



# IMPACT REPORT

Fall 2024

# 2024

# INNOVATION FOR IMPACT

## Our Mission and Strategic Vision

Myasthenia Gravis Foundation of America is working to create connections, enhance lives, improve care, and ultimately cure myasthenia gravis. 2024 is the first year of a new, three-year strategic plan. Our strategic plan guides our work in four areas of focus:



Globalization  
and Impact



Education, Advocacy,  
and Awareness



Research



Revenue Growth  
to Expand  
Stakeholder Impact

## Meet the Board Chair

This marks Brian Gladden's final year as chair of the Board of Directors. We are grateful for his significant leadership as the MGFA underwent a period of rapid growth, financial stabilization, and meaningful organization development.

Robert Thomas, our current Board vice chair, who joined the Board of Directors in 2022, will transition to chair. Robert's deep experience in human resources has already influenced the organization, and his dedication to guiding the MGFA through our current strategic plan will serve us well as we continue our growth.



Brian Gladden



Robert Thomas

## Impact by the NUMBERS

**150–200**

out of every million  
people are living with  
myasthenia gravis globally

**9**

months mean time to  
diagnosis from symptom onset

**1/5**

of individuals diagnosed with MG were  
misdiagnosed with another condition initially

# LETTER FROM THE PRESIDENT AND CEO

Dear MGFA Friends and Family,

This year marks the first of our new three-year strategic plan. I am proud to share that we are already making advancements towards our goals and making a difference for those living with myasthenia gravis and their families.

As you read through this report, I invite you to take ownership in the accomplishments and excitement in the opportunities. As an investor in our mission, you should understand exactly how we have improved the lives of those with MG this year and how we are getting that much closer to a cure.

Our global expansion is one of the most exciting areas of growth — we are serving as the leader in the global MG space amongst researchers, providers, patients, and care partners.

In 2025, we will host the 15th MGFA International Conference on Myasthenia Gravis and Related Disorders, our signature research event that brings together the brightest minds from around the world for knowledge sharing, discussion, and innovation. For the first time, we are hosting the event internationally, in the Netherlands, to better include scientists from Europe, the Middle East, and Asia.

A critical gap exists in access to educational resources for patients living in other countries; the MGFA regularly hears from people in places like India, Turkey, Ghana, Malaysia, and Iran, hungry for information about living with this disease. To address this unmet need, we are translating educational materials into nine languages this year. We will soon launch our first international support group, in Jamaica, and recently matched our first MG Friend overseas. You will hear more about the ways in which we are helping patients in the United States and around the world inside this report.

We are also leading the development of a new International Consensus Guidance, which is the standard of care for myasthenia gravis. This crucial publication has not been updated since 2021 and must include revised guidance for patient care based on the extraordinary developments that have taken place in our understanding of what causes MG and how to treat it.

Research is, and always will be, an essential pillar of our work. This year we have allocated more than \$1 million to research initiatives. With nine active MGFA grant-funded research projects underway at institutions in the United States and Sweden, we are moving the needle on biomarkers for MG, mapping the acetylcholine receptor, understanding congenital myasthenic syndromes, and more.

I cannot wait for you to read how we are taking our programming to the next level and addressing unmet needs for patients and their loved ones.

Thank you for investing in this critical work as we strive to ensure no patient takes this journey alone — we are in this together, with you by our side, to make life better for all those living with MG. And, one day, we *will* find a cure.

With gratitude,



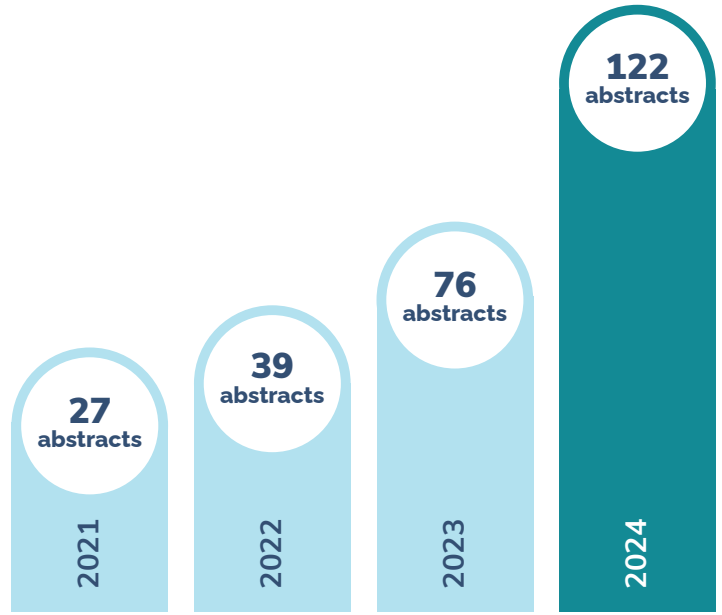
**Samantha Masterson**  
President and CEO

# RESEARCH



## MGFA Scientific Session at AANEM Annual Meeting

Each fall, investigators present peer-reviewed research on MG and related disorders of the neuromuscular junction. This year, our Medical and Scientific Advisory Council invited 114 researchers to present their findings on topics including MG etiology, immunopathology, therapeutic developments, and management.



Submission growth in past four years



SCIENTIFIC SESSION KEYNOTE SPEAKER:

### Mechanisms of Myasthenia Gravis Immunopathology

**Kevin O'Connor, PhD:** Chief Scientific Advisor for the MGFA Medical and Scientific Advisory Council and Professor of Neurology and Immunobiology at Yale School of Medicine

## MGFA Global MG Patient Registry

Patient-reported data is the most valuable perspective on myasthenia gravis and will help researchers discover new treatments and ways to manage MG. MGFA has sponsored this registry since 2013, and in doing so created the largest longitudinal study of real-world MG patient data. This year, five active research projects are using data from the registry, including projects led by George Washington University and Johnson and Johnson Innovative Medicine.

## 15<sup>th</sup> MGFA International Conference

The pace of scientific discovery in the MG and autoimmune space is proceeding so fast we can barely keep up. As a result, this premier research event will now be held every three years instead of every five. In line with our strategic priority of globalization, the MGFA will host the 2025 conference internationally for the first time.



Read the summary of research presented at the **14<sup>th</sup> International Conference** and published in the journal *Nerve and Muscle*.



## Research Grants

This year the MGFA awarded three High-Impact Pilot Project Award grants totaling \$330,000, as well as investing \$30,000 in MGFA Global MG Patient Registry research awards that enabled investigators to use data from the registry in their work.

Over the past five years, the MGFA has provided more than \$3.5 million in research funding to the field's most promising researchers, all awarded through a rigorous application process.

We currently fund nine active projects at eight institutions — Yale University, Mayo Clinic, Columbia University, George Washington University, University of California San Diego, University of California Davis, Duke University, and Uppsala University in Sweden.



## International Consensus Guidance Update

MGFA has convened a committee to develop and publish updated, globally accepted standards of care for treating myasthenia gravis. The committee is comprised of 17 clinicians from nine countries.

The most recent international consensus guidance was published in 2021, so this updated guide will include new findings and best practices in patient care, including information about new treatments.

# Impact by the NUMBERS

# \$1M

invested in research  
by the MGFA this year



# 9

active MGFA grant-  
funded research projects



# 3,500

patients enrolled in  
the MGFA Global MG  
Patient Registry



# CHANGING LIVES THROUGH SUPPORT

## MGFA Patient Helpline

In May, the MGFA launched a helpline staffed with trained counselors who can provide support and guidance to people with myasthenia gravis and their families. Studies show that many MG patients struggle with loneliness, frustration, and grief and may not know where to turn for help. Our helpline, funded by a generous supporter, seeks to fill that gap.

**MGFA**  
 **HELPLINE**  
**1.833.647.8764**

Professional counselors are available to support those living with myasthenia gravis and their care partners. The MGFA Helpline can direct callers to resources and information to help them with their MG journey and provide emotional support.

## MG Friends

The MG Friends program matches a person seeking support with a volunteer willing to offer support. We have expanded this program to include care partners and patients living in other countries.

The first international patient to formally participate in this program lives in Turkey and was paired with an experienced volunteer leader this fall. Despite a language barrier, these new friends have been able to communicate via translation services on email and WhatsApp.

Care partners turn to the MGFA for support too. This year, by expanding MG Friends to include care partners, we can support a critical part of the patient's network.

## Specialty Support Groups

People affected with MG, including patients and their families, find solace and guidance in support groups. We offer specialty support groups for specific populations to better serve the patient and caregiver community.

- Pediatric Support Group
- Parenting Support Group
- Young Adult Support Group
- Caregiver Support Group
- Spanish Support Group
- Seronegative Support Group

**According to a study conducted by Alira Health, a third of people living with myasthenia gravis suffer from depression and anxiety. Patient support programming, with an emphasis on mental health, is important to make life better for those living with MG.**

Impact by the **NUMBERS** in 2024



**2,059**

patient packets distributed

**8**

languages in which you can read MGFA materials



**140**

patients supported by MG Friends



**1,040**

community health fair registrants



**32+**

Support Groups



**165+**

patients and care partners supported by the MGFA Helpline



**29**

MG Friends

# GATHERING TOGETHER, WORKING TOWARDS A CURE

Bringing together the MG community is a valuable way to create connections, find commonality, deepen relationships, and celebrate progress towards achieving a world without MG. This year, we hosted various types of in-person events across the country.

## MGFA National Patient Conference

The MGFA National Patient Conference is an opportunity for all members of the myasthenia gravis community to gather together for connection, education, and support. This year, thanks to the generosity of our partners, we were able to offer the conference at no cost to patients and care partners. Three hundred and thirty-nine attendees joined us in Tampa, along with over 300 virtual attendees, making it the largest conference to date.





# Impact by the NUMBERS

## MGFA Stakeholder Roundtable

In April and September, the MGFA hosted stakeholder roundtable meetings to bring together leaders in the MG space. This included medical providers, researchers, MG patients, pharmaceutical leaders, and other MG experts in the field. The purpose of these events is to bring all key stakeholders together, in one room, to discuss our collective vision, share resources, and, together, improve quality of life for those living with myasthenia gravis.

## MGFA Community Health Fairs

We brought our Community Health Fairs to 11 cities this year, reaching more patients in their own communities than ever before. At these events, patients and families can come together to learn from experts in the MG space and connect with others in the MG Community.

Newly diagnosed patients benefit significantly from attending these events. We often hear that someone had never met another person living with MG until they attended a health fair. Connection is an invaluable resource that these events facilitate.

## MG Walk

The MG Walk program is back — we hosted three walks this year in New York, Boston, and Tampa Bay. Fundraisers and participants raised more than \$45,000 to support the organization's most critical needs. The MG Walk program is here to stay, and we look forward to hosting more walks next year in six cities across the country.

# 11

MGFA Community  
Health Fairs



# 3

MG Walks



# 2

MGFA Stakeholder  
Roundtable Meetings



# PHILANTHROPY WITH HEART

Philanthropists are individuals and families who are dedicated to a mission and choose to give their *time, talents, treasure, ties, or testimony*. We are immensely grateful for all philanthropists who work together with us to make life better for those living with MG and their families.

## Impact by the **NUMBERS**

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# 7

MGFA  
Ambassadors

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# 281

Partners in  
MG Care

## **MGFA Ambassadors**

A new program — and high honor — at the MGFA is our MGFA Ambassador program. These dedicated volunteers applied and were selected to serve as lead volunteers, each in a specific area: Legislation & Advocacy, MGFA Community Health Fairs, the MGFA Global MG Patient Registry, MG Awareness, Peer Support Networks, Education and Virtual Learning, and Fundraising.

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## **Partners in MG Care**

Partners in MG Care are clinicians who are dedicated to providing high-quality care to those diagnosed and living with myasthenia gravis. Each clinician is required to apply and go through a rigorous vetting process prior to being accepted into the program.

Partners in MG Care provide quality care to their own patients, as well as working with us to ensure patients across the globe have access to essential education. These Partners give their time by helping us create evidence-based resources, speaking at our in person and virtual events, leading support groups, and so much more.



## A Mother's Commitment

One autumn day four years ago, Maureen's daughter, Anne, suddenly lost her voice and had trouble breathing. Anne was an ICU nurse, long-distance runner, and single mother to a seven-year-old daughter. She was active, energetic, and busy. Neither she nor her family knew what could be wrong, and they suspected the worst.

After six weeks and a barrage of tests, Anne and Maureen sat together in the neurologist's office, both worried that Anne's symptoms indicated multiple sclerosis. They were unexpectedly relieved when the doctor told them that Anne had myasthenia gravis.

"We both had the feeling like it was good news because neither of us knew much about MG," Maureen said. "Anne is an RN, so she had heard of MG, but it's not her specialty."

Of course, they would soon learn the heartbreaking truth: that myasthenia gravis can be devastating for patients and their families. Since her diagnosis four years ago, Anne has struggled to manage her symptoms. She had to leave her job as an ICU nurse and has difficulties with daily tasks, like making her daughter's school lunch. She still struggles to speak, which makes it challenging to interact regularly with friends and family.

As a mother, Maureen hates to watch her daughter lose her identity and cope with the feelings of

loneliness. Her optimism and positivity help carry Anne through on her toughest of days.

To make a difference for others facing the same situation, Maureen makes giving to the Myasthenia Gravis Foundation of America a priority.

**"My greatest focus has been to support awareness. The driving force behind my commitment to the organization is to help people know about MG. I wish people better understood that MG is something you live with. You may look like you're doing fine one day, but the next, you have to pay the toll and spend the day in bed. Understanding this disease is really the baseline for everything."**

Maureen's philanthropic investment enables the MGFA to fund educational programs and awareness campaigns to help the general community — along with patients and their friends and care partners — understand myasthenia gravis. MGFA's commitment to shining a light on the MG experience is something Maureen believes is making a difference for Anne and all those living with MG.

"You are doing so much to create this environment that I want for MG, in the world, in the nation. I really focus on contributing to the MGFA with any funds that I have."

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*Thank you to Maureen, and committed donors like her, who fuel our efforts to make life better for those living with myasthenia gravis and their families.*

## OUR VISION

A World Without MG

## OUR MISSION

Create Connections, Enhance Lives, Improve Care, Cure MG



For more information or to support our mission with a gift, visit [myasthenia.org](http://myasthenia.org)