MGFA community continues to grow, we ask each 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 lead 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](#)

ADVOCACY

Join MGFA at Rare Disease Week!

You are invited to join RDLA, MGFA and more than 500 other advocates for Rare Disease Week on Capitol Hill 2019 from February 24 to 28. [Rare Disease Week on Capitol Hill](#) brings the rare disease community and their caregivers together to advocate on federal healthcare issues. This is a great opportunity to meet other advocates, share your unique stories, and urge the importance of passing key healthcare legislation.

The event is hosted by [EveryLife Foundation](#) and registration is [open](#) for all of the events during this exciting and powerful week in Washington, DC.

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

If you are interested in learning more about advocacy opportunities in the MG community, please contact Nakeshia Betsill, MGFA's Director of Volunteer and Advocacy Programs at nbetsill@myasthenia.org

Take Part in Rare Disease Day!



February 28, 2019 will be the 12th International Rare Disease Day. On this day, hundreds of patient organizations from around the world raise critical awareness about rare disease.

We encourage you to get involved in Rare Disease Day by telling your story or joining the campaign on social media. To see ways that you can get involved in 2019, please visit the Rare Disease Day page [here](#).

Make sure to use the following tags on social media to help spread the word!

#MGStrong
#ShowYourRare
#RareDiseaseDay

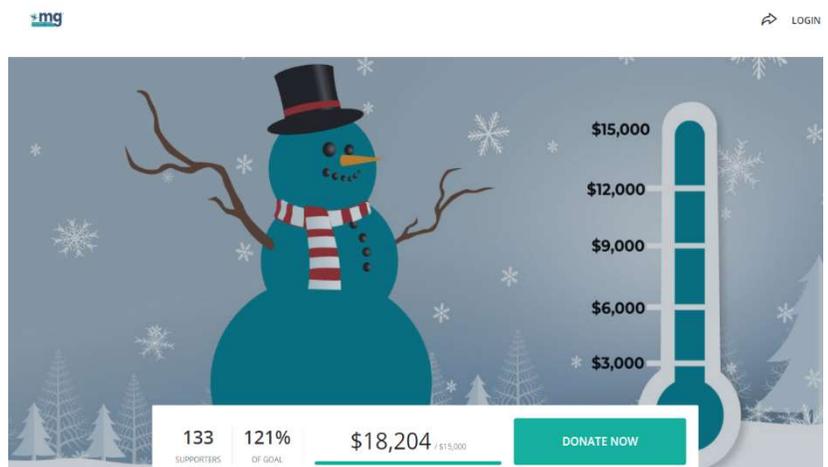
@myastheniagravisfoundation
@myastheniaorg
@rarediseaseday

AWARENESS & ALERTS

Thank You for Your Support of the “Build a Snowman” Campaign!

On Giving Tuesday, November 27, 2018, MGFA launched an awareness and fundraising campaign, titled “Do You Want to Build a Snowman?” This unique fundraising campaign was designed to honor someone you know affected by MG, whether a person living with MG, a family member or a caregiver.

Thanks to your support, we surpassed our 15K goal- raising more than 18K! Thank you for helping us turn the snowman teal to raise MG awareness.



Special thanks to Celia Meyer, who spread the word on social media, and to Roger Morse, who helped honor those affected by MG with certificates.

Spring 2019 MG Walks Announced!



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 Spring 2019 MG Walks below. New MG Walks launch daily, so make sure to stay tuned via MGWalk.org!

- February 23, 2019: Tampa Bay, FL
- February 24, 2019: South Florida, FL
- March 10, 2019: Tallahassee, FL
- **March 30, 2019: National MG Walk in Atlanta, GA**
- April 6, 2019: New Orleans, LA
- May 4, 2019: Boston, MA
- May 11, 2019: Green Bay, WI
- May 19, 2019: Charlotte, NC
- June 1, 2019: San Francisco, CA

Prepare Your Health This Season with Help from the CDC



The Center for Preparedness and Response of the Centers for Disease Control and Prevention has a number of resources to help you prepare your health in the event of an emergency. Make sure to protect your health this year, given the longer cold and flu season. More information available from the CDC [here](#).

COMMUNITY & PROGRAMMING

Join Us for the 2019 MGFA National Conference in Atlanta!

The **2019 National Conference** and **National MG Walk** will take place in Atlanta, Georgia from **March 30 through April 2**.

We have over 30 educational sessions planned, featuring a wide range of topics. We'll have information on the latest in MG clinical trials and treatment, nutrition, functional medicine, mental health and more!

We also have exciting social activities planned to help you connect with others in the MG community. To learn more, please visit our conference website [here](#).





Upcoming Webinars in 2019!

Respiratory Issues & MG Monday, March 4, 2019 at 8 pm ET



Our upcoming webinar on respiratory issues and MG will be presented by Dr. Nicholas Silvestri.

Nicholas J. Silvestri, M.D. is the Clinical Associate Professor of Neurology and Assistant Dean for Graduate Medical Education at the Jacobs School of Medicine & Biomedical Sciences, University at Buffalo. He currently practices at Jacobs Neurological Institute and is affiliated with Kaleida Health Buffalo General Hospital. Dr. Silvestri accepts multiple insurance plans including Aetna, MVP Health Plan and Empire Blue Cross Blue Shield. Dr. Silvestri also practices at UBMD Neurology, Buffalo General Medical Center (BGMC) and at the Muscular Dystrophy Association clinic at BGMC, where he serves as co-director.

Dr. Silvestri has specialized training in clinical neuromuscular medicine, with expertise in clinical care and in performing electrodiagnostic studies (nerve conduction and electromyography). Dr. Silvestri conducts both clinical research studies and basic science research in collaboration with physician-scientists from multiple disciplines, including neurology. His clinical research is focused on several studies that address illnesses such as Guillain-Barre syndrome, myasthenia gravis and polyneuropathy. These studies include both treatment trials--to find more effective treatments for these diseases--as well as research investigating the impact of the diseases on patients' quality of life.

Seronegative MG: Treatment

As a follow-up to our January webinar, we will be providing a second webinar on “Seronegative MG”, focusing on treatment options. We thank you all for your positive feedback about our January webinar and look forward to providing you with more information on this very important topic. *Date to be announced.*

Antibodies & MG

This webinar will focus on recent advances in clinical research around antibodies, in particular, LRP4, agrin and titin. [Dr. Pushpa Narayanaswami](#), of Beth Israel Deaconess Medical Center and Harvard Medical School Teaching Hospital, will present on this critical topic. *Date to be announced.*

Stay tuned for more details about our 2019 [webinars!](#)

MAYA Virtual Meeting

Starting a Family and Parenting with MG

Wednesday,
February 6, 2019 at 8 PM ET

Calling all young adult MG patients between 18-35 years old to attend MAYA's upcoming Virtual Support Group meeting “Starting a Family and Parenting with MG”.

Please RSVP [here](#)

Get to know other young adults living with MG!

Follow MAYA on FB: <https://www.facebook.com/groups/MGFAMAYA/>
Sign-up for MAYA updates: <https://goo.gl/forms/NMMJwniNydJGRdnT2>

