

Turning MG Awareness into Action in June

**WE'RE #MGSTRONG
AROUND THE GLOBE!**



Turn awareness into action this June!

June is MG Awareness Month around the world. It is an important time to Take Action and create awareness and understanding of the challenges and opportunities faced by everyone in the MG Community. This year, we are

actually “changing” the theme of MG Awareness Month to “MG Action Month – Turning Awareness into Action” – and we are offering specific calls to action for the MG Community and beyond to find creative ways to show that **WE ARE SO MUCH MORE THAN OUR MG.**

MGFA has created an online Action Toolkit this year to provide guidance and ideas for taking action to drive awareness. We really need your help to step up and engage in tangible ways to show the power of the MG Community and spread the word about the challenges and experiences that MG patients and caregivers face when dealing with myasthenia. You can find the toolkit online on our [MG Action Page](#).

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MGFA's Annual National Conference Showcases Momentum Against MG

By Michael Antonellis

The annual MGFA National Conference is a time to bring members of the MG Community together for the largest gathering of MG patients, caregivers, myasthenia specialists, MG-focused organizations, and volunteers in the world. It is similar to a reunion of friends and colleagues who truly enjoy coming together and engaging in all things MG.

Yet, like the 2020 edition, this year's conference in April was held online and in the middle of the continuing COVID-19 pandemic. But that did not stop the more than 1,300+ registered attendees from joining and experiencing a packed agenda

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of medical experts, volunteers and patients, consultants, and industry presenters.

Though our attendees could not come together in person, they enthusiastically chatted, shared stories, discussed symptoms and guidance, and listened to three days of presentations that informed and inspired them. The conference truly offered multiple examples of Momentum Against MG.

MGFA president & CEO Samantha Masterson kicked off the speaking sessions with a high-energy welcome to all attendees and an introduction to MGFA Board Chair Nancy Law. And then, the “legend” – Dr. James “Chip” Howard highlighted what COVID-19 means for MG patients. Throughout the three-day conference, attendees were treated to sessions that covered everything from navigating insurance denials and planning gifting investments to navigating the ER as an MG patient and utilizing the power of hope as part of your treatment.

Medical presenters also highlighted what to know as a newly-diagnosed patient while energizing attendees with research updates, thymectomy surgery considerations, and the challenges of being seronegative. The audiences actively asked questions throughout the sessions, and presenters effectively and immediately addressed the inquiries. MG patients absolutely love having direct access to knowledgeable professionals – and MGFA makes this possible.

Volunteers and MG patients were enthusiastically represented in sessions that showcased yoga and the hula as physical exercise options while other sessions served as opportunities for patients to tell their own poignant and hopeful stories about their experiences with MG. These stories are always well-received by the MG Community and showcase the amazing perseverance and commitment of our patients. This year’s community spotlights featured Evan Greene, Mackenzie Connor, Sara Rutledge, and Audrey Getman.

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.

290 Turnpike Road, Suite 5-315, Westborough, MA 01581 | 800.541.5454 | mgfa@myasthenia.org | www.myasthenia.org



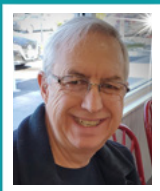
Attendees flooded the virtual event and headed to the always-informative Exhibit Hall where inspiring partners and sponsors highlighted their services, advocacy efforts, and treatments and clinical trials. These organizations chatted and engaged with attendees in a multi-media experience that included video and instant chats, awareness video segments, private chats, and resource links to all kinds of informative materials. Several industry organizations also participated in a “round table” of mini-sessions aimed at highlighting new treatments and clinical trials that could generate new ways to fight myasthenia.

WE DEEPLY THANK OUR GENEROUS SPONSORS:

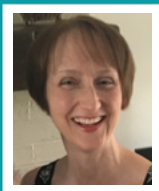


Our attendees are always extremely excited about MGFA’s Award recipients. The award presentations are consistently one of the major highlights of the conference each year. This year, the awards were revised and new ones were created to recognize and acknowledge the incredible, selfless achievements that our volunteers strive for each year. These award winners show their love and passion for the MG Community through their partnership and support of the MGFA and everyone who is living with MG.

THE 2021 MGFA AWARD RECIPIENTS ARE AS FOLLOWS:



**Volunteer of the Year
PIERRE CLEMENT**



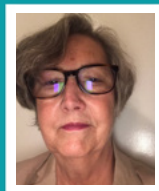
**Ambassador of the Year
KIM ELDRIDGE**



**Emerging Leader Award
JESSICA MILANES**



**Medical Professional of the Year
DR. JAMES “CHIP” HOWARD**



**Outstanding Service Award
DENISE ROSSI**



**Corporate Partner of the Year — UCB
Pharmaceuticals**



**Impact Award
BRIAN GLADDEN**



**Ellsworth Award
MARC KALISH**

Congratulations to all our award winners.

One of the biggest takeaways from the conference this year was that in spite of a completely virtual environment, the MG Community took it all in stride and looked beyond the constraints of an online conference to actively engage with each other like they were throwing their arms around close friends. It shows the adaptive nature of our community. We accept things for how they are and push through and work so hard to make the best out of challenging circumstances. These qualities and characteristics make the MG Community such a close-knit and passionate group. And we showed off our dedication again at this year’s National Conference.

For those who want to view sessions and resources from the conference online, you can visit or register at the following link: onlinexperiences.com. You can view this past year’s agenda online at myasthenia.org. ✨



THE CEO'S LETTER

Dear Friends,

As we welcome spring, the season of growth and all things anew, it is also a great time of new beginnings and growth for our MG Community and for MGFA collectively. There is so much to be excited about and so much promise before us as a Community.

Without a doubt, there is more movement in the MG space than there has been in its history. This movement translates to progress, from potential treatments in the pipeline with promising clinical trials, to improvements in quality of life. We are learning more about MG at an expedited pace with more focus and attention than ever before. This is not only exciting for MG but for rare disease as a whole. For we are part of a greater Community with dedicated partners like National Organization for Rare Diseases (NORD), Rare Diseases Clinical Research Network, American Brain Foundation, and MGNet, to name a few. We all work together to enhance efforts, share knowledge, and to, ultimately, improve patient outcomes.

MGFA, as an organization, has in many ways begun a new chapter, too. Last year we planted seeds to cultivate a future of significant growth. Now, in year one of our new strategic plan, we have expanded programming to include more robust education, actionable advocacy, and an increase in research funding. We have, also, started to diversify the way in which we fundraise to make it easier for our supporters to engage with the organization and to contribute through DIY and the Birthday Club! We are leveraging technology to improve our MyMG mobile app, and we have plans to grow our MG Registry. Our team also continues to raise greater awareness and to expand our reach through a global presence. And, with regards to “the team”, we have staff in place with a high-level of expertise and experience to support and manage this ambitious growth set forward by our strategic plan...which is a reflection of the needs of our Community. Did I add that we are just in year one of our new three-year strategic plan? There is so much to be thankful for and to look ahead to through a lens of promise and hope.

Our Community is in full bloom. We could not be more grateful for the expertise and guidance of our medical and health partners; the funding and support of our sponsor partners; the dedication and loyalty of our volunteers and donors alike; and the leadership and hard work of our Board of Directors and staff. As we look ahead, the future is bright.

Sincerely,

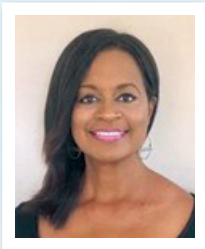
Samantha Masterson
President and CEO

Last year we planted seeds to cultivate a future of significant growth.



Meet New MGFA Team Members

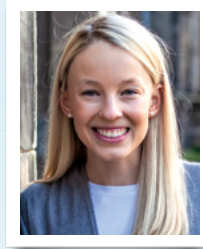
The Myasthenia Gravis Foundation of America continues to grow and take on an increased number of critical tasks to improve the lives of the MG Community. We have added some new team members, and we wanted you to meet them in this issue of Focus on MG. These team members are knowledgeable professionals who are empathetic leaders and understand what it takes to better assist the MG community while driving fundraising and awareness to expand the programs and services that we provide for those living with Myasthenia. We are excited to welcome these great people.



WENDI HUFF — Vice President of Programs and Clinical Care

Wendi Huff is the Vice President of Programs and Clinical Care for MGFA. She has a diverse background

servicing healthcare organizations, specifically rare disease and health disparities. She has worked with global thought leaders to advance medical research, convene stakeholders and improve patient health outcomes. Through program development, Wendi has implemented patient advocacy, education and disease navigation initiatives. She has worked collaboratively with the FDA, National Cancer Institute, academic researchers, pharmaceutical companies and patient advocacy organizations to remove the barriers to rare disease. Her extensive experience in national non-profit and private sectors have included executive leadership positions as Senior Director of Industry Affairs and interim Chief Advancement Officer at the National Brain Tumor Society Foundation, Associate Vice-President at the Morehouse School of Medicine and Chief Executive Officer of a YWCA chapter. Wendi will be responsible for developing and implementing comprehensive MGFA programming to support the MG community and activate mission deliverables as guided by the organization's strategic plan.



CAROLINE GAYLER — Director of Development

Caroline is the Director of Development for MGFA. Her passion is understanding the interests of each donor she works with, and learning how

best to connect their passions with investing in our mission. She has worked for multiple health-related non-profit organizations in development, including her most recent role at March of Dimes, and has served as a global health consultant for various international organizations. Caroline has a master's degree in Global Health Implementation with a focus on reproductive health highlighted through her research work. As the Director of Development at MGFA, Caroline works directly with donors to share the impact of their giving and aid donors in reaching their philanthropic investment objectives. ✨



But even if you don't have access to the Internet, there are so many fun and creative ways to drive awareness no matter where you live in the world. Check out all the ways you can get involved and take action for the MG Community:



PAINT N' SIP: MGFA

has lined up several artists from the MG Community to run a fun, online, Paint n' Sip event so you can learn some best practices and techniques for watercolor painting. *Check the MGFA website for dates and times.*



PROCLAMATIONS: Meet with or call legislative leaders to secure a PROCLAMATION officially declaring June as MG Awareness Month. *Use our handy PROCLAMATION SAMPLE DOCUMENT to help you write a request included on page 9.*



OUR MG VOICE: Make your voice heard in Washington DC by advocating for the Speeding Therapy Access Today (STAT) Act of 2021 (Bill H.R. 1730/S,760) (STAT Act). The STAT Act is a bipartisan bill aimed at improving the development and access to therapies for rare disease patients like those with myasthenia. *Contact The Every Life foundation for more information.*



LIGHT UP THE WORLD IN TEAL: As many know, the color teal is the official color of the MG Community. You can help us light the world in teal by contacting the real estate management companies of buildings and structures in your region or take a digital photo of yourself in an engagement activity and send to the MGFA. *See page 7 for details.*



MEDIA COVERAGE OF MYASTHENIA: Reach out to local broadcast and print media in your region, and "pitch" reporters to cover the challenges that MG patients face. Tell them your story, pitch them on key legislation, talk about your life with MG, and make sure they know that June is awareness month. Even write a article that you can post in their publication. *More training coming but you can use these Media Document Guidelines on page 8 to help you.*



MGFA COOKBOOK CHALLENGE: Pull out your favorite recipe and send it to MGFA with the subject line MGFA Cookbook Challenge. We will select the best recipes and combine them as part of an MGFA MG Cookbook that we are producing for the holiday season. *Begin sending recipes to mgfa@myasthenia.org on June 1.*



MGFA T-SHIRT DESIGN CHALLENGE: Build a creative T-shirt design and submit it. We will select winning designs and create actual T-shirts. Tie in the message of Turning MG Awareness into Action. *Send in your submissions starting on June 1, 2021.*



WELLNESS ONLINE SEMINARS: Volunteers will run fun, online seminars to improve your wellness and strengthen your body and mind. *Check the MGFA website for dates and times.*



SOCIAL MEDIA: Create videos, take photos of yourself or family with signs and MG shirts, wear teal, share MGFA social content, and spread the word about the challenges the MG Community faces through social media and email. Send notes and content to your friends and family, and publish fun, creative stuff so everyone knows what myasthenia is all about. **Use the hashtag #MGStrong.** *Submit content to the MGFA or find the MG Action Month webpage.*

We hope you'll get involved and engaged and do even more than last year to spread awareness and make sure people know what myasthenia is. **Remember to submit entries to MGFA@myasthenia.org.** ✨





Tools to Achieve Awareness Success

We are so pleased to be able to offer this tool for your outreach purposes. These pages will provide you with education and outreach tactics to increase awareness of myasthenia gravis, MGFA as an organization, and your upcoming events. For use during MG Awareness Month in June, or anytime this year, the these pages offer valuable ideas and tips for rallying your community and local businesses, as well as suggestions for posting on social media. **These tools will help our ambassadors raise greater awareness around MG and assist in expanding the MGFA reach!**

If you have any questions, please contact us at mgfa@myasthenia.org. We can't wait to hear about your successes! You can access the entire MGFA Awareness Toolkit at myasthenia.org/Portals/0/June%20Awareness/2021/MG%20Toolkit%202021.pdf?ver=uMttwaZ1lCbzlYHqGXuOg%3d%3d

Sample Letter – Monuments and Buildings

[Date]

[Name of official and address block]

Dear [Name of official],

I am writing to you on behalf of Myasthenia Gravis Foundation of America to request your support and authorization to illuminate buildings, as well as [Name of well-known local landmark/s or monument/s], in teal on the night[s] of June [dates] to mark Myasthenia Gravis Awareness Month.

Myasthenia gravis (MG), is a disorder causing extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe and even smile.

The Myasthenia Gravis Foundation of America is planning a variety of events this month to raise awareness of MG, including: **[Insert events or activities your Support Group is doing – especially if open to the public]**. On a national level, Myasthenia Gravis Foundation of America is also working with the government and other organizations to encourage iconic buildings and monuments to light up.

I hope that you will join us in our efforts to raise awareness of this serious disease. Thank you for your consideration, and look forward to your reply.

Respectfully,

[Your name, title, support group]



Sample Pitch Email for Media

New Message

To _____ Cc Bcc

Subject [Town] Resident Inspires Community

Hello,

On [date] at [location], [resident] is [conducting activity, such as: “hosting a virtual gathering” or “organizing a vehicle parade”] and can share her experiences with how the incurable, autoimmune neuromuscular disease myasthenia gravis (MG) inspired her to become an advocate in her community. We hope you can cover this event on [date/time].

[Add more details, particularly any visual components.]

More information about MG and the Myasthenia Gravis Foundation of America are included below my signature. Please let me know if you are interested in covering this event or have questions.

Thank you,

[Signature and phone number] [Include Media Alert – see below]

Send

Media Alert

A media alert is similar to an invitation for newspapers, radio and TV news outlets to attend and cover an event. When creating this document, be sure to highlight the local impact of what you are doing and note the community/city where the event will take place. We included brackets around the items you may want to tailor to your event. Here is an example:

[City] Resident Highlights MG Awareness Month by [Activity]

WHAT: On [date], residents of [city/town] will take part in the [event name] to raise awareness about myasthenia gravis (MG). MG is a disorder causing extreme muscle weakness that can impact a person’s ability to see, walk, talk, breathe, and even smile. It strikes people of all races, genders, and ages. [Add 1-2 sentences about the event.]

WHEN: [DATE] and [TIME]

WHERE: [LOCATION] and [ADDRESS]

CONTACT: For more information, please contact [NAME, NUMBER, EMAIL]

WHY: Myasthenia gravis is rare and non-contagious. In MG, the body’s immune system attacks the connection between the neurons and the muscle fiber, which limits the ability of the brain to control muscle movement. The degree of muscle weakness can vary from person to person, and day to day. Due to the high number of misdiagnoses, the precise number of people with MG is unknown, but MG is estimated to affect approximately 100,000 Americans. There are effective treatments for most, but not all with MG. There is currently no cure.

[Insert 2-3 sentences describing a personal story, if applicable.]

Photo and interview opportunities available.



Proclamation Request and Format – Sample

City of _____ / Town of _____ / State of _____

WHEREAS, myasthenia gravis is a disorder causing extreme muscle weakness which can impact a person’s ability to see, smile, walk, talk and breathe, and it is often misdiagnosed. It’s controllable by medication and other treatments for most MG patients, and although rare, it can prove fatal; and

WHEREAS, because of its rarity (approximately 100,000 people are living with MG in the United States today), many Americans are often undiagnosed; and

WHEREAS, the Myasthenia Gravis Foundation of America, Inc. (MGFA) is a not-for-profit organization founded in 1952; and

WHEREAS, the MGFA’s mission is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and to improve their lives through programs of patient services, support groups, public information, medical research, professional education, advocacy and patient care.

NOW, THEREFORE, BE IT RESOLVED that I, _____, Mayor of the City of/Chairman, Board of Selectmen of the Town of/Governor of the State of _____, do hereby proclaim June 20XX, as:

MYASTHENIA GRAVIS AWARENESS MONTH

in the City/Town/State of _____ and urge all residents to join with me, during the period, in an attempt to focus attention on the need for education, treatment, research, and ultimately, a cure, for this currently incurable disease.

IN WITNESS WHEREOF, I hereunto set my hand and cause the Seal of the City of/Town of/State of _____, to be affixed this _____ day of _____ in the year of our Lord, Two Thousand XXX.

Mayor/Chairman, Board of Selectmen

Contact:

MGFA National Office Address:
290 Turnpike Road, Suite 5-315, Westborough, MA 01581

[April/May] XX, 20XX

TO:

Board of Selectmen **OR:** Mayor or Governor
Town of: _____ City of or State of: _____

The Myasthenia Gravis Foundation of America, Inc. (MGFA) is pleased to designate June as Myasthenia Gravis Awareness Month. Myasthenia gravis (MG), is a disorder causing extreme muscle weakness that can impact a person’s ability to see, walk, talk, breathe and even smile.

Please join with other municipalities in issuing a proclamation for **Myasthenia Gravis Awareness Month** in your **[town, city, or state]**. Attached is a sample proclamation that is being declared in several other communities nationwide. Thank you for your attention to this important matter.

Local contact: _____
Name: _____
Phone number: _____



COVID-19 Resource Center Provides Guidance to Patients

People living with MG have had unique concerns during the COVID-19 pandemic. You may be worried about how the virus would affect you or your treatment plan if you were infected, and you may have questions about the vaccines.

MGFA's COVID-19 Resource Center myasthenia.org/MG-Community/COVID-19-Resource-Center is here to help. The resource center is a hub of information for MG patients. It is updated frequently so you have the latest studies, data, and advice at your fingertips.

Will MG or immunosuppressant therapies put me at greater risk of contracting COVID-19?

It is unknown whether myasthenia gravis or treatments for autoimmune MG increase the risk of contracting COVID-19 or experiencing more severe disease. However, as with other viruses, getting sick with a COVID-19 infection can bring on an MG exacerbation or crisis.

Is the vaccine safe for people with MG?

Patients with autoimmune conditions were not included in clinical trials for the Pfizer, Moderna, or Johnson & Johnson vaccine. However, as the vaccine rolls out around the world, immunosuppressed people have received the injection. The CDC has not reported any bad outcomes among immunosuppressed people who have taken the vaccine and says that the vaccines “may be administered to persons with underlying medical conditions who are not allergic or have no contraindications to vaccination.” We suggest that you discuss the COVID vaccine with your neurologist and primary care provider.

Is the vaccine as effective for people with MG or those who are immunocompromised?

Past research on vaccine efficacy for those who are immunocompromised suggests that you may not get the full efficacy as reported in clinical trials for the COVID-19 vaccines. However, vaccines can provide some immunity, which can lessen your degree of illness should you get infected.

When will I be able to get the vaccine?

Priority tiers vary by state. Many states have placed people with underlying medical conditions in an early phase of vaccine distribution. Most states are also distributing the vaccine to those over 65. It is important to stay in contact with your physicians and monitor your state health department guidelines as the vaccination process unfolds.

Visit myasthenia.org for the latest news and resources. ✨

“My experience with the vaccine was that my arm was very sore, but that pales in comparison to the joint pain and headaches I had for days with the real coronavirus. When I get any vaccination, like the flu shot, I tend to have that fatigue, a little more eye droop the next day. But, I can plan for that and manage it effectively.

If it saves you from the agony of full-blown COVID – and instead you have a light case that you could manage at home – it’s absolutely worth it to get the vaccine.”

— ROSEANN DEVLIN,
Torrance, California;
MG patient and certified
oncology nurse



READ ROSEANN'S
STORY ON PAGE 21



HAVE YOU BEEN DIAGNOSED WITH COVID-19?

Ask your physician to submit your case to the CARE-MG registry. This registry, overseen by physicians from Stanford, Duke, Yale and elsewhere, tracks MG patients who have contracted COVID-19 to monitor their symptoms and outcome. This research will help us understand more about how the virus affects people with MG. Go to myasthenia.org/Professionals/Resources-for-Professionals/CARE-MG to learn more.



NORD
National Organization for Rare Disorders

NORD Provides Financial Assistance to MG Community

People with MG can now benefit financially from a nonprofit program that supports research and advocacy activities for those with rare disorders.

The National Organization for Rare Disorders (NORD) created its patient assistance program to help families with rare disorders cover costs associated with their treatment. Myasthenia gravis was recently added to the list of NORD-supported conditions.

“Paying for medical care or other financial considerations such as bills or insurance on an ongoing basis — especially costs of experimental or new treatments that may not be covered by insurance — is a huge drain on the finances of MG families,” says Wendi Huff, Vice President of Programs for MGFA. “We are grateful that NORD has opened this resource up to patients with MG.”

The financial assistance program helps those with demonstrated financial need, both with and without insurance. The program may cover costs including health insurance premiums, deductibles, co-pays, medical visits, testing, medication, therapies and travel for health care. Assistance is provided on a first-come, first-served basis as resources are available.

Once accepted into the program, patients may use the doctor, pharmacy or other provider of their choice. NORD will reimburse applicable expenses. ✨



How do I apply for assistance from NORD’s Myasthenia Gravis Patient Assistance Programs?

P: 860.498.4307

E: MG@rarediseases.org

More information:
Visit rarediseases.org or
[rarediseases.org/
wp-content/uploads/
2021/01/MG-PAP-
FAQ-1-2021-1.pdf](http://rarediseases.org/wp-content/uploads/2021/01/MG-PAP-FAQ-1-2021-1.pdf).



Catch up with the MG Community

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

myasthenia.org



MGFA OUTLINES IMPACT OF PLASMA SHORTAGES FOR MG PATIENT TREATMENTS

COVID-19 Influences Drastic Decreases In Public Plasma Donations: Threatens Myasthenia Gravis Patient Treatment Options

Human plasma continues to be in urgently-short supply for important treatments for autoimmune diseases. MGFA is asking the public to consider donating plasma that can be used in life-saving treatments for those living with MG. Without access to plasma, patients may be denied treatments such as IVIG that would help greatly improve their quality of life.

MGFA is driving a campaign to highlight the ease of plasma donation that focuses on a new sense of urgency for healthy people around the world to donate plasma in much the same way blood donors give. However, donors in the United States must go to a plasma donation center to donate their plasma, not hospitals or blood banks.

Based on the latest information concerning the state of nationwide plasma storage, and considering the current COVID-19 pandemic, plasma donations have decreased to unprecedented levels. Since COVID-19 quarantines started, there has been a 30% reduction in donations. If donations do not increase, we will experience a shortage of the product intravenous and subcutaneous immune globulin (IVIG/SCIG) therapy, which is derived from plasma. It takes 250 individual donations to treat one IVIG/SCIG patient with MG and other autoimmune diseases for one year.

Human plasma in the blood is used as a treatment for MG. Treatments such as Plasmapheresis (relieves the symptoms of the disease by filtering out the antibodies from the plasma) or the infusion of plasma-based Immune Globulins (IgG), are proven to improve patient lives. These treatments rely on personal human donations of plasma – similar to donating blood.

Donating plasma is a relatively quick and easy process and can save lives. The Myasthenia Gravis Foundation of America is imploring healthy people across the country to donate their plasma at local plasma donation centers.

To learn more about plasma treatments, you can go to: myasthenia.org/What-is-MG/Treatment-Strategies-Goals. You can find out where to donate HERE: donatingplasma.org/donation/find-a-donor-center or contact MGFA@myasthenia.org. ✨



Living with Generalized Myasthenia Gravis (gMG)?

You may be eligible to participate in one of UCB's investigational studies for adults with gMG. We're committed to transforming the lives of people living with gMG and other rare diseases. [Contact UCB at ucbCARES@ucb.com](mailto:ucbCARES@ucb.com) or [844-599-2273](tel:844-599-2273) to learn more.



Inspired by **patients**.
Driven by **science**.

Ra Pharma now a part of UCB

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US-P-DA-2000069. September 2020.

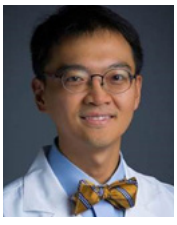


MG Clinicians Rely on Your MG Registry Data to Find Better Treatments and a Cure

The Myasthenia Gravis Patient Registry is an active database of persons with myasthenia gravis (MG), developed for the purposes of research, treatment, and patient information. The Registry is managed by the Coordinating Center of the University of Alabama at Birmingham (UAB) with oversight by the MGFA Patient Registry Committee.

Researchers and clinicians utilize the critical data in the registry – supplied and entered by actual MG patients – to structure and develop studies and clinical trials that truly test using the most accurate methodologies and criteria. Without this data, clinicians would not have the “map” they need to create studies that would do the most good for the MG Community.

We need more MG patients to voluntarily add data to the registry and continue submitting information over months and years. Without this data, new treatments cannot be discovered. Please consider continually submitting your data to the registry. To see a list of current and past research studies and to learn more about adding your data to the registry, please access the MG Registry page on the MGFA website: myasthenia.org/Research/MG-Patient-Registry



WHAT'S HOT OFF THE PRESS FROM MG PATIENT REGISTRY?

Ikjae Lee, MD — Department of Neurology, Columbia University

Sarah M. Jones, MD — Clinical Faculty, UVA Neurology



Myasthenia gravis (MG) is commonly a lifelong disease requiring long-term treatments. The symptoms of MG generally respond to treatment with acetylcholinesterase inhibitors and/or conventional immunosuppressive treatments. However, some people

continue to endure ongoing symptoms despite multiple therapy attempts or experience intolerable side effects from the available treatments. These people are classified as treatment-refractory MG. The following two studies explore the burden of refractory MG by analyzing MG Patient Registry data.

EMPLOYMENT IN REFRACTORY MYASTHENIA GRAVIS

MG may lead to disabling symptoms such as double vision, slurred speech, difficulty swallowing, limb weakness and shortness

of breath. Medication used for MG can have side effects or require scheduled infusions that further increase the burden of the disease. The burden is particularly high in refractory MG patients who did not respond well to treatments. In the current study, Harris and colleagues (2019) used MG Patient Registry data to examine the impact of refractory MG on employment status and absences from work in the United States of America (USA).

Individuals included in this study were self-enrolled in the MG registry between July 2013 to Feb 2018, between 18-64 years of age (working age), and were diagnosed MG for at least 2 years. Participants were classified as refractory MG if they had moderate to severe disease despite of current and past treatment with multiple immunosuppressants such as prednisone or azathioprine for at least 6 months each or at least one immunosuppressant with repeated IVIG or



plasmapheresis treatments. Moderate to severe disease was represented by MG-ADL score of 6 or more. Participants who did not meet the treatment criteria were considered nonrefractory. Authors compared demographic characteristics, current and previous treatments and disease severity between the refractory and nonrefractory groups. Employment status and absences from work were compared between groups.

The study included total 825 participants of whom 9.2% had refractory MG. There was no significant difference in age, gender, ethnicity, marital status, living arrangements or level of education between refractory and nonrefractory MG groups. As expected, refractory MG group received more treatments and had higher disease severity compared to nonrefractory group. The main finding of the study is that the proportion of individuals who were not employed was greater in refractory MG group. For example, 68% of the participants in the Refractory MG group answered not employed currently while 44% in the Nonrefractory group answered the same. This was found for both past and current employment status. Age, gender and level of education were also significantly associated with employment status. Males, younger individuals, those with bachelor or post graduate degrees were more likely to have a full- or part time job. Even after adjusting for demographic variables, employment status and MG disease status (refractory or nonrefractory) were demonstrated to be significantly associated. Individuals in the nonrefractory group were more than 2.5 times more likely to have full-time job rather than part-time job or a part-time job rather than no job. Among those who were employed, absences from work did not differ significantly between groups.

This study indicates that individuals with refractory MG reported that they were more likely to work fewer hours per week than individuals

with nonrefractory MG. The authors suggest that this study highlights the burden experienced by patients with the refractory disease as employment status may subsequently affect an individual's financial circumstances and health related quality of life. The retrospective study design, however, makes it difficult to establish causal relationship between refractory disease status and unemployment and thus the results need to be interpreted with caution.

**14+ CLINICAL TRIALS
DESIGNED USING
THIS PATIENT DATA**

LONGITUDINAL ANALYSIS OF DISEASE BURDEN IN MG

Retrospective studies suggest that patients with refractory MG more frequently have disease exacerbation, emergency room visits and hospitalizations (Engel-Nitz et al 2018), long term follow up study of this group of patients was lacking. Harris et al (2020) used data from the MGFA Patient Registry to compare yearly outcomes and long-term temporal trends in functional status, MG exacerbations, and healthcare resource utilizations in people with refractory and nonrefractory generalized MG.

Participants of the registry were included if they reported a physician diagnosis of generalized MG more than 1 year before enrollment, had completed enrollment between July 2013 and February 2018, and completed at least one follow-up questionnaire by February 2019, and provided sufficient information to allow for determination of refractory status at enrollment. Refractory or nonrefractory status at each follow up was determined according to the previous and current treatments, MG-ADL score based on the criteria as the above article. Based on this, participants were grouped into “ever-refractory” if they qualified for refractory status at any follow up, or “nonrefractory” if they never qualified for refractory status. Baseline demographic and clinical characteristics

were compared between ever-refractory and nonrefractory participants. Statistical model was used to assess longitudinal trends in study outcomes such as disease severity represented by MG-ADL score, number of MG

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exacerbations during the past 6 months, overnight hospital stays, emergency room visits, intensive care unit use and feeding tube use during the past 6 months.

Overall, 782 participants met the inclusion criteria and were enrolled in the study. Based on the results of all surveys, 26% of participants were grouped as ever-refractory while 74% were nonrefractory. Ever-refractory group was younger, more frequently women and had higher disease severity at baseline. The average follow-up period was 2 years. Disease severity measured with MG-ADL scale gradually decreased (improved) in both groups without significant difference between groups. The probability of experiencing an exacerbation was highest at baseline in both groups and was significantly higher at all timepoints in the ever-refractory group. The proportion of patients with recent emergency room visit and the probability for any recent overnight hospitalization was higher in the ever-refractory group at all timepoints, but these were not found to be statistically significant. Intensive care unit use was significantly higher in the ever-refractory group at baseline with further increased probability in this group at 2 years (2.5 times more frequent).

In summary, people who have ever had refractory generalized MG may have worse functional status, more exacerbations and higher utilization of healthcare resources such as emergency room visits or hospital admissions. Importantly, this study quantifies and emphasizes on the unmet need that calls for further attention. The study included large number of participants treated in real-life clinical practice, which increases the generalizability of the results. On the other hand, an important limitation of the study is that the data were patient-reported. Therefore, assessment and quantification of the outcome measures are reliant on the patient's memory which may not be always precise. ✨

References:

- Harris L, Aban IB, Xin H, Cutter G. Employment in refractory myasthenia gravis: A Myasthenia Gravis Foundation of America Registry analysis. *Muscle Nerve*. 2019 Dec;60(6):700-706. doi: 10.1002/mus.26694. Epub 2019 Oct 22. PMID: 31478207; PMCID: PMC6900169.
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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.



You May Be Able To Help Researchers Understand More About MG

See if you are eligible to join this two-year-long **MyRealWorld™ MG** study.

MyRealWorld™ MG is a global research project focused on understanding myasthenia gravis. The study relies on anonymous data recorded in the **MyRealWorld™ MG** app by adult patients diagnosed with MG. The more information the study collects, the more researchers may be able to understand MG and how it shapes the lives of people who live with it every day.

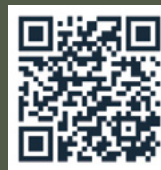
Why you may want to participate:

- **You may be able to help increase understanding** by joining this international study of myasthenia gravis.
- **You may be able to help researchers and the medical community** better understand the lives of people living with MG.
- **You may learn more about MG** through educational content provided via the app.
- **Your participation may support the larger MG community** by increasing knowledge about the patient experience.

US-NON-20-00175 V2 2/2021

Once you download the **MyRealWorld™ MG** app, you'll be asked to set up a medical profile where you can record information about your MG experience and management. You'll also receive regular surveys about additional diagnoses, symptoms and your daily-life activities. Over a two-year period, the **MyRealWorld™ MG** app aims to capture more real-world evidence data of MG's effects than ever before.

HOW TO JOIN THE STUDY.



This app is available in Spanish.



MyRealWorld™ MG | myrealworld.com

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Delivered to you by





MGFA Pilot Grant Awards Announced

Funding Research for New Treatments and a Cure

By Genna Mvalo

The Myasthenia Gravis Foundation of America (MGFA) is pleased to award research grants each year to help advance the understanding of myasthenia gravis and ultimately find better treatments for the disease. We fund some of the most promising and results-oriented MG research around the world to help improve the lives of those living with myasthenia now and in the future.

We award grants to get these research projects off the ground – and we couldn't do this without the many generous donations and sponsorship opportunities from our dedicated supporters. Thank you for enabling us to help find better treatments and a cure for MG.

MGFA employs an extremely objective and structured selection process that convenes medical professionals across the globe that are focused on myasthenia and rare diseases. We announce and conduct a Call for Papers application process, asking researchers to submit their research abstracts for evaluation. Our MG medical experts carefully review and assess each proposal and rank them based on an established and time-tested set of criteria.

The selected research projects must fall within the following five broad research priorities:

- **Biomarkers**
- **Disease Mechanisms**
- **Targeted Therapies**
- **Patient Outcomes**
- **Pediatric Treatments**

We are so proud to provide several types of grant funding areas such as high-impact pilot project awards, transformative research awards, targeted and special research projects, and young investigator and clinician awards. Through our grant funding process, MGFA has funded a number of extremely important and impactful research projects with key outcomes in the past.

This year, we received nine submissions for pilot grants and three submissions for our Seronegative grants. Our reviewers scored the proposals based on National Institutes of Health scoring criteria, feasibility, and creativity.

We are extremely excited to announce the following 2020 Grant Winners.

PILOT GRANTS

(each at \$55,000 – One year awards)

IDENTIFICATION OF BIOMARKERS THAT LEVERAGE MECHANISMS OF AUTOANTIBODY PATHOLOGY IN ACHR MG

Dr. Kevin O'Connor – Yale University

MG is characterized by the presence of acetylcholine receptor antibodies in the blood, which cause the disease by different mechanisms which are not fully understood. We are developing a group of assays that classify and quantify these antibody types to predict treatment response, monitor disease progression, and enable personalized therapeutic decisions that avoid severe side effects.

MEASURING ADVERSE EVENT BURDEN IN MYASTHENIA GRAVIS: VALIDATION ON ADVERSE EVENT UNIT

Dr. Michael Hehir – University of Vermont

There is increasing emphasis on long term side effect burdens for patients with MG as we attempt to understand differences between treatments. Understanding the side effect burden is paramount when designing unique treatment strategies. We have created a patient and physician consensus unit (akin to currency such as the US Dollar) called the Adverse Event Unit (AEU) to better measure this burden. The goal of the project is to evaluate the validity, utility, and feasibility of using the AEU as a measure of MG treatment burden.

SERONEGATIVE GRANTS

(each at \$150,000 – 2 year awards)

DEFINING THE CLINICAL PHENOTYPE AND IMMUNOPATHOLOGY OF SERONEGATIVE MG

Dr. Jeffrey Guptill – Duke University

Dr. Kevin O'Connor – Yale University

Seronegative MG (SNMG) is a disease subset of MG defined by the absence of detectable autoantibodies that are otherwise present in a majority of patients. Little is known about SNMG and it has not been well-studied. Two major goals of this project include: 1) to better understand the characteristics of SNMG patients, and 2) to better understand the abnormal immune system functions that contribute to this disease subset. This work will define the features that will lead to better treatment guidance in the future.

We congratulate these amazingly creative medical professionals and researchers as they embark on the projects – and we hope to announce exciting outcomes in the future. For more about our grant process, visit myasthenia.org/Professionals/Research-Grants. ✨



MG EDUCATION

Introducing the MGFA Blog

This spring, we launched a blog on the MGFA website. On the blog we provide space for patients to tell their stories, we give the latest updates about treatments and research, and we share news from MGFA.

If you're interested in telling your story on the blog, we'd love to hear from you. Email Michael Antonellis at mantonellis@myasthenia.org if you have questions or want to write a blog.

Read more at myasthenia.org/About-Us/Blog ✨



By Kate Stober



Golfing for Good

IN THREE YEARS, JEFF ABRAMSON'S DIY GOLF TOURNAMENT IN MEMORY OF HIS WIFE PATTI HAS RAISED OVER \$70,000 FOR MGFA.

When he decided to host a charity golf tournament for MG awareness, Jeff Abramson had never organized a major event before. His wife, Patti, had recently passed away, and a friend suggested that a tournament would be a meaningful way to channel their grief. Jeff and Patti had recently retired to a golf community in Sarasota, Florida, where they'd visited and played regularly over the previous eight years.

Though a novice organizer, Jeff approached the staff at the golf community about hosting the tournament. Their support encouraged him and his friend Liz Kinnisten to pursue the idea. Patti's father, Bob Medlar, and brother, Dave Medlar, who also live in Florida, were on board. Friends and family helped out tremendously.

"The first year was word of mouth through the clubhouse, and family and friends came down from New York," Jeff said. "We took home \$17,000. We were really shocked about that. It's pretty much a mom and pop operation."

The second year, they raised an incredible \$29,000 to support MGFA's mission.

This year was different. At first Jeff wasn't sure they could host the tournament because of the pandemic. He felt strongly that if they didn't, they'd lose the momentum they'd built among their community the previous two years. With support of the golf pro and other staff, the community's board of directors let them proceed with a smaller tournament with adjustments for health and safety.

"We usually have a shotgun so it goes faster, but we had different tee times," Jeff said, allowing the groups to socially distance. Only 18 foursomes were allowed to play – short of the 100 golfers who'd participated the previous year. Fun activities like 50/50 raffle, putting contest, longest drive award,

raffles, beer and snack stops on the course, and the post-tournament dinner proceeded as usual.

Despite the circumstances, the tournament's dedicated donors help them raise \$24,000 to support MGFA.

And that's what matters to Jeff.

Patti passed away from stomach cancer, but she suffered from MG her entire life. To Jeff, raising awareness of the disease that Patti fought and conquered – she was a successful controller and small business owner who didn't let her illness define her – is the most important part of the event.

"Nobody really understands or knows what MG is. When we first did this, 95% [of the participants] had no clue what MGFA was." Now, hundreds of players and donors know what MG is and how MGFA makes a difference.

The 2020 golf outing ended just as those in 2018 and 2019 had – sending up balloons in the MGFA colors, and thinking of Patti.

The next Patti Abramson Golf Outing is scheduled for October 22, 2021. If you live in the Sarasota area and would like to attend next year's outing, please contact mgfa@myasthenia.org. Registration is \$100 per golfer and includes dinner. A sponsorship fee of \$500 includes four golfers and a tee sign. ✨



ROSEANN DEVLIN – Proudly Rolling Up Sleeves for COVID-19 Vaccine

TWO MYASTHENIA PATIENTS ROLLED UP THEIR SLEEVES FOR COVID-19 VACCINATION

On December 23, 2020, Roseann Devlin proudly pulled up the sleeve of her MG Walk t-shirt to receive her first COVID-19 shot. A certified oncology nurse at Little Company of Mary Hospital in Torrance, California, Roseann was eligible to receive her vaccination as part of the first wave of health care workers. She is diagnosed with myasthenia gravis and has lived with the disease for a number of years.

Though she has MG and is taking immunosuppressant drugs, she did not hesitate to get the vaccine. As a nurse, she has seen many patients with severe COVID-19 symptoms and wanted to avoid any serious complications. Though there is some debate in medical circles about vaccine efficacy levels for people with autoimmune diseases, “it’s still worth it to me to be vaccinated because getting full-blown COVID is absolutely terrifying to me,” she says.

She knows firsthand and has a unique perspective... because she contracted COVID-19. On that day in December when she received her first shot, Roseann was unexpectedly exposed to a COVID-19-positive patient at work. Seven days later, she developed symptoms – a racing heart, joint pain, fatigue, dry cough, and a low-grade fever. She tested COVID-19 positive the next day.

“It takes your body about three weeks [after a vaccination shot] to create antibodies against the thing you’re trying to prevent,” Roseann shares. The vaccine had not yet done its job of creating protective antibodies in her blood at the time of her exposure to the virus.

She spent the next two weeks feeling exhausted, weak and feverish, and she had to isolate from her loved ones.

“My boyfriend would drop off a plate of food outside my door. I’d eat on the bed. I could feel the joints in my jaw – even eating was painful.” After the worst of her symptoms ended, she still felt tired – “like I’d done some kind of boot camp exercise club.”

She says she understands why people with MG might have concerns about taking the vaccine. It has not yet been widely tested on people with autoimmune disorders or other chronic diseases. People may be worried about side effects, or the likelihood of the reduced efficacy. But she hopes that her story can encourage others in the MG Community to take the vaccine.

“My experience with the vaccine was that my arm was

very sore, but that pales in comparison to the joint pain and headaches I had for days with the real coronavirus. When I get any vaccination, like the flu shot, I tend to have that fatigue, a little more eye droop the next day. But, I can plan for that and manage it effectively.”

“...it’s still worth it to me to be vaccinated because getting full-blown COVID is absolutely terrifying to me”

— Roseann

She also stresses that lower efficacy is better than no efficacy.

“If it saves you from the agony of full-blown COVID – and instead you have a light case that you could manage at home – it’s absolutely worth it to get the vaccine.”

Her colleague, Job Clay, agrees.

Like Roseann, Job is a registered nurse at Little Company of Mary Hospital. Also like Roseann, he has MG. The medical cardiology telemetry floor where he normally works has been converted into a COVID ward, so he has treated many COVID patients since the pandemic began.

“The decision to get vaccinated is ultimately up to you – with guidance from your doctor – but I am working every day in the face of COVID, and believe me, the vaccine’s side effects are way more appealing than the symptoms that come with full-blown COVID,” he says.

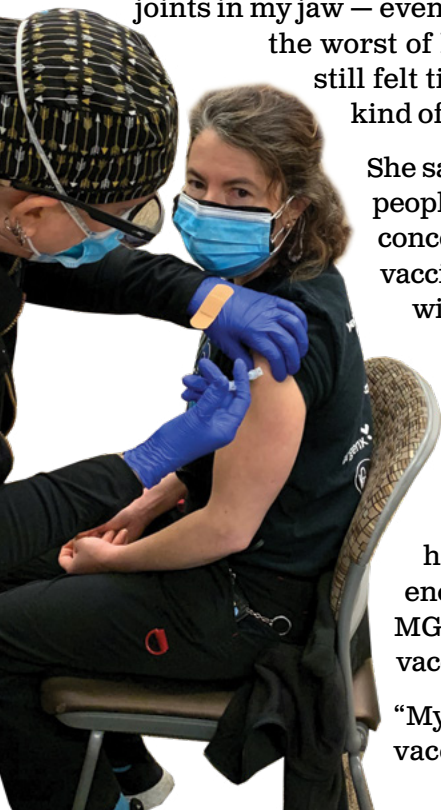
Job received his first dose of the Pfizer vaccine on December 23, and his second on January 7. While side effects from the second shot were worse than the first and lasted about 48 hours, “they were not bad enough to prevent me from going to work those two days.”

As COVID infections begin to decline after a devastating winter wave, and vaccines offer hope for the future, health care workers like Roseann and Job still face crushing patient loads.

They send out the same plea that doctors and nurses have shared for months:

“Whether you decide to get the vaccine or not, please continue to be diligent about your hand hygiene, wear a mask and practice social distancing,” says Job. “But strongly consider rolling up your sleeve and getting the vaccine.”

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PAULA MCGINNIS — MG Superwoman — Taking it One Day at a Time

Receiving a myasthenia gravis diagnosis can be frightening and upsetting. It's never easy to get bad news, especially about your health. But for Paula McGinnis, having MG and other autoimmune disorders has helped her grow in ways she never imagined.

"I've learned to cope with the disease with a positive attitude," she said. "I truly know what it means now to smell the roses, like my grandma always told me, and live life one day at a time."

Paula was a neurology nurse when she first developed generalized weakness and muscle issues. She could recognize that her symptoms needed attention. After tests and question marks about the cause of her symptoms, she developed eye weakness that eventually led to an inability to open her eyes. She was diagnosed with MG in 2006.

It was an insurance claim denial in 2014 that spurred Paula into advocacy. She became active with MGFA and was asked to be part of a panel discussion at the MGFA National Conference. This opportunity "opened up my life," Paula said. "I decided it was time to become the voice of MG for all us that walk the shoes of MG, and bring awareness to our region."

Paula lives in Metropolis, Illinois, a small town with a towering Superman statue in front of the county courthouse. She decided to organize a local walk to raise awareness and funds for MG. The first walk was held in November 2014, with 70 people from southern Illinois, Missouri and western Kentucky. They

walked just a few blocks, from the statue of Lois Lane to Superman, to make the event accessible for those with MG, who tire easily.

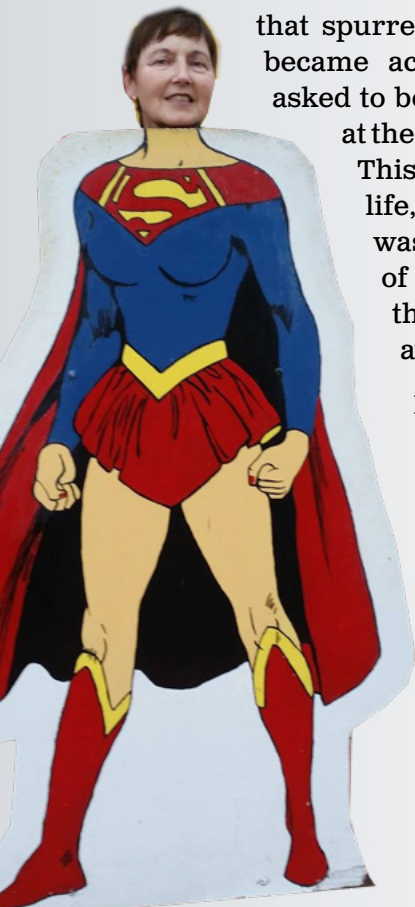
Since then, she's coordinated the annual walk in Metropolis. She started a Facebook page – MG Southern IL Region – which serves as a hub for the region's MG advocacy and awareness activities.

"I was really shy when I was younger. Having myasthenia and stepping out of my comfort zone really opened me up – I take my myasthenia advocacy with me wherever I go."

A few years after organizing her first walk, Paula took her advocacy 4,000 miles west to Kauai, Hawaii. Paula and her husband Gary had been to the island many times when a local friend suggested coordinating a walk in Kapaa, on Kauai's east side. They garnered city support, started another Facebook page, promoted the event in the local media, and welcomed about 80 participants in February 2017.

"I heard from someone at the walk who said, 'I thought I was all alone in this disease.' There were many people who came who didn't know anything about myasthenia."

In the future, Paula hopes to see a walk on every island. ✨



DREA CARBONE — Spreading MG Awareness One Day at a Time

Drea Carbone began her MG advocacy almost as soon as she was diagnosed. She hasn't slowed down since.

For several years I had been experiencing worsening double vision, but not one doctor ever mentioned it could be something serious. I was given prisms in my glasses and sent on my way.

By 2017, I was headed for eye surgery. The first step was a series of blood tests to rule out any potential causes, like Graves Disease or Myasthenia Gravis. “But don’t worry,” the strabismus specialist said dismissively, “you don’t have any of them.”

Then the lab tests came back. I had Myasthenia Gravis. I headed home from the doctor’s office and started Googling.

The more I read about MG, the more I could relate.

Weakness? Yes

Fatigue? Yes

Trouble swallowing? Yes

Memory issues? Yes

Biiig? Yes

All the issues I’d been dealing with for years suddenly made sense.

It would be six months before I could see a neurologist to treat my MG. In the meantime, I found the MGFA website and the MG Walk. Now that’s something I knew what to do with. I’ve been doing volunteer work and fundraising for my entire life.

Friends and family joined me on that first walk in Virginia, and it was wonderful in so many ways. It was the first time I met someone else who had MG. After that, my involvement just grew.

I had done fundraising before so I knew where to go and how to do it. A friend of mine owns a restaurant, so for three years we’ve done a fundraiser there. A good friend lives in San Francisco, so I flew out to do the walk there. My parents live near Boston, so our team did that walk, and then in Maryland, too.

Having my parents and friends involved is huge. I “voluntell” them to do various things, like taking photos at the event. They will share on their social media, and that spreads awareness even more. And it’s eye-opening for them to see everybody else with MG.

That first year in Virginia I met folks working for MGFA. I think they were impressed with my attitude and creative fundraising efforts, so they asked me to be “the Virginia MG Walk Hero” in 2018.

My mom sewed me a teal cape with a snowflake on



the back for the event, to match the tutus we wear. Our costumes help grab attention, and then we can explain to people who notice us that we’re raising awareness for MG.

The 2018 walk led to advocacy opportunities. I spoke to the scientists and doctors of a Belgian biopharmaceutical company at their 2019 Rare Disease Day event, and last year joined others at the Capitol for Rare Disease Week. We had seven different meetings with staff from Congressional offices, and I met a ton of people with MG and other rare diseases.

How do I make it work? I’m definitely persistent. I’m real. On a personal level, I cope with humor. I think a lot of times when people hear the word “disease,” the first thing they think is the plague! People kind of tense up. When someone hears about your MG, you have to disarm them. Humor just works for me.

I would encourage more people to get involved, whether you have MG or know someone who does. Meeting other people with MG helps you. You have this instant support network, and your involvement can help others, too. If you try to go it alone, you are doing a disservice to others and yourself. You could find some joy and some healing and some peace just from being involved, which I don’t think a lot of people think about. They get a diagnosis, and it just stops there.

Volunteering is not necessarily work. It’s another healing method. It’s another treatment. Half of what you’re doing is medical — you do need those medicines — but the other half is in your head and what the disease does to you. Having a positive experience, you feel a lot less alone. You’re doing something positive, and when you put that out in the world, it comes back to you. The happier you are, the better off you do. ✨





MGFA Partners with Rare Across America to Advocate for MG and Other Rare Disease Patients

During the week of March 1, 2021, ten MG advocates volunteered their time to participate in RARE Across America hosted by the EveryLife Foundation for Rare Diseases. The volunteers had meetings with United States senators and representatives to discuss key advocacy issues in the rare disease community. Meetings were held virtually, and advocates were paired with other advocates from their state or local district.

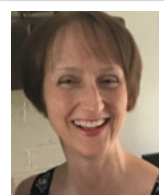
Key Legislative asks included:

- **Cosponsor the Speeding Therapy Access Today (STAT) to strengthen rare disease patient access to FDA-approved therapies.**
- **Support Rare Disease Programs Appropriations to improve the accuracy of diagnosis of rare disease, increase funding for rare disease infrastructure and expand support.**
- **Cosponsor the Newborn Screening Saves Lives Reauthorization Act, HR 482.**

MGFA was proud to support this advocacy effort and to make an impact on federal policy for the needs of the MG Community. We ask that others in the MG Community join the Rare Disease Caucus to learn more about the challenges that the rare disease community faces and the policy priorities of the community.

Listen to what some of our volunteer advocates said:

KIM ELDRIDGE, MGFA Board Member, Advocacy Workgroup Lead, Kentucky



While the virtual experience pales a little in comparison to being in person (there is just something so exciting about being in THE capitol buildings!), it was still an amazing experience. Many staffers that we met with last year remembered us.

Congressman Guthrie (KY) attended our meeting with his office. He was so engaging! He was asking questions, and shared his own experiences that his son went through as a child that were similar to those

experienced by a member of our group. He spoke about a meeting with President Biden and VP Harris just the day before our meeting. They are discussing a bipartisan special agency, possibly in NIH, that will work on rare diseases. He acknowledged that the Marketplace does not work well for people like us. It was truly an uplifting conversation. Congressman Yarmuth also attended our meeting with his office. We had a similar experience with him. They were compassionate, they listened intently, and joined in on discussions about the “asks” from each of us. One underlying theme across all meetings was “thank you.” Not from us, but from those we were meeting with. Each office thanked us for taking the time to come and talk to them, to share our concerns and issues, and for fighting for what we need and believe will help others.

LAURA CHANDLER, Volunteer, Kentucky



I echo a lot of what Kim said about the experience. Adjusting to online meetings created a learning curve, although it was certainly easier than hoofing it around Capitol Hill!

However, walking the halls of our government, sitting in the offices of our senators and representatives, and knowing that you are working to make a difference at the highest level is so rewarding. Many of us have to advocate for ourselves in everyday life. We have to find ways to make MG make sense to our friends, families, coworkers, and doctors. It can make us feel very vulnerable; we have to share the shortcomings of our bodies, our lives, and sometimes our worst fears in order to be heard. But, using my story to effect change is one of the most empowering experiences I’ve had. I also find strength in advocating for MG alongside people with different rare diseases. Our symptoms may be different, but our experiences are similar. Putting our collective needs together makes our voice stronger and louder. I encourage every MG-er to practice telling their story and being honest about their needs.

continued on page 26

Looking to connect with others in the generalized myasthenia gravis (gMG) community?



Making Connections

Education and support for
generalized myasthenia gravis

Register for a free webinar
or in-person event at the
link below*



Register at AlexionMGEvents.com

Based on the event you'd like to
attend, you could receive information
about one or more of the following:



Disease education
from a physician



Stories from people
living with gMG

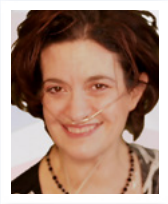


Tips for managing
symptoms

*These events are open to gMG patients and caregivers in the United States.

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DEBORAH VICK, Volunteer

I was able to advocate at all 6 meetings I attended. I used my personal stories, especially as seronegative MG patient, to introduce the ask for the STAT Act.

My talking points began with my connection to the rare disease community, my advocacy endeavors followed by the limitations and at times, life threatening experiences. After which, I discussed the types of treatments available to me and the absolute need for the research, cohesive connections between researchers, clinical trials, FDA approval and then bringing said treatments to the marketplace, with additional focus on the medicare and medical coverage. As Kim stated, virtually does not have the same feel of the “rustle and bustle” one feels when on the “Hill”. There is a certain feel of camaraderie, connections and networking that is not emulated in this virtual world. Just as being present, despite the lack of accessibility in DC, has an immense feeling. Especially being present, in the epicenter of American Politics surrounded by historical buildings and places. That being said, the virtual experience still took its toll on me, but much less so than that of being in DC trying to attend all the amazing programs.



KRISTINA VOSKES, Volunteer

Rare Across America was a great opportunity to learn about upcoming legislation that can directly impact those living with a rare disease, and a chance to share my personal MG

story with my state representatives. Myasthenia Gravis can be a particularly challenging condition to live with. Every experience is different, FDA approved treatment options are limited, and funding for research pales in comparison to other diseases. Facing MG can feel like an uphill battle at times, but Rare Across America felt like a huge step in the right direction. Getting the opportunity to advocate for a Rare Disease Center of Excellence was both empowering and hopefully impactful. Meeting with Congresswoman Bonamici (OR) was particularly meaningful. She was compassionate and genuinely interested in my life with MG, and recognized that the frequency at which a disease occurs should not determine the level of care or quality of options that patients have access to.

NATALIA TRAVIS, Volunteer

This was my first year attending, so I don't really have a basis for comparison. However, I think it is important to mention how difficult it is to travel when one is chronically ill, and that difficulty likely would have dissuaded me from attending this year. Having a virtual option may have provided the opportunity to get involved that some may not have otherwise had. That being said, it was really encouraging to see both local rare disease advocates doing their best to represent their loved ones with rare diseases, and to see that the offices of our elected officials truly do take an interest in our experiences and are willing to listen to our stories. I'm hoping to attend next year, if given the opportunity. ✨

ACTION ALERT — PLEASE TAKE ACTION:

MGFA Advocates for the STAT Act: Volunteers Should Contact Members of Congress

The United States House of Representatives and Senate have introduced the Speeding Therapy Access Today (STAT) Act of 2021 (Bill H.R. 1730/S.760). This is exciting because MGFA advocated for the need of the STAT Act during the March 2021 Rare Across America advocacy meetings with political leaders.

The STAT Act is a bipartisan bill aimed at improving the development and access to therapies for rare disease patients like those with myasthenia. The MG Community would greatly benefit if this becomes a law.

As part of our MGFA Our MG Voice action alert, we ask that you contact your regional members of Congress in the House and the Senate and ask them to read and pass the STAT Act as soon as possible. Since this is a bipartisan effort, we hope our efforts can help move this to pass. The Every Life foundation has a clickable link to help you take action and contact your political leaders. everylifefoundation.org/stat-act/take-action/

If you are interested in participating in MG advocacy efforts, please contact Genna Mvalo at gmvalo@myasthenia.org.



Clinical Trials for MG Patients Only

MGFA is dedicated to driving research to better understand, treat and cure myasthenia gravis for good. To achieve this goal, we are committed to creating awareness about clinical trials for those with myasthenia gravis and related neuromuscular joint disorders. There are a number of active MG-focused clinical trials that are currently accepting patients now. Please consider joining one of these active trials so you can help us get to better treatments and a cure for myasthenia.

You can go online to National Health Institute Clinical Trial Research Database to find MG-related trials. Also, utilize the link below: clinicaltrials.gov/ct2/results?term=myasthenia&recr=Open

Following are the names of active trials that you can join. Search for these on the MGFA website myasthenia.org/Research/Clinical-Trials

Active Clinical Trials

- Evaluating the Pharmacodynamic Noninferiority of Efgartigimod PH20 SC Administered Subcutaneously as Compared to Efgartigimod Administered Intravenously in Patients With Generalized Myasthenia Gravis (ADAPTsc). Active and recruiting.
- Efgartigimod Expanded Access for Generalized Myasthenia Gravis. Active and recruiting.
- The MINT study is a randomized, double-blind, multicenter, placebo-controlled phase 3 Study with open-label period to evaluate the efficacy and safety of inebilizumab in adults with Myasthenia Gravis. Active and recruiting.
- A Phase 3, Multicenter, Randomized, Double Blind, Placebo-Controlled Study to Confirm the Safety, Tolerability, and Efficacy of Zilucoplan in Subjects With Generalized Myasthenia Gravis, Active and recruiting.
- A Study to Test Efficacy and Safety of Rozanolixizumab in Adult Patients with Generalized Myasthenia Gravis, Active and recruiting.
- A Study to Evaluate the Safety and Preliminary Efficacy of Descartes-08 CAR T-cells in patients with Generalized Myasthenia Gravis, Active and recruiting.
- An Open-Label, Multicenter Study to Evaluate the Efficacy, Safety, Pharmacokinetics, and Pharmacodynamics of Eculizumab in Pediatric Patients with Refractory Generalized Myasthenia Gravis. Active and recruiting.
- A Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study to Evaluate the Safety and Efficacy of Ravulizumab in Complement-Inhibitor-Naïve Adult Patients With Generalized Myasthenia Gravis. Active and recruiting.
- RVT-1401-2002: A Phase 2a, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study of RVT- 1401 in Myasthenia Gravis Patients, Active and recruiting.
- A Randomized, Double-Blind, Placebo-Controlled, Multicenter Phase 3 Trial to Evaluate the Efficacy, Safety and Tolerability of ARGX-113 in Patients With Myasthenia Gravis Having Generalized Muscle Weakness, Active, Not recruiting. For more updated information.
- Catalyst Pharmaceuticals Clinical Trial for Firdapse in MuSK-MG Patients, Active and recruiting ✨



By Kevin O'Connor, PhD
Associate Professor of
Neurology and Immunobiology,
Yale University School of
Medicine | Vice Chair, MGFA
Scientific Advisory Board

Thymectomy and MG

Thymectomy is a procedure to remove the thymus, a small gland located behind the sternum (breastbone) that helps the immune system develop. In most people, the thymus does its work while you are young, helping develop T cells as your body matures. As you age, the thymus involutes (shrinks) as it becomes essentially inactive.

In some people, however, the thymus increases in size, possibly due to a combination of genetic and environmental factors, but the causes are not fully understood. The increase in size can be due an infiltrate of lymphocytes (immune cells), a condition called thymic lymphofollicular hyperplasia. The infiltrating lymphocytes often organize in the same way as is found in lymph nodes. In some patients with MG, these infiltrating lymphocytes are self-reactive and include those producing acetylcholine receptor (AChR) autoantibodies, which cause MG.

About 60-70% of AChR-type MG patients have thymic lymphofollicular hyperplasia. In these patients, it's clear that the thymus is harboring cells related to MG pathology. Because of this correlation, thymectomy has been recommended to some patients. If the thymus is harboring cells that cause MG symptoms, then removing it should also remove the cells causing the disease. Yet

physicians have found patients with thymectomy take a while to feel better, and that symptoms never fully disappear.

In research recently published in the Proceedings of the National Academy of Sciences, colleagues and members of my laboratory set out to find out why. We know that immune cells – B and T cells – are mature in lymph nodes and then disperse throughout the body. We designed our study to test whether this same process was true for the thymus-infiltrating B cells in MG patients.

For the study, we took blood and tissue samples at the same time patients were getting a thymectomy. Then we took blood again years later. Using a sophisticated approach that allowed us to identify clones (copies of one original B cell), we found B cell clones in the thymus and in the blood at the time of the thymectomy. One and two years later, the clones were still in the patient's blood.

Our interpretation is that these persistent B-cell clones, present in the blood after thymectomy, contribute to disease in MG patients. Thus, removing the thymus improves disease burden but does not eliminate it; suggesting that patients will need other treatment options as well to manage their disease. ✨

*This article shares study results and is not meant to be medical advice. Talk to your physician if you have questions about how this study's findings may affect your individual course of treatment.



MGFA WEBINARS SERIES

As the pandemic brought most in-person events to a halt, it was our goal to support you however possible. Last year, we introduced the MGFA Wellness Webinar Series and the What's New in MG Research? Webinar Series. These webinars connect, educate, and empower MG patients, care partners, and medical professionals. You can also learn about the latest research results, key clinical trial phases, and current outcomes from top research trials taking place right now.

You can watch recordings of all the webinars on our website:

Wellness Webinars myasthenia.org/MG-Community/Wellness-Strategies/Wellness-Series

What's New in MG Research? <https://myasthenia.org/Research/Whats-New-in-MG-Research>

To hear about the latest offerings, make sure you've signed up for the MGFA email list or contact us at mgfa@myasthenia.org.

iMAGINE
→ my MG



We are excited to announce
that our Phase 3 study in
**Generalized Myasthenia
Gravis** will be starting soon.



MGFA CARE-MG Identifies How COVID-19 Impacts MG Patients

COVID-19 ASSOCIATED RISKS AND EFFECTS IN MYASTHENIA GRAVIS (CARE-MG)

CARE-MG, a physician-reported registry, is a joint effort of the International MG/COVID-19 Working Group and neurologists from across the globe to capture outcomes of people with MG who have developed COVID-19 infections formally launched on 09 April 2020. Robust international participation and collaboration is critical to our collective success in answering fundamental questions: Do MG patients face special risks? Do baseline therapies impact risk? Together, the two groups along with several independent experts have designed and launched this international registry.

We hope to capture outcomes in all types of myasthenia gravis (AChR, MuSK, LRP4, Seronegative) irrespective of current treatment status who have confirmed or suspected COVID-19 infection.

Definitions:

- Laboratory Confirmed COVID-19 - Positive viral RNA tests or positive serology for SARS-CoV-2.
- Suspected COVID-19 but not confirmed - Fever with Dry cough, +/- anorexia, myalgias, dyspnea, anosmia/ageusia, potential exposure, Chest imaging suggestive of COVID.
- Myasthenia Gravis: As defined by treating physician based on antibody status and if seronegative (based on standard testing such as repetitive testing, single fiber EMG, response to acetylcholine esterase inhibitors).

MG-CARE RESEARCH FOR COVID-19 IMPACT ON MG PATIENTS RECEIVES IRB EXEMPTION

We ask you as a medical professional to register any appropriate patient, regardless of severity (including asymptomatic patients detected through screening). Please report only after a minimum of 7 days and sufficient time has passed to observe the disease course through resolution

of acute illness or death. Reporting a case to this database should take approximately 10 minutes. Necessary permission to collect these data from university institutional review board (IRB) has been obtained.

We would like to acknowledge all those who have participated in developing, guiding and launching CARE-MG. An initial steering committee (SC) has been assembled which will be revisited to include broader representation in the coming months. CARE-MG Steering Committee: Drs. Srikanth Muppidi (Stanford University, USA), Saiju Jacob (University Hospitals Birmingham NHS Foundation Trust, UK), Jeff Guphill (Duke University, USA), Henry Kaminski (George Washington University, USA), James Howard Jr (University of North Carolina, USA), Gary Cutter (University of Alabama, USA), Heinz Wiendl (University of Münster, Germany), Richard Nowak (Yale University, USA).

We are counting on international physician participation and collaboration, and hope to capture the majority of cases of COVID-19 in people with MG. We will rapidly define the impact of COVID-19 on patients with MG and how factors such as age, comorbidities, and treatments are associated with COVID-19 outcomes.

Cases can be reported by physicians two ways:

To report a case directly through the EDC (REDCap) system, redcap.duke.edu/redcap/surveys/?s=H4EKCWLFKR

To report a case using the paper case report form (CRF), please download the paper form and complete it. myasthenia.org/Portals/0/CRF_CARE-MG_09APR2020.pdf

If you have questions pertaining to CARE-MG, or wish to submit the form, please send to Dr. Srikanth Muppidi via email to COVID-19MGstudy@duke.edu ✨



Start Your Own Community Event Today

If you've been to an MGFA walk or golf tournament, you know how fun these events are. Meeting other people with MG, sharing your story, getting your friends and family involved – the joy and positivity last far beyond the event itself. These events are an important way to foster awareness of MG, as well as raise funds to support our advocacy, research, and patient support activities.

Did you know that you can host your own MGFA event or fundraiser in your community? It's true! Here are two simple ways you can activate your community to support MGFA's mission.

- 1. Host an event...** a walk, softball tournament, golf outing, yoga class, or anything you set your mind to! There are different ways to raise funds through these events, from registration fees to sponsors. You can keep it very small, or go as big as your time and energy allow.
- 2. Host a fundraising initiative,** such as a birthday fundraiser or asking a local restaurant to donate a portion of checks one evening to MGFA.

While you're the organizer and handle logistics and outreach for your event, we have a lot of resources to support your initiative. Here's what you can expect from MGFA:

Staff support: Our Fundraising Director Samantha Gardner is just an email or call away. Review your event with Samantha, obtain key resources, and learn about additional ideas to make sure your event is a success! Contact Samantha at sgardner@myasthenia.org

Social Media: We'll amplify your posts and photos if you share your information with us or tag the Myasthenia Gravis Foundation of America.

Website: MGFA works with a fundraising platform called CLASSY that will allow you to design a fundraising page suited for any type of event you choose to host. We will work with you to create your page and then give you the resources to help you manage it.

Materials: Request materials for your event such as a disposable banner, pamphlets on MGFA, and more.

Press Kit: We want to make it easy for you to share your event with your local community and media, so we'll provide you with a templated press kit and a how to guide on marketing your event.

Community Events

Calendar: We'll share events in our national event calendar on the MGFA website.



Are you ready to host your event? Contact Samanta Gardner at sgardner@myasthenia.org and visit the community event resource page: myasthenia.org/Get-Involved/Community-Events-Do-It-Yourself-Fundraising. ✨

WE CAN'T WAIT TO WORK WITH YOU!

PS – Need inspiration? Check out [Drea](#), [Paula](#), and [Jeff's](#) stories on the myasthenia.org/About-Us/Blog.





Understanding How Your Impact Equals Change in the MG Community

By Caroline Gayler



If you are a donor to any organization, no matter the size of your gift, it can be challenging to directly understand the impact your gift is making. And I can assure you, no matter the size, your gift matters. We are ready to change that challenge at the Myasthenia Gravis Foundation of America (MGFA) and make sure you, as a donor, understand exactly how your gift continues to make an impact.

I am thrilled to be part of the MGFA team as the new Director of Development. I have worked for a variety of health-related non-profit organizations in the past, including my most recent role in Development at March of Dimes HQ in the Washington D.C. area.

As the new Director of Development at MGFA, my focus is to ensure the sustainability of the organization by connecting donors with impact.

What exactly does that look like and what does it mean?

Growth and change are driven by our donors. It's the only way we are able to fund new research, launch new programs, and support all the rock star individuals in this field and on our team who make things happen. So, my role as Director of Development is solely to make sure that each donor knows exactly how their support made that growth and change happen - and to help donors who want to continue investing in our mission do so in a way that is meaningful to them.

One of the many ways we are demonstrating impact to our donors is through our newly-launched Giving Circles. By joining a giving circle, you as a donor will have the opportunity to hear more directly from our team. As a result, you can be more up-to-date on inside information from the organization. More importantly, it gives our team a way to appropriately recognize and share our gratitude with these individuals who make change happen here at MGFA.

Joining a Giving Circle allows you to take a more active and engaged role in the organization. We offer benefits that are unique to each circle to demonstrate our recognition of how critical donors are to our operations. More benefits become available based on the level of investment you, as a donor, decide you'd like to make. This is just one of the many ways we hope to share our gratitude with you for supporting us in continuing this critical work.

I am incredibly grateful to be part of this team and serve as a resource for each of you. Thank you for letting me be part of your journey to helping achieve a world without MG. For more information on joining a Giving Circle, visit myasthenia.org/Get-Involved/Donor-Giving-Circles or email me directly at cgayler@myasthenia.org.

**P.S. If your annual individual giving exceeds \$1,000, you'll automatically become part of a Giving Circle and will receive information directly from me. You can join a Giving Circle anytime! ✨*

MGFA GIVING CIRCLES



GET INVOLVED

Walk with Us

**JOIN US! THE MG WALKS
ARE COMING BACK FOR
THE FALL SEASON.**



The MG Walk is dedicated to creating awareness, renewing hope, and generating a vast support network for MG patients, all while raising important funds to support MGFA's mission. The MG Walk 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 allows patients with MG to open up and discuss their journey in a safe and nurturing environment, many for the first time. This sense of community is what brings many MG patients and their families and friends back to the MG Walk year after year.

Drea Carbonne has been active in MG Walks around the country since 2017.

"Friends and family joined me on that first walk in Virginia, and it was wonderful in so many ways," she says. "It was the first time I met someone else who had MG."

She says that having her friends and family participate is meaningful to her personally, but also helps them understand the spectrum of symptoms that people with myasthenia face. That helps them recognize what she and others with the disease are going through.

Join us as we come together to raise vital funds to support all of you, around the world, who live with this rare disease every day. MG Walk 2021 registration is now open at MGWalk.org.

This year, walks will tentatively take place September through December, barring any safety concerns with COVID-19. Our goal is to host in-person events, but we will make final decisions in the next few months. Check back at MGwalk.org for the latest updates. Your safety is and will continue to be our primary concern. You can contact Sam Gardner at sgardner@myasthenia.org for more information.

START A TEAM

Create a team, and invite your friends and family to join you.

JOIN AN EXISTING TEAM

Use the MG Walks webpage to find an existing team and join up to raise funds and walk together!

CREATE YOUR FUNDRAISING PAGE

Once you've created or joined a team, all that's left is to personalize your fundraising page, share your connection to MG, and tell your story of why you have joined the fight to stop MG...one step at a time.

Questions?

1-855-MG-WALKS (1-855-649-2557)

mgfa@myasthenia.org ✨



STAY CONNECTED   

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



GET INVOLVED

Join Our MGFA Birthday Club

Celebrate your birthday with friends and family and help those with myasthenia gravis at the same time – join the [MGFA Birthday Club!](#) On your birthday, you can raise awareness about myasthenia while you raise funds for important MG research and programs.

A birthday fundraiser is easy to set up. And everyone has a birthday, so anyone can participate!

You have two ways to start your MGFA birthday fundraiser:

1. Join the Birthday Club online.
2. Download the MGFA Birthday Fundraiser Mobile App on the Apple App Store or Google Play. Search for “MGFA Birthday Fundraiser” to find it.

Either way you sign up, you’ll be able to create a birthday page, invite your friends and family to give, and easily see the success of your fundraiser. You can also see and donate to other Birthday Club members.



Birthday Club members also receive special benefits (it is your birthday, after all):

- Recognition of monthly club members on the Birthday Club website
- An MGFA coupon for the MGFA Pop-Up Store:
 - Raise \$200 = \$10 off coupon
 - Raise \$500 = \$25 off coupon
 - Raise \$1,000+ = \$50 off coupon
- Raise \$500+ and be entered into quarterly drawing for an MGFA jacket.
- The Birthday Club member who raises the most funds in 2021 wins an MGFA prize package, including a hat, duffle bag, and jacket!
- One lucky Birthday Club member each month will receive a gift certificate for an ice cream cake.

Plan to celebrate your birthday with us in 2021! Join the MGFA Birthday Club at classy.org/campaign/mgfa-birthday-club/c312646. Questions? Contact Director of Fundraising Samantha Gardner at sgardner@myasthenia.org. ✨



SMILE FOR MGFA

Did you know you could donate to the Myasthenia Gravis Foundation of America while shopping on [amazon](#)? 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!





MGFA Support Groups

Are you looking to connect with others who share common life experiences? Support Groups can offer you support, resources, educational programming as well as social and recreational activities.



SHARE YOUR STORY. Support Groups are an opportunity to share your experiences openly and freely in a safe setting. Sharing your journey will not only offer you a sense of empowerment, but will help others in finding reassurance and learning new strategies to living with MG.

LEARN FROM LOCAL PROFESSIONALS. Support Groups offer educational programming and invite guest speakers directly from your community to present on a variety of topics. There are opportunities to learn about exercising techniques, insurance information, wellness, diet and more.

OFFER SUPPORT TO YOUR FAMILY & FRIENDS. Support Groups are led by the community and naturally become family-oriented. We typically turn to our family and friends first, but they may need support too! Support Group meetings are an opportunity for your family, caregiver and / or friends to learn more about MG.

ONLINE SUPPORT GROUPS are open to anyone regardless of where you live. In the face of the COVID-19 pandemic, we have been conducting virtual Support Groups using the Zoom video conferencing platform. These online groups are open to anyone in the MG Community no matter where you live. Many groups have educational guest speakers so anyone can learn from their expertise.

If you are interested in starting a support group, please reach out to Dova Levin at dlevin@myasthenia.org.

As we continue to experience the uncertainty and volatility of the Coronavirus/COVID-19 pandemic, MGFA has asked all Support Group Leaders to not host in-person support group meetings until further notice. However, MGFA has provided Support Group Leaders with the ability to conduct online videoconference meetings. Please check our virtual Support Group schedule links below to find a meeting.

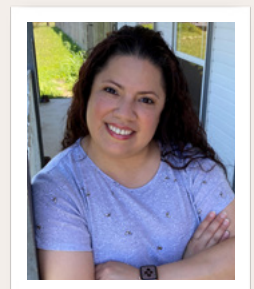
Online Support Groups are available to anyone regardless of where you live. You can live in any region across the country or around the world and access this valuable information.

We want to reiterate that our top priority is the safety and wellbeing of all members of the extended MGFA family. Should you have any questions, please do not hesitate to contact the MGFA at 1-800-541-5454 or email mgfa@myasthenia.org. ✨



We invite our spanish speaking community members to join our spanish-language support groups.

These take place on the 4th Saturday of every other month
– Cuarto Sábado del mes cada otro mes at 11am PT, 1pm CT, 2pm ET - 11am (pacífico), 1pm (centro), 2pm (este) • January 23, 2021, 23 de enero del 2021, March 27, 2021, 27 de marzo del 2021, May 22nd, 2021, 22 de mayo del 2021, July 24, 2021, 24 de julio del 2021, September 25, 2021, 25 de septiembre del 2021, November 20, 2021, 20 del noviembre del 2021. **Contact: Leah Gaitan-Diaz langchampions@gmail.com**





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www.myasthenia.org     

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.

Focus on MG is published by the Myasthenia Gravis Foundation of America, Inc. If this issue was mailed to you, you are on our subscriber list. If you would like to add, remove or update a subscription, or request that you receive future issues by e-mail, please contact the MGFA home office.

If you would like to receive Foundation Focus by email only, please email mgfa@myasthenia.org.

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**THANK
YOU**
...to all of our
wonderful donors!

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

CONSIDER GIVING IN YOUR WILL OR TRUST



MGFA is there for you when you need resources, information, and the support of others who know what you are going through. Help us ensure our work continues far into the future. When you make a gift to MGFA through your will or trust, you will make a difference for the MG community.

You can make a bequest in our will, name MGFA as a beneficiary, or consider other estate gift options. Contact Craig Strenger at cstrenger@myasthenia.org today so we can answer any questions you have or help you set up your gift.