

MAKE JUNE #MGSTRONG AND LIGHT THE MAP TEAL!



Philip Williams, bodybuilder with MG and speaker at 2019 MGFA National Conference

By Tommy Santora, MGFA Communications Committee Chair; New Orleans Support Group Leader

From illuminating sports stadiums and business buildings, to garnering city, town and state proclamations, and participating in a satellite media tour in more than 25 cities, MG awareness messages spread across the nation. Through news publications, health care journal articles, and social media channels, the messages of #MGStrong and MG awareness were heard around the globe in 2018.

Thanks to YOU, our MG community, for making 2018 one of the best June Awareness Months ever! Let's make 2019 even bigger and better! To get there, we're asking YOU to get involved – and there's lots of ways to do it!

The Myasthenia Gravis Foundation of America (MGFA) is excited to announce a "Light the Map Teal" campaign. We'll start with a blank map of the United States, with each state lighting up teal for June Awareness

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RSA Battle House Tower, Mobile, Alabama



2019 MG Walks

CA: SAN FRANCISCO June 1

NY: QUEENS June 8

NJ: BLOOMFIELD June 9

CT: MERIDEN June 9

KY: LOUISVILLE
September 7

MISSOURI: COLUMBIA
September 14

OH: CLEVELAND
September 14

Please go to mgwalk.org for more information on a walk near you!

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WEBSITE WELCOME!

Welcome to MGFA's new website! Our address is still the same – www.myasthenia.org – but we are new and improved! We've taken into account feedback from the MG community, MGFA Board Members, MGFA staff and more to make sure that we are developing a useful and dynamic site to help meet the needs of people with MG, their loved ones, health professionals, researchers and dedicated volunteers.



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CEO'S LETTER



THE TIME IS NOW!



More than just the theme of our 2019 National Conference, this one word speaks to our determination – and the urgency we feel – like no other. For so many years it seemed to us “impatient patients” like research just crawled along.

Not anymore. We are at a tipping point and the world of MG as we know it is changing before our eyes.

NOW! we can point to **scientific research** that has led to greater understanding of MG: the landmark thymectomy study and the development of treatment guidelines. There is greater understanding of the neuromuscular junction, and research into biomarkers that could expedite treatment decisions.

NOW! there are **clinical trials** to create pathways to new and better treatments. Several of these are targeted disease modifying therapies (DMTs) specifically for MG: with one DMT (Soliris) approved by the FDA, and 5 others moving forward to either phase 3 or phase 2 trials. You will be hearing a lot from us about these trials in 2019 and beyond.

NOW! through a dedicated team of community and support group leaders, our telephone peer support program, MG Friends, and our representatives in social media, people living with MG can connect with others—no matter where they live. Now, **no one needs to ever face MG alone.**

NOW! a **unified MG Community** is coming together to raise our voices and be heard by people who can make a difference. Just a month ago, a delegation of eight mighty MG warriors joined with 500 other activists to educate our legislators about the challenges facing the 25 million Americans living with rare diseases like MG. They met with representatives across the nation and, advocated for research funding. They raised their voices to increase recognition of “real world evidence” to improve access to effective MG treatments, which are often denied by insurance because they are used off-label.

NOW! there are **educational tools and materials** for emergency room personnel and first responders that can improve care for patients in crisis. Our new video training program and accompanying materials give each patient tools to educate those involved in urgent care.

NOW! as we launch our **brand new website**, it is easier for everyone to find the MG information they need – whether searching for basic information on MG, locating an MG specialist, or connecting with a support group or MG Friend.

NOW! is a time of **great hope**. Changes are coming, and they can't happen fast enough for those living with MG. The promise of new and better treatments is incredibly exciting, but we want more. We want a cure!

Our work will not be done until we can say,
“NOW! FINALLY! THERE IS A WORLD WITHOUT MYASTHENIA GRAVIS!”

Nancy Law

Some highlights of our new website below:

- More information about MG:** We've expanded the content around different types of MG, related conditions, diagnostic testing as well as a section dedicated to those newly diagnosed with MG.
- More resources:** We've included search functions on our homepage so that you can find a doctor or a support group near you. We've put important information and popular resources front-and-center on our homepage with rotating tiles, as well as ways to connect to us on social media.
- How to live your best life with MG:** We've created a new section on our website to help you live your best life with MG. We have information to help you take charge of your healthcare, wellness and daily MG management strategies, caregiver tips and talking points to help you discuss MG with others.
- Paving the way for MG research:** We've expanded information about MGFA's research initiatives, the latest in research news and clinical trials as well as information about grant opportunities for promising research in the field of MG.
- Getting involved with MGFA:** We've included information about the many ways that you can be part of MGFA's work, from volunteer opportunities to fundraising initiatives to June Awareness month.



A special thanks to the following dedicated volunteers and authors in helping shape our new website:

- | | |
|-------------------------|------------------------|
| Rebecca Molitoris | Niki Grossheim |
| Tommy Santora | Garry Morehouse |
| Suzanne Ruff, Ph.D. | Rachel Pegram |
| Yuebing Li, M.D., Ph.D. | Amanda C. Guidon, M.D. |
| Evan Greene | Michael K. Hehir, M.D. |

We hope that you enjoy our new website – stay tuned for more developments, resources and updates at myasthenia.org! ✨

If you or someone you know is experiencing sudden or gradually increasing symptoms of muscle weakness, it could be a sign of MG or another serious condition. Talk to your doctor if you are short of breath, have difficulty smiling, talking or swallowing, or cannot walk any distance without having to rest.

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient.

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efforts completed. Make sure to let us know about all the great work happening in your community by emailing us at juneawareness@myasthenia.org or posting on social media using the **#MGStrong** tag. Show your community's commitment to MG Awareness and help inspire others to do the same. Represent your state and help us go teal nationwide!



Mercedes-Benz Superdome, New Orleans, LA



United Center, Chicago, IL

Please stay tuned via social media on Facebook, Twitter and Instagram during May and June for more information.

We'll provide you with more information and outreach tactics to help you light your state teal and raise MG awareness. Your efforts are important in increasing understanding and diagnosis of MG.



June Awareness Month also lets people know about MGFA's work in supporting those with MG. Through fundraising and research initiatives, MGFA helps pave the way towards improved treatment and, eventually, a cure for MG. MGFA is a resource that you can use year-round, not just during the month of June. Make sure to visit myasthenia.org and follow MGFA on social media **@Myasthenia.org**. You can get the latest information on MG, materials and more!



To help us go teal in your state, JUNE AWARENESS efforts can consist of any of the following:

- **Lighting Up Teal:** corporate buildings, sports stadiums, bridges or street lights
- **Proclamation Nation:** establishing city, town, and state proclamations
- **Press Coverage:** receiving any press around June Awareness; newspaper, magazine articles or TV station interviews (MG Walk promotion included here too!)
- **DIY Fundraising:** complete a Do-It-Yourself fundraiser during the month of June
- **Showing Support:** send us your support group meeting photo with everyone dressed in teal



Alexis Rodriguez accepts House Resolution 696 from GA Rep Tom Rice, recognizing March 30 as Georgia Myasthenia Gravis Day at the State Capitol

CREATE MG AWARENESS YEAR-ROUND

Here are some other great ways that you can increase MG awareness in your community:



Write an Op-Ed: Write about the need for greater awareness of MG and funding for research. Opinion Editorials (op-eds) are articles written by local citizens, organization leaders, experts, or others who are knowledgeable about an issue. The topic of an op-ed is the writer's choice, but more relevant and timely op-eds are more likely to be published. By submitting an op-ed you can call attention to your issue. Check out your local paper for requirements regarding length and where to submit.



Share Your Story with the

Press: Consider using awareness raising activities as the timely

reason for a reporter to tell this story. Reporters typically need particular components when developing a story. Thinking through their needs in advance can help strengthen your story suggestion for them. Make sure to have the following elements in your event to ensure media success: 1) good turnout; 2) one or more participants has an intriguing story to share; and 3) there is action happening and something to experience



Be a Social Media

Bug: Social media is a great way to share

your story and your events. Use Twitter, Facebook, Instagram to share your experiences with MG, using the hashtag **#MGStrong**. Please consider adding this hashtag to your profile photo and maintaining that photo through the month of June. Share the photo among your social media friends and encourage them to champion our cause.



Connect the Community: Engage scout groups, churches, sororities/fraternities etc. in community service projects to

design posters, make snowflakes, or decorate a large area of your town/city with snowflakes. Consider working with a school or nearby arts community to produce an art show focused on the challenges of MG, learning to cope, and finding joy despite MG. Share your story, artists unveil interpretations of MG in painting, poetry, sculpture, and other creative means.



2018 MGFA National Conference, MAYA Paint & Sip activity



The Weiss Guys — Top Fundraising team from Tampa Bay team, raising \$9,644

Join an MG Walk:

In nine years, the MG Walks have raised more than \$6 million in research funds, awareness and advocacy efforts. 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, in finding a cure. In addition to fundraising, the MG Walk also allows patients with MG to open up and discuss their journey in a safe and nurturing environment, as part of the MG community. Find a Walk near you, participate, fundraise and spread the word. Visit mgwalk.org to find a Walk near you.



Post Around Town:

Request permission to post MG Awareness posters in libraries, stores, pharmacies, senior centers, churches, and other public places. If you require materials for June Awareness month, please contact mgfa@myasthenia.org



Give Presentations:

Turn the tables on the medical community! To help educate others about MG, offer to give a talk about your experiences at schools, medical centers, religious associations, church groups and other gathering points.



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Tampa Support Group



Give Support, Share Support: Attend a local Support Group meeting. We have 70 groups and counting across the country.

Visit myasthenia.org to see a Support Group near you. We also have a tele-support program, MG Friends, for peer-to-peer support so that no one with MG, no matter where they live, has to face MG alone.

Already part of a Support Group? Schedule a meeting for June and center the topic around MG Awareness. What is MG? What treatments are available? What research is happening? Help increase attendance by noting “New MG Patients and Caregivers Welcome” on the flyer.



Educate Others About MG: Help create awareness about MG in your workplace, school, or other community gathering spots by explaining what MG is, and how it affects you.

When someone you encounter casually looks at you doubtfully perhaps because of eyelid ptosis or your inability to smile, take this as a teachable moment. Try to explain succinctly. You might say, “I see you are wondering why my eyelids seem so droopy (or why I’m wearing an eye patch, etc.). I have MG. It’s an autoimmune disease that causes muscle weakness. This is one symptom. If you are curious you can learn more at www.myasthenia.org.” Become the teacher, and share your knowledge to educate people around you.



Join the MG Patient Registry: Last, but not least, if you haven’t done so already, join the MG Patient Registry at www.mgregistry.org. You’ll be helping the entire MG community. Through the Registry, the MG community provides information about their experiences with diagnosis, treatment, insurance and impact on daily life. The Registry provides a wealth of information to encourage research and treatment development for MG. ✨

Whatever you decide to do for June Awareness Month, do not forget that you are not alone in this journey. Do not hesitate to ask a fellow MG patient what has worked for him/her in the past to spread awareness to help you build your own initiative. As you battle every day, please know that there is significant work going on behind the scenes to help us find a cure for MG. This is a great time to do your best to let people know about it.



Sarasota Golf Outing Becomes Annual Fundraiser

Patti Abramson was a beautiful soul who was always happy helping others according to those that knew her best. Patti was diagnosed with myasthenia gravis around the age of 12. Although Patti passed away two years ago, her memory lives on in the **Patti Medlar Abramson Golf Outing**. What is now an annual event at the Heritage Oaks Golf and Country Club in Sarasota, was held for the first-time last September and is scheduled again for October 25, 2019.

Last year's event exceeded fundraising expectations, netting \$17,000 for MGFA.

According to one of the event organizers, Liz Kinnisten, each of the 18 holes were sponsored with all signage donated. "It's amazing how giving

He was most proud of the work she did mentoring young people, taking them under her wing, making sure they moved forward, because, "that's just what she did...moved forward."

people are," Liz said. The event has the support of an active committee including Patti's husband, Jeff.

Patti and Jeff relocated to Sarasota from New York just a few years before Patti passed away. Liz said Patti loved sports and was just getting into golf. It was her love of sports that led to a golf outing in her memory. The event is well-attended by family and friends from New York. A friend of Patti's from Australia even cooked "shrimp on the barbie" at the 12th hole.

Michael Lifshitz, a MGFA Board Member and Fundraising Committee Chair, had the opportunity to talk with Patti's dad, Bob Medlar, during the tournament. Bob

is extraordinary man who wants to make sure that Patti's work is not forgotten, Michael shared. Bob recalls how, despite her MG, Patti never stopped, personally or professionally. He was most proud of the work she did mentoring young people, taking them under her wing, making sure they moved forward, because, "that's just what she did...moved forward." Michael was struck by how alike Patti and her father must have been.

As many people do not know about MG, the committee believes the event offers the

When asked what advice she would offer others considering a fundraising event like this, Liz said, "Just do it! It's not as hard as you think and lots of people will help!"

opportunity to increase awareness for a disorder that has touched their lives and the many others that knew and loved Patti. Save-the-Date announcements are already in the mail for the October event.

When asked what advice she would offer others considering a fundraising event like this, Liz said "Just do it! It's not as hard as you think and lots of people will help!"

For more information on planning a golf tournament or any other type of fundraiser, please contact Betty Ross, Director of Development, at bross@myasthenia.org. ✨





MG STRONG

Highlights from the **NOW!**

2019 NATIONAL CONFERENCE

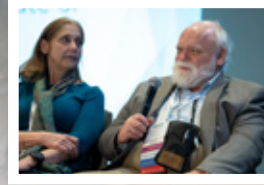
Connect. Learn. Empower.

MAR 30-APR 2, 2019 | ATLANTA, GA

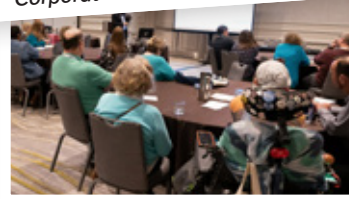
Our National Conference is the world's largest meeting of the MG Community, bringing together people with MG, their families and caregivers, as well as a number of clinical and scientific experts and industry partners. Thanks to the amazing leadership of our Atlanta Support Group and invaluable contributions of our National Conference Planning Committee, our 3½-day event was filled with education, support and social connections that endure beyond the conference dates. Here are some highlights:

This year's conference had record attendance, with more than 300 attendees: nearly 200 patient and family members, 40 expert speakers, and 21 representatives from industry. Nearly 350 people attended our National MG Walk, hosted by our Atlanta Support Group and community.

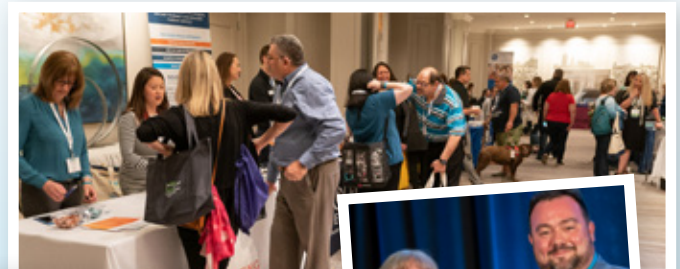
Nearly 40, both new and experienced, MG community leaders and peer support volunteers participated in a ½-day training and networking session. These leaders attended the full conference, taking the education gained and connections built back to people with MG in their community. Whether through in-person support groups or through MGFA's peer counseling program, MG Friends, learning and insight gained can now be shared across the U.S. and Canada!



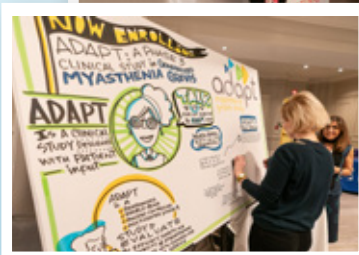
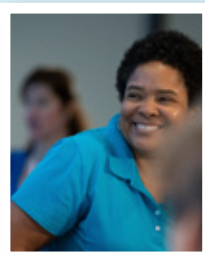
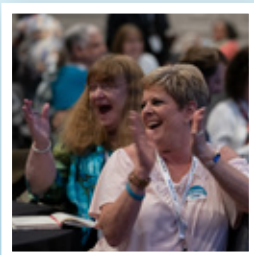
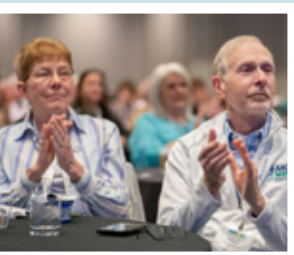
Corporate Stars Awards (l-r): argenx, Briova, Catalyst, Alexion



Team from Immunovant at 2019 MGFA National Conference



Nancy Law, MGFA CEO and Alexis Rodriguez, Keynote Speaker and Volunteer of the Year





Rudrani Banik, MD



Yuebing Li, MD, PhD



Amanda Pratt, LCSW, CPLC

Popular sessions included “MG Pipeline: What’s New in Clinical Trials & Treatment?” from Dr. Michael Pulley and Dr. Shruti Raja – our newest post-doctoral fellowship recipient. A session on the “Importance of Clinical Trials” followed, with representatives from seven different industry partners. Information provided helped to de-mystify the clinical trials process, while allowing each company to share their unique experience in working towards FDA approval of their treatment.

The exhibit hall was bursting with information and interactive activities from 17 sponsors and exhibitors, allowing partners to connect with attendees.



New volunteer, and recently retired Administrative Law Judge, Elaine Deloach presented on “Navigating SSDI: Applying & Appeals”, preparing attendees with important information about Social Security Administration eligibility and benefits. Elaine Deloach is also featured on page 12, in our MGFA Expert Profile. Dr. Ricardo Roda and Dr. Michael Rivner also dived into the complex issue of the role of antibodies in their “Understanding Antibodies & MG” general session, making it understandable for attendees. Dr. Rudrani Banik and Dr. Raghav Govindarajan also presented a hugely popular session on “MG & Overall Wellness”, which featured information on functional medicine, nutrition and more. Attendees gained important information on how to be proactive about their health while living with MG.

And maybe, best of all, even if you weren’t able to attend the conference in person, it doesn’t mean that you have to miss out on the information! If you have internet access, you can follow us on YouTube at “Myasthenia Gravis Foundation of America, Inc.” and view sessions from our ballroom presentations. You can also download our free conference app from our website, myasthenia.org, to view presentation slides, photos, speaker bios and more from the conference.

While the conference was happening, several people with MG and their family members participated in video interviews, sharing their stories about living with MG. These touching stories will be featured on our new website (same address – myasthenia.org), and will help develop public service announcements and more to raise awareness of MG. ✨



Do You Want to Wake up to a World without MG?

YES?

Then help by joining the MG Patient Registry

The MGFA Patient Registry is helping to expand our knowledge of MG and move us closer to improved treatments and a cure. By making a patient community more accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developers to pursue drug discovery in a disease.

To learn more about the registry please visit www.myasthenia.org home page banner and click on the banner when it turns to MG Patient Registry. Or, call the MGFA office at (800) 541-5454 and request the *MG Patient Registry* brochure.



CREATING CONNECTIONS: Loretta and Nadine's Story

Over 300 people attended the MGFA National Conference in Atlanta this year. They come from all walks of life and all areas of the country. The one thing that they have in common is myasthenia gravis (MG). This draws them together and offers the opportunity to make unique connections that benefit them for years to come.

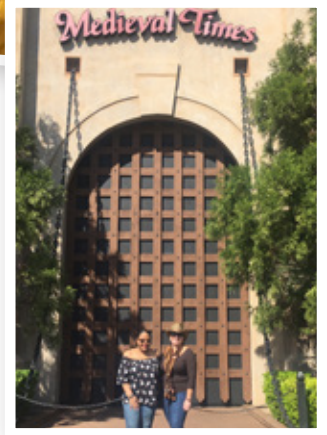
Loretta Sotile and Nadine Sagaille, both people with MG, attended the 2018 MGFA National Conference in Kansas City. They met there and became fast friends. They really hit it off. They have similar personalities, similar symptoms, and they are both foodies! Post-conference, they continued their friendship via text, leaning on and supporting each other when their symptoms flared. Through sharing photos and mutual support, their friendship stayed strong despite their geographical distance.

Nadine summarizes their friendship perfectly. "I am beyond grateful to have found MGFA in 2016, it has tremendously changed my life. Friendships such as Loretta's helped me find my purpose. Living with MG from a young age had been challenging but having a friend who understands your journey is golden. **My favorite quote is from Martin Luther King, Jr. 'Faith is taking the first step even when you don't see the whole staircase', as it really describes my life for the past 22 years with MG.**"

Nadine did her first MG Walk in New York, and Loretta supported her with a donation. Nadine encouraged Loretta to do the MG Walk in California. Loretta soon signed up for the Santa Monica MG Walk, and Nadine gladly supported her with a donation. Both also planned to attend the 2019 MGFA National Conference in Atlanta. To reduce costs, they shared a room. Before the conference kicked off, they

joined efforts to participate in the National MG Walk. They made one team name and got team shirts made. Loretta says it "doesn't matter how much support you have at home with family or friends, nothing beats being able to talk to someone that knows exactly what you are going through. My family is a great support but sometimes I just need to hear from my MG buddy in New York."

As you can see from their photos, they are beautiful women who support each other through friendship, no matter the miles between them! Nancy Law, CEO of MGFA, shared her thoughts on this wonderful friendship, "the silver lining to the MG cloud can be the amazing people we meet that we would never have known without MG—and how they enrich our lives."



"...nothing beats being able to talk to someone that knows exactly what you are going through. My family is a great support but sometimes I just need to hear from my MG buddy in New York."

Riding the Information Highway: The Key to Patient Empowerment

Annette Zampelli, MSN, CRNP, IgCN

Whether you are the patient or the caregiver, your journey to learn more about myasthenia gravis, or MG, may take many different paths. Fellow patients, medical professionals, support groups and more may be part of your journey. The information highway can also be a wonderful resource in your travels to learn more about MG. Along the way, make sure to know what sources are trusted, ones that will truly empower you and your loved ones in managing MG.

Today, patients and caregivers have all sorts of information at their fingertips. The majority of our community have access to smartphones, tablets or computers. These devices can provide immediate access to information via the internet, social media, chat rooms and blogs. You can gain more information on MG now than ever before! While it can be exciting to research on your own, please use caution. Be wary when reading about MG on social media, chat rooms and blogs. Some information you see may not be factual or accurate. While natural and homeopathic medicine may be helpful, it is best to discuss these practices with your healthcare provider. These practices may be implemented in accordance with traditional MG management. This is called “adjunct therapy”, which works in combination with current FDA approved treatments.

“Naturopathic Medicine” is defined as use of clinical nutrition, acupuncture, botanical medicine, physical medicine, lifestyle counselling and homeopathy.

“Homeopathy” is defined as a holistic system of treatment that originated in the late 18th century. Remedies are believed to stimulate the body’s own healing processes.

Your neurologist may be able to provide you with some helpful resources to learn more about MG treatment options and care management.

THREE “C”S TO KEEP IN MIND WHILE RESEARCHING ONLINE:

- 1. Credibility:** The website is from is a credible organization, institution or company providing current references on MG treatment and management. Below are a couple of websites that are both accurate and referenced.
 - myasthenia.org
 - ninds.nih.gov/Disorders/All-Disorders/Myasthenia-Gravis-Information-Page
- 2. Consult:** Do not make any changes in your current treatment without discussing them first with your doctor or healthcare provider. Keep in mind that some treatments are not proven or FDA approved, and may actually worsen MG symptoms.
- 3. Communicate:** Talking online with other patients or caregivers can be great tools to manage your MG, especially from an emotional standpoint. However, do not make any changes to your treatment (even if recommended by other MG patients) until you have discussed it with your healthcare provider. MG is a “snowflake disease”, symptoms and treatment can vary greatly from patient to patient.

Be informed and empowered by understanding the best way to manage your MG. Keeping these important tips in mind will help you in your journey, ensuring that you get the best information possible to become an empowered patient or caregiver. ✨



Elaine Deloach

“Our first responsibility is to lend an ear and only share experiences, if asked.”

MGFA is proud to highlight the work of our amazing volunteers and team members around the globe. We had the pleasure of connecting with Elaine Deloach in 2018, and she has brought a wealth of knowledge and insight to MGFA, which we’d love to share with the MG community. As a member of our team, Elaine provides valuable insight as a former Administrative Law Judge for the Social Security Disability Administration. She has always found teaching and educating others to be very rewarding and is happy to share her knowledge to help others.

ABOUT ELAINE:

I earned my law degree from Loyola Law School in New Orleans in May 1983. After 5 ½ years in private practice, I started work at the Social Security Administration Office of Hearing Operations as a staff attorney, drafting decisions for an Administrative Law Judge who heard disability claims. I moved into management in December 1999, supervising both writers and technical staff who provided the support for a group of Administrative Law Judges. In August 2010, I received my appointment as an Administrative Law Judge. I retired in January 2019 after 30 years of government service.

My spouse, Steven Graalman, was diagnosed with MG in 1987. Two years after I went to work at the Social Security Administration, he came to work there as a staff attorney. He also went into management and received his appointment as an Administrative Law Judge in April 2008, where he served until his passing in March 2016.

How She Can Help:

Elaine is able to provide guidance about medical and cash benefits under the Social Security Administration, as well as the eligibility criteria for each benefit. She can provide information about how to file your claim as well as the information needed to support your claim. Elaine is very knowledgeable about the “five-step analysis” used to evaluate your claim. As a former Administrative Law Judge, she can provide insight on how to appeal a denied claim to the Social Security Administration.

Elaine has also kindly offered to speak with local support groups, regional meetings/ conferences and other education forums to help educate people about Social Security Insurance (SSI).

If you are interested in connecting with Elaine, please contact Nakeshia Betsill, Director of Volunteers & Advocacy at nbetsill@myasthenia.org

**Disclaimer: Please note that Elaine Deloach is unable to provide legal advice. While she can share information about the Social Security Administration, please do note that she is not a representative of the Social Security Administration.*





Michelle B. Vogel, MPA

“My hobby is assisting patients to successfully navigate their health insurance policies and ensure that they get covered for their treatments and services.”

In 2016, Michelle joined CSI Pharmacy as Vice President of Patient Advocacy and Provider Relations. She is passionate about continuing her outreach with patients, ensuring that no patient goes without lifesaving therapy in an affordable site of care.

Michelle began her career 30 years ago as a Senior Legislative Assistant on Capitol Hill for a Member of Congress, where she specialized in health care policy. She enhanced her knowledge of the health arena as a Partner and Senior Associate at three firms where she represented academic medical centers, patient organizations, specialty hospitals, and health care coalitions. Michelle also served as the Vice President of Government Affairs and Reimbursement Services for the Immune Deficiency Foundation where she further developed her knowledge of patient groups, advocacy and health policy.

Michelle has a wealth of experience in testifying before Congress, federal agencies, and state legislatures. She is also a prominent speaker on topics such as Medicare reimbursement, the economics of the plasma industry, health insurance reform, Social Security Disability, navigating health insurance, and patient advocacy. Michelle maintains a personal dedication and professional commitment to helping patients navigate a complex healthcare system.

If you are interested in contacting Michelle, she can be reached via email at: michelle@csipharmacy.com or via phone at: 202-329-8643.

**Disclaimer: Please note that Michelle Vogel will provide unbiased advice and information regardless of her professional affiliation with CSI Pharmacy.*



UP YOUR MG IQ WITH MGFA WEBINARS!

Did you know that MGFA provides educational webinars year-round? From the latest advances in MG treatment options, emergency management of MG for first responders and living your best life with MG, we offer a wide range of topics for people with MG, their families and caregivers.

Our webinars are live, so you can interact with experts in the field in real-time! There is time for questions, as well as opportunities to learn about other members of the MG community. Please stay tuned on our website at: myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx





Patient & Community Services: Young Adults Making an Impact

Young Adults with MG are stepping into big roles at the MGFA and becoming leaders in service delivery of patient resources. Service programming is critical to how the MGFA keeps the community connected while lending support, resources, education and awareness. In this edition of Focus on MG, we will highlight our patient services and young adult volunteers who are leading Support Groups, changing the lives of MG Friends and a being a voice for the community through advocacy.

THE ‘UNIQUE’ MG FRIEND CONNECTION

Our free peer-to-peer phone support program, MG Friends, helps ensure that everyone in the community receives the information they need, and know they are not alone in living with myasthenia gravis. The amount of referrals is steadily rising, and those living with MG are relying more and more on tele-support to meet their individual needs. MG Friends is a great way to share unique experiences with someone who understands.



Meet our ‘young adult’ MG Friend, **Niki Grossheim**, who connects with expecting mothers with MG. Niki has been an MG warrior for many years and is also a proud mom of two boys, ages three years and five months.

“Recently, I received a referral from the MG Friends program and was asked if I could connect with a Spanish-speaking MG patient who just had a baby,” expressed Niki. “This new mom was only hour away, and I couldn’t pass up the opportunity to meet her in-person.”

Niki set-up a meeting through a health professional who was able to secure a Spanish translator and meeting time at a local library. “Upon meeting, we shared our MG story and began to talk about the challenges we face with motherhood and having MG,” says Niki. “We shared our difficulties, but more importantly, we

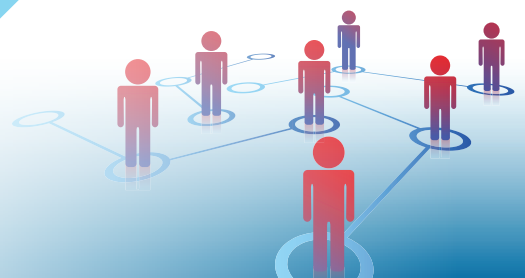
shared tips and tricks to help make things easier. For example, using a stroller rather than carrying the car seat or newborn in our arms.”

In addition to being an MG Friend, Niki is a Support Group Leader and serves as the Co-Chair for the Myasthenia Advocacy for Young Adults (MAYA) group. MAYA is a national committee that develops programming for young adults (18 to 35 years old) to help others live a positive MG lifestyle. Niki has been instrumental in developing

programming for young adults who are navigating the workplace and are thinking about starting a family.

“During our meeting, many tears were shed...Our meeting was helpful for both the new mom with MG and myself. By sharing this experience I hope it encourages others to meet one another and support each other, after all, we are MG Strong!”

– **Niki Grossheim**, MG Friend,
MAYA Co-Chair & Support Group Leader

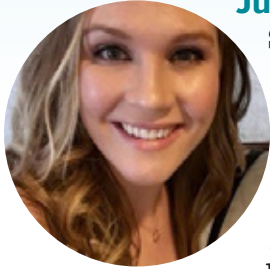




If you are a person living with MG, or a caregiver of someone with an MG diagnosis, and can provide practical advice, an understanding ear, and emotional support, consider becoming an MG Friend!

MG Friends provide the opportunity for a person with questions and concerns to connect to someone else with MG—no matter where they live in the United States. Are you or someone you know looking for phone support? Contact us at mgfa@myasthenia.org or 1-800-541-5454

FROM ACTIVE MEMBER TO SUPPORT GROUP LEADER!



Julia Naumes has always been a vital member of the MG community, actively attending Support Group Meetings in the Pacific Northwest and guest speaking at support groups in Oregon, Washington, and Maryland. Additionally, Julia has presented at the MGFA National Conference on several occasions, has conducted and published research on MG, and named the 2016 Portland MG Walk Hero.

Julia has widened her scope and recently filled the leadership role for the Kitsap Area Support Group in the Pacific Northwest. Julia represents a handful of young adults that lead Support Groups across the country.

SUPPORT GROUP FACILITATOR

ARE YOU INTERESTED IN FORMING AN IN-PERSON OR VIRTUAL SUPPORT GROUP IN THE MG COMMUNITY?

We have resources and training to help you get started!

Our Leaders and Co-Leaders are trained volunteers who organize and give structure to meetings for those living with MG and their families. Leaders establish and run Support Groups through coordinating meeting spaces, guest speakers and promoting locally. Leaders receive facilitator training to ensure members feel welcomed, listened to and supported.

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SMILE FOR MGFA

Did you know you could donate to the Myasthenia Gravis Foundation of America while shopping on [amazon](https://www.amazon.com)? It's simple to set-up on an existing account or by creating a new one. You can shop as you normally do, there's no change in cost or convenience to you. Tens of thousands of products are covered.

Go to smile.amazon.com/about to learn more and make MGFA your charity!



Catch up with the MG Community

Learn more and share your story... on our website, Instagram, Facebook, Twitter and YouTube.



[myasthenia.org](https://www.myasthenia.org)





YOUNG ADULTS WITH MG ARE RAISING THEIR VOICE ON CAPITOL HILL!

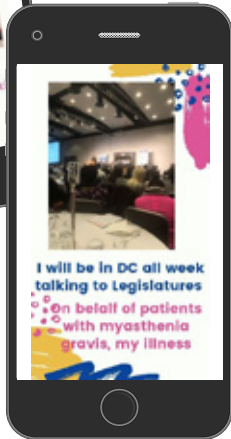
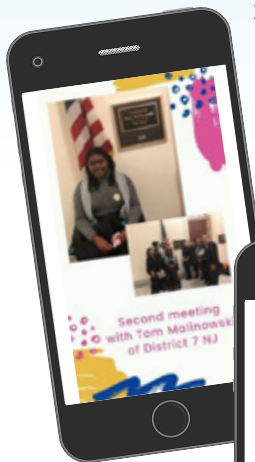
Anaya Mitchell serves as an inspiration to many teens and young adults across the MG community. Joining with advocates during Rare Disease Week on Capitol Hill, Anaya raised MG awareness among legislators!

In meetings with Members of Congress, Anaya shared the importance of reauthorizing the Newborn Screening Saves Lives Act, as well as increased funding for the National Institutes of Health and Food and Drug Administration. Joining efforts with the Rare Disease Congressional Caucus, they collectively raised awareness about issues affecting the rare disease community.

In addition to raising the voice of the MG Community, Anaya also served as a Young Adult Representative of Rare Disease Legislative Advocates' (RDLA) YARR program. YARR, the Young Adult Representatives of RDLA, is a highly motivated group of 16 to 30 year-olds from the rare disease community.

Check out Anaya's IG Story about her exciting and inspiring day on Capitol Hill!

"My illness hasn't changed, every day is still unknown. However, I now approach every day as a chance to write my own story rather than let my illness write it for me." – Anaya Mitchell



MG COMMUNITY HITS THE HILL FOR RARE DISEASE WEEK!

Rare Disease Week on Capitol Hill took place from February 24 to February 28. More than 800 rare disease advocates traveled from across the nation to raise their voice on issues important to the rare disease community! Approximately 450 advocates participated in 298 meetings with Members of Congress.

Members of the MG Community were among the many advocates, representing California, Maryland, Connecticut, Philadelphia, New Jersey, Montana and North Carolina! Our special thanks to Lisa Douthit for helping to organize.

The week kicked-off with advocates joining in-person for the Legislative Conference, with an additional 100 participating remotely via livestream. Experts from Capitol Hill and patient advocacy organizations discussed 2019 legislative priorities. Advocates learned how to build effective relationships with Members of Congress and how to introduce your own legislation.

450 Rare disease advocates converged on Capitol Hill, participating in meetings with Members of Congress, making it the biggest Lobby Day ever! ✨





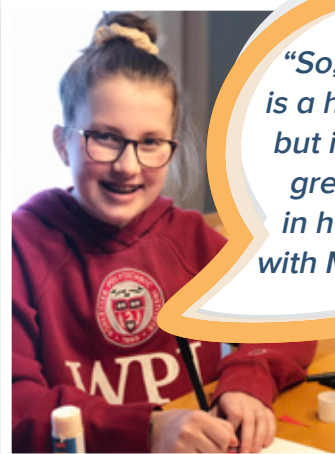
Crafting Isn't Just My Hobby

By Abby Nordhausen

Hi! I am Abby. I am 13 years old and I am in love with crafts! But I struggle with a disease called myasthenia gravis, an autoimmune disease that effects my muscles. I was barely 5 years old when my parents were told I had MG. My mom is a nurse and wondered for a while if I might have MG because my muscles were so weak. When I first started to walk, I fell and broke my leg. It finally took a blood test to help confirm what was wrong. So, it makes my eyes droopy, my muscles twitchy, my legs achy, and my body very tired. I really enjoy making cards. I started a little business to sell my cards. The money I make goes to the MGFA to help find a cure for my disease. So, my crafting is a hobby I love but it also has a greater purpose in helping others with MG.

I live in a little town called Littleton, Massachusetts. I have two amazing older sisters, Emma (17) and Anna (16). And I have two loving parents. I have never been able to do many things like other kids can, so I got into arts and crafts when I was very little. I probably started my "business" when I was 9 or 10, and I loved it! We always had parties with my family and cousins, and I would set up my cards and sell them! I sell my cards at my house, for \$1 each card.

I decided to donate because I've always wanted to sell cards, but I don't really need a lot of money because I have my family, and I'm lucky. I decided to donate the money so it can let other people



"So, my crafting is a hobby I love but it also has a greater purpose in helping others with MG."

know about myasthenia gravis. **At school, I have a special chair with a tall back to help support my muscles. I don't get embarrassed when other kids ask what's wrong. I see it as a chance to spread awareness!** I love making cards, and maybe I will have a REAL business some day! I have already donated more than \$200 to the MG Walk!

My MG Walk team, Abby's Entourage, raised money for the New England (Boston) MG Walk on May 4. Last year, my team raised \$5,510 and included 33 people! I'm excited about a BBQ at my house after this year's MG Walk. The theme? The event is on May 4, so the theme is Star Wars, of course! ✨



Editor's Note: For now, Abby must limit the sale of her cards to family and friends only. If you're interested in supporting her fundraising efforts, visit her MG Walk fundraising page at mgwalk.org and search for "Abby Nordhausen".





2018 CIRCLE OF STRENGTH

We have been fortunate to be blessed by the generosity of many individuals and families who have written checks and made bequests to help in the fight against MG. This is a list of all those who have made contributions over \$1,000 in 2018. Thank you to these generous supporters, our Circle of Strength. Thank you too, to all of you who have given to the Foundation at whatever level, and to all those who give their time and energy to our cause. Thank you!



\$25,000+

Susie Johnson
(Ayco Foundation)

Anonymous Benefactor
(\$50,000)

\$10,000 – \$24,999

Jeff Abramson
Elaine DeLoach
Brian Gladden
Janet Myder
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Mark Aitken-Cade
Anne Dayton
Maryellen Donohoe
Peter Jaquillard
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Susan Klinger
Thomas Larsen
Nancy Law
Dave and Jessica Lindsey
Michael Rubin
Edward Walsh
Linda and Darrell Webb

\$2,500 – \$4,999

Jack Ambrosio
Gregg Brody
Judith Craver
Charles Daniels
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Petra Duda
Angel Fletcher
Jason Gershwin
Steven P. Grant
Ralph Jones
Justin Lambert
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Vicki Kerbeck
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Helen Machado
Ronald Mills
Jay Murnick
Beth Nash
Joan Pinkerton
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Dinah Afsahi
Philip Aitken-Cade
Michael Alderman
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Gina Behrie
Jimmy Blankenship
Joanne Boswell
Daniel Butterfield
Debora Buzinkai
Duke Caldwell
Booth and Georgeanne Chapman
Bob Connors

\$1,000 – \$2,499

Betty Crosby
Virginia Cunningham
Trisha Daly
Frank D'Amico
Mike Davidoff
Anthony Della Salla
Gary Eder
Robert Elliott
Diana England
J. Foerster
Jerry Friedman
Cathy and Mark Gallagher
Sheldon Gartenstein
Stephen Geffner
Mark Goldberg
Roberta Greenberg
Harriet Griesinger
Stanley Halter
Irene Hecht
Ingrid Henrichsen
James Hook
Sandra Ientile
Robert Johns
Julia Johnson
Patricia Jones
Sarah Kiesling
Linda Kusner
Katherine La Gosh
Sandra Larkin
Libby Leonard
Michael Leppo
Yuebing Li
Harry Lipstein
Marcia Lorimer
Charlene Macko
Maria Martini
Kaitlin Masters
Ed and Kathy Mateer
Paula McGinnis
Jackie McSpadden
James McSpadden

\$1,000 – \$2,499

Samuel Meals
Mandira Mehra
Joseph Messina
Celia Meyer
Nicole Moers
Joan Monk
Charlene Munhall
Howard Muser
Jonathan O'Brien
Miguel Passarinho
Christina Perez
Christopher Powers
Michaeline Roach
Alan Robinson
Anne Rubin
Robert L. Ruff
Suzanne Ruff
David Saperstein
Lawrence Sarf
Lucy Ann Sciandra
Phillip Shaw
Betty Shine
Pasqua Simone
Darren and Ramona Southard
Gary Strauss
Sue Summer
Mark Swift
Elizabeth Swize
Don Taylor
Bethany Thomas
Thomas Ursic
Dawn Warsofsky
Charlene Watkins
Richard and Julia Webb
Michael Williamson
Bonnie Wolfe
Gregg Wolpert
Wayne Woodliff Sr.





2018 Scientific Session Summary

By Robert Ruff, M.D., Ph.D.

The 2018 MGFA Scientific Session was held on October 10, 2018, in conjunction with the annual meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM). The location was the Gaylord Conference Center at National Harbor, MD outside of Washington, DC. There is a large Ferris Wheel in the National Harbor, which was lit up with teal lights in honor of MG on the night the Scientific Session was held. The session was attended by about 200 people. Scientific Program Chairs were Michael Hehir (University of Vermont Medical Center), Amanda Guidon (Massachusetts General Hospital) and Araya Punwanant (University of Pittsburgh Medical Center). Before the presentations began, Edward Walsh, Chair of the MGFA Board of Directors, thanked the MGFA Content Development and Review Committee led by Dr. Yuebing Li (Cleveland Clinic Foundation, Cleveland OH) for his committee's work reviewing and updating the MGFA's medical information literature for patients. Nancy Law, Chief Executive Officer of the MGFA, welcomed care providers attending the session to join the Partners in MG Care program.

Below, I summarize the Speaker Presentations (platform presentations) and “Data Blitz Presentations” from the meeting. There were also 12 posters displayed.

KEYNOTE PRESENTATION

CIRCULATING MICORNA AS BIOMARKERS FOR MYASTHENIA GRAVIS

Anna Punga – Uppsala, Sweden

The purpose of biomarkers is to predict the course and perhaps what types of treatment a person with a disease such as MG will best respond to. A biomarker is a chemical or other “crystal ball” to help the patient and clinician plot the smoothest course while navigating the obstacles that will occur with MG. Micro RNAs (miRNA) are short segments of RNA that are in effect incomplete copies of the RNA that a cell uses as the template for making proteins. MiRNAs are kicked out of cells in packets called exosomes or vesicles. The packeted RNA is stable enough to measure in blood samples. RNA and DNA are made by linking small chemicals called nucleotides. The miRNAs can be analyzed based upon the sequence of nucleotides present and the length of the miRNA (number of nucleotides present). By comparing the composition of the miRNAs, Dr. Punga's group found that a few miRNAs were present in different proportions in people with different forms of MG – early vs. late onset of disease. The compositions of miRNAs changed in response to immune

treatments with medications such as prednisone and also with thymectomy. Dr. Punga's group also found that exercise was safe for people with stable MG and that exercise altered the miRNA pattern in patients in a specific way. People with MuSK MG have clinical differences and may lack the thymus change found in people with AChR MG. Her group found that people with MuSK MG had different patterns of miRNAs compared to AChR MG. Early and late onset MG had distinct patterns of miRNAs. There were also variations in the miRNA patterns associated with people who had mild or severe MG. Can miRNAs predict which people with ocular-only MG will progress to generalized MG? Amazingly, the amount of one particular miRNA was able to predict with high accuracy which patients with ocular MG would develop

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generalized MG and which would not. Therefore, the miRNA patterns would distinguish who had early versus late onset MG, AChR vs. MuSK MG and whether a person with ocular-only MG would progress to generalized MG. Dr. Punga's group is collaborating with researchers in other countries, including the U.S., to further study the role of miRNA in MG.

Submitted abstracts that were selected for platform presentations

ISOLATING AND INVESTIGATING RARE AUTOANTIBODY-PRODUCING B CELLS IN MYASTHENIA GRAVIS

K. Takata, P. Strathopoulos, M. Ficchner, P. Suarez, E. Bennotti, R. Nowak, K O'Connor – Yale Univ, New Haven, CT

In MuSK MG, the predominant pathogenic antibody is immunoglobulin type 4, IG4. This group is working to identify the antibody producing B cells that underlie MuSK MG. The IG4 antibodies bind to the same part of MuSK that agrin binds to so the anti-MuSK IG4 antibodies may act by disrupting the normal interaction where agrin binds to MuSK to initiate AChR clustering. They directly demonstrated that the IG4 antibodies prevented MuSK-mediated clustering of AChRs. Impaired clustering will reduce the number of AChRs present on the endplate membrane. Thus, this presentation suggested how AChR function is compromised in MuSK MG.

MUSK MYASTHENIA GRAVIS IS ASSOCIATED WITH AN IMBALANCE IN TFH17 CELL SUBSETS

Y. Li, J. Guptill, M. Russo, J. Massey, Vern Juel, L. Hobson-Webb, S. Raja, J. Howard, M. Chapra, J Li (Duke, Durham NC; Univ of North Carolina, Chapel Hill, NC) and W Liu Sun Yat Sun Univ. Gunngzhou, Guangdong China

TFH (follicular helper T cells) are a class of T cells that activate B cells so that B cells produce antibodies. The TFH class 17 cells are dramatically increased (upregulated) in people with MuSK MG and regulatory T cells (which would reduce B cell activation) are downregulated in people with MuSK MG. Another class of TFH cells that were upregulated was TFH21 cells. CD4+ T cells may be the ones that upregulate the TFH17 cells thru cytokines secreted by the CD4+ T cells.

HIGHLY PURIFIED STAPHYLOCOCCAL PROTEIN DECREASES DISEASE ACTIVITY IN THE MOUSE MODEL OF MYASTHENIA GRAVIS

L. Kusner (Wash DC GW Univ.) M. Catalina (Florham Park NJ)

PRTX-100 is a peptide produced by staph type A bacteria. PRTX-100 is used by the staph bacteria to suppress the immune system of the being that the staph is attacking. PRTX decreases the activity of the immune system by binding to immunoglobulins and attacking immune cells. This study compared the beneficial action of PRTX-100 relative to IVIG in a mouse model of MG. MG was induced by sensitizing mice to AChR protein. Both PRTX and IVIG comparably reduced disease severity including reducing weakness in mice with induced AChR MG. Both treatments reduced IgG class 1 (IgG1) and class 2 (IgG2) antibody levels. The treatments reduced the amount of complement deposition and membrane attack complex deposited at the nerve-muscle junction (NMJ). Both treatments also preserved the AChR content at the NMJ. This study suggests that PRTX could have clinical benefits for MG treatment, but the study needs to be followed up with additional studies followed by clinical trials.



MYASTERIX A PHASE 1B CLINICAL TRIAL OF CV-MG01, ACETYLCHOLINE RECEPTOR MIMETIC PEPTIDES, THERAPEUTIC VACCINE CANDIDATE FOR MYASTHENIA GRAVIS.

R. Mercelis (Antwerp), S. Huberty, N. Havelange – Netherlands

CV-MG01 is a complement of a segment of the AChR (peptides 67-76) that is designed to induce antibodies that bind to and inactivate pathogenic immune cells that are making antibodies against the AChR region containing peptides 67-76. The current report is of 24 patients with MG treated with high or low doses of CV-MG01. The vaccine was safe with only local site reactions. Only one patient was removed from the study due to episodic weakness which was unrelated to MG. In this small pilot study, there was no clear improvement in the vaccine treated vs. untreated groups of people with MG. The investigators are working to making a more potent vaccine. In effect the mechanism of action of the vaccine seems to be valid. The vaccine worked in animals, but so far not in humans. The problem may be that the vaccine would only be active against those B-cells producing antibodies against one specific region of the AChR and in human AChR MG antibodies are directed toward many regions of the AChR. An additional challenge is that the targeted regions of the AChR vary among people with MG. The vaccine is very effective in the animal model, because the animal MG is induced by sensitizing an animal to the specific region of the AChR that the vaccine targets. It is not known how many peptides need to be represented in a vaccine for it to be effective in clinical AChR MG.

RESULTS FROM THE MGTX EXTENSION STUDY OF THYMECTOMY IN MYASTHENIA GRAVIS.

G. Wolfe (Univ of Buffalo, Buffalo NY) H. Kaminski (GW Univ, Wash DC), I Aban (Univ Alabama, Birmingham AL) G Cutter (Univ Alabama, Birmingham AL) and MGTX Study Group (Buffalo, NY)

MGTX study end points were clinical state and reduction in prednisone dosing. The study had 67 sites around the world including N. America, S. America, Europe and Asia. The original report of the MGTX showed that thymectomy improved QMG scores by about 3 and reduced prednisone

dosing by about 22 mg QOD (every other day). The extension study extended the finding by following a subset of the initial study group (68 patients) out to 60 months after thymectomy. The improvement in QMG score persisted as did the reduction of prednisone dosing. By the end of the extension study the prednisone dose in the Thymectomy group was reduced by about 60 mg QOD compared with the onset of the study. This report indicated that thymectomy produced prolonged benefits for people with AChR MG.

LONG TERM EFFECTIVENESS AND SAFETY OF ECUUZUMAB IN GENERALIZED MYASTHENIA GRAVIS: BEYOND MG-ADL AND QMG

S Muppidi (Stanford Univ, Stanford CA), F O'Brien (Yale, New Haven CT), J Wang (Yale, New Haven CT), K Fujita (Yale, New Haven CT), J Howard Jr. (Univ of North Carolina, Chapel Hill, NC)

This is a report of the open-labeled extension (patients able to get Eculizumab if they were on placebo or continue on Eculizumab if they had been receiving that treatment). Total of 42 prior placebo and 43 Eculizumab patients completed this extension study. The patients who were initially on placebo received Eculizumab and caught up to those who had been treated from onset with Eculizumab. Benefits continued for the 3 year duration of study. So far 60% of subjects reached minimal manifestation status.

OVERLAP SYNDROME OF MYASTHENIA GRAVIS AND MYOSITIS IS A COMMON ETIOLOGY OF NEUROMUSCULAR WEAKNESS ASSOCIATED WITH IMMUNE CHECKPOINT INHIBITORS IN A MULTICENTER RETROSPECTIVE STUDY OF 15 PATIENTS.

A Guidon (Boston MA) S Raja (Durham, NCA) D Dubey (Boston MA) N Clement (Boston MA) K Reynolds (Boston MA) J Guptill (Durham NC) W David (Boston MA)

Checkpoint inhibitors are used in patients with advanced cancers to rev up the immune system and encourage a patient's immune system to mount an immune attack against the cancer. A side effect of therapy is to activate or initiate an autoimmune disorder such as MG. Autoimmune disorders involving the nervous system occur in about 1-2% of patients who receive checkpoint

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inhibitor Rx. This study of 15 patients who developed MG and/or myositis as a consequence of checkpoint inhibitor treatment demonstrated that 6/15 developed both myositis and MG. Myositis refers to immune attack directed against the entire length of a muscle fiber as opposed to being limited to the NMJ (neuromuscular junction). People with both myositis and MG frequently had muscle pain (myalgia), difficulty breathing, eye movement weakness (diplopia), difficulty swallowing and impaired walking. Only 4/15 had detectable AChR antibodies. Diagnosis was usually made by EMG and other supporting testing. The weakness did improve with treatment in most patients but a subset had severe and fatal disease. Fortunately, only 1-2% of people who are given immune checkpoint inhibitors develop autoimmune disorders involving the nervous system including the NMJ.

THE RISK OF SERIOUS INFECTIONS AND FRACTURES IN MYASTHENIA GRAVIS

C Kassardjian (Univ of Toronto, Toronto, ON), J Widdifield (Toronto, ON), M. Paterson, C. Barnett (Toronto, ON), C. Nagamuthu, A. Kopp, A Breiner (Toronto, ON)

The presentation started with case reports. Questions that emerged were: how common do these adverse consequences occur and what should be done. Two groups MG vs. Control. The MG group at baseline had more disease burden such as diabetes. During the follow-up period, the Infection rate was doubled for MG patients and infections occurred sooner. Infections were often respiratory. Fracture rates were similar for MG and controls. I was surprised that people with MG did not have increased risk of fractures compared to the control group. One person commented that perhaps people treating MG, usually neurologists, are well aware of the side effects of prednisone or other glucocorticoid steroids (note glucocorticoids are very different from anabolic steroids, androgens, estrogens and progesterone) and prescribe vitamin D and calcium supplements for people receiving prednisone to reduce the risk of dangerous bone thinning caused by prednisone.

SUBCUTANEOUS IMMUNOGLOBULIN IN MYASTHENIA GRAVIS: A NORTH AMERICAN OPEN LABEL STUDY


M. Dimachkie (Univ of Kansas, Kansas City, KS), V. Bril (Toronto ON), T. Levine (Phoenix AZ), J. Trivedi (Dallas TX), N. Silvestri (Buffalo NY), M. Phadnis (Kansas City KS), D. Saperstein (Phoenix AZ), S. Nations (Dallas TX)

This was a seven year duration study to see if patients on IVIG can be safely converted to Sub Cutaneous (Sub-Q) IG. This study is ongoing. Agent used is Hizentra. 23 subjects, all AChR positive. Drop-out rate was about 5%. 86% had appreciable improvement while on the SubQ IG. So far the Sub-Q IG has been successful. People learn how to administer the SubQ IG to themselves or to have a family member/friend trained to administer the Sub-Q IG. This program is particularly useful for people who live in remote areas where it may be very difficult to obtain IVIG or may have difficulty with IV access.

THYMECTOMY MAY NOT BE ASSOCIATED WITH CLINICAL IMPROVEMENT IN A MULTICENTER COHORT OF PATIENTS WITH MUSK MYASTHENIA GRAVIS

K. Clifford (Burlington VT – AANEM trainee award winner), L Hobson-Webb (Durham, NC), M. Benetar (Miami FL), T Burns (Charlottesville, VA), C. Bennett (Toronto, ON), N Silvestri (Amherst, NY), J Howard (Chapel Hill, NC), A Visser (Portland, OR), B Crum (Rochester, MN), R Nowak (New Haven, CT), R Beekman (New Haven, CT), A Kumar (New Haven, CT), K Ruzhansky (Charleston, SC), I Chen (Charleston, SC), M Pulley (Jacksonville, FL), S Laboy (Jacksonville, FL), M. Fellman (Miami, FL), N Kolb (Burlington, VT), S Greene (Providence, RI), M Pasnoor (Kansas City KS), M Dimachki (Kansas City KS), R Barohn (Kansas City KS), M Hehir (Burlington, VT)

This was a retrospective analysis of a study or patients who were in a randomized controlled trial of Rituximab. From that study the investigators identified 26 subjects who had a thymectomy and 29 subjects who did not. MGFA Post-Intervention Score (PIS) of minimal manifestations (MM) or better was the primary outcome measure.



Whether or not a subject previously had a thymectomy did not improve the likelihood that a subject would improve in response to Rituximab. Rituximab increased the likelihood of appreciable improvement by 7-fold for the group of subjects with MuSK MG. Note, that a repeat of the International Thymectomy Clinical Trial is unlikely to occur; therefore, this study gave some useful information on the decision of doing thymectomy or not for patients with MuSK MG. My take on this study is that whether or not a subject had a thymectomy did not alter the likelihood that a subject achieved improvement to MM status. One attendee raised concern that the patient sample may not be a representative sample to determine if thymectomy is beneficial for people who have MuSK MG.

VALIDATION OF THE TRIPLE-TIMED-UP-AND-GO TEST FOR CLINICAL ASSESSMENT IN LAMBERT-EATON SYNDROME PATIENTS

S. Raja (Durham, NC) D. Sanders (Durham, NC), V Juel (Durham NC), Y Harati (Houston, TX), A Smith (Richmond VA), A Peltier (Nashville TN), J Lau (Fargo ND), D Richmond

This described a physical test where a person rises from sitting in a chair without assistance of their arms and then walked in a short loop. The process is repeated three times for one measurement. The test measures lower extremity weakness and mobility. The investigators reported that results using this test did not depend upon who did the measurement (inter-rater reliability was good) and the values were consistent when repeatedly studied (values were consistent). The measure is influenced by lower extremity weakness and walking ability, thus the value of this instrument should be sensitive to what it intends to measure – lower extremity strength and walking ability. At present this instrument appears to be a good measure of physical performance for people who have Lambert Eaton Syndrome. Further studies may show that this instrument is a useful clinical tool for determining the status and response to interventions for Lambert Eaton patients.

DISEASE BURDEN AND TREATMENT HISTORY IN THE MYASTHENIA GRAVIS FOUNDATION OF AMERICA PATIENT REGISTRY

G. Cutter (Birmingham AL), H Xin (Birmingham AL), I Aban (Birmingham AL), T Burns (Charlottesville, VA), R Far (Cambridge MA), P Duda (Cambridge MA), H. Kaminski (Washington DC)

There are currently 2,800 entrants in the MG Patient Registry. The registry is comprised of patient reported data and data are not compared to medical records. This study evaluated the data in the registry in July 2017 when there were 1,140 entries. Only about 30% of patients indicated that they knew their antibody status – AchR+ or MuSK+ or seronegative. Patients in the registry tend to have moderate to severe disease burden. Surprisingly, many were not receiving immunotherapy other than prednisone. About 30% had received IVIG or PLEX (plasma exchange). Fewer participants indicated that they received agents such as mycophenolate mofetil or Imuran (azathioprine). It is not clear whether the participants were not receiving non-steroid immunosuppressant medications other than IVIG or plasma exchange or perhaps participants were not able to correctly enter their medications.

BASELINE DECREMENT IN PATIENTS WITH MILD MG PREDICTS IMMUNOMODULATION TREATMENT.

A Abraham (Tel Aviv, Israel) the following were from Univ of Toronto, Toronto ON – A Ali, C Barnett, H Katzberg, L Lavblom and V. Bril

134 patients classified by clinical status and EMG findings of Repetitive Nerve Stimulation (RNS) and Single Fiber EMG jitter. Patients with higher levels of jitter had worse clinical status and generalized MG. Patients with higher levels of jitter or abnormal RNS were more likely to receive IVIG and PLEX. Future studies may look at whether abnormal EMG findings may be an indicator of more rapid disease progression and indicate that more aggressive treatment is needed early in the course of MG.

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What's Hot Off the Press in Neuromuscular Junction Disorders?

*Ikjae Lee, MD, Department of Neurology, University of Alabama at Birmingham
Sarah M. Jones, MD, Department of Neurology, University of Virginia*

Women with myasthenia gravis report more difficulty tolerating prednisone treatment

Prednisone is arguably the most important immunosuppressive treatment in myasthenia gravis (MG) and has been used over 50 years. However, the usage of prednisone is often limited due to adverse effects which can range from immediate to long-term, mild to severe, sleep disturbance to life threatening gastrointestinal bleeding. Lee and colleagues designed a study¹ surveying patients with myasthenia gravis regarding their experience in adverse effects associated with prednisone treatment in order to understand whether there was a difference in how men and women tolerated prednisone.

The Prednisone Survey included 11 questions asking the participants about their prednisone use: doses and frequencies, adverse effects (33 items) and willingness to increase prednisone dose for better disease control. It was sent to 1,859 MG patient registry participants along with the semi-annual follow-up survey. Among the 398 participants that returned the Prednisone Survey, 57% were women. Women respondents who took prednisone were younger overall, were younger at treatment onset, and reported more limitation in daily activity due to myasthenia gravis and reported worse quality of life compared to men. The dosages of prednisone were

comparable between men and women despite shorter height and lower weight in women. Women reported more adverse effects (95% vs 81%) and more intolerable adverse effects (77% vs 50%) than men. For example, 60% of women reported “moon face” and 30% of women thought the “moon face” side effect was intolerable, while 27% of the men reported this adverse effect and only 8.8% thought it was intolerable. Women were also less agreeable to increase prednisone if the disease worsened (26% vs 44%).

The study demonstrated that prednisone adverse effects are extremely common. Women had a higher degree of intolerability and were less willing to increase dosage, based on this select population from the MG patient registry. The

Women respondents who took prednisone were younger overall, were younger at treatment onset, and reported more limitation in daily activity due to myasthenia gravis and reported worse quality of life compared to men.

authors speculate that different drug metabolism, potentially higher dosage of prednisone per unit weight in women, may have affected this observation. The difference might also derive from different perception or reporting tendency of adverse symptoms between two genders. Firm conclusions, however,



could not be drawn due to the study design, recall bias with self-reporting and lack of comprehensive information regarding other disease conditions or medications used. Nonetheless, the study reinforces the importance of discussing these potential treatment-associated adverse effects with the patient when starting a long-term prednisone treatment and being cognizant of gender differences.

Sedentary behavior is common among MG patients but does not correlate with disease severity

Active lifestyle and exercise are known to help maintain good health. MG causes muscle weakness and fatigue that might affect exercise ability and reduce daily physical activity. While it seems intuitive that MG may reduce one's ability to exercise and result in a more sedentary lifestyle, there has been no study that looked at the patterns of habitual physical exercise and sedentary behavior of MG patients. Punga and her colleagues² measured the pattern of physical activity in Swedish patients with MG by using accelerometer worn at the lower back for seven consecutive days. Four measures of different physical activity qualities were conducted: amount of moderate and vigorous intensity activity, physical activity level, number of steps per day and sedentary time. The Metabolic Equivalent Time (MET) concept was used to define intensity of activity and sedentary time. The measures were then correlated with current MG severity measured by myasthenia gravis composite (MGC) score. Physical activity level was compared to historical data from healthy adult individuals. Energy expenditure and steps per day were compared to patients with chronic obstructive pulmonary disease (COPD) and mitochondrial myopathy patients.

A total 27 patients participated in the study. Among them, 10 patients (37%) were overweight and 7 patients (26%) were obese. The mean physical activity level among the participants was 1.5, which is in the range of a sedentary behavior. During a 24-hour period, 78% of the time was sedentary (lying or sitting), 20% was standing/moving and 2% was not wearing the device. Physical activity level was lower in MG patients with older age. MG patients were less active when compared to historic data on age-corresponding healthy individuals. The

mean number of steps among MG patients was 7,462 per day. Only 6 patients (22%) achieved the internationally recommended level of 10,000 steps/day and the number of steps was lower in older patients. Surprisingly, physical activity level or sedentary time did not correlate with MG severity measured by MGC.

Of note, most patients achieved the recommendations of time spent in daily deliberate exercise. The mean of total uninterrupted (more than 10 minutes) moderate and vigorous intensity activity was 181 MET min/day. 78% of the MG patients achieved above the recommended minimum average of recommended activity 64 MET min/day.

This study demonstrates that overall sedentary behavior is common among MG patients with reduced physical activity level and lower number of steps per day. The majority of the patients still achieved the recommended minimum MET which indicates that the intensity of activity is vigorous enough among the most MG patients when they are in action. Intriguingly, MG disease severity did not correlate with any of the different measures of physical activity suggesting that the sedentary behavior and reduced physical activity might be from disease perception, mood and attitude rather than from direct muscle weakness or fatigue from MG. The study result may not be representative of the general MG population as it included small number of motivated patients who were willing to participate. Also, the study was carried out during the summer time in Sweden. The same study might have shown different results if conducted during the winter time with shorter daylight hours. This study contributes important findings on such behavior in the everyday life of patients and implies a need to promote physical activity on all levels.

Regular Physical Exercise Improves Muscular Function in MG

Patients with MG and neuromuscular disorders frequently feel worse after repetitive use of their muscles. As such, it may be perceived that exercise could be deleterious or potentially harmful. In the past, some MG patients have been advised to restrict or even avoid regular exercise. Still, it is reasonable to assume that people with myasthenia gravis could benefit from the positive cardiovascular effects of exercise. There is only

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sparse research looking into this topic. Westerberg and colleagues³ performed a 12-week study evaluating whether the guidelines provided for the general population could affect skeletal muscle parameters in MG patients, cardiovascular risk factors, and well-being.

The study was designed around guidelines recommending that healthy adults engage in 150 minutes of medium-level aerobic exercise weekly and strength training twice weekly. This small unblinded study evaluated 14 myasthenia gravis patients, age 28 to 83, with mild and stable disease. The patients remained on stable doses of MG medicines, with the exception of three patients who

were able to lower their cholinesterase inhibitors (e.g. pyridostigmine) during the trial. Three patients discontinued the study due to lack of time or work-related health problems. Pre-exercise physical activity level and strength was measured. Multiple outcomes were evaluated, including clinical myasthenic status, muscle function and thickness, blood samples, blood pressure, BMI, body composition, and quality of life.

Nonetheless this study, among other recent pilot studies in the field, have demonstrated that regular exercise can be safe and even beneficial to patients with myasthenia gravis.

This study demonstrated that regular aerobic exercise and strengthening resulted in a statistically significant improvement in muscle function measures in the muscles of the legs including isometric muscle force, thickness, nerve conduction study response, clinical muscle fatigue and one of the physical performance measures. There was neither improvement nor any worsening in arm muscle function measures, other physical performance measures, blood pressure, cardiovascular risk associated anthropometrics, blood tests, or quality of life metrics. The authors acknowledge that the small sample size (14 participants) and short duration (12 weeks) as some of the limitations of this study. Nonetheless this study, among other recent

pilot studies in the field, have demonstrated that regular exercise can be safe and even beneficial to patients with myasthenia gravis.

Amifampiridine phosphate might help patients with MuSK myasthenia gravis

Muscle-specific receptor tyrosine kinase (MuSK) is a protein located in the neuromuscular junction and help maintain the normal structure and function of this connection. The antibody that binds to MuSK causes myasthenia gravis (MG). Amifampiridine phosphate is a drug that has been used for symptomatic treatment of Lambert-Eaton myasthenic syndrome, another autoimmune disease affecting neuromuscular junction. There has been some evidence that this drug might be helpful in MuSK-MG, however, a randomized clinical trial was lacking.

Bonanno and her colleagues⁴ reported the result of this randomized, double-blind, placebo-controlled study in MuSK-MG patients to determine the safety, tolerability and efficacy of amifampiridine phosphate. Adult patients with definitive diagnosis of MG, positive for anti-MuSK antibody and generalized disease were included in this trial. All patients were required to have a stable regimen of immunosuppressive medication. Patients with epilepsy, uncontrolled asthma or long QT syndrome were excluded as the drug can potentially worsen those conditions. All participants went through open label screening and run-in phase where the dose of amifampiridine was titrated to maximum benefit within 30-100mg total daily dosage divided by 3-4 times per day. They were randomized to two different groups: APA and PAP. The APA group started with Amifampiridine and PAP group started with Placebo for the first 7 days. The APA group then crossed over to Placebo and then PAP group to Amifampiridine for the next 7 days. Then during the next 7 days they finished with another cross over to the original treatment: Amifampiridine for the APA group and Placebo for the PAP group. This cross over design was used due to the small number of participants. Finally, all patients withdrew from study medications and were monitored for another 7 days, making this study a total of 28 days. Safety measures were collected with adverse event

records, vital sign and clinical laboratory tests. Efficacy of the drug was measured 45 minutes after the last dose of medication by various scales including Quantitative Myasthenia Gravis (QMG), Myasthenia Gravis-specific Activities of Daily Living Profile (MG-ADL), Myasthenia Gravis Composite (MGC) and Myasthenia Gravis Quality of Life (MG-QoL 15) scores.

The onset of improvement was rapid, and stopping the drug immediately resulted in worsening of symptoms. Overall role of this drug is thought to be similar to a pyridostigmine – a symptomatic treatment to help manage MG.

A total of 10 patients were recruited to the study. Every patient had moderate to severe MG with a positive MuSK antibody. Three of the 10 patients were not randomized as they did not reach a stable therapeutic dose during the run-in period. Mean age was 43 years old and six out of seven patients were female. Four patients were assigned to the PAP arm and 3 patients to the APA arm. When the patient was changed from amifampiridine to placebo, there was a significant worsening in all the assessment compared to baseline (while taking amifampiridine phosphate). For example, QMG score was 6.9 points higher than baseline (worsening of disease) when the drug was changed to placebo, while this worsening resolved

during the period when the patient was back on the study drug. The medication was well tolerated without serious adverse events. The most common side effect was an intermittent tingling sensation.

This is a pilot study demonstrating the efficacy and safety of amifampiridine phosphate in MuSK-MG patients with a randomized, placebo-controlled trial. The onset of improvement was rapid, and stopping the drug immediately resulted in worsening of symptoms. Overall role of this drug is thought to be similar to a pyridostigmine – a symptomatic treatment to help manage MG. The small sample size is an obvious limitation of this pilot trial and a large multi-center trial is needed to confirm these results. ✨

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RETROSPECTIVE ANALYSIS OF OUTCOMES AND SAFETY AFTER RITUXIMAB USE FOR MYASTHENIA GRAVIS IN PATIENTS > 65 YEARS OLD.

C Doughty (Boston MA), A Amato (Boston MA)
W David (Boston MA) A Guidon (Boston MA)

There were 40 patients in the study. Compared older (> 65 years old) and younger patient responses. Older patients did about the same as younger patients. About 1/3 of all patients developed an infusion reaction that was mild in most cases. Older patients did as well as younger and tolerated the treatments including rituximab well.

IMBALANCE OF TWO MAIN CIRCULATING DENDRITIC CELL SUBSETS IN PATIENTS WITH MYASTHENIA GRAVIS

W Liu, P Chen, Y Li, H Huang (Nanning China),
Y Li, Z Chen, X Liu, C Ou, L Oui, Z Huang, Z Lin
and H Ron (researchers were from Sun Yat Sen
Univ. Guangzhou China unless otherwise indicated)

This study examined MG patients who had not yet been treated (at start of treatment). MG patients had more B cells that were antibody producing cells compared to controls or patient with MG in remission. Immune treatments such as tacrolimus reduced the population of antibody producing B cells. ✨

Register for a 2019 MG Walk TODAY!



**CELEBRATING 9 YEARS
OF RAISING AWARENESS
AND FUNDS FOR THE
MG COMMUNITY!**

2019 MG Walks

MA: BOSTON May 4

WI: GREEN BAY May 11

NC: CHARLOTTE May 19

CA: SAN FRANCISCO June 1

NY: QUEENS June 8

NJ: BLOOMFIELD June 9

CT: MERIDEN June 9

KY: LOUISVILLE September 7

MISSOURI: COLUMBIA
September 14

OH: CLEVELAND September 14

IL: SOUTHERN IL September 21

IL: CHICAGOLAND September 22

OR: PORTLAND September 28

WV: HUNTINGTON September 28

WA: SEATTLE September 29

PA: DELAWARE VALLEY October 6

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TX: AUSTIN November 10

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**PLEASE GO TO MGWALK.ORG
FOR MORE INFORMATION ON
A WALK NEAR YOU!**

THE 2019 MG WALK SEASON IS OFF TO A GREAT START AND YOU CAN STILL JOIN US IN THE FIGHT TO STOP MYASTHENIA GRAVIS! CONSIDER JOINING US AT A SPRING OR SUMMER MG WALK, OR PARTICIPATE VIRTUALLY TO HELP MGFA REACH ITS \$1 MILLION GOAL!

We Need You! If you haven't already, now is a great time to reactivate your team from last year. New to MG Walk? It's quick and easy to start a team and join the MG community in this fight! To check out upcoming MG Walks or to register, visit MGWalk.org

Want to grow your team? We can help! The MGFA team will help you with goal setting, team recruitment and community engagement. Every dollar raised by an MG Walk participant is one more dollar to fight MG! Contact us at 1-855-MG-WALKS (1-855-649-2557) or info@MGWalk.org.

Volunteer! If you are interested in volunteering for an MG Walk, please go to www.mgwalk.org and click on "Volunteer" to learn more!



**NEARLY 350 PEOPLE
ATTENDED OUR NATIONAL
MG WALK IN ATLANTA!**



HELP US GROW THE MG WALK MEDICAL AMBASSADOR PROGRAM!



MG Walk Medical Ambassadors are medical professionals who provide leadership in their local communities in the fight against MG. At every MG Walk, we strive to recognize these passionate, dedicated professionals who help MG patients every day. Alongside these professionals, MGFA aims to reach more people affected by MG; aiding them in their MG journey with critical funds, resources and support.

Medical Ambassadors can be doctors, nurses, researchers, lab technicians or a medical staff member.

Can we count on your help? Spread the word about our MG Walk Medical Ambassador Program in your community! MG Walkers are the biggest recruiters for the Medical Ambassador program! For example, our 2018 Seattle MG Walk Hero, Corey Russell, actively spreads awareness by asking any medical professional he meets if they know about MG, even though he does not have MG himself. You can do this too! Corey recommends having a few MGFA flyers in your back pocket during every doctor appointment. Simply ask if they have heard about MG and offer information!



We would be thrilled to follow up with any medical professional who can promote a local MG Walk, become a sponsor or lead a walk team! Please reach out to us at info@MGWalk.org or 855-649-2557 with any possible leads!

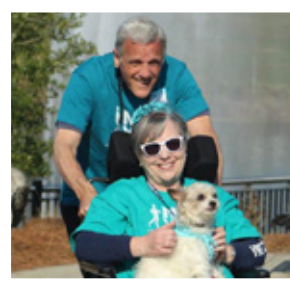
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National Walk photos : © Michael A. Schwarz Photography

STAY CONNECTED   

1-855-MGWalks (649-2557) | Info@MGWalk.org | MGWalk.org



4 Easy Ways to Fundraise for Your MG Walk

- 1. INVEST IN YOURSELF!** Show friends and family how important the MG Walk is to you by kicking off the campaign with a donation to yourself.
- 2. GET SOCIAL!** Are you on Facebook? Instagram? Twitter? Share your fundraising link — and your reasons for supporting the MG Walk. It's a great way to get support and spread awareness!
- 3. SEND, SEND, SEND!** Did you know the #1 way to raise funds for the MG Walk is by sending e-mails to friends and family? We suggest sending a minimum of three (3) e-mails during your fundraising campaign: in the beginning, mid-goal and the week of your walk. It's that simple — just send and watch the donations roll in!
- 4. SHARE YOUR STORY!** Your friends and family want to support you, so tell them in your own words what the MG Walk means to you. You can share your story via email, on your MG Walk page or on social media.

DONATE



“My advice for MG Walk fundraising is to tell your story. MG is the scariest disease that no one has heard of. I found that by telling our story and explaining MG, people were compelled to help through donations.”

— **Heather Hilton**, First Time Walk Captain, North Carolina MG Walk

“My tip would be to start earlier. I spoke to family and friends in person as well as reaching out on social media, but I started a month before the walk. As soon as it becomes available next year, I will be reaching out. I want to build a bigger team next year!”

— **Kimberly Wilson**, First Time Captain, Northern Wisconsin MG Walk

“I would say the best thing to do while fundraising is sharing on all social media and talking to businesses to help support you on the walk!”

— **Kelsey Toon**, First Time Captain, National Kansas City MG Walk



STAY CONNECTED   

1-855-MGWalks (649-2557) | Info@MGWalk.org | MGWalk.org



TAKING THE MYSTERY OUT OF PLANNED GIVING

Did you know there are ways to support MGFA that do not affect your current lifestyle or your family's security? Have you wondered how you can support vital research efforts into better treatments for MG and ultimately a cure while still managing your budget? Whether you want to have impact today or as part of the legacy you leave behind, there are many ways to make a meaningful contribution.

Include a bequest to MGFA in your will or living trust.

Have a lasting impact on MGFA's work that does not cost you anything during your lifetime, but is a priceless part of the legacy that you leave. You can designate cash, a specific property, or a share of your estate. If you already have a will, consider making an update to include MGFA. This bequest can ensure we continue our mission for years to come.

Name MGFA as a beneficiary in retirement plans and/or life insurance policies.

This is an easy way to give and you can review and make changes anytime you want. You can choose how to support our mission for years to come while leaving less-taxed assets to your loved ones.

Create a new life insurance policy or donate a paid-up policy of coverage you no longer need.

This is a long-term gift that won't draw funds from your estate and might increase your ability to make a significant gift to MGFA as part of your legacy.

Use Required Minimum Distributions from your IRA to support MGFA.

If you are 70½ years of age or older, you can take advantage of a simple way to support MGFA and receive tax benefits in return. You can give up to \$100,000 from your IRA directly to a qualified charity such as MGFA without having to pay income taxes on the gift. You can make annual gifts to our organization anytime. Best of all, you can put your donation to work today and benefit even if you do not itemize deductions.

For more information on planned giving, contact Betty Ross, Director of Development at bross@myasthenia.org. For legal advice on how you can support MGFA through a planned gift, please consult an attorney or tax advisor. ✨

JOIN The Ellsworth Society



When you make a planned gift to MGFA, you'll be invited to join **The Ellsworth Society, named in**

honor of Jane Dewey Ellsworth, our founder. Ms. Ellsworth launched the Foundation in 1952 when her daughter Patricia was diagnosed with MG. Today, thanks to her vision, MGFA now touches the lives of hundreds of thousands of patients, families, friends, and medical professionals around the globe.

Your membership involves no dues, obligations, or solicitations, but it does allow us to recognize you for the plans you have made, and it may inspire generosity in others. Benefits include a commemorative Ellsworth Society pin, as well as opportunities for future acknowledgement at events. However, the most important benefit you will receive from joining The Ellsworth Society is the lasting impact you will have on creating a world without MG.

Once you complete your estate plans including MGFA, please fill out the member profile on our website in the "Planned Giving" section.

For further questions, please contact Betty Ross, Director of Development at bross@myasthenia.org.



Caring for Others with MG (*and some Self-Care too!*)

By Suzanne Ruff, Ph.D.

MGFA Board of Directors and Executive Committee member

If someone you love is diagnosed with myasthenia gravis, you want to provide support in the most helpful and meaningful way. Research has shown us that family and friends play a very important role in helping deal with a chronic illness. When a person is diagnosed with myasthenia gravis, many things may change. A new diagnosis can be scary. And, everyone needs reassurance that the important things will stay the same. People diagnosed with a serious illness can feel helpless at first. How people interact with the person diagnosed can truly make a difference. It's important that the person with MG feels truly cared about.

There are three crucial steps in providing meaningful support:

- 1. Learn all you can about MG:** The MGFA website has a wealth of information to help you better understand MG. Make sure to use reliable, credible sources for information.
- 2. Communicate:** Every relationship is different, so it's important to discuss ways that you can be the most helpful in your particular relationship as a spouse, parent, sibling, friend or someone else close to someone with MG.
- 3. Take care of yourself:** Learn how to ask for and accept help when you need it. This is not always easy. If you're overwhelmed, it makes it more difficult to care for your loved one with MG.

Learn all you can about myasthenia gravis. We recommend that you start with the MGFA website, myasthenia.org. We have gathered experts to explain topics important to understanding and managing life with MG. Please make sure that the sources that you use are reliable ones. For example, the National Institutes of Health, WebMD, the National Organization for Rare Disorders, the Cleveland Clinic and others. Attend local MG meetings and support groups with your family member. However, keep in mind that MG is known as a "snowflake" disease", meaning that each person's experience with MG is different. And, the disease can appear differently in the same person. Symptoms can vary from day-to-day and needs can vary from day-to-day as well.

It's also important to learn how to support your loved one. People differ in the ways they feel supported. For instance, some prefer practical help, some prefer spending time with others, some like to partner on difficult tasks. Everyone needs to know they're still loved as much as ever.

COME UP WITH A PLAN TOGETHER

Availability is very important. Life continues to make demands of us and sometimes MG makes it very difficult or even impossible to meet those demands. That creates stress, which is a trigger that can worsen MG symptoms. Knowing that someone is available to help can lend important support.

- **Check in with your loved one.** They may not want to seek you out for help but will respond to a specific offer of help.
- **Use phrases that you both feel comfortable with.** You'll learn with time if you don't already know the good approaches - simple, funny, compassionate - or, just doing what you know needs to be done:
 - *"I'm here now. What can I do?"* is simple and direct
 - *"Hope I'm not being a pest, but you haven't told me how I do the laundry."*
 - *"You look like you're having a hard day. I'm going to drive you to..."* Or, *"I'd like to drive you to..."*
- **Check to see if you are truly being helpful.** Ask after you have made an attempt or two to see how the other person is feeling.
- **Communicate often.** Needs change, availability (including yours) changes, and it is important to have regular check-ins to determine if the current plan is still the best plan.

Please keep in mind that it can be quite difficult for some to ask for help. And, that it feels good to help someone. Using both of these principles, barter responsibilities where possible. Perhaps a person with MG cannot do a physically demanding task, but can take on a chore that does not take much physical stamina. Having a shared sense of purpose tackling tasks is the best way to make everyone feel needed, competent and valued.

Just spending time with your loved one is a precious gift. It is very important to spend time on things you both enjoy — these can be simple pleasures or special outings. Family visits, volunteering, entertainment, being in nature can all make for great memories. Be sure to savor the good times!

Listening to your loved one is, perhaps, the greatest gift of all. Everyone can learn this crucial skill by keeping a few things in mind:

- Listening means being silent when another speaks, not making assumptions and letting them finish their thoughts before responding. (*The same letters are in the words SILENT and LISTEN!*)
- Reflecting back what you think you heard and allowing the other person to affirm or correct you is another key element.
- It is human nature to want to help - but our 'solutions' may not be the best for another. Try to collaborate in problem solving rather than make the first suggestion.
- Again, check in on a regular basis to ensure that the current plan is meeting everyone's needs.

Recognize that everyone in the relationship needs to monitor their energy - physical, emotional and psychological. This applies to those with the diagnosis of MG and caregivers as well. Learn to care for yourself as well as your loved ones.

Be sure to get enough sleep, monitor your energy levels, and include pleasant activities in your daily routine.



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SELF-CARE FOR THE CAREGIVER

Learn to ask for and accept help for yourself. This can be quite difficult for some people.

People differ in how much help they need. In fact, caregivers are also “snowflakes” in what they need!

- **Ask for specific help — this makes it easier on everyone.** “I need a few groceries and can’t get out now. When you go to the store, could you pick up some eggs and bread please? Thank you so much!”
- **Accept help when others offer.** It may be almost automatic to say, “No thanks, we’re fine” only to realize that you have far too much to do today. Remember, it does make others feel good to be helpful. However, you will learn that not everyone will help in a meaningful way. Recognize this early on, so that you are not spending emotional energy on someone who is not reliable or helpful.

- **Create a back-up plan.** There may be times when you feel that you cannot provide the support your loved one needs. Professional, volunteer and community services can be a wonderful resource during these times. All of us need extra help at difficult periods in our lives.

Learn all you can about MG and stay up-to-date. There is always new information out there that can help. Stay connected to others, whether it be a local support group, a community resource or with other family and friends. Keep in mind that empathy and concern are vital to someone with a chronic illness—this is about them and your support can make all the difference. Often forgotten, but equally important, is to remember to take care of yourself—emotionally, physically and mentally. ✨



PARTNERS IN MG CARE: Is Your Health Professional Connected?

Through physician outreach, MGFA is striving to make our Partners in MG Care program as comprehensive as possible. To make that a reality, we need your help! As a patient with MG, a caregiver for someone with MG, or a community leader, you are knowledgeable about MG care in your area. Our request is small; if you have, or know, a great MG health professional in your area, encourage them to be part of the Partners in MG Care program!

WHO’S A GOOD FIT FOR PARTNERS IN MG CARE?

- Experience with, and interest in, treating MG patients
- Ability to refer patients to MGFA for support and resources
- Involvement in the MG community
- Willingness to promote and support MGFA’s work

HOW DO THEY GET CONNECTED?

Interested health professionals can contact MGFA:

Toll-Free: 1-800-541-5454

Email: mgfa@myasthenia.org

Want to step up outreach efforts in your community? Contact MGFA for more information on how you can get started!



WHERE'S THE NEXT MG NATIONAL CONFERENCE, HOSTED BY MGFA?

Let's look at a few clues:

What city is known for its cattle drives, nicknamed "Cowtown"?

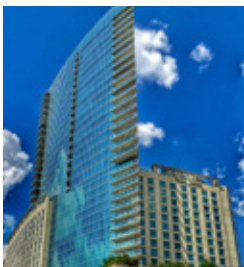
What city is home to the Kimbell Art Museum?

What city experienced an oil boom in 1917?

What city prints approximately 60% of the paper money in the U.S.?



If you replied *Fort Worth*
to these questions, you've got it!



We'll be at the beautiful Omni Fort Worth, 1300 Houston Street

Put this on your calendar and plan to attend the National MG Walk and Conference.

Add a little R&R if you wish. Visit the Fort Worth Civic Opera Association, the oldest continuously performing opera company in Texas. Check out the historic Stockyards Hotel, where Bonnie and Clyde hid out in 1933. Visit the Kimbell Art Museum, which has a world-class collection of works by Matisse, Picasso and Cezanne. Or kick-up your heels at the "World's Largest Honky-Tonk", Billy Bob's Texas.





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Myasthenia gravis is an autoimmune neuromuscular disorder. Symptoms may include double vision, drooping eyelids, slurred speech, difficulty chewing and swallowing, weakness in arms and/or legs.

MGFA is committed to finding a cure for myasthenia gravis and closely related disorders, improving treatment options, and providing information and support to people with myasthenia gravis through research, education, community programs, and advocacy.

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YOU**

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*your generosity
brings us closer
to a world
without MG.*



The goal of the MG Walk Campaign is to expand into new markets where we can bring together patients, create a community of active/engaged MG families and raise vital

awareness & funding for myasthenia gravis! It is crucial that we go where we know we can garner the support needed to ensure success. If you are interested in seeing the MG Walk come to your area and you are excited to play an active part in its planning, promotion and production, we want to hear from you! Please contact the MG Walk Office at 1-855-MG-WALKS or Info@MGWalk.org or fill out our interest form found online at www.MGWalk.org. Thanks so much!