2024 ANNUAL IMPACT REPORT

myasthenia.org

IMPACTING Global Research and **EMPOWERING** the MG Community Like Never Before

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

2024 was a year of unprecedented global research grant funding and the launch of new signature programs

There is so much to celebrate this year, and our IMPACT has been unmistakable across the MG community around the world! Thank you for your support and commitment to those diagnosed with myasthenia gravis during this past year. We cannot deliver our rich and robust set of programs, resources, and funding opportunities without your generous support. WE APPRECIATE YOU and all that you do for the MG community.

MGFA achieved extraordinary growth in 2024 with a strong focus on funding new, groundbreaking research as well as launching new programs and signature nationwide-fundraisers.

MGFA brought back our MG Walk program as a way to bring community members together to raise funds to support the work that we do for the MG community.

THANK YOU

MGFA Vision:

A World Without MG

MGFA Mission:

Create Connections, Enhance Lives, Improve Care, Cure MG

For patients and caregivers who need extra support and guidance finding resources, we unveiled the MGFA Helpline. This new service features trained counselors ready to assist in the United States and Canada.

It is extraordinary to see our signature events, including our annual National Patient Conference and our Community Health Fairs, grow in attendance each year. These in-person events are life-changing opportunities for MG patients and their families to come together for education and community building.

2024 BY THE NUMBERS

90,000

individuals diagnosed and living with MG in the United States

1.2 MILLION

individuals diagnosed around the world

6

FDA-approved biologic therapies for MG

$5.8 MILLION

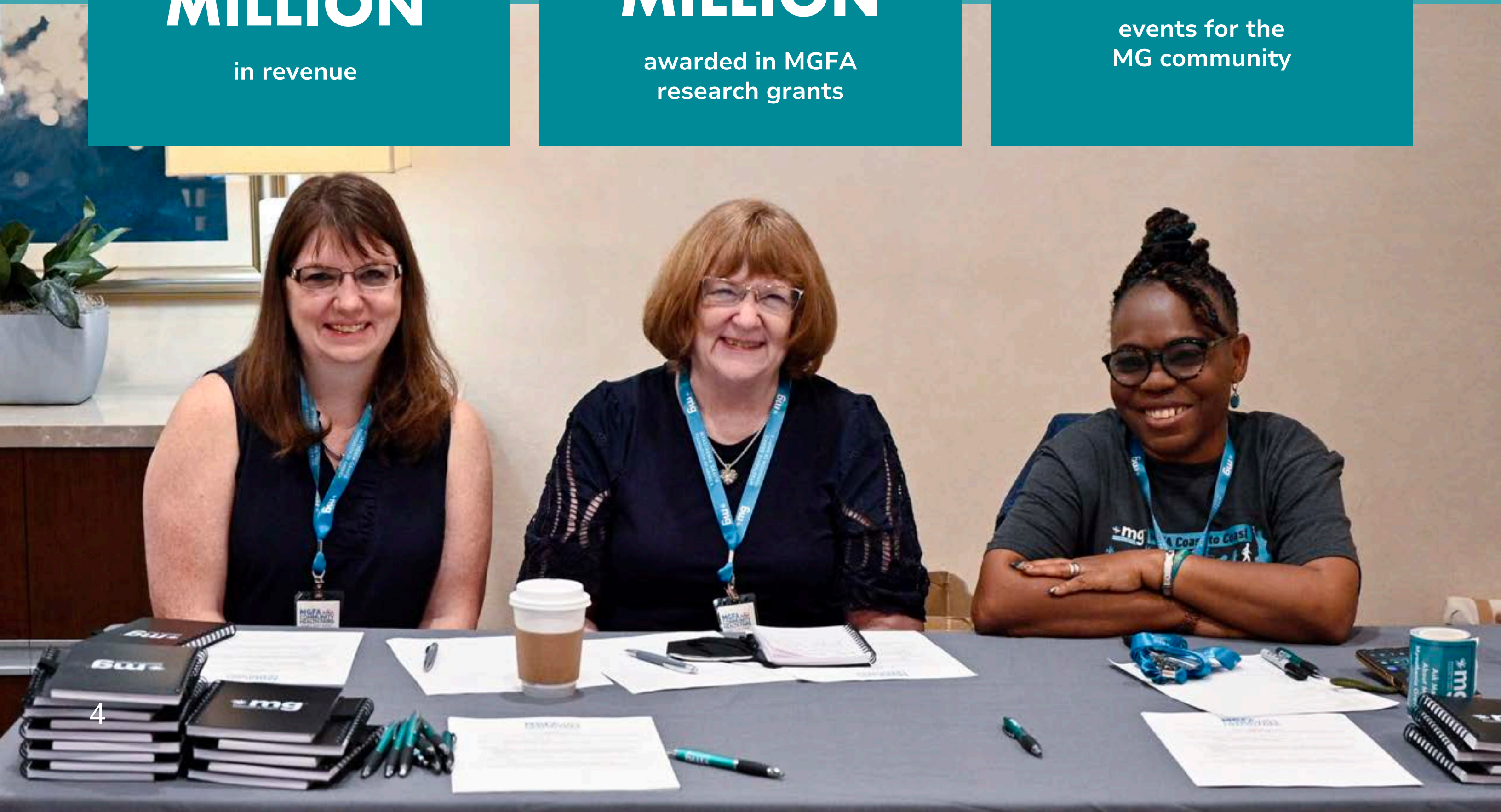
in revenue

$1 MILLION

awarded in MGFA research grants

28

events for the MG community



FUNDING NEARLY $1 MILLION IN NEW MG RESEARCH GRANTS

Clinician and scientist investigators are engaged in groundbreaking myasthenia gravis research all over the world. Through our grant program, the MGFA funds promising research to discover potential new treatments and ways to improve the quality of life for those with MG. Our grant recipients represent both top and emerging researchers. In 2024, the MGFA officially expanded grant funding opportunities to researchers outside of the United States. As result, we experienced the largest number of grant applications ever from a wide, diverse pool of MG researchers. The MGFA funded nearly $1 million in new grant funding—an unprecedented amount. You can learn much more about this extraordinary research and the primary authors at: **https://myasthenia.org/mg-research/grant-funding/grant-recipients/**

RESEARCH GRANT RECIPIENTS FOR 2024

Nancy Law Impact Award

The Nancy Law Impact Award supports high-impact clinical research or scientific investigations.

Kevin C. O'Connor, PhD

Yale School of Medicine

Amount Awarded: $300,000 over 3 Years

Project Funded: Defining new autoimmune mechanisms in seronegative MG

Myasthenia gravis is characterized by the presence of immune system proteins called autoantibodies that are found in most patients. MG autoantibodies cause disease by disrupting normal communication between nerves and muscles.

Seronegative MG (SNMG) is a disease subset of MG characterized by the absence of detectable autoantibodies. Little is known about SNMG, and it has not been well studied.

Several new therapeutics have become available for treating autoantibody-positive MG, many of which are very beneficial. Patients with SNMG are often excluded from certain therapeutic treatments and clinical trials that are open to autoantibody-positive patients. The reason for this is that logical treatment approaches for SNMG are uncertain due to our lack of understanding the disease mechanisms.

Accordingly, Dr. O'Connor's research project is designed to better understand the abnormal immune system functions contributing to SNMG. He and researchers in his lab will investigate whether SNMG shares immunologic features with other subtypes of MG or has features that are unique. Defining these immunologic features is fundamental to guiding treatment decisions for SNMG, as many therapies function only in certain disease subtypes that are defined by the immune system pathology.

We anticipate that this work will answer fundamental questions related to the immunopathological features of SNMG. This will allow clinicians to treat the disease more effectively and guide researchers toward developing new targeted treatments.

Global MG Registry Publication Award

Through this grant, the MGFA is funding highly meritorious projects that enable academic investigators to use patient-reported data in the MG Patient Registry.

Richard Nowak, MD, MS

Yale School of Medicine

Influence of race/ethnicity on clinical features of MG and inequalities in clinical care

Various studies have reported differences in MG disease characteristics and outcomes based on race/ethnic groups, yet no studies have confirmed these results on a large nationwide dataset. Dr. Nowak's research group's recent analysis of the physician-reported registry (EXPLORE-MG, based at the Yale MG Clinic) showed significant differences in clinical features between races, such as age of symptom onset, thymectomy usage, and hospitalization rates. The team is using the MG Patient Registry to further validate their findings. This study is comparing disease characteristics between White, African American, Asian, and Hispanic patients while simultaneously identifying racial groups more likely to experience hospitalization for MG. Ultimately, the results of this study will provide clinicians and the community with a better understanding of racial differences in MG, allow them to mitigate these differences in terms of clinical care, and identify areas of improvement in MG patient care.

Amanda Guidon, MD and Zoe Sheitman, PT, DPT

Massachusetts General Hospital

Physical activity and factors associated with exercise participation among patients with myasthenia

Few studies have been performed regarding physical activity and factors associated with exercise participation among individuals with myasthenia gravis (MG). This is a critical gap for clinical and research programs. Clinicians and MG patients require improved guidance regarding exercise participation. Additionally, physical activity and exercise may be a critical outcome measure and/or confounder needing to be measured in future clinical trials. This project aims to address these knowledge gaps through analysis of data from adult patients in the US with MG enrolled in the MG Patient Registry. The primary outcomes the researchers are examining are participation in any physical activity and achievement of recommended thresholds for exercise. This study will examine the association of patient and disease demographics on these outcomes. They aim to use this information in future studies, specifically those involving the use of structured physical therapy and digital outcomes/wearables to promote physical activity and improved quality of life in patients with MG.

Yaacov Anziska, MD

State University of New York Downstate Medical Center

The role of race and income in management of myasthenia gravis

This study is investigating whether certain patients with myasthenia gravis, either non-White or with lower incomes, have worse disease outcomes compared to their fellow patients.

High Impact Pilot Project Award

This award supports promising, results-oriented research projects.

Yingkai “Kevin” Li, PhD

Duke University

Deciphering Immunological Biomarkers in Myasthenia Gravis by Using Multiomics

Development of new treatments for diseases often relies on the identification of biomarkers, which are measurable indicators and must have the potential to predict responsiveness to therapy. Biomarkers can also assist clinicians in tailoring a treatment strategy that is most effective based on the patients’ biomarker profile. Consequently, biomarkers can help in limiting over-medication or unnecessary medication, maximizing disease control while minimizing side effects. Unfortunately, the lack of effective biomarkers in MG has greatly affected the pace of development for novel therapeutics.

Considering these facts, the need for a reliable biomarker in the treatment of MG is critical and urgent. The current project aims to (1) identify and characterize the changes of immune cell networks and pro-inflammatory cytokine networks in MG patients by using Cellular Indexing of Transcriptomes and Epitopes by Sequencing (CITE-seq) and Olink proteomic platform, respectively, and (2) then to validate the identified biomarkers in predicting the responses in MG patients with mycophenolate mofetil treatments.

Gianvito Masi, MD

Yale School of Medicine

Novel mechanistic insights into the MuSK-specific autoantibody repertoire

A subset of patients with MG has antibodies that target a protein known as muscle-specific tyrosine kinase (MuSK). In MuSK MG, muscle weakness is typically severe, with most patients having trouble breathing, swallowing, and talking. Despite recent advances in MuSK MG research, many aspects of the immune mechanisms underpinning the disease remain unknown, including the initiation of MuSK autoimmunity and how antibodies secreted by different B cells contribute to muscle pathology.

Dr. Masi and his colleagues are conducting a comprehensive investigation of the antibody response against MuSK to study (1) how newly generated B cells recognize MuSK, and (2) the functional impact of different MuSK antibodies on the neuromuscular synapse. Through focused examination of the MuSK-specific autoantibody repertoire, the investigators anticipate that findings from this research will enhance our understanding of MuSK MG and facilitate the development of targeted treatments for this disease.

Anna Punga, MD, PhD

Uppsala University, Sweden

Validating diagnostic and prognostic serum biomarkers for AChR antibody seropositive MG

A major concern in the MG field today is that we do not have disease-specific biomarkers, which results in the absence of personalized treatments for specific MG subgroups or reliable tests to predict how the disease will progress or see if treatments are working. This research project aims to address these challenges by confirming biomarkers in the blood that could predict MG development and treatment effectiveness. Specifically, we will study small RNA molecules and inflammatory proteins in the blood of MG patients with and without antibodies against the acetylcholine receptor (AChR). Previous and preliminary data from our research suggest that certain biomarkers can distinguish MG patients from healthy individuals and identify different MG subgroups, enabling personalized treatment approaches.

The project will validate these biomarkers in MG patients with acetylcholine receptor antibodies and explore their role in patients without detectable antibodies. Additionally, control groups (healthy and with other neuroimmunological conditions) will be included to establish the accuracy of these biomarkers. This research could lead to the discovery of blood-based biomarkers for MG, potentially improving personalized treatment for MG patients in the future.

MGFA RE-LAUNCHES ITS SIGNATURE MG WALK PEER-TO-PEER FUNDRAISERS

In 2024, the MGFA relaunched our popular MG Walk in three cities: Boston, New York, and Tampa. These fun and energizing events bring together MG patients, caregivers, healthcare professionals, and industry partners in a fun, family-friendly environment. Attendees have been inspired by a variety of MG expert speakers while participating in games and onside activities, culminating in a low-impact walk walk—all to raise funds for MG research and educational programs. We thank our volunteers, sponsors, and all our attendees, and we are excited to expand the program in 2025 and 2026.

MGFA HELPLINE UNVEILED TO PROVIDE LIVE SUPPORT TO MG PATIENTS

We went live with the MGFA Helpline this year to ensure that our most vulnerable community members can receive the support and assistance they need and be directed to critical resources with the help of trained counseling professionals. Whether you are newly diagnosed with MG or have been living with the disease for some time, you're likely to have questions about MG management from time to time. Having a reliable source of information is vital. Professional counselors are available to answer questions about living with myasthenia gravis, provide emotional health support, and guide community members to resources to help manage MG.

MGFA
HELPLINE
1.833.647.8764

1-833-647-8764 (United States and Canada)
9:00 AM-8:00 PM Eastern Time

FIRST STAKEHOLDER ROUNDTABLE SERIES CONVENED IN BOSTON

In 2024, the MGFA hosted its first ever series of Stakeholder Roundtable meetings in Boston. These two events featured multi-day meetings that brought together industry companies, medical and research professionals, and several of the most influential MG experts across the MG community. The meetings provided opportunities for attendees to share collective vision, intellect, and resources with a focus on improving quality of patient care for those diagnosed with myasthenia gravis. The events were moderated by Dr. Pushpa Narayanaswami of Beth Israel Deaconess Center/Harvard Medical Center. The roundtable meetings produced important discussions and a plan of action to deliver a first-of-its-kind MG terminology Lexicon with the aim of helping improve communication between patients and medical professionals to fill gaps in understanding MG.

SIGNATURE EVENTS HOSTED IN CITIES ACROSS THE UNITED STATES

MGFA held its annual National Patient Conference in Tampa, Florida in April 2024, and we witnessed record-breaking numbers——more than 1,000 people registered to attend either in-person or virtually. In addition to inspiring and informative sessions presented by MG patients and MG experts, we recognized our 2024 Volunteer Award Recipients. These extraordinary volunteers and partners are leaders in the community, driving fundraising, awareness, and patient empowerment.. We thank all our volunteers for their time, passion, and expertise.

Community Health Fair programming continues to expand

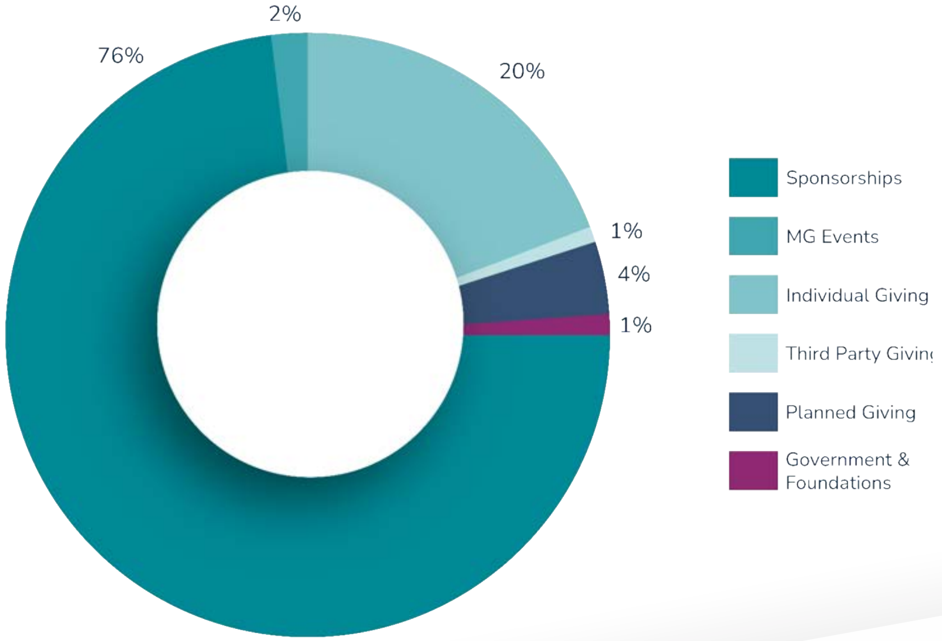
Based on enthusiastic feedback from patients and their families, the MGFA expanded this in-person event series in 2024. We brought Community Health Fairs to ten cities, including new locations Phoenix and Boston. We also updated our format to provide an enriched experience to attendees, adding expert speakers who shared information about MG treatments and management.

YOUR GENEROUS SUPPORT LEADS TO OUR IMPACT AND PROGRESS AGAINST MYASTHENIA GRAVIS

PUBLIC SUPPORT	2022	2023	2024	2024 %
Individual Giving	934,174	518,989	943,213	20%
Third Party Giving	82,550	151,236	56,855	1%
Planned Giving	436,831	259,478	203,417	4%
Government & Foundations	30,244	47,403	34,433	1%
Sponsorships	2,066,307	1,985,000	3,586,366	76%
MG Events	216,409	-23,580	-114,831	-2%
Total Public Support	3,766,515	2,938,526	4,709,454	100%

REVENUE	2022	2023	2024
Research Studies	171,148	56,668	133,332
Conference & Other Fees	284,921	76,042	71,341
Total Revenue	456,069	132,710	204,673

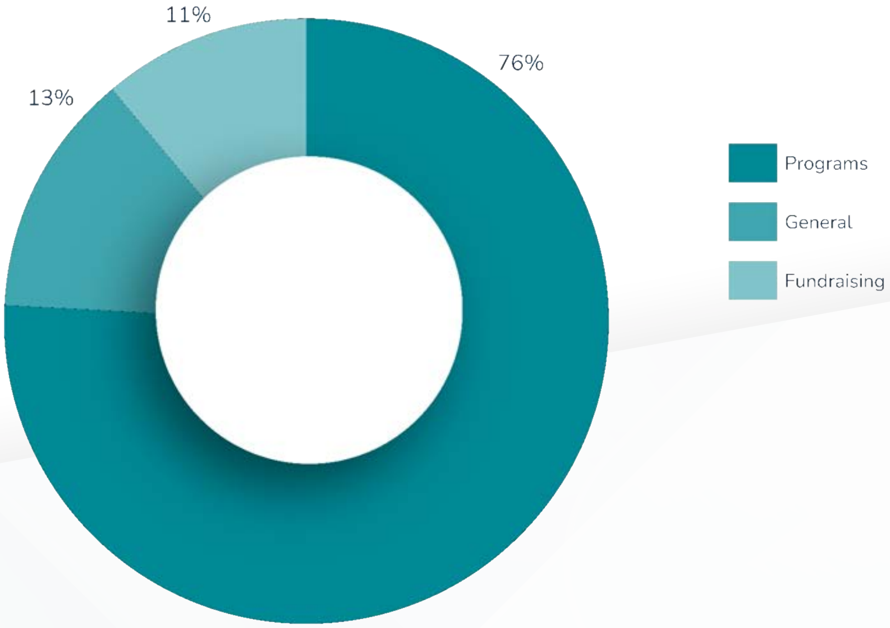
TOTAL SUPPORT & REVENUE	**4,222,584**	**3,071,236**	**4,914,127**



PROGRAM EXPENSES	2022	2023	2024
Community & Patient Services	465,807	377,411	522,810
Education & Advocacy	568,693	922,537	1,372,862
Research	1,807,779	1,067,875	1,652,360
Total Program Expenses	2,842,279	2,367,823	3,548,032
Management & General	384,341	504,747	616,598
Fundraising	578,735	523,411	532,503
Total Supporting Services	963,076	1,028,158	1,149,101

TOTAL EXPENSES	3,805,355	3,395,981	4,697,133
Nonoperating Income	1,243,145	903,033	876,136
Net Change in Assets	2,842,279	2,367,823	3,548,032

NET ASSETS	10,032,823	10,611,110	11,704,240



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MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Our Vision

A World Without MG

Our Mission

Create Connections, Enhance Lives, Improve Care, Cure MG

How You Can Support the MGFA

Give today

Raise funds and plan events

Double your impact with a matching gift from your employer

Help spread awareness about the need for research

For more information, visit **myasthenia.org** | Contact us at **mgfa@myasthenia.org**