Myasthenia Gravis Foundation of America

ANNUAL REPORT 2020

Evolution and Progress in the Face of Adversity

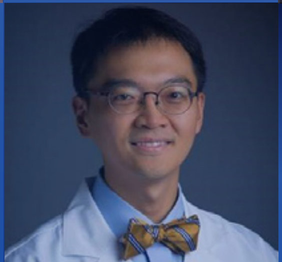
mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

OUR VISION:
A World Without MG

OUR MISSION:
Create Connections,
Enhance Lives,
Improve Care,
Cure MG

mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

2020



Evolution and Progress in the Face of Adversity

REFLECTIONS ON 2020 – A MOST CHALLENGING YEAR

Samantha Masterson

President & Chief
Executive Officer

Myasthenia Gravis
Foundation of America

We knew from the beginning that the COVID-19 pandemic would affect every aspect of our business. So we started to look through a new lens and approach it with vigor. We asked ourselves, “How can we see this as an opportunity?” Our top priority was to maintain the quality of programming and services that we had been providing as an organization, and to be as least disruptive as possible to our MG Community. We were adamant not to formally cancel any program or event but rather utilize new virtual formats to connect and empower MGFA constituents.

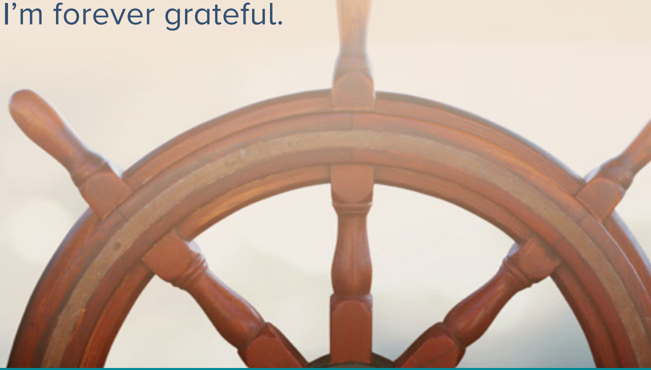
When we talk about the last year with our Board, with volunteers or funding partners, we always say, “we not only survived but we thrived.” It’s true. We had great partners who supported our decisions and stayed with us as we transitioned our programs and events to virtual, and our community was amazing – also adapting to supporting us virtually and continuing to fundraise.

If you choose to shift your paradigm, and you choose to see the silver lining, which we did, then there are opportunities all around that have presented themselves. It was simply seeing things through a new lens. The team actually never felt hindered – we felt that we could be as creative and innovative as possible.

I am a strong believer that all ships rise together. This past year was the epitome of what community means and coming together to get to the other side. Our staff and volunteers were amazing. Everyone just mobilized and adapted. I’m extremely proud of our team. I’m also so proud of our Board of Directors. They supported every decision and embraced being in unchartered territory. I’m forever grateful.

Samantha Masterson

“I am a strong believer that all ships rise together.”



THE MYASTHENIA GRAVIS FOUNDATION OF AMERICA

2020 AT A GLANCE

The Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure for the rare neuromuscular disease myasthenia gravis (MG) while improving the lives of people living with MG. MGFA is focused on funding the most promising research discoveries for better treatments and a cure while providing impactful programs, guidance, and education to help support members of the MG Community. **In the face of a global pandemic, MGFA was proud to deliver these impactful results.**

70,000+ people are **diagnosed** and **living with MG** in the U.S. alone

2020 Online MGFA Annual National Conference

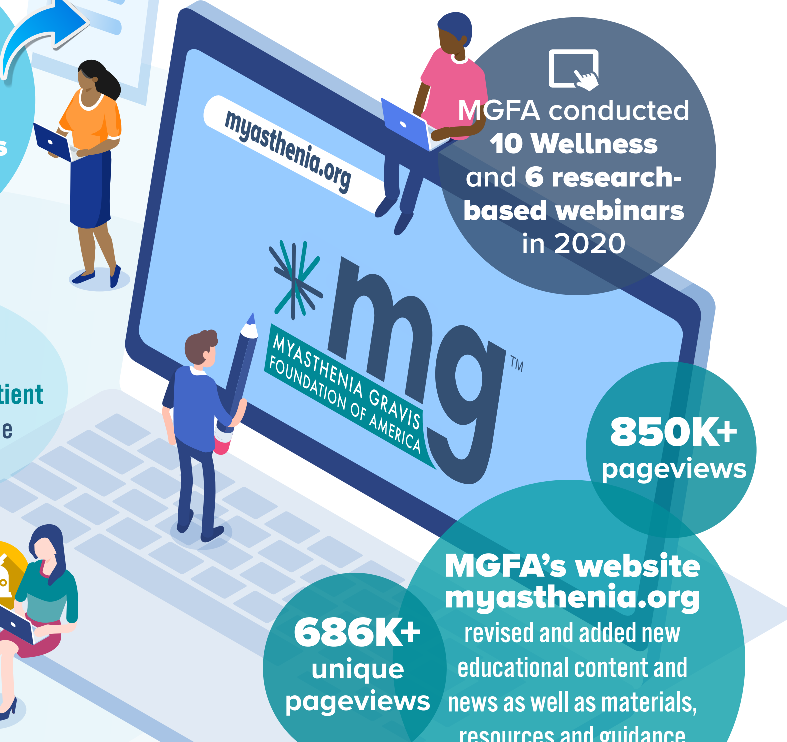
1,500 attendees from **15 countries** participated

mg 2020 NATIONAL CONFERENCE
PROMISE
Caring • Connecting • Commitment

We supported **100+** online MGFA Support Groups

We served **80K contacts** around the world

We distributed **100+** national and event **emails** this year



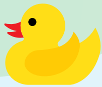
MGFA conducted **10 Wellness** and **6 research-based webinars** in 2020

mg PATIENT REGISTRY

We maintain the **only U.S. MG Patient Registry** that has grown to include more than **3,000 participants.**

850K+ pageviews

MGFA conducted a **New England regional conference** and **the inaugural lucky ducky derby** during the COVID-19 pandemic.



MGFA funded **$400K+** in new research grants this year

MGFA's website myasthenia.org revised and added new educational content and news as well as materials, resources and guidance that drove pageviews

686K+ unique pageviews

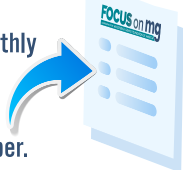
MGFA utilized Facebook, LinkedIn, Twitter, YouTube, and Instagram to communicate our programs and events

40,000+ fans and followers

We provided **20+** educational and informational brochures on treatments, cautionary drugs, MG facts, and MGFA-related information

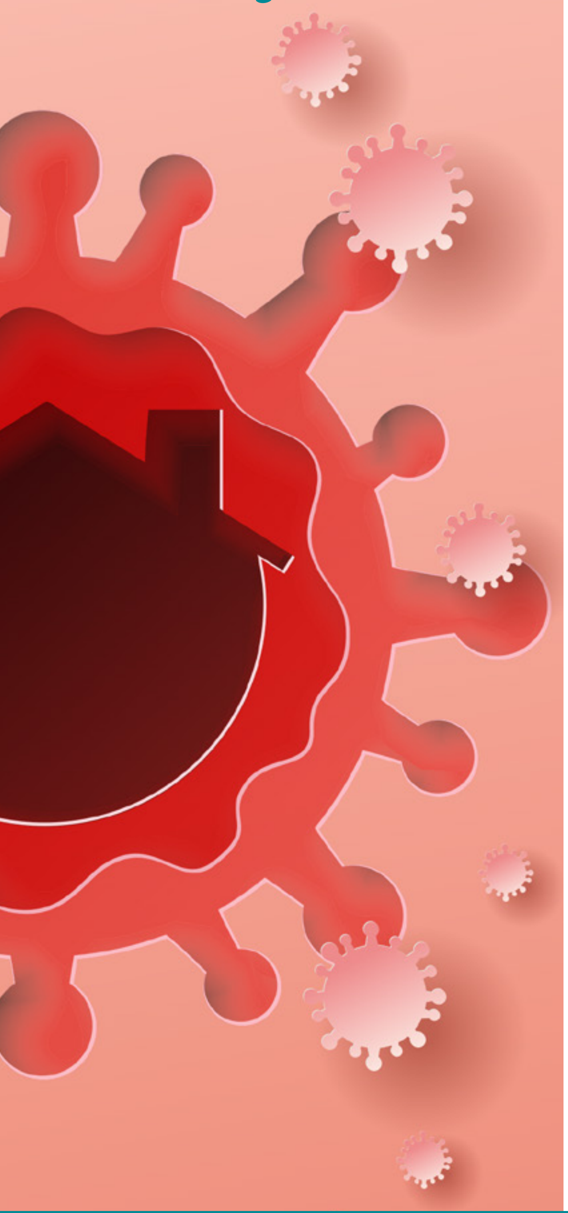
300+ registered attendees

2020 Online Scientific Session



We issued 12 monthly eNewsletters and a Focus on MG magazine in October.

“We knew that the pandemic would affect everything that we had planned for the year so we had to get creative.”



COVID-19 PANDEMIC: AN UNPRECEDENTED TIME IN THE WORLD’S HISTORY

It was always going to be a transformational year.

On February 24, 2020, MGFA welcomed a new CEO, Samantha (Samm) Masterson. Samm joined the organization with deep experience in nonprofit executive management and development. She had an ambitious charge to move MGFA forward under a new strategic plan.

We all know what happened next: on February 25, the CDC predicted that the coronavirus outbreaks dotting the globe would soon be a pandemic. By March 11, the World Health Organization had officially declared it such. On March 19, California became the first state to issue a stay-at-home order, kicking off a nationwide closure of businesses, schools, public transportation, and anything deemed ‘non-essential.’ Ten MG Walks were scheduled for that spring around the country, from Boston to Tallahassee. The National Conference was scheduled for April in Fort Worth. More than 300 people had joined the 2019 conference in Atlanta, and the 2020 conference in Fort Worth was expected to be even bigger. Support groups were meeting across the country. Clinical trials were under way at hospitals and research institutions across the country.

The pivot came quickly for MGFA. With a dispersed workforce, we didn’t need to close an office and retrain staff how to work remotely, but plans had to be retooled quickly.

At the time, most people thought the stay-at-home orders would delay things for a few months at most. Rather than canceling anything, MGFA transitioned the spring walkathon events to the fall, decided to host our annual conference virtually, moved all support groups to Zoom, and began a new slate of virtual programming.

“Once we made our decision, we were all in,” says Samm. *“We knew that the pandemic would affect everything that we had planned for the year so we had to get creative.”*

We provided support group leaders with Zoom accounts so they could transition their meetings to a virtual space. While Zoom is a household word for teleconferencing these days, in the pandemic’s early days the software was new to many. MGFA staff ensured that group leaders had the training to successfully navigate the new technology and keep the groups moving forward.

The virtual sessions proved successful, opening up new communications channels and providing an avenue for connection during a very challenging time.


@MyastheniaOrg

Following

MGFA WELLNESS SERIES WEBINAR

Staying Calm When the World Is Not

DATE

Friday, July 17, 2020
2PM (EDT), 1PM (CDT), 11AM (PDT)

PRESENTER

Nancy Law,
MGFA Board Chair

REGISTER TODAY!

212 likes

#MGStrong

2,797 Total webinar views

MGFA launched two webinar series, one on Wellness and one on Research, a new format for MGFA to share knowledge and information from different experts.

"We wanted to engage the community and to bring them great content, some of which was updates on COVID," says Samm. *"The community really responded – we've had great attendance and so many of the topics have been identified by our community."*

MGFA's scientific and medical advisors volunteered to provide updates on research and clinical trials. The convenience of the webinar format, and access to physicians who are experts in MG, has been helpful for patients and their families.

The MGFA team came together in the earliest days of the pandemic to ensure that the MG community would continue to hear from such experts at the **MGFA Annual National Conference**.

The conference is usually a time for people in the MG and medical communities to gather and discuss all aspects of MG, from research and treatment updates to techniques for managing the disease. The 2020 conference was planned for April. As shut down orders rolled across the country, it was clear that no one would be traveling to Texas that year. We could cancel and leave our community disappointed. Or we could go virtual. The decision was obvious – we simply could not go a year without an opportunity for the MG community to connect. From the time the decision was made to go virtual, the MGFA team had two weeks until the event was supposed to take place.

5X INCREASE
1,500+
Attendance

We mobilized and started to navigate the virtual conference world. We developed a virtual program, trained speakers, found a platform to host the conference, and communicated the change to the community. The event not only met expectations — it was a phenomenal success. Attendance topped 1,500, five times the previous years attendance.

mg MYASTHENIA GRAVIS FOUNDATION OF AMERICA
2020 NATIONAL CONFERENCE
PROMISE
Caring ★ Connecting ★ Commitment

"It was amazing and a testament to what a team is capable of when determined to do the right thing and to stay the course," says Samm.

As the year 2020 turned from spring to summer, we saw the country open back up, and the second COVID wave hit. The resources we provided to the MG community became more and more critical as infection numbers and deaths increased around the country. Through blog posts, webinars, and our newsletter, we kept the community informed of the latest scientific information on how COVID-19 was impacting immunocompromised people, and how the pandemic was impacting healthcare and medicine overall.

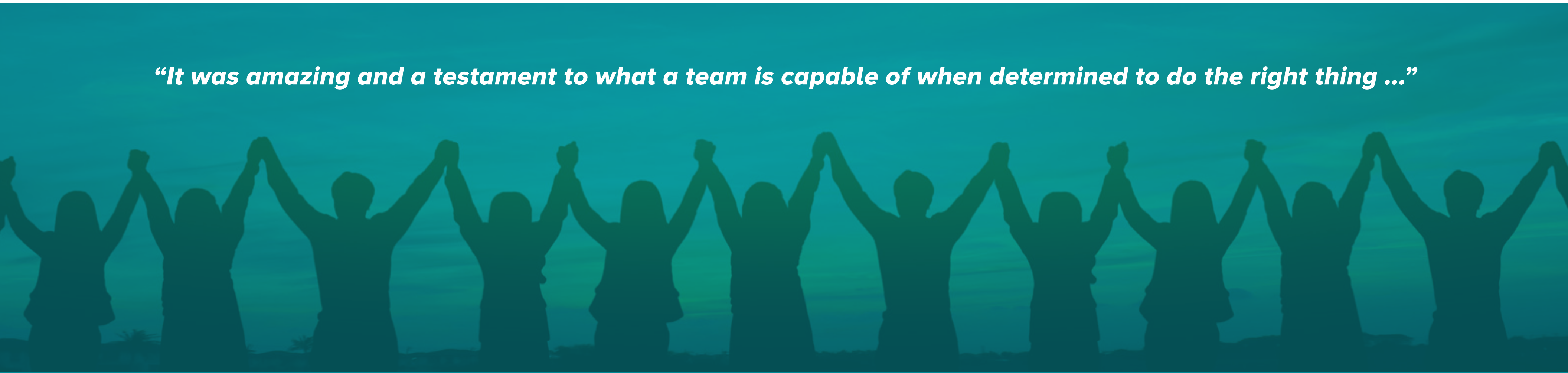
We realized we wouldn't be able to host any live events for some time to come. Our walks, postponed to fall 2020, transitioned to virtual. Around the world, people in the MG community walked — on their own, with their family, in their neighborhoods and parks, in nature preserves and in town squares. Socially distanced, these walks nonetheless connected people across the miles, and served to raise both funds and awareness for the MG cause. **And our virtual MGFA Together We Stand event to replace the MG Walks raised nearly $800,000.** Astonishing!

The popularity of the virtual conferences, support groups, community events, and webinar series helped us realize we were filling a gap that had always existed. Offering events and activities online means that everyone can attend. A patient can lie in their bed and still get questions answered at a support group. A physician can present on their research without leaving the office.

"We know that we will need to move forward offering a virtual component to everything we do," says Samm. ***"Reaching more patients and medical professionals in remote areas is a big part of our strategic plan for 2021-23. A lot has come to light that we didn't see before — there are a lot of opportunities for growth."***

Instead of halting growth, the pandemic pushed MGFA to think creatively, innovate, and reassess the best ways to meet the mission and support the MG community. We moved forward in many important ways, from finalizing a new strategic plan, to growing our professional staff, to expanding programming and services, to launching a new website with better functionality and an improved end user experience.

In a year like no other, we've seen the MG community come together like no other.



"It was amazing and a testament to what a team is capable of when determined to do the right thing …"

FOUNDATION NEWS
MEET NEW MGFA TEAM MEMBERS

The Myasthenia Gravis Foundation of America navigated through many changes in 2020 as we all have, and we added some key internal staff positions to help our organization grow and thrive. 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.

SAMANTHA MASTERSON — Chief Executive Officer

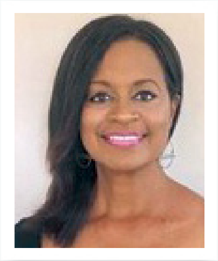
Samm comes to MGFA with more than two decades of non-profit experience, serving in executive leadership roles for healthcare non-profits such as March of Dimes, National Brain Tumor Society, and the American Liver Foundation. She has an extensive background in organizational management, strategic planning, board and volunteer development, and revenue generation that results in growth and impact. As MGFA's Chief Executive Officer, Samm is responsible for providing the vision and strategy to fulfill the work identified in the organization's strategic plan that supports MGFA's vision and mission, and to ensure that both the operational and board structures support this work.

CRAIG STRENGER — Vice President, Development

Craig joins MGFA with more than 30 years in the non-profit sector and has served as an executive leader with Muscular Dystrophy Association, American Diabetes Association, and National Brain Tumor Society. Craig is known for his creative and innovative approach and for his keen ability to cultivate teams that are results-oriented and that drive impact. As Vice President of Development for MGFA, he leads all areas of donor stewardship and individual giving, field operations (event fundraising), and corporate engagement.

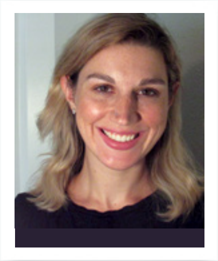
MICHAEL ANTONELLIS — Vice President, Marketing & Communications

Michael brings more than 25 years of marketing and communications experience to MGFA, serving in impactful leadership positions at healthcare non-profits, high technology corporations, and marketing and public relations agencies including the National Brain Tumor Society, Harte Hanks, Stratus Technologies, VISTAGY (Siemens) and Lois Paul & Partners. As Vice President of Marketing & Communications for MGFA, he leads all awareness, communications and promotional marketing campaigns that drive development, programs, research, and patient support initiatives across a wide variety of audiences and channels.



WENDI HUFF — Vice President of Programs and Clinical Care

Wendi has a diverse background serving 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 at national non-profit and private sector organizations, including executive leadership positions at the National Brain Tumor Society Foundation, Morehouse School of Medicine and Chief Executive Officer of a YWCA chapter. At the MGFA Wendi works collaboratively medical professionals and specialists, academic researchers, pharmaceutical companies and patient advocacy organizations to remove the barriers to rare disease. She is 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.



GENNA MVALO — Director, Patient Advocacy & Community Engagement

Genna brings a wealth of experience in nonprofit management and public health program implementation. most recently having served as the National Director of Development at the Patient Empowerment Network. Previously, Genna held development and management positions at prominent non-profit organizations including National Brain Tumor Society, Partners in Health, Accion International, Princeton University, and Delta Community Supports. At the MGFA, Genna builds and executes on strategic programming, leads our Our Voice patient advocacy program, and our young adult programs while managing educational resources such as webinars and patient-centric campaigns.

MGFA PROGRAMMING FLOURISHED IN 2020 – MAKING AN IMPACT

In the face of challenging circumstances during the year with the pandemic raging, high unemployment, and an unprecedented level of anxiety and fear, the MGFA stepped up to provide new, robust programming as well as program stability in order to help the MG Community. MGFA launched a number of new programs and drove forward with support groups, events, and deep research-based grant and clinical trial opportunities to ensure the MG Community continued to experience progress and impact.


@MyastheniaOrg Following

MGFA WELLNESS SERIES WEBINAR
Hacks for Living with MG

DATE
Friday, August 21, 2020
2PM (EST), 1PM (CDT), 11AM (PDT)

PRESENTER
Kim Eldridge

REGISTER TODAY!

@MyastheniaOrg Following

WHAT'S NEW IN MG RESEARCH WEBINAR
"The Raise Study"
Tuesday, December 8, 2020
3PM (EDT), 2PM (CDT), 12/Noon (PDT)
Presenter:
Dr. James "Chip" Howard
Brought to the MG Community by our industry partner UCB.
REGISTER TODAY!

♥ 212 likes
#MGStrong #IhaveheardofMG #AWorldWithoutMG

MGFA WELLNESS WEBINAR SERIES – Looking Out for the Health of the MG Community

COVID-19 created a new and unique set of educational challenges for the MG community. To meet this urgent need for improved and frequent education efforts, the MGFA designed and launched a Wellness Webinar Series. The program was designed to connect, educate, and empower myasthenia patients, caregivers, and medical professionals as part of an online setting. Launched in the summer of 2020, this Wellness Series **focuses on four aspects of wellness: physical, social, emotional, and psychological**.

The series provides community members with clear information in an accessible format. The information is broken out into "mini"-sessions which range from top-level wellness topics such as anxiety and stress as well as more in-depth, detailed information for practicing specific areas of wellness such as nutrition and exercise. Presenters include topical experts to patient advocates with deep knowledge and experience in the myasthenia gravis space. Each webinar consists of a formal presentation followed by time for patients to ask questions directly to the experts during a live Q&A segment. You can access the Wellness Series webpage to register for upcoming webinars or view previous versions at this **link**.

MGFA "WHAT'S NEW IN MG RESEARCH" – Webinars That Showcase The Latest MG Research

The brand new MGFA "What's New in MG Research" webinar series was launched in the fall of 2020 and is offered on a bi-monthly basis. Topics range from current results in key clinical trials, to effective treatments, to how grants are awarded. This program fills a gap in research communication, identified by the MG community, as there is a very real desire to learn more about the latest research updates. The MGFA responded to this need, and enlists some of the top MG experts in the world to present and address questions posed by the MG Community. You can access the What's New in MG Research webinar series using the following **link**.

NATIONAL SUPPORT GROUPS – Moved Online and Increasingly Valuable to Connect Our Community

COVID-19 changed the landscape of our Support Group Meetings in 2020. Many of our Support Group Leaders (SGLs) gracefully moved their meeting format from in-person meetings to virtual Zoom meetings. Zoom accounts were supplied by the MGFA to enable Support Group leaders to continue their meetings. These SGLs took 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 shifted in the first few months of 2020.

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**.

Some of our Support Groups have joined forces to work together to allow multiple groups to meet virtually as one. We also have wonderful, credible, and exciting speakers and medical professionals at these meetings now that they are online. There is an overwhelming response to these “guest presenter” meetings.

Many of our SLGs reported that patients and caregivers who are not able to attend a physical meeting due to the pandemic, as well as 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.

NOVEMBER IS NATIONAL FAMILY CAREGIVERS MONTH

@MyastheniaOrg

November is Family Caregivers Month!

Show your support by joining our MGFA Caregiver Gallery of Gratitude.

212 likes

#MGStrong #IhaveheardofMG #AWorldWithoutMG

We are so thankful for our caregivers in the MG Community. And what better time to show our deep gratitude to all caregivers than in November — National Family Caregivers Month. The Myasthenia Gravis Foundation of America (MGFA) celebrated and recognized our amazing and strong caregivers with a series of poignant, powerful tributes. The first-ever, interactive, and engaging “caregivers recognition” campaign enabled patients and others alike to share videos, photos, and powerful written testaments of love together on our online platform.

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 June of 2020 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.

MGFA thanks 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.**

FUNDING NEW MG RESEARCH IS A PRIMARY RESPONSIBILITY OF MGFA – AND INCREASED FUNDING MAKES AN IMPACT

RESEARCH AGENDA

We support research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. The committee has identified five broad research priorities:

- Funding high-impact research with promising treatment pathways.
- Providing post-doctoral fellowships to bring the best and brightest to the field of MG.
- Fostering collaboration and innovation through national and international conferences.
- Advocating for critical research funding.
- Advancing understanding through the MG Patient Registry and clinical trials.

GRANT PROGRAMS SUMMARY

We support research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. We have identified five broad research priorities: 1) Biomarkers; 2) Disease Mechanisms; 3) Targeted Therapies; 4) Patient Outcomes; and 5) Pediatric Treatment.

GRANT FUNDING AREAS

- **High-Impact Pilot Project Awards**: pilot studies leading to new federal, pharmaceutical or private foundation supported investigations.
- **Transformative Research Awards**: focused, innovative investigations that are highly likely to produce fundamental alterations in understanding myasthenia gravis.
- **Targeted Research and Special Projects Awards**: further greater understanding of MG and its impact on quality of life.
- **Awards to Engage and Support Young Investigators and Clinicians**: recognize the importance of good clinical research and encourage young investigators' involvement in clinical studies.

2020 PARTNERS IN MG CARE

1. **Children's Health/University of Texas Southwestern**
   Dr. Diana Castro, specializing in child neurology and pediatric neuromuscular | Dallas, Texas
2. **Dr. Gregg L. Friedman**
   Hallandale Beach, Florida
3. **Northwest Neurology**
   Dr. Andrew Gordon
   Barrington, IL
4. **University of Kentucky**
   Dr. Zabeen Kaizer Mahuwala,
   Dr. Stephen J. Ryan,
   Dr. Kevin Nelson, Dr. Ima Ebong
   Lexington, Kentucky
5. **Neurology Associates**
   Dr. William David Honeycutt,
   Dr. Arnaldo Isa, Dr. Daniel Nieves-Quinones, Dr. Adam Slansky,
   Dr. Christina Duffy-Henriques
   Maitland, FL
6. **Children's Hospital of Philadelphia**
   Buerger Center
   3500 Civic Center Blvd
   Philadelphia, PA 19104
7. **Montreal Neurological Institute & Hospital**
   Dr. Agela Genge
   Montreal, Canada
8. **Osceola Neurology Care Specialists**
   Dr. Afra Janarious | Kissimmee, FL

CONGRATULATIONS TO OUR 2020 MGFA GRANT FUNDING RECIPIENTS

PILOT GRANTS

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

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.

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

HOW TO DONATE PLASMA

STEP ONE: MAKE AN APPOINTMENT AT YOUR LOCAL DONATION CENTER.

STEP TWO: DONATE YOUR PLASMA! BE SURE TO BRING A GOVERNMENT-ISSUED ID AND WEAR YOUR FACE MASK.

STEP THREE: TELL US @myastheniaOrg WHO YOU DONATED FOR AND WHY YOU CHOSE TO KEEP YOUR MG COMMUNITY #MGStrong.

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 shortage, 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 **HERE**. You can find out where to donate **HERE** or contact MGFA@myasthenia.org.

MGFA 2020 EVENTS

HISTORIC NATIONAL CONFERENCE GOES VIRTUAL... AND GLOBAL

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.

mg 2020 NATIONAL CONFERENCE
PROMISE
Caring ★ Connecting ★ Commitment

Our first-ever VIRTUAL National Conference was held 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 1,500 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.

MGFA SCIENTIFIC SESSION – MAKING SCIENCE WORK FOR THE MG COMMUNITY

The MGFA Scientific Session is our annual symposium focused on professional education. This annual meeting provides medical professionals the opportunity to learn from colleagues about current, pre-publication research in the field of myasthenia gravis. Medical professionals and clinicians present their latest findings, clinical research, progress, and posters on discoveries that could lead to better treatments and a cure for myasthenia. The session is geared towards medical professionals but is open to the public. The meeting is held in conjunction with the annual meeting of similar professional societies of physicians who focus on neuromuscular medicine.

This year, the Scientific Session was also online, but featured a robust agenda of MG experts and neurologists who presented new research data and information. Dr. Henry Kaminski gave the keynote this year, and recognized

experts including: Drs. Araya Puwanant, James Howard, Hans Frykman, Jeffrey Guptill, Araya Puwanant, Miriam Fichtner, Ki Hoon Kim, Pritikanta Paul, Faraz S. Hussain, Omar Sinno, Amanda Guidon, Srikanth Muppidi, Shruti M. Raja, Kevin Li, Megan Barra, PharmD, Donald Sanders, Richard J. Nowak, Suraj Muley, and Sangwook Oh. All provided inspiring and illuminating presentations and posters. Top national industry partners and pharmaceutical companies also presented new data and clinical research that could one day become new treatments for MG patients. Check out the agenda and event details at this **link**.

MGFA TOGETHER WE STAND VIRTUAL EVENT – CELEBRATING THE POWER OF COMMUNITY, LOVE, AND HOPE

In a unique and unprecedented year of change and challenges, MGFA responded by bringing the power of the MG community together virtually and online during our MGFA Together We Stand event on Saturday, October 10, 2020. In light of the pandemic, MGFA was unable to host in-person events in 2020. The health and safety of our community was our top priority. Instead, we CAME TOGETHER and combined 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.

This event was MGFA's first-ever, live multimedia broadcast experience! MGFA shined the spotlight on 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. The event included live interviews, highlights of the history of MGFA, video segments from a number of amazing volunteers and MG patients, volunteer recognition, interactive experiences, and exciting developments in the MG space. Donors, participants, and supporters of the MG Community could register teams and make donations to the event, which essentially replaced our normal set of in person MG Walk events. It was a celebration of the power of community, love, and hope around the world. Together We Stand as one community in the fight against MG. The recording of the event can be viewed **here**.

INAUGURAL LUCKY DUCKY DERBY

The first annual Lucky Ducky Derby, a specDuckular event, was held on September 26, 2020 at 1:00 pm EST on Facebook LIVE. Many MG Community members joined to see thousands of rubber ducks “duke it out” on the water, and see whose duck crossed the finish line first! Rubber ducks were let loose on a small canal to race down and toward the finish line. The winning ducks that were assigned to contestants, raced for the win with help from MG volunteer Jessica Simmerman and MGFA staff members. You can **VIEW** the recorded video.

MGFA NEW ENGLAND REGIONAL CONFERENCE


MGFA WELLNESS SERIES WEBINAR

MGFA New England Regional Conference

A Two-Day Virtual Event for MGFA Community Members

DATE

October 31 & November 1

REGISTER TODAY!

New Englanders are hearty, tough, strong people who care about history and come together with our family and friends to celebrate summers (that are too short) and take advantage of gorgeous fall seasons and winter activities. And when people in our region have to deal with adversity in their lives, such as living with the serious neuromuscular disease Myasthenia Gravis, then we come together to help, provide guidance, and offer support and options.

This year at our MGFA New England Regional Conference, we came together VIRTUALLY and online, to celebrate the Power of the MG Community in our New England States. In light of the COVID-19 pandemic, we could not see each other in person, but as always, we highlighted important research, celebrated milestones and progress, and connected in a way that ensures those living with MG have a support system to navigate their lives with this disease. Special thanks to Glenda Thomas and all the New England volunteers.

Attendees of the event:

- Learned about new advancements and progress around treatments for MG.
- Heard from medical professionals, clinicians, and government officials focused on the fight against MG.
- Learned about developments in the research industry space in the New England area.
- Obtained information about MG wellness and navigating your life with MG.
- Heard from MGFA executives and New England-based patients who will highlighted the latest news in the MG Community.

You can watch videos and check out the agenda at this URL **link**.


@MyastheniaOrg

MGFA TOWN HALL

Learn About Patient Advocacy, Research Grants, and DIY Fundraising from Members of the Community

Wednesday, December 16, 2020

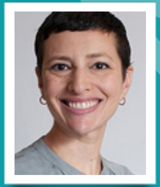
JOIN US ON ZOOM
at 3PM ET or 7PM ET

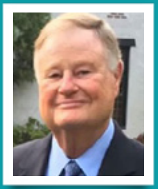
MGFA TOWN HALLS INTRODUCED TO THE MG COMMUNITY

MGFA kicked off its first series of online Town Halls in 2020. These events served as a platform for MGFA leadership. They are hosted so that our Community can better understand how MGFA influences critical MG research, education, advocacy, etc. and how we demonstrate impact. These quarterly events were open to anyone, and they continue in 2021.

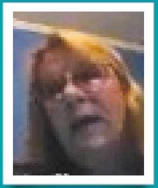
THE 2020 MGFA AWARD RECIPIENTS:

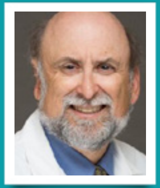

Volunteer of the Year
RACHEL HIGGINS


Doctor of the Year
AMANDA GUIDON, M.D.

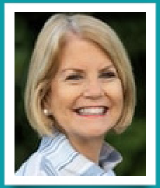

Lifetime Achievement Award
EDWARD WALSH


Lifetime Achievement Award
HENRY KAMINSKI, M.D.


Outstanding Service Award
SUZANNE RUFF, PH.D.


Outstanding Service Award
ALLAN WEISS, M.D.

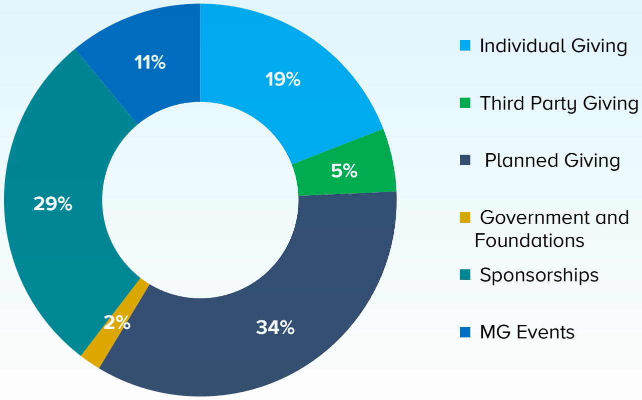

Outstanding Service Award
CHARLENE HAFER-MACKO, M.D.

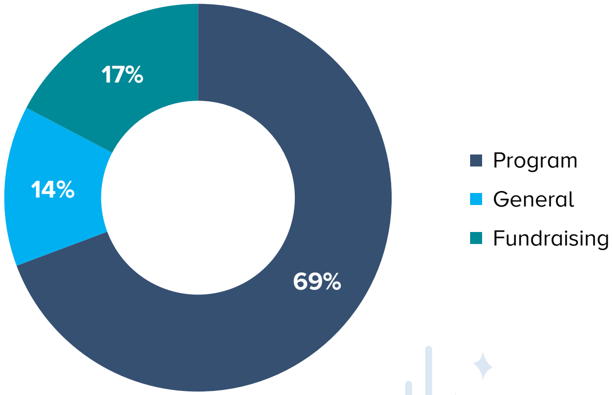

Philanthropist of the Year
SUSIE JOHNSON


Family of the Year
THE JARMAN/ DANIELS FAMILY


Young Person of the Year
ABBY NORDHAUSEN

MYASTHENIA GRAVIS FOUNDATION OF AMERICA FINANCIAL INFORMATION — 2020





PUBLIC SUPPORT:	**2019**	**2020**
Individual Giving	413,818	626,734
Third Party Giving	161,481	171,348
Planned Giving	44,067	1,126,496
Government and Foundations	203,146	58,619
Sponsorships	365,050	937,250
MG Events	950,367	361,862
Total Public Support	**2,137,929**	**3,282,309**

REVENUE:	**2019**	**2020**
Research studies	106,360	30,078
Conference and Other Fees	71,075	5,380
Total Revenue	**177,435**	**35,458**
Total Support and Revenue	**2,315,364**	**3,317,767**

PROGRAM EXPENSES:	**2019**	**2020**
Community and patient services	539,490	585,018
Education and Advocacy	546,239	334,375
Research	636,901	764,067
Total Program Expenses	**1,722,630**	**1,683,460**
Management and general	336,136	325,122
Fund raising	319,175	420,833
Total Supporting Services	**655,311**	**745,955**
Total Expenses	**2,377,941**	**2,429,415**
Nonoperating Income	1,264,287	305,055
Net Change in assets	1,201,710	1,193,407
Net Assets	**8,540,640**	**9,734,047**

2020 MGFA BOARD OF DIRECTORS
(served on Board for all or part of 2020)

Phil Cogan

Kim Eldridge

Brian Gladden

Dr. Jeffrey Guptill
(Incoming Chair MSAB)

Susie Johnson

Michael Lifshitz

Charlene Hafer-Macko, MD

Celia Meyer, RN

Jeffrey D. Pilgrim, JD.

Denise Rossi, PhD

Robert L. Ruff, MD, PhD

Suzanne Ruff, PhD

Katherine Ruzhansky, MD

Michael Ursic

Jurgen Venitz, MD, PhD

Edward T. Walsh, CPA,
Chair, Board of Directors

Allan Weiss, MD

Annette Zampelli, MSN,CRNP, IgCN
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Beth Ulbrich, CPA, CFO

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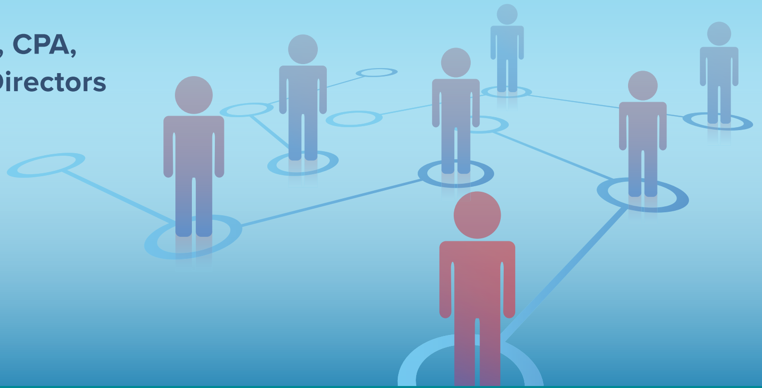
Marc Kalish, JD

Susan Klinger

Esther Land

Marcia S. Lorimer, CPNP, RN

Samuel A. Schulhof



mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

MGFA and the entire MG Community would like to thank all our generous donors. Without you, we could not make the impact needed against myasthenia gravis.

ALEXION

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Samantha Masterson

Samm Masterson
President and CEO