



**Support • Education • Awareness • Research**

## **FOUNDATION NEWS**

### **MGFA Announces Samantha Masterson as new *Chief Executive Officer***

On behalf of our Board of Directors for Myasthenia Gravis Foundation of America, we are pleased to announce the selection of Samantha (Samm) Masterson as our new Chief Executive Officer.

Samm comes to MGFA with nearly two decades of non-profit experience, most recently serving as the Vice President, Donor Stewardship for the March of Dimes, where she was responsible for operationalizing an integrated donor relations strategy across all functional areas of the business. Her work resulted in revenue generation and long-term, meaningful investment by donors across all channels.

Prior to joining the March of Dimes, Samm served as the Chief Advancement Officer for National Brain Tumor Society, the largest national research and advocacy organization dedicated to the brain tumor community. Samm provided the vision and strategy on all aspects of development, marketing & communications, field operations and special events.

We are thrilled to welcome Samm to our team, and look forward to working with her to grow MGFA and expand upon our current programming and fundraising. The combination of Samm's deep development background and expertise, and the passion and commitment of our community will be an undeniable force.

As retiring CEO, Nancy Law will assist in Samm's orientation, serving as a consultant for MGFA until the April 4 meeting of the Board of Directors, when she expects to accept the position of Board Chair for MGFA. Nancy looks forward to serving the MG Community in this new capacity—working with Samm and MGFA staff and volunteers to ensure a smooth transition and continued organizational growth.

"I am grateful to the Board of Directors for the privilege and honor to serve as MGFA's next CEO. I look forward to serving the MG community and getting to know our many supporters and building meaningful relationships. Hand in hand we will work to fulfill the vision of a world without MG," Samm said.

Samm's official first day was February 24, 2020. We look forward to everyone getting the chance to meet Samm in the near future. Please join us in welcoming Samantha Masterson as the incoming CEO. For any questions, please contact: [nancy.law@myasthenia.org](mailto:nancy.law@myasthenia.org)

## **RESEARCH**

### **Potential Therapeutic Role for zilucoplan in generalized MG as per JAMA Neurology**

Many patients with generalized myasthenia gravis (gMG) have substantial clinical disability, persistent disease burden, and adverse effects attributable to chronic immunosuppression. Therefore, there is a significant need for targeted, well-tolerated therapies with the potential to improve disease control and enhance quality of life.

The findings of this study, “[Clinical Effects of the Self-administered Subcutaneous Complement Inhibitor Zilucoplan in Patients With Moderate to Severe Generalized Myasthenia Gravis](#)”, published by [\*JAMA Neurology\*](#), support a potential therapeutic role for zilucoplan in generalized myasthenia gravis and further evaluation in a phase 3 study.

## **Strengthen MG Research By Joining the MG Patient Registry Today!**



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.

More than 3,000 patients strong, the MG Patient Registry is the largest database to help propel research for MG. We ask you to help strengthen research and understanding about MG by joining now.

[\*\*Join the MG Registry here\*\*](#)

## ADVOCACY

### MGFA Hits the Hill for Rare Disease Week!

MGFA, [EveryLife Foundation](#), [Rare Disease Legislative Advocates](#), and 800+ advocates join together on Capitol Hill for Rare Disease Week this week.

Are you at Rare Disease Week? If so, make sure to tag us on social media:

**Facebook:**

**@MyastheniaGravisFoundation**

**Twitter: @Myasthenia.org**

**Instagram: myastheniaorg**

Want to join in on advocacy, but can't attend in person? Watch Rare Disease Day at NIH via videocast on 2/28 [here](#).



## AWARENESS & ALERTS

### MGFA Featured on Give.org!

See how MGFA advances collaboration with the [Better Business Bureau's Wise Giving Alliance](#)! To view the article and download the full interview, 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](https://www.mgwalk.org)!

- February 29, 2020: Tallahassee, FL
- March 14, 2020: Atlanta, GA
- March 14, 2020: New Orleans, LA
- April 4, 2020: Fort Worth, TX - [National MG Walk](#)
- May 2, 2020: Meriden, CT
- May 9, 2020: Green Bay, WI
- May 16, 2020: Boston, MA
- May 17, 2020: Charlotte, NC
- May 30, 2020: Knoxville, TN
- May 30, 2020: Bloomfield, NJ

If you are interested in volunteering for an MG Walk, please see [here](#).



## COMMUNITY & PROGRAMMING

**Register for MGFA's National Conference Today!**

When: April 5-7, 2020 | Where: [Omni Fort Worth](#)



The National Conference is the largest gathering of the MG community in the U.S. We welcomed more than 300+ attendees to our conference in Atlanta in 2019. Let's make 2020 in Texas even bigger and better!

Presentations and breakout sessions cover all aspects of MG, from medical to personal to social. MG experts, MG community leaders, people with MG and family members come together to share their experience. Join us to gain knowledge, share resources and speak with others "who understand!"

To view the working program, social activities and more see [here](#).

To register, see [here](#).



## SoCal Support Group Leaders Join Together to Kick-off New Group in Orange County!



*pictured left to right: Dova Levin, ConnieDiPasqua, Paul Driskell, Leah Gaitan-Diaz, Veena Mathew*

A new Support Group has been established in Orange County, California! The Support Group Leader, Veena Mathew (pictured far right), has worked for many years with clinical trial patients at a myasthenia clinic at the University of California, Irvine. Neighboring Support Group Leaders, Connie DiPasqua (Greater Palm Springs), Paul Driskell (Greater Palm Springs), Leah Gaitan-Diaz (USC/LA) in South California showed their support by joining the inaugural meeting. After a great kick-off meeting with 17 attendees, a planning meeting for the first Southern California Regional Conference took place.

Stay tuned via [myasthenia.org](http://myasthenia.org) for more information on the next Orange County Support Group meeting and the Regional Conference!