



Bringing The MG Community Back Together

MGFA 2022 Annual Report

FY22 Annual Report | Leadership Letter

Dear Friends,

This last year was a testament to the resilience of our MG Community. We came back together, we celebrated together, and we grew together. We experienced milestone moments together and witnessed how the MGFA continued its evolution in parallel with the unprecedented growth of the MG space. Our mission continues to be "A World Without MG," and together we are making progress and raising more awareness than ever before. Thank you for your continued support and dedication to this shared mission.

MGFA prides itself on being a convener, a thought leader in the space, and an Educator-in-Chief. One of the ways we accomplish the important work that fulfills our mission is to bring together key stakeholders to consider, discuss, and debate the greatest needs for our collective MG population. Our charge is to come together to identify the most crucial unmet needs of the patient community - and fill these gaps to ensure our community members have what they need to better educate themselves about myasthenia gravis. We were able to create synergies through forums such as our MGFA Annual Patient Conference and our MGFA Scientific Symposium, through fostering strategic partnerships that raise greater awareness of MG, through advocating and empowering patients and caregivers, and through education that regularly informs those living with MG so that they can live their best life.

Some highlights from this past year include hosting the MGFA International Conference in Miami which convened 500 researchers, scientists, and clinicians from around the world. This was our first in-person program in over three years (because of COVID) – and what a way to come together! We announced that we will now be hosting the Conference every three years going forward instead of five, and that the next Conference will be hosted outside of the United States.

Another major event that returned as an in-person conference was our Scientific Symposium, which was part of the AANEM Annual Meeting in Nashville. We had the greatest attendance of medical professionals and researchers to date with standing room only.

It was a year of tremendous growth. It was also a transformational year in a lot of ways. We created and launched a unique, one-of-a-kind Online Community for patients, caregivers, and medical professionals. Imagine stepping into an online version of a small town, with buildings and rooms filled with MG resources, videos, educational materials, and chat rooms so you can connect with other MGers around the world! We also revamped our MyMG Mobile App, completing phase 2 with expanded functionality that positively benefits end users. Our organization has experienced significant growth in recent years and we are proud to share that we continue to increase our commitment to MG research funding which is paramount to our vision of a day without MG. We were also developing and building the underpinnings of an improved, global MG patient registry that would be launched in 2023. All exciting developments for the MG community.

We are able to share this progress and growth, and fulfill our commitment to the greater MG Community, through partnership and collaboration with friends and supporters like you. Thank you for your support in all of its forms...for joining us on social media, for signing up for our newsletter, for making a donation, for volunteering, or for filling out a survey. **Together we are making a difference.**

Sincerely,



Brian Gladden
Chair
MGFA Board of Directors



Samantha Masterson
President and CEO

2022 Program Highlights

Bringing the MG Community Together

14th MGFA International Conference On Myasthenia And Related Disorders

Every three years, medical professionals and MG researchers from around the world come together to share myasthenia research, progress, and new discoveries at the MGFA International Conference. This year, we gathered in Miami, Florida at the 14th MGFA International Conference held on May 10 – 12. We were excited to welcome Angela Vincent, a giant in the field of neuroimmunology, as our keynote speaker. Dr. Vincent's research over the past 35 years has contributed to our understanding of the role of antibodies in neurological disease. Other critical topics included the latest therapeutics, biomarkers for MG, autoantibodies, updates in MG management, pediatric MG, and patient case studies. Presenters joined us from 50 countries around the world and included some of the top MG experts from MGNet, Partners in Care, and the most prestigious university medical centers and healthcare institutions/hospitals.



MGFA Kicks Off First-ever Community Health Fairs

Bringing the MG Community Together – in-person - for a unique connected experience. The MGFA kicked off its first-ever local, in-person Community Health Fairs in 2022 in various locations around the country. These events helped connect members of the MG Community while supporting those diagnosed with MG and their caregivers. The Community Health Fairs helped patients and caregivers CONNECT with each other to SHARE stories and guidance, to LEARN more about managing MG. At the fairs, attendees interacted with MG patients and medical experts to answer questions, obtained educational materials, connected with treatment providers and local businesses, and learned more about MG research and treatments. In 2022, we hosted five in-person fairs in San Francisco, CA, Austin, TX, Alexandria, VA, Atlanta, GA, and Tampa Bay, FL.





Introducing the Unique MGFA Online Community

Imagine stepping into a completely one-of-a-kind virtual neighborhood where the MG Community can join together, connect, share ideas and discoveries, and access MG-specific educational materials such as live broadcasts, webinars, and information libraries – all in one place! This graphically-oriented online space called the MGFA Online Community was launched in spring of 2022. It displays all the charm of a small town with the combined power of the MG Community through chatting, networking, and learning. Members can enter unique online buildings and rooms or witness live events. Each building in the MGFA Online Community contains rooms with resources, chat areas, videos, and educational materials. *To learn more, visit myasthenia.org/MG-Community/MGFA-Online-Community.*

MGFA Global MG Patient Registry Developed – Securely Enter Patient Data

The MGFA Global MG Patient Registry is a confidential means for MG patients around the world to provide information and real patient data that will be critical to medical/research communities in the assessment of disease course, use of various therapies, and estimation of disease costs. Researchers and clinicians need ACTUAL, REAL patient data in order to build their studies and trials. Patient data is anonymous and secure in the registry, and it provides researchers with accurate information that could help answer many open questions about MG biology and treatment efficacy. This fully-functional patient registry is being updated in collaboration with our development partner Alira Health, to ensure patients have easier, more efficient options for adding their data to our registry surveys. We will relaunch the registry in 2023. *Check out the registry at MGRegistry.org.*



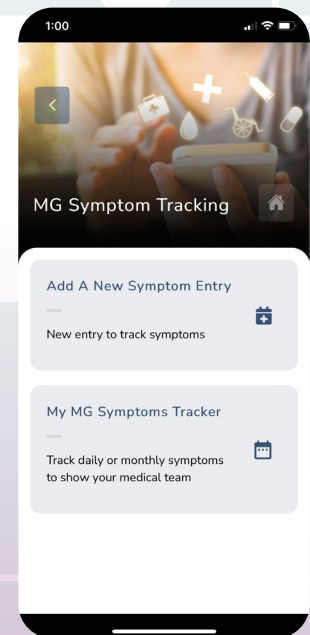
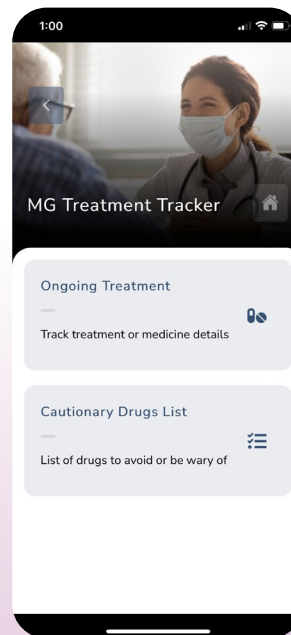
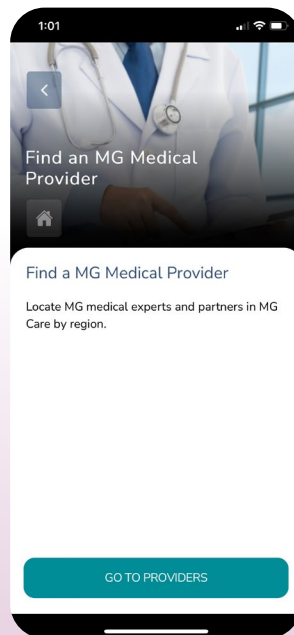
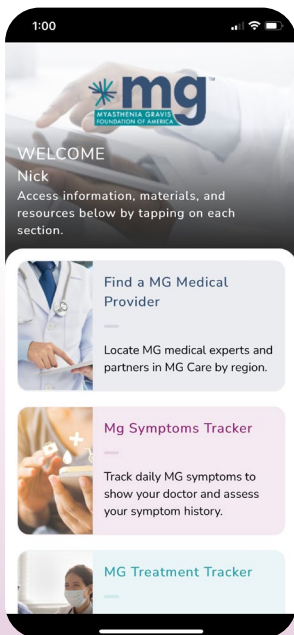
MGFA Coast-to-Coast 2740 Walk Challenge Drives Fundraising in 2022

The MGFA Coast-to-Coast National Fundraising Event took place on November 12, 2022. This virtual walk was MGFA's largest fundraiser and enabled participants to (virtually) walk no matter where they lived while raising critical funds for the MG community and MG research. It provided hope for the thousands of families who face the challenges caused by myasthenia gravis (MG). The year-long fundraiser culminated in an online event that included virtual recognition of all our participants' and teams' hard work. The event highlighted various walk teams as well as our partners and patients all across the country. We also recognized top fundraising teams and individuals and celebrated all that we have accomplished together for the MG community.



MyMG Mobile app launch

Manage and Learn About Your Myasthenia Gravis in a New and Personal Way – from the Palm of Your Hand. MGFA introduced its completely brand new MyMG Mobile App for the Apple iPhone or Android phone. This state-of-the-art mobile app provides a host of new features that enables patients to help manage and track their myasthenia symptoms and treatments while helping anyone across our community access critical MGFA resources including webinars, brochures, research information, events and blogs, and MG assistance and guidance. Features include an easy-access homepage, symptom and treatment tracking, Apple Watch integration, and access to events and MG materials.



Making History in Grant Funding for MG Research

Perhaps one of the most outstanding achievements to share from 2022 is progress with our grant program and the research that MGFA has funded. This year, we increased our funding yet again and will fund nearly \$1M in innovative research. This funding included the inaugural Nancy Law Impact Award, which was MGFA's largest grant award in the organization's history at \$300,000. We also were able to increase funding due to the very generous investment made by some of our donor families. Given this commitment to increasing our support of research, we now offer two funding cycles instead of one which allows us to review and consider more proposals and support an increased number of projects.

2022 Grant Funding Recipients

Clinician and scientist investigators are engaged in groundbreaking myasthenia research all over the world. The MGFA funds promising research studies and clinical trials to discover potential new treatments and methods of living a better quality of life with MG.

Jackie McSpadden Post-Doctoral Fellowship Award

Measuring AChR autoantibody effector functions in myasthenia gravis patients

Dr. Fatemeh Khani

Yale University School of Medicine



Dr. Khani's proposed research project is part of her postdoctoral fellowship and is funded specifically to support her salary over a period of 3 years (\$75,000/year) and will officially begin on January 1, 2023. Her fellowship training will be conducted in the Laboratory of Dr. Kevin O'Connor at Yale University. The project investigation is focused on providing the framework for the development of MG biomarkers that can directly help patients by predicting treatment efficacy and disease progression. Dr. Khani seeks to understand immune mechanisms underlying MG that are anticipated to more precisely define this heterogeneous disease. These collective studies

will provide a set of well-characterized biomarkers which will serve as tools for the community to more accurately model AChR in vitro. In addition, the work will provide a framework for understanding the association between autoantibody binding properties and effector functions in MG and identify candidate biomarkers that may proactively predict response to therapeutic complement treatment and avoid severe side effects from unnecessary interventions.

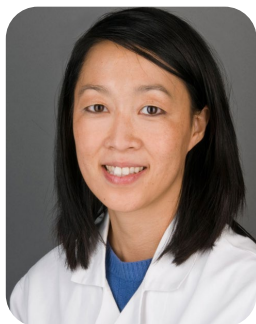
Inaugural Nancy Law Impact Award - 2022

The Nancy Law Impact Award is an MG research funding opportunity named after former MGFA Board Chair and CEO.

Preclinical models and biomarkers for predicting MuSK-CAART clinical outcomes (\$300,000 over 3-year period)

Dr. Aimee Payne

University of Pennsylvania



MuSK MG is caused by MuSK autoantibodies that lead to life-threatening muscle weakness, so the ideal therapy would be to eliminate autoantibody-producing B-cells while preserving healthy B-cells. CART cells in the body are currently being re-programmed to eradicate B-cell cancers, prompting researchers to explore whether this precision medicine can be used for other diseases like myasthenia gravis. The project researchers are testing a novel autoantibody receptor T-cell therapy designed to re-program MG patient T-cells to selectively kill anti-MuSK B-cells that cause MuSK

MG. The research is designed to test the working hypothesis in hopes of leading to a safe and lasting disease response and develop protocols for the detection and characterization of MuSK-CAART to validate novel biomarkers. Dr. Payne presented her ongoing work in this area during the 2022 AANEM MGFA Scientific Session in September.

MGFA High-Impact Pilot Project Award Recipient for 2022

The MGFA High-Impact Pilot Project Awards are pilot studies typically leading to new federal, pharmaceutical, or private foundation supported investigations. **Advancing patient-centered care and research for ocular myasthenia gravis: Validation of a novel patient reported outcome measure (\$50,000 funded over 1-year)**

Dr. Lindsey De Lott, M.D.

University of Michigan



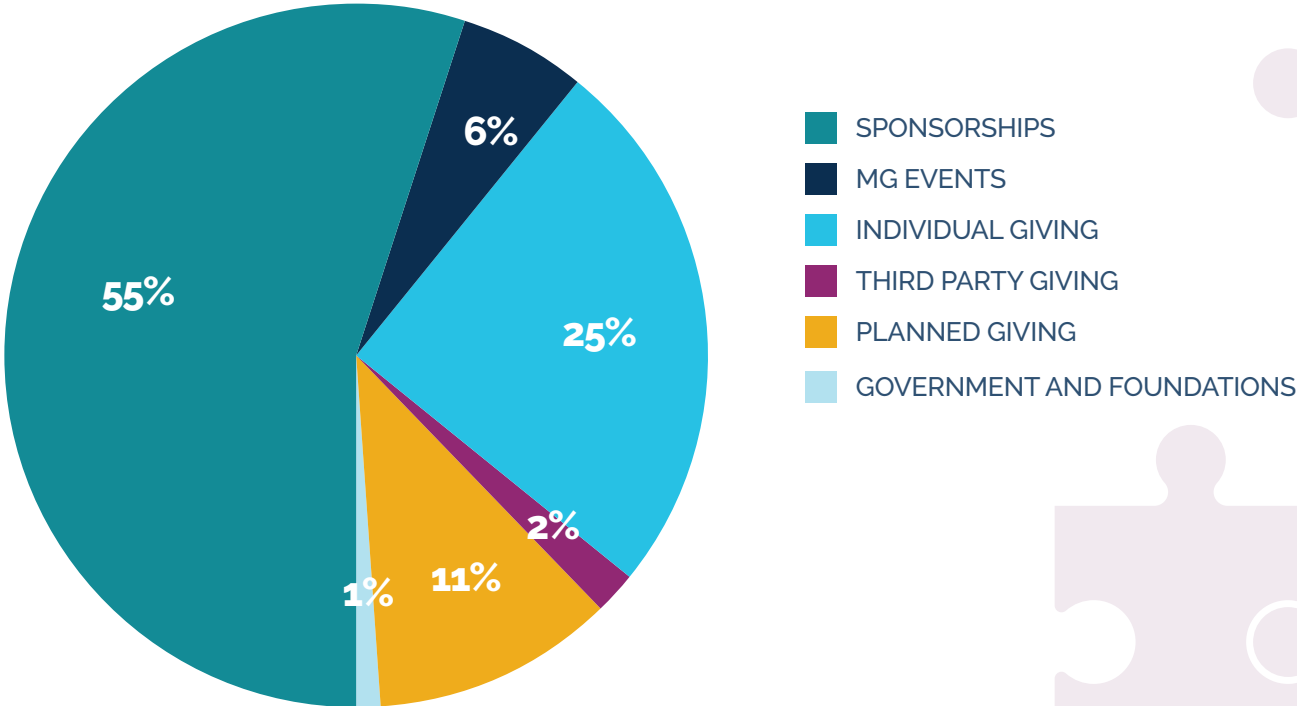
The ocular symptoms of Myasthenia Gravis (MG) are disabling and affect quality of life - the impact of double vision and droopy eyelids can be profound. We need to fully understand the extent of how ocular symptoms impact daily function. Patient-reported outcome measures (PROMS) are valuable tools for measuring the aspects of MG, such as double vision, that matter most to patients while enhancing patient-physician communication and support. However, there are no PROMs focused on the impact of the ocular symptoms of MG or OMG nor sufficient scales to measure OMG.

Financial Information

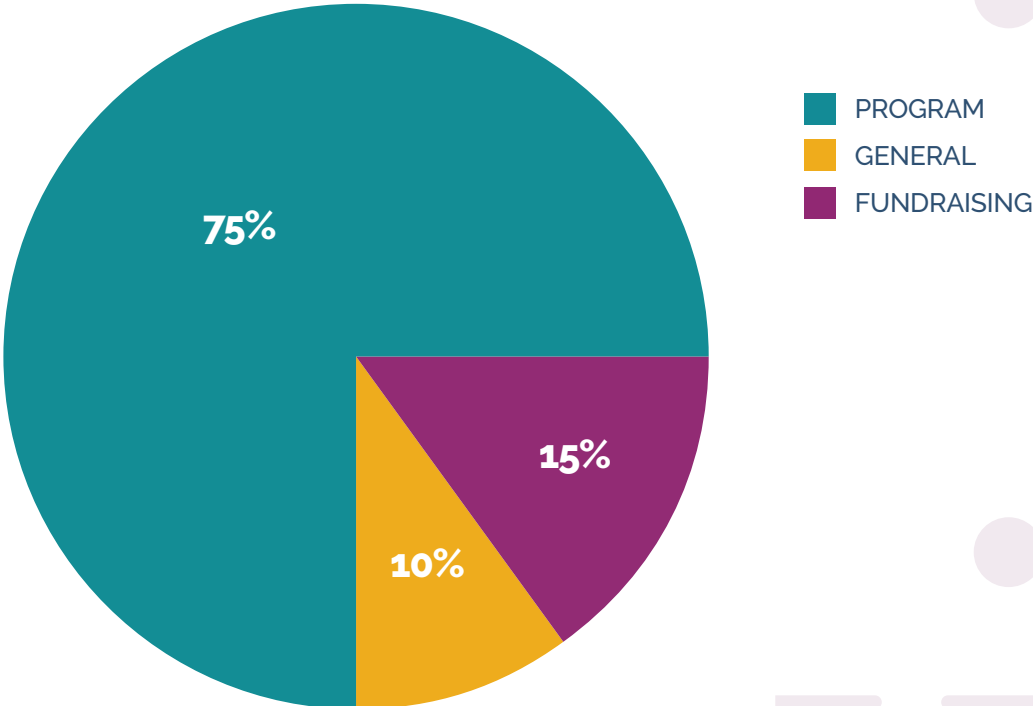
PUBLIC SUPPORT:	2020	2021	2022
Individual Giving	626,734	603,374	934,174
Third Party Giving	171,348	196,434	82,550
Planned Giving	1,126,496	455,143	436,831
Government and Foundations	58,619	82,754	30,244
Sponsorships	937,250	1,314,030	2,066,307
MG Events	361,862	251,624	216,409
Total Public Support	3,282,309	2,903,359	3,766,515
REVENUE:			
Research studies	30,078	189,501	171,148
Conference and Other Fees	5,387	157,922	284,921
Total Revenue	35,465	347,423	456,069
Total Support and Revenue	3,317,774	3,250,782	4,222,584
PROGRAM EXPENSES:			
Community and patient services	585,018	516,881	465,807
Education and Advocacy	334,375	497,162	568,693
Research	764,067	1,066,956	1,807,779
Total Program Expenses	1,683,460	2,080,999	2,842,279
Management and general	325,122	411,185	384,341
Fund raising	420,833	513,929	578,735
Total Supporting Services	745,955	925,114	963,076
Total Expenses	2,429,415	3,006,113	3,805,355
Nonoperating Income	305,055	880,016	(1,243,145)
Net Change in assets	1,193,414	1,124,685	(825,916)
Net Assets	9,734,054	10,858,739	10,032,823

FY 22

CONTRIBUTIONS



BUDGET





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The Howard & Nikki Applebaum Foundation
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Thank you to all of our donors. With your generous gifts, we are able to continue supporting the MG community while also investing in research to find a cure.

If you would like to learn more, or become a donor, please contact Caroline Gayler at CBowline@myasthenia.org.

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



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