

# MG NEWS



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

**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

## Rare Disease Week is here!

Rare Disease Legislative Advocates (RDLA), MGFA and more than 500 other advocates will hit the Hill 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. The event is hosted by [EveryLife Foundation](#).

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](mailto:nbetsill@myasthenia.org)

## Get Social for Rare Disease Day!



**February 28, 2019** will be the 12<sup>th</sup> 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  
@rare diseaseday

# AWARENESS & ALERTS

## *I Am MG Strong Video Contest*

Did you hear? MGFA is launching our first-ever video contest! We launched the contest via social media on Rare Disease Day, February 28. The competition is a great way to show how you are #MG Strong. The competition aims to increase awareness of MG and demonstrate the strength of our community through creative videos. Don't worry, you don't need to be a professional to join the contest!



### **How Do I Get Started?**

- Videos should be less than two minutes in length
- Tell how you are #MG Strong in daily life; how do you get past the challenges of MG?
- Share your top three tips for managing your MG
- Want to be even more creative? You can submit more than one video to the contest, as long as they meet the submission requirements

### **Submission Rules, Eligibility and Prizes**

- **Official Contest Rules, Eligibility and Judging terms [here](#) – please read to make sure that we can use your submission!**
  - MGFA has the right to un-tag and disqualify any video deemed inappropriate
  - Posts must contain the hashtag #IAmMGStrong so that it is searchable in order to be eligible
  - Tag @MyastheniaGravisFoundation and @MyastheniaOrg

We hope you will join the buzz on social media for our Video Contest campaign to raise critical awareness of MG and to show our strength!

## MG Walk Team Eden Makes Local News!

[Click here for full story](#)

Love can transcend borders and defy expectations. Just ask Joe Ferraro, whose motivation to help his niece has crossed state lines and galvanized a community of volunteers.

The high school lacrosse team coach's mission: to give hope to his niece Eden Nelson, an 11-year-old who lives with a condition called myasthenia gravis.

Each year, Ferraro coordinates Team Eden to help raise funds for the Myasthenia Gravis Foundation of America. The busy coach, who retired from the insurance business, now chooses to lead the lacrosse team to victory. Instead of kicking back or cruising the Caribbean, he jumped in to help his niece after learning about her diagnosis.



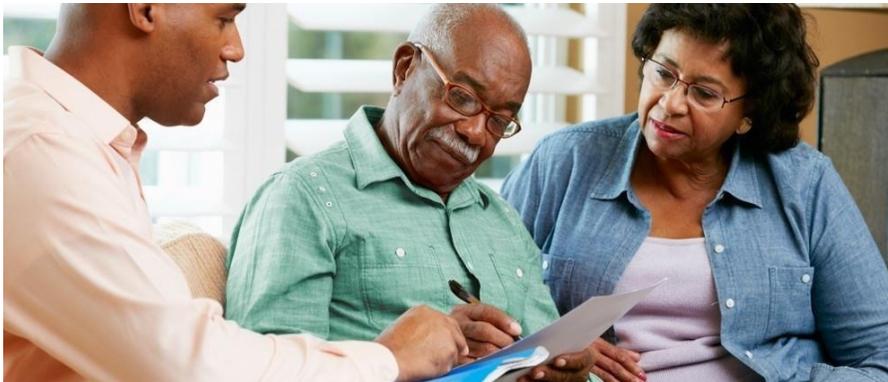
## Join the Momentum of the MG Walk!



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](http://MGWalk.org)!

- 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
- June 8, 2019: New York City, NY
- June 9, 2019: Bloomfield, NJ
- June 9, 2019: Meriden, CT



## **Important Information on Advance Care Planning**

Learn more about States' efforts to educate and improve access around advance care planning. See more about this initiative as well as important facts to help you get prepared by visiting the U.S. Government Accountability Office website [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](#).



## Respiratory Issues & MG Webinar 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.

**To register, please click [here](#). Call-in and presentation information will be provided via Survey Monkey following registration.**