*mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

IMPACT REPORT
Fall 2023

Dear MGFA Friends and Family,

It brings me such joy each year to write this letter to you as part of our annual Impact Report. It gives me an opportunity to purposefully reflect on the impact you have made on the growth of the organization and how advancements are made possible because of you.

As you take time to read through this report, I invite you to notice how we have highlighted key strategic priority areas of our work where there has been significant movement in the past year – research, clinical expertise, our partnerships, and patient leadership. I note this to share with you how much of a pivotal year this has been for the MGFA; the end of 2023 signifies the conclusion of our current three-year strategic plan and the beginning of a brand new three-year strategic plan. We continue to move the needle forward on the most important work while planning for our next phase of growth in 2024 – 2026.

In 2023, we had two research funding cycles – one in the spring and one in the fall – where we funded nearly $700,000 in research. With the launch of our new grant portal, this year we have received more applicants for our research grants than ever before.

Our clinical partners provide key expertise and insights to the MGFA to help inform patient education, our research agenda, strategic priority focus areas, and much more. In 2023, we restructured our Medical and Scientific Advisory Council and re-launched our Partners in MG Care program to better leverage the talents and time of the best and brightest clinical leaders. You can learn more inside the report about our partner relationships and growth in this area of our work.

Patient leadership is at the core of MGFA and thanks to many leaders across the globe, the MGFA continues to provide critical support to patients, including those who are newly diagnosed. Our patient leaders work together with us to lead Support Groups, serve as MG Friends, host our MGFA Community Health Fairs, and so much more. We are sincerely grateful for the impact patient leaders make on our work to make life better for those living with MG.

I am excited for you to read more about the progress that has taken place thanks to your generous support. My hope is that through this report you will gain a deeper understanding of how you have helped make an impact this year and how your ongoing support will propel us into our next phase of growth in our 2024 – 2026 strategic plan. Thank you for the investment you have made in the MGFA and the role you play in changing the lives of patients living with MG.

With my sincerest gratitude,

Samantha Masterson
President & CEO

Leading with Passion, Initiating Innovation

An advocate, an MG patient, a physician, an MGFA Board Member and a champion for research – Dr. Paul Strumph is the epitome of a well-rounded leader for the MG Community.

In 2019, Paul was diagnosed with myasthenia gravis after living with type 1 diabetes for more than 57 years. **Living with two chronic autoimmune disorders, he has a unique perspective on the patient experience and manages to turn his daily challenges into motivation for giving back.**

"Life is a gift. I look at my two autoimmune diseases as uninvited passengers on my trip of life. We are together on this journey, and have found a way to co-exist as we travel together with friendships and additional support provided by the MGFA."

Shortly after his MG diagnosis, Paul turned lemons into lemonade by harnessing his personal experience to make positive change for the future of the MGFA. He joined the Board of Directors and currently serves as the MGFA Global MG Patient Registry volunteer lead, which allows him to directly impact the trajectory of MG research. Through the registry, patients can provide their own health data (by tracking their symptoms), which will ultimately help inform and influence research in the MG space.

Dr. Paul Strumph

Why is the MGFA Global MG Patient Registry important? As Paul explains,

"The data from the registry will contribute to an understanding of the progression and remission of MG over time, and what risk factors are important for progression and remission and the risks associated with the types of MG."

As we work **to find a cure (or clinical remission, as it's referred to in the medical community), the registry will undoubtedly play a key role** in helping researchers connect the dots among patient symptoms, leading to publications that will ultimately help educate physicians around the globe.

It is because of volunteer leaders like Paul that an organization like MGFA can continue to advance and experience transformative growth. He leans into what he knows well – the patient experience, his knowledge as a physician, and his experience in research – and shares his talents to make a significant impact at the MGFA.

What is the MGFA Global MG Patient Registry?

The MGFA Global MG Patient Registry (mgregistry.org) was established in 2013 and is a longitudinal, online registry containing myasthenia gravis patient-reported health and symptom data.

Patients from around the world safely and securely add their data, which is protected and private as part of a HIPAA and GDPR-compliant platform, powered by Alira Health.

The actual, up-to-date MG patient data in the registry has enabled researchers to improve their understanding of myasthenia gravis while developing new treatments to help patients manage their MG. Data from members of the MG Community directly influences and informs the clinical trials process. Without patient data, these critical trials cannot move forward, and we would not have new discoveries or treatments.

Making Waves with Translational Research

Understanding Patient Response to Treatment to Make Life Better for Patients Living with MG

As a child in Iran, Dr. Fatemeh Khani Habibabadi was always interested in the world around her. At university, she studied cell and molecular biology, life at its most basic level, then went even deeper for graduate studies, focusing on molecular genetics. It was here that her fascination with autoimmune disease piqued while exploring the molecular approach to studying multiple sclerosis.

Dr. Khani joined a collaborative group of researchers at Yale University School of Medicine in 2022. In the same year, she was awarded the Jackie McSpadden Post-Doctoral Fellowship Award. This prestigious award was funded by the McSpadden Family to enable the brightest minds in MG research to continue their work and in hopes of one day finding a cure for MG.

MG patients respond differently to the variety of treatment options available. Dr. Khani's research focuses on deciphering precise roles of autoantibodies in MG pathogenesis – this will ultimately help clinicians better predict treatment efficacy and disease progression for their patients. Her research works to make life better for patients living with MG by improving daily quality of life and working to help patients ultimately achieve clinical remission.

The Jackie McSpadden Post-Doctoral Fellowship Award enables Dr. Khani to continue pursuing this important research for a three-year term. In October 2023, Dr. Khani had the opportunity to meet the McSpadden family in person at the MG Insider Fall Event in Dallas, Texas.

Dr. Khani and Danny McSpadden at the MG Insider Fall Event in Dallas.

The MGFA Research Process: A New Approach for Growth & Expansion

MGFA will fund nearly $700,000 in research this year.

Our process to determine which research to fund made significant strides in 2023.

This year, MGFA launched a new grant process and portal which enables the organization to:

1 Extend applicant submissions to international researchers

2 Align with National Institutes of Health (NIH) standards

3 Institute a formalized Conflict of Interest Policy

4 Create a more efficient, streamlined process to review Letters of intent and applications

The review panel for grant applications was established and is comprised of:
7 Medical and Scientific Advisory Council members across **5** countries.

United States

Netherlands

Sweden

United Kingdom

Canada

In this first year, letters of intent more than doubled for Pilot Grant funding. In 2023, 18 letters of intent were received from researchers across five countries – the United States, Italy, Germany, The Netherlands, and Sweden.

There is significant value in allowing international applicants to apply for MGFA grant funding as it creates more diverse proposals and more robust science.

The new grant portal improves MGFA's ability to track and realize the impact of the work the organization is funding. We can collect better data and track publications through this new system. Additionally, it enables MGFA to empower applicants by offering better feedback to drive future research and provides clinicians and researchers a better understanding of NIH protocols.

The Power of Clinical Expertise & Partnerships at MGFA

The MGFA Medical and Scientific Advisory Council

Earlier this year, the Medical and Scientific Advisory Council (MSAC) was restructured to better align with organizational strategic priorities. Council members are engaged through project-based work with specific goals and outcomes, resulting in meaningful impact for the greater MG Community.

This cohort of 18+ Council members includes expert clinicians and researchers from the United States, Canada, the UK, the Netherlands, Sweden, and Italy.

Each member of the MSAC serves on a Sub-Council, which includes:

- **MSAC Steering Committee:** These individuals are the governing body of the MSAC.
- **Research:** This cohort oversees the grant review process.
- **Partners in MG Care:** This cohort oversees the Partners in MG Care program, including its expansion.
- **Education:** This cohort is tasked with reviewing, monitoring, and assisting in the development of educational resources.

The MSAC will be continuing to grow with the addition of a Global Sub-Council and Nursing and Allied Health Professionals Sub-Council.

Meet the Partners in MG Care Council

The Council members are:

Amanda Guidon, MD
Chief of the Neuromuscular Division at Massachusetts General Hospital

Michael Hehir, MD
Division Chief, Neuromuscular Medicine at University of Vermont Health

Srikanth Muppidi, MD
Neuromuscular Medicine at Stanford Medicine

Nicholas Silvestri, MD
Neuromuscular Medicine at Buffalo General Medical Center

This council has led the way in creating a more meaningful application and vetting process. This will ensure partners that are in this network are both qualified to provide the best possible care to MG patients and are engaging on an ongoing basis with MGFA.

The MGFA Partners in MG Care Program

The MGFA Partners in MG Care program is a cohort of MG care providers who are committed to making life better for those living with MG. Applicants must apply and undergo a thorough vetting process, which was re-established in 2023 by the Partners in MG Care Council, in order to become part of the network.

The Partners in MG Care program serves a critical role in patient access to care as patients are able to look to this network to find committed, quality care providers to treat their myasthenia.

Partners in MG Care are also vital to fulfilling MGFA's mission of providing educational and support services to patients. The Partners in MG Care program shares educational tools and resources with clinicians that can be shared with each patient during their visit. This might include details about joining a support group, registering for the MGFA Global MG Patient Registry, or simply connecting a new patient to myasthenia.org for high-quality educational materials.

Historically, the Partners in MG Care program has existed as a network of providers but, with the establishment of the Partners in MG Care Council, expansion and growth are key areas of focus to serve more patients across the globe.

We are grateful to the clinicians we work with as they are essential to the success of the organization and provide quality healthcare to MG patients every day.

Thymectomy Survey and Workgroup

Thanks to the generosity of a donor family, an Education Initiative was launched to improve education regarding treatment options to help patients make better-informed decisions. One component of this Education Initiative included the creation and dissemination of a thymectomy survey.

The MGFA team partnered with three physicians, who formed the Thymectomy Workgroup, and volunteered their time to create and review this survey. The aim of this work is to better understand the use of thymectomy as a treatment option, and to understand how neurologists view thymectomy as a treatment option for MG.

The thymectomy survey was disseminated to over 25,000 neurologists nationwide.

This survey was one component of a larger initiative to support patients making informed decisions about their care.

Learn more at the online Thymectomy Resource Center, funded by donor generosity.
Visit Myasthenia.org/Thymectomy-Resource-Center

Thymectomy is the resection of the thymus gland and is most commonly performed for patients with myasthenia gravis and thymoma. It is currently performed using a minimally invasive approach with the use of video-assisted thoracoscopic or robotic-assisted surgery.

Patients Helping Patients Feel Seen & Heard

You've Got a Friend in Me

MGFRIENDS
PEER-TO-PEER CONNECTIONS

For 20 years, Bridget Marie Noujaim has helped others with MG navigate the complexities of doctor's appointments, insurance claims, and daily life with the disease. As an MG Friend, she talks to patients who have questions or need one-on-one support.

"The first thing I tell people is that the calls are confidential," she says. "The second thing is that there's absolutely nothing they say that can shock me – I've probably already felt or thought it."

Diagnosed as a college student, Bridget felt overwhelmed at first. Her doctor referred her to a volunteer nicknamed "Mr. Myasthenia," Irv Beck, who served as an unofficial ambassador for newly diagnosed patients.

Featured in photo: Bridget Marie Noujaim (second from right) and family

"When my parents started reaching out, Irv guided us about what I would need," she shares. She was inspired by Irv and others she met, and in time began to volunteer. She finds deep meaning in the one-on-one support she provides. Each interaction is a teachable moment for her or the next person she talks to.

"There were so many people who stepped up when I was first diagnosed, and they did it before I was even ready for it," she says.

"With how many people have helped us, we owe it to the world to help others. What are we here for if not to help other people in the ways that we have been helped? I'm always trying to pay it forward."

Bridget continues to serve as an MG champion, leader, and, most importantly, a caring friend to everyone she meets both in her local community in Connecticut and nationally through the MGFA.

The MGFA Community Health Fair Program

The MGFA Community Health Fair program launched in 2022 and is led by patients and caregivers, who take on crucial leadership roles. Each event is organized with a local volunteer lead who helps identify and confirm vendors, encourages local participation, and supports marketing and promotional efforts.

This year, MGFA Community Health Fairs took place in eight cities around the United States – New York, San Francisco, Charlotte, Seattle, Chicago, Houston, the Greater DMV, and Tampa.

These events directly connect patients to resources they need. **Patients in all stages of their MG journey benefit, but fairs are *particularly helpful* for those who are newly diagnosed or who may not have connected with other MG community members before.**

In 2024, we are bringing MGFA Community Health Fairs to ten cities across the United States. We are also adding a new element to each event – an educational component so patients and caregivers can hear directly from local leaders on key topics related to MG care.

Leading the Way for Newly Diagnosed Patient Resources

PATIENT PACKET

Request a kit with information relevant to patients and their families, including what you need to know to begin to understand treatment options, resources, and more.

SUPPORT GROUPS

Connect with others in your region or join a specialty group based on your needs.

MG FRIENDS

If you need help, you won't have to wait. Get paired with a fellow patient with deep experience who can guide you, listen, and make sure you don't feel alone.

ONLINE RESOURCES

Our website and Online Community house extensive educational material to learn more about MG symptoms, treatments, and research.

Strategically
Paving
The Way

This year signifies the end of a three-year strategic plan, and our next three-year strategic plan launches in 2024. Our team, in collaboration with the MGFA Board of Directors, has been working diligently to develop key priority areas and an operational plan to achieve our next stage of growth.

We have focused on four key priority areas:

- **Research**
- **Global Impact**
- **General Education and Underserved Communities**
- **Financial Growth**

MG Insiders Making an Impact, Together

Our MG Insider events bring together local leaders, donors and volunteers, care providers, and other key stakeholders for connection, networking, and to learn more about the status of the organization. Our inaugural events were hosted this year in Boston and Dallas.

While much of our work can be done remotely, nothing can replace coming together in person. In 2023, we prioritized a variety of on-ground events, including MGFA Community Health Fairs and the MGFA National Patient Conference. These events allow us to educate and support patients and caregivers while also connecting with community members and local leaders who have an interest in making life better for people with MG.

Advocacy Initiatives

Advocating for the health and wellbeing of patients is a priority for the MGFA. This includes advocating on the local, national, and global level with government, community members, and leaders.

This year, our advocacy team focused on:

→ Raising awareness about MG so local leaders and community members can play a stronger role in accommodating the needs of MG patients.

→ Encouraging and supporting legislation that advocates for affordable and equitable access to treatments and comprehensive healthcare.

→ Helping the community better understand the role of research and drug development in improving patient care. MGFA focuses on supporting evidence-based approaches to further our understanding of how providers diagnose, treat, and manage MG.

→ Creating stronger relationships with other patient advocacy organizations to work together towards common goals. We work together with these organizations to create pathways for patients and families to find and use available resources.

"Advocacy is about meeting the community where it is at. Sometimes it's giving people the tools they need to have conversations about their chronic illness or connecting MG patients with one another. Other times it's building an inclusive society or educating people about their disease. The MGFA works tirelessly to make a positive impact within the MG community and will continue until we find a cure."

Meridith O'Connor
Assistant Vice President of Patient Engagement, Advocacy, and Policy

OUR VISION:
A WORLD WITHOUT MG

OUR MISSION:

CREATE COMMUNITIES, ENHANCE LIVES, IMPROVE CARE, CURE MG

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