



# IMPACT REPORT

Fall 2021





Dear Friends,

It is our absolute pleasure to share this Impact Report with you and all of the progress that MGFA has been making as an organization this past year. As we continue to forge forward in what will be remembered as one of the most difficult times in our history, **we have been able to persevere because of the support of our MG Community and the investment made by our donors.** Your support has been remarkable during a time that has challenged the way that we do everything and has forced us to charter a new path in a lot of ways. We thank you for your unwavering support and for your confidence and trust....it truly has meant everything.

Though COVID-19 has presented great challenges, we have continued to pivot and engage our community members not only in programming, but in fundraising. Our team has worked closely with our Medical Advisory Council (MAC) to be proactive in keeping our MG Community **well informed in the most timely and accurate fashion...** and to make decisions that are **thoughtful, and patient-focused...the health and well-being of our community is paramount.**

MGFA continues to serve in a critical role as the leading patient advocacy organization solely focused on MG nationwide. We are pleased to share that MGFA continues to **expand and enhance our programming through patient and community services and education, as well as our physician and research networks,** to meet the growing needs of our MG Community. This year, we will host 19 webinars on both wellness and research, expand our regional conferences from two to five, and we have not only expanded but repurposed our networks to ensure greater alignment with our strategic plan. Information is power and we are proud to serve as the leading resource of information for so many. MG Friends continues to grow as a peer network, Partners in MG Care has expanded to include additional specialties, and MAYA, our young adults network, has been overhauled and has a new charter that encourages our youngest community members to actively participate and lead initiatives.

In an effort to **ensure that the patient voice is front and center,** our team has developed the national **Patient Leadership Advisory Council (PLAC)** to ensure that the patient's voice and influence are *instrumental* in the evolution of program design at MGFA.

We listened to our valuable stakeholders and have continued to **leverage technology and improve our systems.** This past year, the MGFA team has been working with a developer to redesign our MyMG Mobile App which is a key component of our strategic plan. Phase 1 of this new redesign will be completed by end of year and we will begin beta testing the new functionality which will include a symptom tracker. Very exciting!

Finally, and so very important for our donors to know, MGFA has **increased its research funding and overall research activity in 2021.** This year will mark the greatest contribution to research in the organization's history funding *over \$700,000 in research.* You will learn all about the ways we've continued to expand our research in this report.

Our extraordinary team is wholly invested in the continued growth of our organization as the leading PAO in the MG space, and we want to *thank you* for your loyalty and dedication as MGFA donors. We consider it our charge to *empower our community members* to be able to make decisions that improve their quality of life. We do this through education, advocacy, community services, and funding research...and this all happens as a result of YOUR support. **This year, we will surpass our financial goals and continue the journey of building a sustainable future.** Thank you for your continued collaboration and, again, for your confidence and trust.



Samantha Masterson  
President & CEO  
MGFA



Brian Gladden  
Board Chair  
MGFA



## • PATIENT STORY •

# the Boyle Family

**“She received a thymectomy at age 15 and since then has been in remission and symptom free... that’s one of the reasons we give to the MGFA — to ensure all patients and families can learn about and have access to the best treatment options available.”**

**O**ur daughter, Emily, was diagnosed with Myasthenia Gravis at the age of 14 after months and months of searching for a diagnosis. Myasthenia Gravis was not something we had heard of before in adults, let alone in children. As her parents, we were determined to find the best way forward with a treatment plan that would be right for her and give her the best chance at a full life. We researched, asked questions, and ultimately met with a fantastic physician at Johns Hopkins who truly saved Emily’s quality of life. She received a thymectomy at age 15 and since then has been in remission and symptom free. Emily is now a happy, healthy teacher and coach in Georgia. We are so grateful to the team that performed Emily’s thymectomy, and that’s one of the reasons we give to the Myasthenia Gravis Foundation of America – to ensure all patients and families can learn about and have access to the best treatment options available. Through our philanthropic investment, we’ve formed a partnership with MGFA to work to understand the knowledge gaps in thymectomy education and, ultimately, to close those gaps. Working with MGFA on this initiative has allowed us to have a real voice in making change and be so much more than just a donor to the organization. We are true partners.

**TOM AND BETSY BOYLE**  
MG PARENTS

## When we look to the future, we see a world without MG.

With your help, we create connections, enhance lives, improve care, and can cure myasthenia gravis.

**Our work is only possible with the generous support of donors like you.**

**Here's what you help us achieve.**

## Enhancing Lives

Education is a key part of our strategic plan to empower patients and caregivers of those living with MG.

Our **Wellness Series** launched in 2020 to meet the needs of the community during a challenging year. We go beyond disease education to explore mental health and well-being.

**Myasthenia.org** is a hub of information, both for those newly diagnosed and those seeking the newest developments in treatments and disease management.

- treatment options
- research
- support groups
- MG patient registry
- emergency management

## • 2021 IMPACT BY THE NUMBERS •

**4,303**



patients and caregivers reached through the Wellness Series Webinars to date

**69**

connections made between MG Friends and patients to provide 1 on 1 support

**73,577**



average monthly page views on the MGFA website



**21,050+**



monthly reach on social media (Facebook, Twitter, LinkedIn, and Instagram)



**25** blog posts in 2021 to educate and inspire



**22**

pamphlets of information for patients in our resource library

**61,000+**



global email contacts reached through email communication



**20,000+**

community members reached through the print distribution of our *Focus on MG* magazine, a publication that provides program information, organizational updates, and practical advice for MG patients.

“ The MGFA research portfolio currently supports several grants addressing the stated research priorities. This research includes projects to advance our understanding of the risks patients with MG face related to the COVID-19 pandemic and the side effect burden associated with current MG treatments. Another grant supports investigations on the under-researched group of patients with seronegative MG. The most recently funded round of research will evaluate new biomarkers to aid in the diagnosis of MG and increase our understanding of the role of autoantibodies in disease progression, potentially leading to fewer delays in patients receiving an appropriate diagnosis. Finally, MGFA is supporting research to develop a promising targeted treatment approach. Overall, this research is critical to advancing our knowledge of this disease and has high potential to improve treatment approaches and improve the lives of patients living with MG. ”



**Jeffrey Guptill, MD, MA, MHS**

Medical and Scientific Advisory Board, Chair  
MGFA



**BIOMARKERS:**

facilitate early diagnosis, predict clinical outcomes and immunosuppressive therapy response and utilize in clinical trials



**DISEASE MECHANISMS:**

understand basic mechanisms and self-tolerance loss throughout course of disease



**TARGETED THERAPIES:**

develop new therapeutic targets, prevent widespread immunosuppression and off-target side effects, optimize treatment strategies with existing therapies



**PATIENT OUTCOMES:**

understand the full impact of disease on daily living and patient treatment priorities, understand collateral effects of disease; related medical conditions, side effects and financial impact



**PEDIATRIC TREATMENT:**

identify strategies, safety concerns, and long-term outcomes

# Research

## COVID-19 GRANT FUNDING

It's critical that our team adapts, and changes based on the circumstances presented. Amidst the ongoing global pandemic, the Myasthenia Gravis Foundation of America has provided funding for a COVID-19 study to better understand the community's thoughts, attitudes, and opinions about COVID vaccination. In partnership with researchers at Duke University and Stanford University, researchers will work to understand the vaccination status of MG patients, determine if any vaccine-related adverse events have occurred, and develop strategies with a focus on education to prevent COVID-19 in MG patients.

## MORE RESEARCH HIGHLIGHTS

- MGFA worked with the American Brain Foundation (ABF) to fund the **Clinician-Scientist Award**.
- MGFA is reinstating a **Nursing grant** which will be *inclusive* of Allied Health Partners.
- MGFA also expanded our global footprint this year by taking a leading role and participating in the **Aili MG Group Chinese MG Summit**. Board member, Marcia Lorimer, was the keynote speaker.
- MGFA is leading a transition for our **MG Patient Registry** to result in a 2.0 version that will interface with our Mobile App and that will leverage technology to not only help patients but to better inform research.
- MGFA is committed to playing a leading role in **increasing diversity, equity and inclusion in clinical research** and has partnered with Diverse Health Hub.



# Making our Voices Heard on Capitol Hill

When our country's leaders make decisions that impact the MG community, we'll be there. Our staff and dedicated volunteers regularly advocate for MG patients, providing insight that can influence policy changes, progress in research, treatment options, and innovation in care.

This year, we didn't let the pandemic stand in the way of our advocacy. Our volunteers and team advocated for:

- The STAT Act
- The Benefit Act
- The Newborn Screening Saves Lives Reauthorization Act
- Access to Genetic Counselor Services Act

Our action alerts make sure the MG community is informed of the latest policy advocacy efforts and knows how to take action to support this critical work.

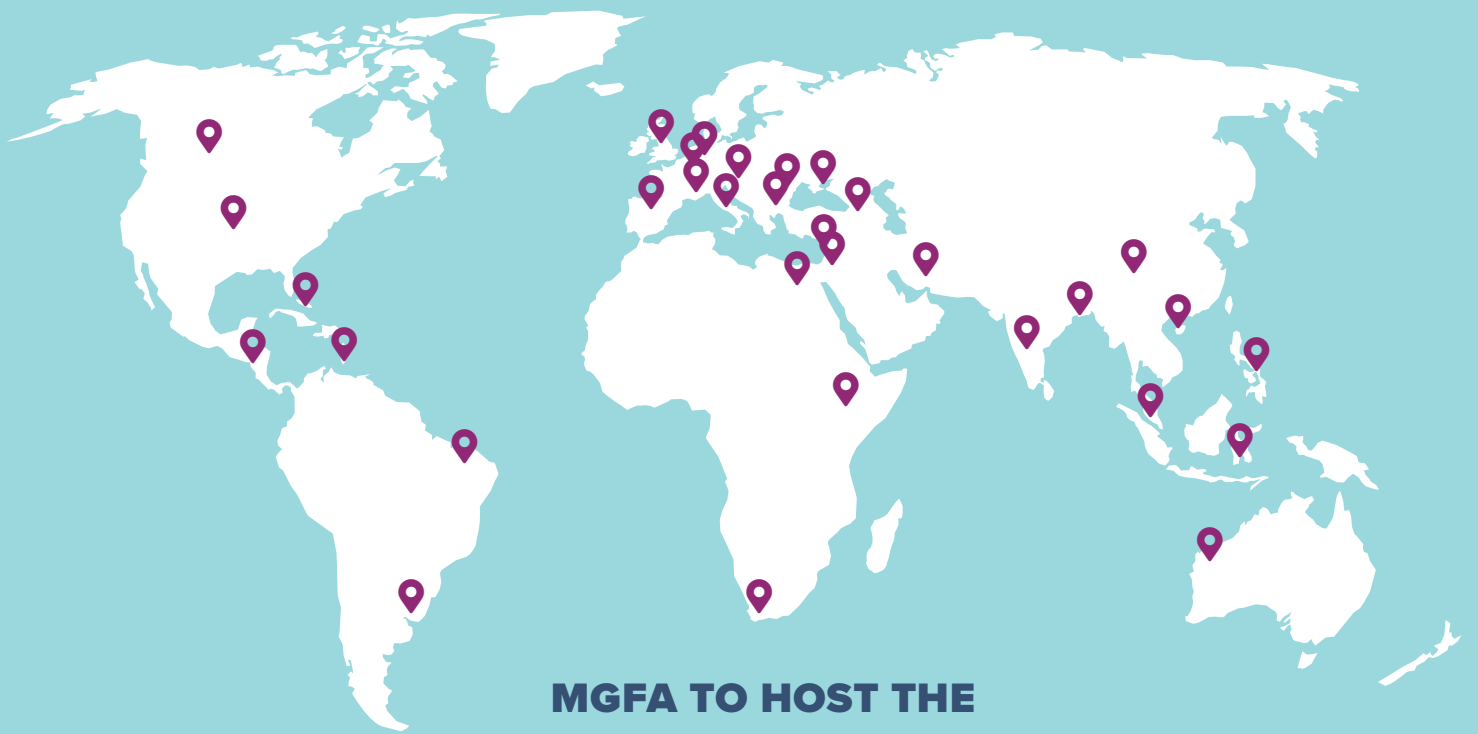
## INSURANCE DENIALS

An important part of our advocacy work is empowering patients with MG to advocate for themselves — with health care providers, insurers, employers, caregivers, and more.

At our virtual conference this spring, The MGFA Advocacy Work Group shared best practices for navigating your insurance to ensure you get the treatments you need. Medical treatments for MG symptoms are expensive and not automatically covered by most insurance plans. Misunderstanding your insurance coverage or skipping a step in the authorization process can be a costly error. The presentation included valuable information about how to get approval for IG therapy and other expensive medicines, how to get assistance paying for IG treatments, and how to appeal a denial of coverage.

**“I advocate for the MG Community in hopes that sharing our stories, struggles and need for legislative support will help to expedite research and/or treatments that will enhance our lives... We know the strongest impact one can have is to share their story. When we can tie our story into that of a legislative act, it can be extremely powerful.”**

**DEBORAH VICK**  
MG PATIENT IN CHULA VISTA, CA



## MGFA TO HOST THE INTERNATIONAL CONFERENCE

In 2021, community members from more than 38 countries attended our National Conference. MGFA is now gearing up to host the International Conference for the MG community, which will take place in Miami, FL from May 10 – 12, 2022. Practitioners, patients, and leaders from around the world will come together to share myasthenia research, progress, and new discoveries.

# Connecting MG Patients around the Globe

**AS A LEADER IN THE RARE DISEASE SPACE, WE CONTINUE TO EXPAND OUR REACH THROUGHOUT AND BEYOND THE UNITED STATES.**



## Launching Our Online Community in February 2022

In February, MGFA will launch a new online community. The community will serve as a hub for patients, families, caregivers, physicians, and supporters to interact and engage in ways unlike anything you've seen before.

**OUR VISION:**  
A WORLD WITHOUT MG

**OUR MISSION:**  
CREATE COMMUNITIES, ENHANCE LIVES,  
IMPROVE CARE, CURE MG

**OUR VALUES:**

**RESPECT:** We strive for an inclusive organization that strengthens our ability to fulfill our mission. We support and celebrate diversity of thought and individual experience. We earn trust through consistent demonstration of integrity, ethical behavior, and uncompromising professionalism.

**EXCELLENCE:** We are committed to excellence in all we do. We are accountable to one another and the public for our decisions on behalf of MGFA and the MG community. Through the judicious use of human and financial resources we are leading the MG community into a world without MG.

**TRANSPARENCY:** We support an organizational culture that promotes broad involvement in decision-making, open and direct communication, cooperation and teamwork.

**COLLABORATION:** We believe that progress is derived from collaboration that emerges from positive relationships in advancing research, education and patient services.

**CONTINUOUS IMPROVEMENT:** We face every challenge knowing that new solutions will be required to manage the increasingly complex environment in which we operate. We approach our work with creativity to solve the issues that we face personally and professionally.



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