



2023

ANNUAL REPORT

**RECONNECTING WITH
THE MG COMMUNITY**

 **mg**TM
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

Accomplishing Strategic Plan Objectives: Achieving Unprecedented

Growth and Results

MGFA executed on a comprehensive strategic plan from 2021 through 2023 that led to unprecedented growth opportunities, significant grant funding increases, improved educational materials and resources, and saw the advent and continuation of events and opportunities to convene all members of the global MG Community. We are proud of our hard work and positive outcomes that have greatly impacted the myasthenia gravis experience.

We are in the process of building a new strategic plan for 2024 – 2026 that will envision a new set of objectives, pillars, and goals to expand our leadership across the global MG community while achieving new levels of research outcomes and service to those individuals diagnosed with MG and their families.

***These are Just
Some of the
Extraordinary
Outcomes
Over the Past
Three Years:***

Research

- Increased MGFA research funding to nearly \$1 million per year through expanded grants.
- Transitioned the MGFA MG Registry to a new platform host and expanded registry to include global patient data.
- Expanded community's only Global Medical and Scientific Advisory Council.

Development and Stewardship

- Doubled the size & impact of MGFA – with annual revenue growing from \$2 million to over \$4 million per year.
- Diversified MGFA revenue portfolio with a strong focus on corporate giving and new fundraising platforms.
- Developed and implemented a comprehensive Stewardship Program that resulted in long-term investment.
- Increased support with strategic partners to grow sponsorships by 2.5 times.

Patient and Community Services

- Established and launched eight Community Health Fairs across the U.S.
- Attracted more than 1,000 registrants at annual National Patient Conferences
- Recorded record attendance at the International Conference in 2022 and Scientific Session.
- Developed a digital ecosystem called the MGFA Online Community to enhance constituency engagement.

Education, Awareness, and Advocacy

- Increased and expanded patient education services/programming.
- 20% increase in MG Community engagement year over year during MG Awareness Month.
- Leveraged mobile (launched MyMG Mobile app) and cloud technology to drive MG community engagement.
- Executed on a Volunteer Ambassador plan to more closely engage with volunteers and patients to share MG information.
- Supported advocacy calls to action that drove legislative opportunities for research and disability rights.



**Research Funding
Process Drives New
Groundbreaking
Outcomes in
Myasthenia Gravis**

MGFA Funded Nearly **\$1 Million** in New Research Grant Funding

in 2023 with the help of our extraordinary donors, fundraisers, and supporters. Through new investments from our partners and the extreme generosity of our donors, we were able fund multiple grants including the continuation of our very influential and prestigious Nancy Law Impact Award. The MGFA research funding process evolved and expanded this year – including a new approach and philosophy that achieved a globally-focused abstract submission process. Our process to determine which research to fund made significant strides in 2023 by opening it up to international researchers. For example, our research Letters of Intent (LOI) more than doubled for new Pilot Grant funding. In an unprecedented achievement, 18 letters of intent were received from researchers across five countries – the United States, Italy, Germany, The Netherlands, and Sweden. Obviously, we found evidence of significant value in enabling international applicants to apply. As a result, the MGFA research committee and judges awarded grants to the most promising MG research.

High Impact Pilot Project Award

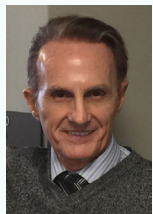


Ryan Hibbs, Ph.D.

University of California, San Diego | Amount Awarded: \$110,000 over 2 years

Project Funded: Purification of the acetylcholine receptor toward atomic-scale mechanisms underlying MG

Our ability to treat patients with myasthenia gravis is limited by our knowledge of muscle receptors and how antibodies attack them. Our long-term goal is to discover, for the first time, the 3-dimensional architecture of the receptor, and how antibodies from patients bind to it. Success in this project will enable success in discovering the structure of the receptor, a process that our laboratory has a strong track record in accomplishing.



Ricardo Maselli, M.D.

University of California, Davis | Amount Awarded: \$110,000 over 2 years

Project Funded: AAV-mediated gene therapy for congenital myasthenia caused by recessive synaptotagmin 2 mutations

The aim of this project is to develop and obtain FDA approval for a gene therapy based on the delivery of the normal SYT2 gene through an adeno-associated virus vector. After the AAV vector is delivered to the central nervous system, the spinal motor neurons are transduced with the normal SYT2 gene and start translating a normal synaptotagmin 2 protein, which, in turn, is transported through the nerve axoplasmic flow to the neuromuscular junction. This results in the re-establishment of normal neuromuscular transmission and potential cure of the disease.

Nancy Law Impact Award



Xin-Ming Shen, Ph.D.

Mayo Clinic, Rochester, Minnesota | Amount Awarded: \$100,000 over 1 year

Project Funded: The 3' untranslated region variants and therapeutic targets in congenital myasthenic syndrome genes

Globally, researchers have identified 35 genes associated with CMS, but there are more to discover. It is believed that there may be more such changes that remain undiscovered due to the complexities of investigation. This project seeks to delve deeper into these genetic variations in CMS patients and to explore an innovative therapy approach involving the influence of these gene regions. This research has the potential to enhance the understanding of these rare conditions and uncover new avenues for assisting those who suffer from them.

For more information about this extraordinary research and our grant recipients, visit myasthenia.org/mg-research/grant-funding/grant-recipients/

Positive Impact on the MG Patient Community

For 31 years, the Helen and Leonard A. Golden Memorial Golf Classic has brought together family, friends, neighbors, and colleagues in New Jersey to raise funds for myasthenia gravis research.

The annual tournament was created in honor of Helen Golden, who suffered from myasthenia gravis symptoms for years before her diagnosis, and her husband Leonard Golden. The type of person who fought things head on, Helen came up with the idea of hosting a charity golf tournament to raise awareness about MG.

Today it is the largest and most successful golf fundraiser benefiting the MGFA.

When the family started the tournament in 1992 thanks to Helen and Leonard's son-in-law, Sam Gershwin, no one expected it would continue so long or become so successful.

"The first year it rained, and they had maybe eight golfers, but nonetheless the charity tournament was born," said Jason Gershwin, Helen and Leonard's grandson, who became chairman of the annual event 18 years ago. Three generations of the Golden-Gershwin family have worked together to run the tournament.

"It's really exciting to witness and, frankly, quite powerful," Samantha Masterson, MGFA's president and CEO, said. "The sense of giving back and being dedicated to something that is bigger than oneself is evident with this family."

Jason remembers riding around in a golf cart as a child and being tasked with taking pictures of the event. His involvement deepened as he got older, and he took the reins as the event's leader in his mid-twenties.

His twin sons Zach and Owen, now 15, have grown up at the tournament.

One of Jason's favorite memories is the time when his boys were little, and baseball legend Yogi Berra, who attended the classic for many years, autographed their Yankees bibs.

Everyone in the family plays a role, from recruiting attendees and silent auction packages to staffing the registration table and greeting attendees at the clubhouse.

Even his "work family" has rallied behind the event – each year staff from his company, R4 Capital, come in droves to sponsor and attend with their friends and clients.

"My favorite part about this event is perpetuating the legacy of my

grandparents, and doing it with my family – my parents, my sister, my wife, my sons, my in-laws, aunts and uncles – and with my work family," Jason said. "And then hopefully to pass it on to my sons. They never met their great-grandparents, but they want to be involved. That it's important to them to keep running the outing is probably the most rewarding aspect of it."

Running a successful event for so long requires a strong group of volunteers with various skillsets and the dedication to create a fun, memorable experience. The family has worked hard to make the Golden Classic a can't-miss event.

Jason said that running a first-class event is essential to attracting people with no personal connection to myasthenia gravis. The more people enjoy a day on the golf course, the more funds are raised to support MG research and education, and the more people walk away with an understanding of what MG is.

"We offer a great course, great giveaways, great food and raffle and drinks, so people say, 'Wow, that was a really fun day,' and mark their calendar for next year," Jason shared.

He says guests come back year after year. They know they're in for a great time in service of a great cause.

For the Golden-Gershwins, the Annual Golf Tournament is a Family Affair





Running the NYC Marathon for a World without Myasthenia Gravis

Zackary Frankel is one of those people who goes all in.

When he picked up running about 10 months ago, he didn't go on casual jogs – he entered the lottery for a spot in the New York City marathon. When he found out he had a spot, he didn't merely want to run – he wanted to run for a purpose.

Enter his girlfriend, Julie Gordon. Julie was diagnosed with myasthenia gravis in July 2019, a year before she and Zack met. Although her MG was stable for about two years, she had a difficult flare up last winter. Experiencing that alongside her, Zack saw first-hand how MG can turn a person's life upside down. He decided to run the marathon for MG awareness and in support of the MGFA's vision of "A World Without MG."

MGFA sat down with Zack and Julie to talk about the marathon and why supporting the MGFA matters to them both.

What made you decide to run for myasthenia gravis awareness?

Zack: Running is something I've always wanted to do. This will be my first marathon. I've never done anything like this before, but I'm very into trying new things, and I knew I wanted to do the race for a good cause. I wanted to support a cause that was a little more personal to me, and Julie's MG is definitely one of those. She was diagnosed about a year before we met. She told me all about MG and her flare ups. She found it hard to talk about it originally but got more comfortable and told me about the symptoms and what the average person deals with every day. It's definitely very difficult when she is having a relapse, though the majority of the time she's ok with no symptoms.

Julie, how did you feel when you heard what Zack was doing?

Julie: I think I cried when he told me or when I read the blurb on the fundraising page.

Zack: You cried both times!

Julie: My myasthenia gravis is something only my immediate circle knows about. I used to be really vocal when I was first diagnosed, and then during remission it kind of left my brain. But I had a major relapse last November through April, with droopy eyes, smile stuff, double vision, all that. Zack saw it all because we had just moved in together. He went to walk the dog and came back with two eye patches – one for him and one for me. That's all anyone can ask for when they're going through a crisis, that you have a support system and a partner who tries to understand and be willing to walk out with an eye patch when he doesn't have to.

Why is it important for you to give back?

Zack: Finding a cure for MG would be the ultimate goal, so supporting the MGFA really resonated. I hope to bring awareness of what MG is to people.

Julie: The first thing I was told when I was diagnosed was that it's manageable, but there's no cure. Hearing that when you're first diagnosed... "This is forever"... Not knowing when a flareup is going to happen is something I'm constantly worried about. Different life events come up, you don't know if you can go. It's a constant almost trauma. The thought of more people knowing about it and increasing treatment options that will work better long-term is my why.

2023 GIVING CIRCLES



LEADERSHIP CIRCLE

Brian and Judi Gladden
Howard and Nikki Applebaum
Jean Evans
Kit and Robert Howard
Kyle and Jocelyn Sell
Robert and Joanne Crown
William Roach
William Sauerwine



CIRCLE OF INFLUENCE

Kevin Keelty
Mark and Kathleen Aitken-Cade
Maureen McClure
Parry Rekers
Peggy Sanford



ELLSWORTH SOCIETY

Laura Walker
Max Issac
Robert and Edith Carlson
Thomas Skibba



THE TEAL SOCIETY

Ann Shinefeld
Arun Saini
Brenda Walker
Cathy Nishizaki
Charles Johnson
David Bashover
Deborah Sugerman
Eleanor Baker
Gary Adams
Howard Budner
Joan Darrah
John Ward
Jon and Katherine Cranney
Kathy Wiertsema-Miller
Ken Connell
Kristin Ingram
Linda Pitts
Lynton Culpepper
Mark Loffredo
Michael Lifshitz
Nicole Moers
Patrick Folk
Paul Nesbitt
Paul Posoli
Raymond Hanechak
Stephen Schwartz-Fenwick
Steven Goodman



CIRCLE OF STRENGTH

Amy Halter
Anthony Chambers
Barbara Tenenbaum
Bethany Han
Betty Adjueyitsi
Brian Silverio
Calvin and Mee Quai Loo
Cathy Nishizaki
Cheryl and Michael Foster
David and Katherine Daline
Debra Fienberg
Diana and Richard England
Elizabeth and Beverly Connolly
Elizabeth Leonard
Elizabeth Robinson
Elizabeth Swize
Everett Snowden
Frederick and Iris Kaefer
Gary and Ilene Eder
Gary Cierny
Gary Strauss
George and Chieko Kujiraoka
Helma Davelaar
Henry Kaminski
Howard Budner

Irene Ersing
James and Sandi Thompson
Jamie Berndt
Jeff Pilgrim
Jessica Buehler
John and Genie O'Neil
Judith Craver
Judith Noel
Judy and Army Task
Karen Ramey
Katherine and Peter Jacullo
Kathleen Clem
Kelly Eddinger
Kelly Gwathmey
Kerry Shea
Leni Fuhrman
Lucyann Sciandra
Marc Kalish
Marcia Lorimer
Mark Swanson
Marsha Waters
Matthew Sitler
Michael Lifshitz
Michaeline Roach
Mike Lobbia

Murray Pitkowsky
Nancy Lucas
Nancy Myder
Nicole Moers
Patricia Dunn
Patricia McNabb
Patricia Sinclair
Peter and Carolina Gennrich
Randy Dean
Rena Humerickhouse
Richard and Julia Webb
Risher Gilbert
Sandra Fienberg
Sandra Williams
Scott Tucker
Stephen Hardis
Steven Goodman
Susan Klinger
Tarek Hassan
Thomas Defanti
Virginia and Donald Cunningham
Walter Capp

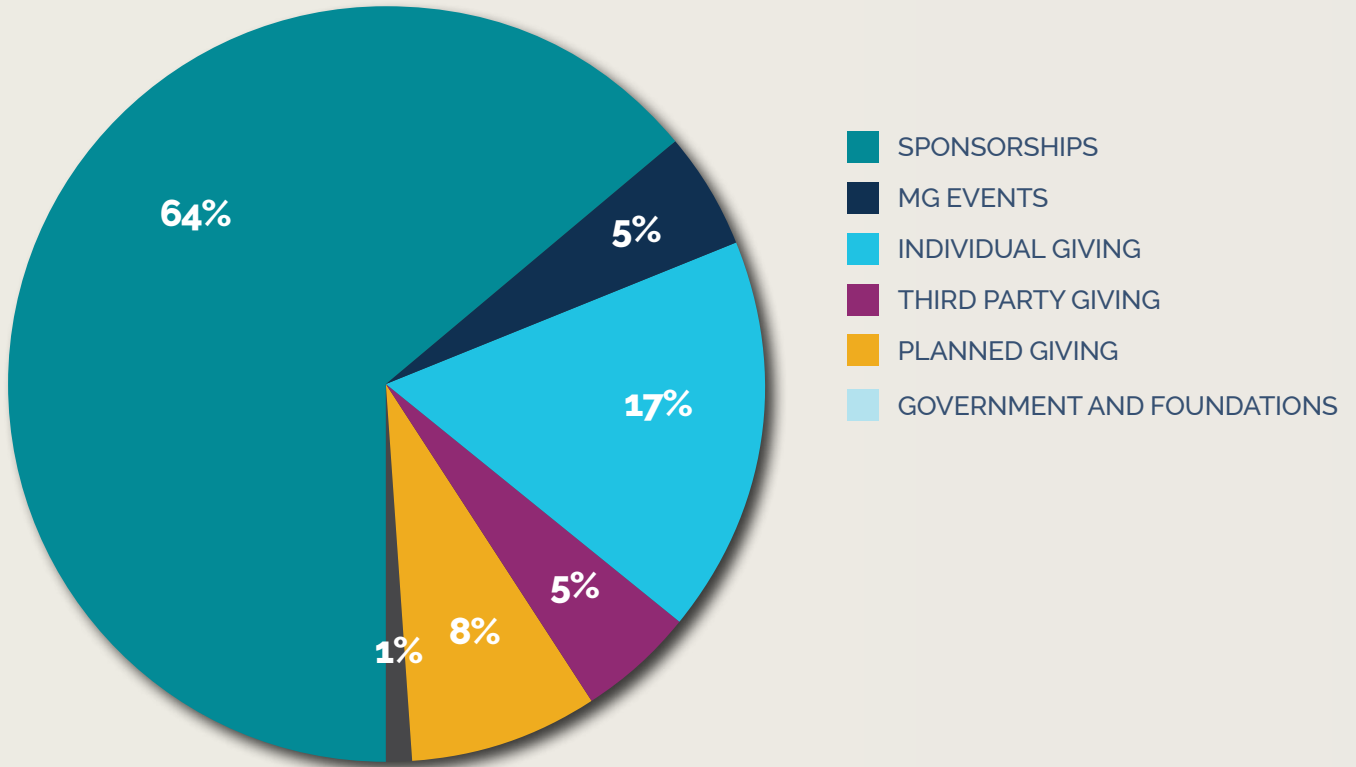
Thank you to all of our donors. With your generous gifts, we are able to continue supporting the MG community while also investing in research to find a cure.

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

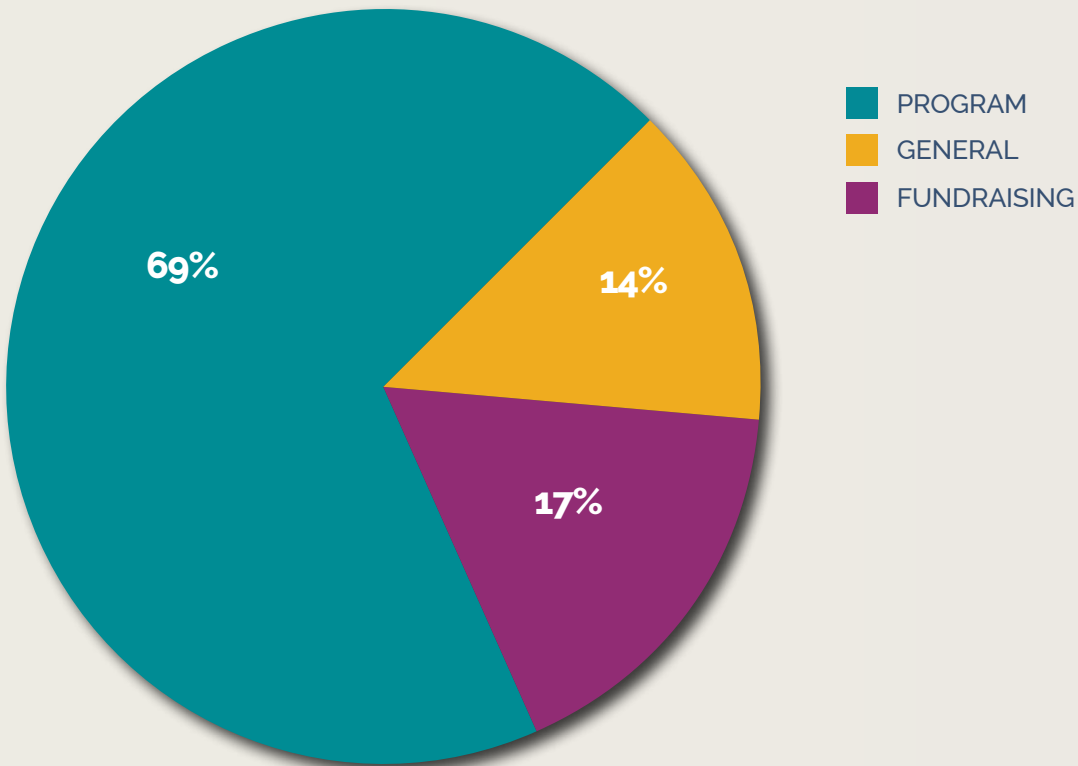
2023 FINANCIALS

PUBLIC SUPPORT:	2021	2022	2023
Individual Giving	603,374	934,174	518,989
Third Party Giving	196,434	82,550	151,236
Planned Giving	455,143	436,831	259,478
Government and Foundations	82,754	30,244	47,403
Sponsorships	1,314,030	2,066,307	1,985,000
MG Events	251,624	216,409	149,704
Total Public Support	2,903,359	3,766,515	3,111,810
REVENUE:			
Research studies	189,501	171,148	56,668
Conference and Other Fees	157,922	284,921	76,042
Total Revenue	347,423	456,069	132,710
Total Support and Revenue	3,250,782	4,222,584	3,244,520
PROGRAM EXPENSES:			
Community and patient services	516,881	465,807	377,411
Education and Advocacy	497,162	568,693	1,002,267
Research	1,066,956	1,807,779	1,067,875
Total Program Expenses	2,080,999	2,842,279	2,447,553
Management and general	411,185	384,341	504,747
Fund raising	513,929	578,735	616,965
Total Supporting Services	925,114	963,076	1,121,712
Total Expenses	3,006,113	3,805,355	3,569,265
Nonoperating Income	880,016	(1,243,145)	903,033
Net Change in assets	1,124,685	(825,916)	578,287
Net Assets	10,858,739	10,032,823	10,611,110

2023 CONTRIBUTIONS



2023 BUDGET



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