



## Join our **MGFA TOGETHER WE STAND** Virtual Event on **October 10 at 12:00 p.m. EDT**

A celebration of the power of community, love, and hope.



In a unique and unprecedented year of change and challenges, MGFA is responding by bringing the power of the MG community together virtually and online during our MGFA Together We Stand event on Saturday, October 10, 2020 at 12:00 Noon Eastern. More details to come – check the MGFA website at [myasthenia.org](http://myasthenia.org) for log in details a week before the event.

In light of the pandemic, MGFA is unable to host in-person events this year. The health and safety of our community is our top priority. Instead, we will COME TOGETHER and combine our 2020 MG Walks and all fundraising efforts to highlight and recognize our Walk leaders, volunteers, medical professionals, MG community members from around the world at our MGFA Together We Stand event.

**WE NEED YOUR HELP MORE THAN EVER.** Please continue your generous, impactful fundraising efforts in the coming week to help people with MG. Please go to our MGFA Together We Stand page to register a Team like you normally would, donate to a current team or participant, or make an individual donation. Go to this webpage to donate today: [mgwalk.org/together-we-stand](http://mgwalk.org/together-we-stand)

And join us for this live, first-ever multimedia broadcast experience!

We'll spotlight our amazing volunteers and support groups, those living with MG, our MG Walk participants, researchers, partners, and medical professionals who work hard to achieve progress every day across the global myasthenia gravis community. Be prepared

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## New Wellness Webinars Helps MG Community Live Well

COVID-19 has created a new and unique set of challenges for the MG community. To meet this urgent need MGFA has designed a video Wellness Series to connect, educate and empower the MG patients, care partners and medical professionals. In addition to this stressful situation, many communities are experiencing civil unrest and uncertainty.

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- 4 Meet New MGFA Team Members
- 6 What's Hot in Research Outcomes
- 8 Driving MG Awareness Around the World
- 10 Managing Life with Multiple Conditions

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# THE CEO'S LETTER

Dear Friends,

It is with great honor that I write my first letter to you all in this important publication “Focus on MG.” The past seven months have been a whirlwind to say the least, and for all that has transpired and changed in our lives – and changed *us* – so much has evolved, grown, and transformed at the same time.

Becoming a part of this awesome MG Community has truly been a remarkable experience. I have often been asked what it was like taking on a new role as a leader in a time of such uncertainty and despair, particularly given the fact that non-profits rely on fundraising as the primary source of funding. My response does speak to the challenges...I share that we paused as an organization to be sensitive to our Community's needs. Our spring and summer seasons were all about programming, and that we deliberately did not push fundraising. I equally share my deep appreciation for our Community and your collective response and purpose to “fight the good fight” and to charge forward *together*. Taking our cues from all of you, we knew when it was time to fully engage.

The time is now. We will move forward in the spirit of our mission. We must do all we can within our power to support one another as we grow and evolve. At times, it will feel like we are beginning anew, and some weeks will feel like we are adapting on a daily basis. This will all become muscle memory to be open and ready for the unknown challenges in a way that we have never been before. This has become our mantra: Day by Day.

I know one thing is certain, and I am sure so many of you will agree who have faced medical challenges...life is unpredictable and it can blindside you in an instant. Sometimes it is hard to wrap your head and heart around the events that unfold. Sometimes you can see the silver lining, and other times you simply cannot see through the fog of despair. In these times, I sincerely want each of you to know that Community is more than a mere word...it means something so much greater than a group of people coming together. It means hope. It means love. It means support. It means familiarity. It means connectivity. It means that we have each other's back. It means that we will be there for one another. It means the ties that bind. It means that someone else understands you and what you are going through. It means we can just sit and listen...to words or silence. It means Together.

Let me share what we have weathered together through *your support* and this awesome community that we live in together...1,500 of us came together from 26 countries, for a National Conference in April to learn about the progress happening in our MG community. In June, we all raised MG awareness throughout the US and around the globe, through creative outlets in our front yards, on our homes and in our neighborhoods. Since the beginning of July, we've sat together for hours through almost a dozen wellness series listening and learning from experts on topics that were important to our community members and that helped us to be better about taking care of ourselves. Over the past several months, so many of our support groups have stayed connected through adapting and “going virtual” and being there for one another and leaning-in and allowing others to do the same. We have worked together on initiatives that drive the growth of MGFA, fundraising events that will support critical research, workgroups and committees where our community members continue to be strong ambassadors of our collective needs, manuals and other important materials for patients and medical professionals alike, and we have continued to move forward Together...Day by Day.

On behalf of the MGFA staff, I want to thank each and every one of you for your presence, for being part of this amazing Community, for inviting us into your lives and for sharing your stories, and for your ongoing support and perseverance and, certainly, for helping us to navigate through this very tough time. We feel nothing short of gratitude for our MG Community. ✨

Sincerely,

**Samantha Masterson**, President and CEO

*Community  
is more than  
a mere word...  
It means hope.  
It means love...*



Together We Stand continued from cover

for live interviews, video segments, volunteer recognition, interactive experiences, and exciting developments in the MG space.

It's a celebration of the power of community, love, and hope around the world. Together We Stand as one community in the fight against MG.

All donations and fundraising for this year's MG Walks will benefit the Myasthenia Gravis Foundation of America to help:

-  **Fund and support new impactful research**
-  **Create new treatment opportunities**
-  **Improve the quality of life for those living with MG**
-  **Provide support groups and offer guidance and resources**
-  **Inform medical professionals and educate people about the challenges of living with MG.**

You can still raise money and fundraise for this year's efforts by registering or if you've already registered previously for an MG Walk, use your on-line fundraising page.

Thank you for your past and future support of the Myasthenia Gravis Foundation of America and we hope you'll tune in for the MGFA Together We Stand event on October 10, 2020.

You can fundraise online or you can send a check to:  
 MG Walk Office: 1707 N. Randall Rd, Suite 200, Elgin, IL 60123 ✨

**Thank you Sponsors**










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*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.

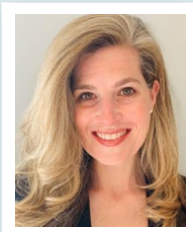
290 Turnpike Road, Suite 5-315, Westborough, MA 01581 | 800.541.5454 | mgfa@myasthenia.org | www.myasthenia.org





# Meet Your MGFA Team

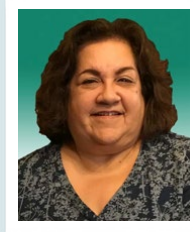
The Myasthenia Gravis Foundation of America has rapidly made some additions and changes to staff over the past six months, and we wanted to introduce your current MGFA Team. We invite you to get to know these talented, experienced professionals. The team is excited to help MGFA grow and evolve into our next chapter to drive research for a cure and assist our MG Community.



## **SAMANTHA MASTERSON**

### **President & Chief Executive Officer**

Samm is lead executive and responsible for the overall strategic direction of MGFA and works in collaboration with our Board of Directors.



## **DOVA LEVIN**

### **Senior Director, Program Management & Education**

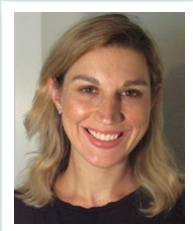
Dova drives MGFA programs and patient initiatives including 120+ support groups, Scientific Session, our National Conference, as well as our Regional Conferences, and is a key liaison for the MG Community.



## **CRAIG STRENGER**

### **Vice President, Development**

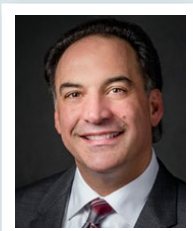
Craig leads the strategy and execution of all development initiatives, including donor stewardship, field operations (event fundraising), and corporate engagement.



## **GENNA MVALO**

### **Director, Patient Advocacy & Community Engagement**

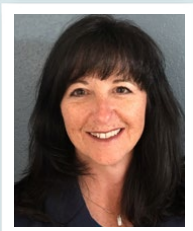
Genna is in charge of patient advocacy and community programs including MG Friends, Partners in MG Care, MAYA, our Wellness series, our pilot grants and special funding.



## **MICHAEL ANTONELLIS**

### **Vice President, Marketing & Communications**

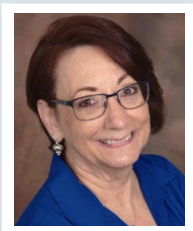
Michael leads the entire marketing and communications function including all awareness and promotions campaigns that drive development, programs, research, and patient support initiatives across a wide variety of audiences and channels.



## **SAMANTHA GARDNER**

### **Director of Fundraising**

Sam is responsible for the MGFA Walks nationwide and is the primary liaison for the Walk and events community. She, also, manages MGFA's "Do It Yourself" (DIY) program.



## **BETTY ROSS**

### **Director of Development**

Betty is responsible for overall donor stewardship and donor recognition programs for individual giving.



The Wellness Series focuses on four aspects of wellness: (physical, social, emotional, and psychological). The series provides patients with clear information in an accessible format. The information is broken out into “mini”-sessions which range from top-level wellness topics as well as more in-depth, detailed information for practicing specific areas of wellness. Each presentation is given by an expert in the topic subject matter and participants are given the opportunity to ask questions during the presentation.

**THE MGFA WELLNESS SERIES HAS IMPACTED OVER 1810 MG PATIENTS AND CARE PARTNERS TO DATE!**

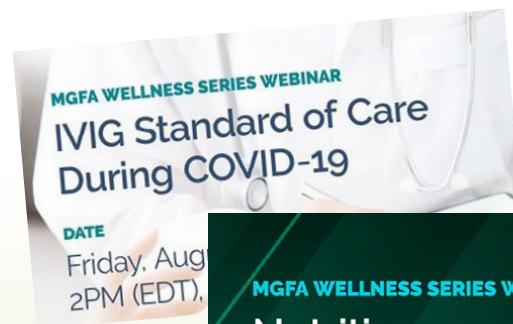
**THANK YOU TO OUR GENEROUS SPONSORS: ALEXION, MOMENTA, ARGENX, UCB AND OUR SUPPORTING SPONSORS: IMMONOVANT AND CATALYST**

*Each recorded webinar is available to view on the MGFA Wellness Series Page*

### WELLNESS SERIES ROSTER

#### Presentation Topic

- 1 Staying CALM when the world is not
- 2 Exercising and staying active at home
- 3 MG and occupational therapy
- 4 Standards of care for IVIG therapy during COVID-19 and beyond
- 5 Preparing for a telemedicine call
- 6 Hacks for living with MG
- 7 Nutrition and MG
- 8 Positivity and social media
- 9 Stress, anxiety, worry and coping during challenging times
- 10 Loneliness



## Catch up with the MG Community

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

[myasthenia.org](http://myasthenia.org)



## What's New in MG Research

### MGFA INTRODUCES NEW RESEARCH UPDATES WEBINAR SERIES

Want to learn more about the hottest new clinical research and outcomes to create better treatments for Myasthenia? Then tune into MGFA's new webinar series **"What's Hot in MG Research."**

These webinars will feature the most connected and dedicated MG experts, researchers, and medical professionals in our community who will provide the latest updates, outcomes, and progress in the fight against MG. In case you missed it, our first webinar was on Wednesday, August 26, 2020 and featured Dr. Jeffrey Guptill, a Duke University researcher and the Chair of the MGFA Medical Advisory Board, as he outlined outcomes from the Momenta Vivacity study and highlighted the CARE-MG COVID-19 MG study.

You can view past webinars and also register for the next one at the following webpage; [myasthenia.org/Research/Whats-New-in-MG-Research](https://myasthenia.org/Research/Whats-New-in-MG-Research)

### LATEST RESEARCH UPDATES:



#### MGFA Transformative Grant Generates New Paper on Potential MG Biomarkers

Circulating Th1/17 cells a biomarker of disease severity and target for early intervention for MG patients.

**Dr. Jeff Guptill** and research staff at the Duke Early Phase Clinical Research Unit at Duke University Medical Center has submitted another new paper that has been accepted by the Journal of Neuroimmunology. The research was the result of a transformative grant provided by the Myasthenia Gravis Foundation of America.

This study focuses on a group of patients with myasthenia gravis (MG) who have anti muscle specific kinase antibodies (MuSK-MG). Patients with MuSK-MG tend to respond well to therapies that lower anti-MuSK antibodies. Follicular helper T (Tfh) cells are a type of immune cell (a subset of T-cells) that help another type of immune cell, called B cells, produce antibodies.

Tfh cells are not well-studied in MuSK-MG patients. In this study, we found that T cells in MuSK-MG promote inflammation. In addition, a subset of Tfh cells, called Tfh17 cells, are higher among patients with MuSK-MG than healthy people without MuSK-MG. These Tfh17 cells are in part responsible for the inflammatory response in MuSK-MG and may help B cells produce more antibodies.



In summary, these results support a role for Tfh cell dysfunction in MuSK-MG. Highly specific treatment strategies to rebalance Tfh cells are a potential target for treating patients with MuSK-MG in the future.

You can read the entire report online at [myasthenia.org/Portals/0/Li%20Y\\_Imbalance%20of%20Tfh%20cells%20producing%20IL-17.pdf](https://myasthenia.org/Portals/0/Li%20Y_Imbalance%20of%20Tfh%20cells%20producing%20IL-17.pdf)

### **Momenta Pharmaceuticals Announces New Results for nipocalimab in MG Patients**

Momenta announced positive topline results from their interim analysis of the Vivacity-MG study investigating nipocalimab in patients with #MyastheniaGravis (MG). Read more about the results here.

Key highlights from the presentation we made this morning:

- 52% of patients who received nipocalimab had rapid, significant and durable reductions in MG-ADL scores (at least a 2-point reduction from baseline for at least 4 consecutive weeks) across all doses, versus 15% of placebo treated patients.
- A statistically significant relationship was observed between autoantibody (IgG) reduction and clinical benefit for patients taking nipocalimab ( $p < 0.0001$ ).
- Patients across all four nipocalimab dosing arms showed rapid reductions in MG-ADL scores, with clinically meaningful changes in scores within two weeks. Anti-MuSK patients were also included in the study and had similar responses.

Nipocalimab was well tolerated, safe and efficacious in gMG patients. There were no severe or serious nipocalimab-related adverse events and most adverse events were characterized as mild.

The study findings support continued clinical development in gMG and subcutaneous formulation dose selection.

### **Active Epstein-Barr Virus Found in Myasthenia Gravis Thymus**

Cavalcante P, Serafini B, Mantegazza R. et al. Epstein-Barr virus persistence and reactivation in myasthenia gravis thymus. *Ann Neurol* 2010;67:726-738.

Investigators report evidence of the Epstein-Barr virus (EBV) in the thymus of six patients with myasthenia gravis. None of the controls had EBV. The Epstein-Barr virus is active in the thymus of myasthenia gravis patients, according to a new study in a small number of patients. If confirmed, this discovery could help explain the cause of the disease and, at least in theory, suggest new treatments.

### **Research survey for rare disease patients and their families about impacts of COVID-19**

How is the novel coronavirus pandemic impacting people with rare diseases and their families? Complete the 20-minute research survey from home or learn more at this link.

[www.rarediseasesnetwork.org/COVIDsurvey](https://www.rarediseasesnetwork.org/COVIDsurvey)

The Rare Diseases Clinical Research Network (RDCRN) is conducting this study. The network is funded by the National Institutes of Health. It includes 23 research teams working to advance diagnosis and treatment of groups of rare diseases. The Myasthenia Gravis Foundation of America and Conquer MG partners with RDCRN through its work with the Myasthenia Gravis Rare Disease Network (MGNet). ✨



# Historic National Conference Goes Virtual...and Global

By Michael Antonellis

Our MGFA National Conference has historically been a time for many in the community to come together. It's the largest gathering of the Myasthenia community in the United States. We meet in person, connect, learn, discuss the challenges of Myasthenia, and learn about new progress and momentum in treatments. It's just a great opportunity to see each other and share life experiences with colleagues, friends, medical professionals, and caregivers. But in the spring of 2020, our conference became historic for a completely different reason.



This year, in light of the COVID-19 pandemic, we needed to completely change our expectations, and “turn on a dime” to create an online, virtual conference. By using the power of technology, we were able to bring the MG community together on their laptops and smartphones.



Our first-ever virtual National Conference theme was help in April 2020 under the theme “Promise: Caring, Connecting, Commitment.” Such a poignant message in a most challenging time in all our lives. But in the face of a terrible, historic pandemic, our Conference lived up to its “promise” and even surpassed all expectations.

Going virtual certainly had its advantages. Without the constraints of travel or hotel costs, many more community members were able to attend. **PARTICIPANT NUMBERS EXCEEDED 1500 PEOPLE**, significantly surpassing past attendee totals. And, now that anyone, anywhere could

view the event, we found that many community members and medical professionals from around the world could easily get in on the action. By all standards, this National Conference generated a higher level of awareness than any in the past. Quite a lot of good news in the face of overwhelming odds.

## Driving MG Awareness Around the World

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

**June is Myasthenia Gravis Awareness Month.** Every year, so many amazing and talented people across the MG Community come together and creatively spread the word about the challenges and issues concerning this debilitating disease. And, this past June was no different in the spirit of spreading awareness....but it WAS completely different than past years in light of the COVID-19 pandemic, But, that did not stop our incredibly resilient community from making some noise and being extremely creative.







We want to thank everyone across our global community for getting creative and helping people understand what myasthenia gravis is—and how it impacts those who live with this disease. From your backyards to city buildings – on your street and in your neighborhood, state, or country – you did everything you could to make MG Awareness Month the best ever – and it looks like you had so much fun too.

Here are some really exciting statistics about MG Awareness Month this year:

-  **40 USA States participated this year including Hawaii.**
-  **11 Countries sent in photos including Japan, China, Indonesia, New Zealand, Nigeria, UK, Germany, Italy, Kenya, Canada.**
-  **MGFA set a record of 15,000 Facebook followers in June.**
-  **We also had a record 2,000 Instagram followers.**

### WHAT A CREATIVE COMMUNITY!

So many volunteers and community members came out to post photos, create artwork, and tell stories about their unique experiences with MG. Thank you so much for being a critical part of this year’s awareness month festivities. We couldn’t do this without you. Check out some of the images from the month and click here to see our global map of awareness activity. ✨



## 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](http://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.







# Managing Life with Multiple Medical Conditions

By Paul Strumph

**Is this one more well-intentioned article that won't help me?**

**I certainly hope not.**

**But then again, what gives me the right to address this issue with you? We will get to this in a little bit.**



As a person with MG, have you been on the receiving end of conversations (dare I say “lectures”) by well-meaning healthcare providers who seem to be convinced that they know your MG better than you? So have I!

As a person who defines yourself as a sum of your life-experiences—do you sometimes feel that non-MG healthcare providers seem to come to the conclusion that your symptoms “may be MG” without a complete analysis? So do I!

As a person who sees many healthcare providers, do you wish there was a way that you could help them coordinate the care between MG and your non-MG conditions? So do I!

To answer the question I asked at the beginning (“what gives me the right...”), I would like to share a little of my life with you. Not too much, but enough. I was diagnosed with MG very recently (less than a year ago) after a gradual decrease in muscle

strength with exertion. The diagnosis was not straightforward - which is “par for the course” based on my conversations with others. Like many of you; my life as 2 phases; The first-before MG, and the second-after MG.

Before MG I had adjusted to a life with more than 50 years experience with type 1 diabetes. My diabetes did not define me. Rather it was an unwelcome visitor that barged into my life when I was 6 years old and has lived with me ever since. I have not been able to get this visitor to leave, and we have learned to live with each other. In fact I like to think the visitor did a lot of positive things for me. My motivation for going to medical school was based on a desire to help people like me, and to become knowledgeable enough to do so. After medical school I went on to become a pediatrician and an internist. I then received additional training to become a pediatric and adult endocrinologist, and then settled in Asheville NC where I treated adults and children with diabetes and related conditions for many years. Then came MG. I am now living in the “after MG” world and learning so much about this disease.

My “before MG” experiences may help me adapt to the “after MG” world. I hope that some of my experiences may be helpful to you.



Life with MG can be challenging; from managing symptoms to multiple medications to worrying about potential worsening. However, we know that these challenges are amplified further when people are managing other conditions in addition to their MG. People with MG that have other medical conditions often require treatment by health care providers who are not experts in MG. Because these health care providers may not know how MG does or does not affect other medical conditions - people with MG may experience barriers in receiving the care required for these other important medical conditions.

Here are some specific examples of situations that can occur, and some suggestions for working through them. I would appreciate additional situations and solutions you can provide.

Diagnosis and treatment for non-MG conditions that takes MG into account.

- This is where a primary care physician is especially helpful. Typically, this is a Family Practitioner or internist, but it doesn't have to be. The American Academy of Family Physicians summarizes the characteristics of primary care in this way: "Primary care is that care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern".
- From my personal experience, It is the "undiagnosed sign, symptom, or health concern" that is so critical for the primary care physician to address. My primary care physician continues to evaluate my existing and new health concerns. Her evaluations consider the most likely causes, and if she feels that MG may be playing a role, she let's me know. To me, this is very reassuring, as it does not automatically assume that MG is the cause.

Strongly related to above is ensuring your health by working to improve communication between your MG expert and other healthcare providers.

Although many people find fault with electronic medical records (EMR), I have found a very real advantage to my MG specialist (and my other specialists) being able to weave the complex physical exam and laboratory data (the "objective" information that is evaluated at your visit) into an

impression of your disease at the time of the visit. This part of the evaluation is the "Assessment & Plan" and too often with paper charts it was illegible or so short as

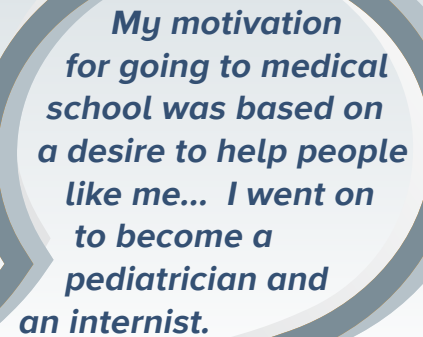
to be uninformative. Now with the power of computers (and physicians learning how to type!) the "Assessment & Plan" can be detailed and understandable enough for your primary care provider to understand the nuances of your MG - and to know what your MG specialist is doing, and perhaps more importantly.... What is not being done by them and would be a great opportunity for the primary care provider to do pick up on.

For maximum benefit of the EMR to be obtained, it is suggested that you may facilitate this communication yourself by:

- Requesting the MG specialist send the EMR note electronically to all your care providers
- Consider logging in to your MG specialist EMR through your patient portal and then downloading the office note. You can then send the note to your primary care physician by old fashioned mail, or by a "PDF" attachment to a message you send them in your primary care patient portal, or you can simply print off the MG specialist note and physically bring it to the next appointment. Most offices will not accept confidential medical information sent as commercial emails (ie gmail, aol, yahoo, etc)
- Consider a telehealth visit with your primary care physician soon after the MG specialist visit to go over the specialist findings, and make sure all your questions about "next steps" are addressed.

### **How can you as a patient with MG best advocate for yourself?**

This is not specific to MG, so there are very useful approaches that you may consider using. It has been my general experience that advocating for yourself at a medical appointment can be challenging, and that planning ahead can lower the stress and help define what your priorities for that visit are. If the



*My motivation for going to medical school was based on a desire to help people like me... I went on to become a pediatrician and an internist.*





doctor is rushed and can only answer 3 questions... what would they be?

## Seeing a Medical Professional

“Being a patient is stressful.” These strategies will keep your mind clearer when you are dealing with a medical diagnosis.

## Prepare for Your Appointment

To ensure you have the best possible experience with your doctor, it’s best to come prepared.

Ideally, you’ll already have your medical history and list of current medications ready to go, but there are a few more steps that could make your visit even more productive.

- Set goals of what you’d like to address with your doctor.
- Make a list of all your symptoms and concerns about your health scare
- Try not to overdo internet research before you get to the doctor’s office.
- Keep in mind that your doctor is only human, and has probably worked a long day. Advocate for yourself, but also be respectful of your medical team and their time.

## Ask Questions

We’re taught to listen to what the doctor says, and while in most cases that’s a good idea, in order to be our own advocates, we also have to speak up and ask questions. Remember: There is no such thing as a stupid question. If something comes up that you hadn’t considered, ask about it. If you don’t understand something, say so. This includes having the doctor explain any complex medical terminology.

But direct your questions appropriately.

- Questions about scheduling appointments? Ask the front desk.
- Getting ready for a hospital stay? Ask the nurse (not the doctor) about what clothes to bring.
- Have a specific medical questions about your diagnosis or treatment? Ask your doctor. Chances are you’ll come up with additional questions as soon as you leave the appointment. Ask the doctor or nurse for the best way to contact them with these follow-up queries.



*Set goals of what you’d like to address with your doctor*

## Keep Track of the Answers

When you’re in the doctor’s office because of a health problem, you may feel anxious or rushed – either way, it’s helpful to record the answers to the questions you ask your medical team, as well as the other information they give you. Bring paper to your appointment (or if you forget it or a pen, just ask the receptionist) to take notes of everything that is said during the appointment. If you’d feel more comfortable having an audio recording of the appointment, ask your doctor if you have their consent to record the office visit. There’s no need to purchase any equipment: most smartphones come with a free recording app, like Voice Memo. Depending on the nature of the appointment, it may be helpful to have a family member, friend or partner either go with you for a second set of ears, or call in on speakerphone so they can hear and take notes on everything being discussed.

## Make Sure You Are Heard

A doctor’s appointment should feel like a conversation, and it’s important for both you and your physician that your voice is heard. Asking questions is one thing, but it’s also necessary to speak up when you don’t think you’re being heard or understood. There is no rule saying that the doctor’s opinion is the be-all and end-all. They are capable of making mistakes or, in some cases, simply ignoring patients and their concerns, which can be especially true when the patients are women or people of color. Therefore, it’s very important that you leave the appointment believing that your doctor is taking your pain seriously.

Be as specific about your symptoms as possible. The more information you’re able to provide to your medical team, the better your chances are of getting an accurate diagnosis. If the doctor is still being dismissive, calmly and respectfully express your concerns, and let them know that you don’t feel as though you’re being fully heard. If this doesn’t work, it may be time to change doctors or get a second opinion.

## Make Sure You Understand

If the doctor ends up making a diagnosis in the appointment and you don’t understand what it is or what it means, feel free to ask additional questions.

Don't hesitate to ask the doctor to refrain from using medical jargon when explaining what is happening to you. Some medical professionals will even draw pictures or diagrams to help illustrate exactly what is going on in your body. If you'd like more information than the doctor is able to provide during the appointment, ask them where you can read more about the condition. This way, they'll point you to a reputable book or website, so if you're going online for information, it will be accurate. You can also ask if there are any online resource groups for people with the condition.

Along with your diagnosis, it's important that you also understand how the doctor plans to treat your condition. Don't leave until you know the plan.

Making decisions regarding your health care or treatment can be difficult.

- If you are faced with having to choose from multiple options, you can ask to speak with a bioethicist or counselor. While not all medical facilities have them on staff, your medical team should be able to point you in the direction of someone who can help walk you through the decision-making process.
- Make a list of the risks and benefits of each option, taking into consideration what is best for treating your current medical issue, as well as what would be best for your health in the long run.
- Once you understand your diagnosis and treatment plan, it may be helpful to let trusted family members or friends know that you're sick so they are aware and can check in periodically. You can also ask them to weigh in on the decision you have to make regarding your treatment if you'd like additional opinions.

### **When You Need (or Want) a Second Opinion**

Some medical conditions have routine, straightforward treatment procedures. Other times, there are multiple ways to treat a patient, and it can be difficult to determine which option would be most beneficial. That may mean it's time to get a second opinion. Moreover, if your doctor recommends a procedure that is invasive or your diagnosis is severe, that's another good time to get a second opinion. This is true for diagnoses and treatment for both your physical and mental health. Doctors should not be offended if you ask for a second opinion, and may even recommend other physicians they trust.

When it comes to selecting a doctor for a second (or even first) opinion, don't be afraid to shop around. If you're going in for surgery, ask potential surgeons how frequently they perform a specific procedure. Even if it's something basic that you assume all doctors know how to do, ask if the procedure is a regular part of their practice." —reprinted with permission of the New York Times.

### **Medication choices for non-MG conditions that are appropriate for MG**

Here there is a real challenge. As people with MG have very different abilities to tolerate medications that can affect MG. What has worked for me is to make healthcare providers aware of internet sites supported by MGFA where medications that have special considerations for people with MG have been posted after appropriate peer-review.

I would strongly recommend websites that are produced by non-profit foundations and that are "peer reviewed" or compiled by groups of experts. I am very reluctant to endorse opinions expressed by individual people - whether they are physicians or not. The reason is that individuals have individual opinions and evaluate information differently. So for me, I highly value information that is arrived at by discussion and consensus, especially by people who won't make money based on whether I follow their list or not!

Examples of websites you may want to consider are below:

- From the Myasthenia Gravis Foundation of America (MGFA) website: "Cautionary Drugs." The link is here: [myasthenia.org/Portals/0/Cautionary%20Drugs.pdf](https://myasthenia.org/Portals/0/Cautionary%20Drugs.pdf)
- If you do a google search for "myasthenia gravis medications to avoid" you get some good results as shown below. [Myaware.org](https://myaware.org) is an MG foundation in England: UAMS.edu is university of Michigan Neurology department with a nice PDF list; UptoDate is an incredibly value subscription medical reference. The information on what drugs to avoid is buried in a longer article.

*Thank you for taking the time to read this article. I hope it was helpful. If you want to reach out, please do so. [pstrumph@gmail.com](mailto:pstrumph@gmail.com) ✨*





CABARET SINGER & MGFA SUPPORTER  
**RONNI FAUST**

**Does What She Loves to Fight MG**

*By Michael Antonellis*



**Ronni Merrill Faust** is a cabaret singer and dedicated supporter of MGFA since her husband was diagnosed with myasthenia gravis six years ago. She has applied her comedic and musical talents to fundraise on behalf of MGFA. She came up with the extremely fun idea

of creating a short musical video that combines hysterical lyrics, catchy show tunes, and everyday situations as part of our currently challenging world and set it all to music as a unique fundraiser. Ronni talked to the MGFA staff in the July 2020 MGFA News e-newsletter.

**MGFA: How long have you been part of the MGFA community with your husband Phil?**

**RONNI:** Phil and I have been part of the community since he was first diagnosed with myasthenia gravis six years ago. It was really quite frightening. He was having trouble walking, breathing and leading a normal life. We had never even heard of the disease, so it was definitely an education process for us. But once we figured it out and got the right doctor, we were able to manage it.

**MGFA: How is he doing with the disease now?**

**RONNI:** Phil's been really lucky that everything is pretty much under control. He's dealing with the

disease well! I think we're really very fortunate because his physician, Doctor Bhatt, is an expert on MG, and he is terrific! And we're just keeping our fingers crossed that he continues to respond to the protocols.

**MGFA: How did you come up with the idea of doing a video series?**

**RONNI:** I am a cabaret singer and have done that since I retired from work 10 years ago. My show "Ronni Faust Has Spring Fever! Or Is It Just Allergies?" was supposed to happen this past spring. Then the pandemic hit. We rescheduled it for this fall, but that will likely not happen either. We are now hoping to do the show live in the spring of 2021 as a benefit for MGFA. A whole hour of video would have been too much, so my director Lennie Watts and I talked about selecting three songs from the show to whet peoples' appetites for the live show when it finally happens, and we could make that a benefit. So we plotted out which three songs from my show would be diverse and fun to take peoples' minds off of the real world.

Phil was my videographer since he was the one person I was sheltering with (and he did a great job by the way!). My music director Steven Ray Watkins came up with some great arrangements; Adam Shapiro did a terrific editing job; and Lennie and I added some funny bits. It was a tremendous team effort.

**RONNI FAUST HAS SPRING FEVER! – OR IS IT JUST ALLERGIES? MGFA FUNDRAISER**  
[www.classy.org/campaign/ronni-faust-cabaret-singer/c290542](http://www.classy.org/campaign/ronni-faust-cabaret-singer/c290542)



**MGFA: What provided you with inspiration for these songs in your shows?**

**RONNI:** My rule of thumb is, I have to really love every song I sing in a show. I like diversity in my selections, so I picked an uplifting pop song and put my own words into the second part of it and filmed it like a movie; the second song was more serious but evocative of the times we are going through now; and the third song was pure comedy – with a twist we added. I have so many others in my show, but I enjoy funny upbeat songs. My first show was more about myself and my life. The second show was about aging so I did it for a big birthday, and it was called “Gravity is a Bitch,” by Miranda Lambert. I wanted my third show to be more of a fun romp, hence “Ronni Faust Has Spring Fever! Or Is It Just Allergies?”



Fortunately we have friends and family who are extremely generous and have really opened their hearts and wallets. I'm thrilled that we are getting such a good response.

**MGFA: How has MGFA helped you and Phil?**

**RONNI:** Phil has been part of various organizations in the past. He wants to make things better for people. He is an incredibly giving person. MGFA gave him another great outlet to do good and this is a personal one, obviously. MGFA gives so much to the MG community. Education and awareness is important. And funding new research that could create better treatments. MGFA provides those opportunities to improve the lives of those living with MG.

**MGFA: How do you have so much energy, and what would you tell the MG community to inspire them?**

**MGFA: What made you see the opportunity that this series could raise money for MGFA?**

**RONNI:** You know, it's just all about doing something for other people. I've never done a show that's not for charity. Once Phil was diagnosed, I changed my charity to MGFA. MGFA needs the money far more than some of the other major diseases for obvious reasons.

I think every dollar that goes to MGFA has much more impact than it would for larger non-profits. Everyone is driven by their own experiences. We had no clue about MG when Phil was first diagnosed.

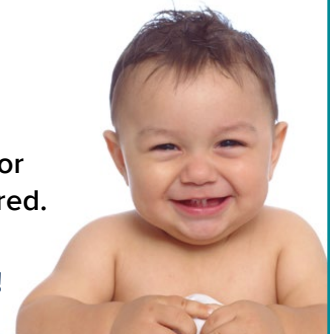
**RONNI:** Really, what is the alternative? We all need to be positive and help where we can - especially during these challenging times. Everyone knows how to do something well, and you can use that as a benefit, whatever it is. If you're a knitter, knit a sweater and use it to get a donation for MGFA. If you sew, sew masks for fundraising. If you bake, sponsor a bake sale. So, you know, if you have a skill or talent that can work to bring money in to help the MG community, that's great!

I'm doing what I know how to do, and love doing, so it's a win-win for us all! ✨

**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](https://smile.amazon.com/about) to learn more and make MGFA your charity!**





# Jessica Collier is a Monday Mermaid... and an Inspiration



**Jessica Collier** began feeling the symptoms of Myasthenia Gravis back in 1997. She was officially diagnosed in 2014. Like many in the community, she was misdiagnosed and had to live with

MG for years before being treated properly.

But, she never let the disease impact her incredibly positive attitude and drive to do good for the community. She took an extremely creative path to drive awareness of the disease by creating the “Monday Mermaids” during MG Awareness Month every year. Her many friends and family who don lovely mermaid costumes every Monday in June are a testament to Jessica’s inspiring and powerful support of the MG community and MGFA.

## **MGFA: Jessica, tell us about your MG story.**

**Jessica:** I grew up in northwest Florida for 34 years and come from a small rural town. When I got sick, I had never ever heard of myasthenia gravis because I was from this bitty town. I now live in Georgia. In the fall of 1997 I began having difficulties. I couldn't get out of bed and I had trouble with my footing. Writing and reading became difficult as I was having double vision. I had a droopy eyelid too. I had so many activities that I loved to do.

I loved playing piano and was active in the boxing club. I was only 17 years old and was right on the cusp of adulthood and I saw my entire life and all the possibilities kind of fall away from me. There were no tests at the time and I finally saw a specialist for a second opinion and was officially diagnosed in 2014.

I went through a lot. I haven’t had a crisis in a while, and my MG was managed well through

meditation. When I had my first crisis, I ended up in the hospital for 20 something days. I was student and I’d have to be hospitalized and would need emergency IV. The first few years were up and down.

## **MGFA: But, you stayed positive and worked through it and your energy is infectious.**

**Jessica:** You know, I would have flares on occasion, but currently I am now on a big support team and a huge key to my health is that I’ve found a good balance. I know how to recognize what’s going on with my body, I have amazing doctors and specialists who communicate with me and each other to give me the best possible outcome with my MG. So it is manageable as long as I do what I’m supposed to do. Bad days are few and far between now. I know that’s not true for many people, but I finally have a good balance and have achieved a good sense of independence.

## **MGFA: How did you come up with the ideas of Mermaid Mondays in June?**

**Jessica:** There is nothing I love more than those “ladies in the ocean,” and I was born in Florida. So, I love the ocean and I just love mermaids. They’re so mysterious and unique and mystical. I have always tried to come up with creative things to focus on and I didn’t really like the term “snowflakes” when talking about MG. I wanted something that resonated with me so I could create awareness and capture people’s attention so they learn more about the disease.

Then I said, hey, this is a good way to incorporate things I’m passionate about into an event in June. And it was a way to help people. My sister Jennifer –





she’s my biggest cheerleader. She helped me with the mermaid theme and incorporated the hashtag – #SeeMeNotMG. I ask my friends, family and others to dress up as the various mermaids in the photos on Instagram. You know everyone in the ocean work together. Whales, dolphins, you know? My “mermaids” are my tribe and my pool of fish, helping me educate the community about MG.

**MGFA: How have you kept the momentum going year after year?**

**Jessica:** Well, it began, with my close friends and relatives, and each year or so it got a little bit bigger. I saw the energy increase each year. On the fourth or fifth of June every year, during MG Awareness Month, I encourage everyone on Instagram to go post. I’m so excited about my Mondays in June. But next year, I’m expanding it to the full year. The annual Mermaid Mondays event will still be held on the in June, but I’m looking forward to sharing all these opportunities where people can participate throughout the year.

**MGFA: What has the Myasthenia Gravis Foundation of America meant to you?**

**Jessica:** Oh, MGFA has meant so much to me in my life. When I first experienced symptoms and then later was diagnosed, I had no answers and nowhere to turn for information until I learned about MGFA. The foundation was the only organization that was able to get my parents

information they needed because all of a sudden their child had a rare disease.

MGFA put them and me in contact with medical professionals and experts. For someone coming from a small town who had no idea about this disease, this meant everything in the world because we didn't have information that is critical to surviving this disease. I am forever grateful to MGFA.

This is why I completely support MGFA in every way, including the MG Walks and all events. I know that donations are important for treating the disease, and those living with the disease need the support and assistance that MGFA provides the community. I have seen the changes that have been made within the organization. The strides and steps they have gone through. I participated in the virtual conference and that was amazing. I’ve participated in webinars and I’m looking forward to the MGFA Together We Stand event on October 10. I just love helping and being part of this community.

**MGFA: What advice would you give to those living with the disease?**

**Jessica:** If I had to tell them anything. I would advise them to never lose a voice. Don’t be brushed aside but fight for yourself and your health. You will have to make big decisions, but you should have lots of energy to use your voice for awareness. I mean we have so many advancements in the field of medicine. Those with MG and people in general need to know about this amazing progress. Just ask questions and require answers. MG is part of my life, but it is not my whole life. Be creative!

I’m in Facebook and Instagram. I created my own personal infographic for people to share. I send out emails and encourage participation in MGFA events because I fell in love these people in the MGFA community. They go out of their way to just show so much support. And remember, money is not so much about “money,” but its about supporting the organization to get to progress against the disease. ✨





### 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

MGFA announced that human plasma is in urgently-short supply for important treatments for autoimmune diseases, and outlined a set of guidelines and a call to action for 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 that would enable them to 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](https://myasthenia.org/What-is-MG/Treatment-Strategies-Goals). You can find out where to donate HERE: [www.donatingplasma.org/donation/find-a-donor-center](https://www.donatingplasma.org/donation/find-a-donor-center) or contact [MGFA@myasthenia.org](mailto:MGFA@myasthenia.org). ✨



# MGFA FUN-raising Challenges the MG Community to be Creative

By Michael Antonellis

## NEW MGFA CONTESTS: WIN PRIZES: SUPPORT THE MG COMMUNITY

The Myasthenia Gravis Foundation of America is excited to offer several new creative **“FUN-RAISING”** contests as part of our Together We Stand Against MG campaign. We hope you’ll participate in these fun events to raise awareness and funds for myasthenia research and community programming. And you can win some great prizes as well! Check out these challenges and register today.

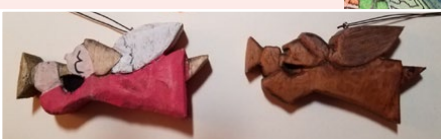


### Lucky Ducky Derby

Are you a Lucky Duck? Then you should have participated in our first Lucky Duck Derby. This specDuckular event was held on September 26 on Facebook LIVE. Hundreds of rubber ducks duked it out on the water, and viewers could see whose duck crossed the finish line first! We raised vital funds to help thousands of Americans living with MG.

### MGFA Together We Stand Art Contest

What does the MG Community mean to you? That is the question our community responded to through your artistic and creative skills. We asked the MG Community to submit a digital photo of an original piece of artwork (a painting, drawing, graphic design, ...any medium you want) that tells us what the Myasthenia community means to you. We received lovely works of art in sculpture, watercolor, acrylics, needlepoint, wood, and even the written word. So many mediums and so many creative works. Winners of the contest will be announced at the upcoming MGFA Together We Stand broadcast event.



Anyone affected by myasthenia gravis can enter the contest and its open to all ages or artistic abilities.

### Together We Seek and Find Research Scavenger Hunt

Are you good at finding information online? Are you excited about doing that for prizes? MGFA Together We Seek and Find online scavenger hunt, where you’ll go to both the MGFA and industry partners’ websites to look for key facts and data that address a series of questions.

Go to [www.surveymonkey.com/r/DGLLNZW](http://www.surveymonkey.com/r/DGLLNZW).

- Simply read through the questions and the hints provided for each website and go to those webpages to find the answers. Fill out the questionnaire.
- Once you submit your responses to the questions based on your online research, you’ll be eligible for great prizes.

Good luck and thank you for supporting the Myasthenia Gravis Foundation of America. Help us drive even more progress for a world without MG. ✨







# MGFA Program Highlights

## MGFA WELLNESS SERIES ADDRESSING THE CONCERNS OF THE MG COMMUNITY



COVID-19 has created a new and unique set of challenges for the MG community, and MGFA is responding with our new MG Wellness Webinar Series to connect, educate, and empower MG patients, care partners, and medical professionals. Learn about some helpful and informative ways to manage stress, get exercise, and better manage your health and lifestyle during these uncertain times. View past webinars and register to tune into our next Wellness Webinar by visiting this link [myasthenia.org/Living-Your-Best-Life-With-MG/Wellness-Strategies/Wellness-Series](https://myasthenia.org/Living-Your-Best-Life-With-MG/Wellness-Strategies/Wellness-Series)

## CLINICAL TRIALS FOR THE MG COMMUNITY



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 clinical trials in process right now. Check out the partial list of trials on the MGFA website or see [clinicaltrials.gov](https://clinicaltrials.gov) for more. Check out this link to the page: [myasthenia.org/Research/Clinical-Trials](https://myasthenia.org/Research/Clinical-Trials)

## STRENGTHEN MG RESEARCH BY JOINING THE MG PATIENT REGISTRY TODAY



The MG Patient Registry is an active database of individuals with myasthenia gravis (MG) developed for the purpose of progressing research and treatments for MG while ensuring clinicians understand the challenges of those with MG. If you've been diagnosed with MG, please consider joining the registry today. It's free and all the data is protected by federal privacy laws. The registry is open to all MG patients in the United States, 18 years of age or older, and it has already made a huge difference for many people with MG. You can join the registry online at the following link: [myasthenia.org/Research/MG-Patient-Registry](https://myasthenia.org/Research/MG-Patient-Registry)

## CAUTIONARY DRUGS: WHAT TO AVOID WHEN DIAGNOSED



Certain medications and over the counter preparations may cause worsening of MG symptoms. Remember to tell any doctor or dentist about your MG diagnosis. It is important to check with your doctor before starting any new medication including over the counter medications or preparations. Check out the MGFA Cautionary Drugs page at this link: [myasthenia.org/What-is-MG/Drugs-and-MG](https://myasthenia.org/What-is-MG/Drugs-and-MG)

You can also download a Cautionary Drugs handout at this link:

[myasthenia.org/Portals/0/Cautionary\\_Drugs\\_2020\\_1.pdf](https://myasthenia.org/Portals/0/Cautionary_Drugs_2020_1.pdf) ✨





# MGFA Support Group News

COVID-19 has changed the landscape of our Support Group Meetings. Many of our Support Group Leaders (SGLs) have gracefully moved their meeting format from in-person meetings to virtual Zoom online platform meetings. These SGLs have taken on the task of learning how to use Zoom to conduct meetings virtually and MGFA thanks them for their flexibility and willingness to pivot their meetings as the circumstances of the world have shifted.

There is a schedule of virtual meetings organized both by state/location and by date that everyone can access to see when Support Group Meetings are taking place. You can access these lists at [myasthenia.org/Community-Resources/Support-Groups-MG-Friends](http://myasthenia.org/Community-Resources/Support-Groups-MG-Friends)

Some of our Support Groups have joined forces to work together to allow multiple groups to meet virtually as one. As a great example, our two Phoenix SGLs are working together on their meetings. We also have wonderful, credible, and exiting speakers and medical professionals at these meetings now that they are online. For example, Dr. Todd Levine from Honor Health spoke at a meeting a few months ago. There was an overwhelming response to this meeting, and we had over 300 people registered for the webinar. That is just one example, and there are many more coming online soon.

Many of our SLGs are reporting that patients and caregivers who are not able to attend a physical meeting due to transportation issues are thrilled and grateful to be able to join virtual meetings. The support that these meetings offer is critical during this global pandemic. To be isolated but able to converse with fellow patients and caregivers in similar situations to your own is extremely valuable. Our New York Support Group had someone join a recent meeting from Canada!

**We currently have virtual meetings going on across the country.**

If you are a Support Group Leader and you are not holding virtual meetings, it's not too late! Call Dova Levin at +1.617.465.0512 (Pacific Time) or email her at [dlevin@myasthenia.org](mailto:dlevin@myasthenia.org). She will work with you to provide you the resources that you need to get a virtual meeting started. ✨



# Ways You Can Get Involved and Raise Funds

No one could have anticipated how quickly we would have to adjust our fundraising plan in early 2020 to do whatever it took to meet the needs of our MG community. For MGFA, that meant acknowledging the potential loss of critical revenue from our largest event, the MG Walk, put on hold when we learned it wasn't safe to sponsor large gatherings especially for those with an underlying health condition.

But with traditional fundraising events on pause, MGFA volunteers turned to other creative ways to support our vital mission increasing awareness for MG while raising vital funds to ensure our critical work continued uninterrupted. While MGFA's Do It Yourself Fundraising Campaign isn't new, the possibilities to turn passion into fundraising took on even more importance in 2020. Consider all the ways in which you can step up and raise money for a cause close to your heart. We included a list of ideas here but Sam Gardner, Director of Special Events, is eager to help you get started. You can reach Sam at [sgardner@myasthenia.org](mailto:sgardner@myasthenia.org) or +1-617-465-0514.

## CELEBRATE A SPECIAL OCCASION

Are you celebrating a birthday, Bar or Bat Mitzvah, milestone anniversary, wedding, or other special occasion? In lieu of gifts, ask your friends and family to donate to MGFA. You can set up a fundraiser on Facebook or we'll help you create your own personal fundraising page. It's a meaningful way to commemorate a special date while making a difference for those with MG!



## SHARE YOUR HOBBY OR PASSION

Whatever your passion, create impact through a fundraiser! Love to cook? Create a Facebook Live event and share your favorite recipe asking guests to donate to MGFA. Is art your thing? Hold an online auction asking friends to bid.

## MEET A PERSONAL CHALLENGE

Even in this time of social distancing, you may be craving the chance to climb the nearest mountain, ride your own century or complete a long-distance run on the trails or on even your treadmill. Whether inside or outside, turn your personal challenge

into a fundraiser by asking family and friends to sponsor you. We have the online fundraising tools to help!



## START YOUR OWN EVENT

Golfing. Spinning. Skiing. Yoga. Duck Derby. Even cardboard boat races. We've seen it all and there's really no limit to your imagination.

## HOST A THEMED PARTY OR VIRTUAL HAPPY HOUR

In person not possible? Plan a Zoom party! Ask family and friends to make a donation to MGFA. You and your guests can party away knowing you did something important in the fight against MG.



**DIY Fundraising puts you in charge! More than ever, your efforts bring hope to those living with MG. Let us help you get started today!**



## CREATE A LEGACY WITH A PLANNED GIFT

When you make a planned gift to MGFA, you become a member of The Ellsworth Society, named in honor of our founder, Jane Dewey Ellsworth. Ms. Ellsworth launched the Foundation in 1952 when her daughter Patricia was diagnosed with MG. At that time, very little was known about myasthenia gravis. Today, thanks to Jane's vision, MGFA now touches the lives of hundreds of thousands of patients, families, friends, and medical professionals around the globe. Your membership involves no dues, obligations, or solicitations, but it does allow us to thank you and recognize you for the plans you have made, and it may inspire generosity in others.



For more information visit [mgfalegacy.org](http://mgfalegacy.org) or contact Betty Ross, Director of Development at [brross@myasthenia.org](mailto:brross@myasthenia.org) or at +1-617-465-0513.

Supporting the vital work of MGFA comes in many shapes and sizes – from fundraising through special events, to responding generously to an appeal for a donation to making a planned gift. Planned giving is more than just naming MGFA as a beneficiary in your will. If you are at least 72 years old and own an IRA you may have the opportunity to make tax free distributions to qualified charitable organizations like MGFA? This is just one more way you can participate in a planned gift for MGGA. For more information on the benefits of giving to MGFA through a QCD, ask your tax advisor, tax attorney or financial advisor for guidance.

Because many companies do not provide a donor's name with IRA distributions, please let us know if you choose to support us in this way so we can recognize your generosity. Contact Craig Strenger, Vice President of Development at +1-617-465-0517 or [cstrenger@myasthenia.org](mailto:cstrenger@myasthenia.org).

RETIREEES ARE USUALLY required to take withdrawals from their retirement accounts each year after age 72. However, the Coronavirus Aid, Relief, and Economic Security Act allows you to skip your 2020 required minimum distribution from a 401(k), IRA, 403(b), 457(b) and inherited IRA. Before making any planned gift to include a QCD we recommend you seek the aid of a tax advisor, tax attorney or financial advisor for guidance. ✨





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Westborough, MA 01581  
(800) 541-5454  
mgfa@myasthenia.org

[www.myasthenia.org](http://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.

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