Myasthenia Gravis Foundation of America

ANNUAL REPORT 2019

mg™
MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

OUR VISION: *A World Without MG*

OUR MISSION: Create Connections, Enhance Lives, Improve Care, Cure MG

2019 MISSION DELIVERY STRATEGIES:

- **Create a robust resource network to improve access and enhance lives for those with MG.**
- **Build a nationwide support network for those affected by MG.**
- **Spearhead and support promising research on MG.**
- **Improve time to diagnosis and care for MG through professional education, diagnostic tools and outreach.**
- **Raise awareness about MG through advocacy, communications and education.**

MGFA'S PROFOUND IMPACT ON THE MYASTHENIA COMMUNITY

This year was an important time in the history, and certainly the future, of the Myasthenia Gravis Foundation of America. The organization is experiencing another impactful evolution as it completed the process for creating a new strategic plan that will forge the direction of MGFA for the next three years. While these transformative efforts were taking place, MGFA continued to fund critical, promising research through **nearly 30 MG Walks** as well as other fundraising opportunities. MGFA, also, was a key player in establishing **the new MG Rare Disease Network**, **MGNet**, which focuses on enhancing therapeutic development for MG. In 2019, we hosted our staple programs like our Annual National Conference and our Annual Scientific Session, as well as three Regional Conferences. It was a very successful and productive year for MGFA and our Community with a number of program and research milestones.

Our stakeholders would overwhelmingly like us to prioritize future investment into research...

MGFA LAUNCHES STRATEGIC PLANNING PROCESS FOR 2021-2023 AND BEYOND — LOOKING AHEAD TO THE FUTURE

How does an organization go to the next level in ensuring relevance to those it serves? Staff and volunteers need to first understand the needs and interests of their key constituents. Only then can they set about developing a plan that has the right goals, and pathways to achieve them. An organization's strategic plan is its roadmap, and getting it right is essential to ensuring that leadership allocates resources for the greatest possible impact.

To ensure the best results, we asked new **MGFA Board member, Brian Gladden**, to lead the process. He not only agreed but also brought talent and resources from his business associates to guide the process. Brian is currently an operating partner for Bain Capital and has extensive executive level business experience having served as Chief Financial Officer for major corporations Mondelēz and Dell. Thanks to Brian's relationships, MGFA was the beneficiary of consulting support from Bain & Company and a non-profit organization called Inspire, which provides world-class assistance in planning to nonprofits. It was a tremendous gift for MGFA to have this leadership and expertise enabling us to conduct the deepest and most thorough planning process in our history—one that will set the direction for the organization for 2021-2023 and beyond.

Joining Brian in leading the Strategic Planning Task Force was Board Chair Emeritus, Sam Schulhof, current Board members, Phil Cogan, Mike Ursic, and Dr. Katherine Ruzhansky, and Georgia Support Group Leader, Alexis Rodriguez. As one of the first steps, we conducted an online survey designed to gather detailed feedback from members of the broad MG community on how they felt about MGFA and what they want from MGFA in the future. The survey was open for the month of September and we received almost 850 responses! We heard from family members, clinicians and others, but the vast majority of respondents (85%) were MG patients, with almost half having connected with MGFA in just the past 3 years.

Perhaps the most important message: Our stakeholders would overwhelmingly like us to prioritize future investment into research ... both in improving treatment and disease management, as well as finding the underlying causes and mechanisms of MG that could lead to a cure. MGFA CEO Nancy Law stated, "Thanks to Brian, the team from Inspire, the planning team, the MGFA Board and staff, and ALL who are participating in the survey and interviews. Working together, we will create the right plan to make MGFA the organization that the MG community needs and deserves. We are at an exciting time for the MG community, with growing understanding of our disease from scientific research and unprecedented interest from industry in developing new and better treatments—while growing programs and connections for those who live with the disease every day. We expect to be able to share a draft of the 2021-2023 Strategic Plan at our National Conference in April 2020—a plan that we hope will bring us closer to a world without MG."

MGFA PART OF $7.8M INITIATIVE TO ESTABLISH RARE DISEASE NETWORK FOR MG

MGFA is proud to represent the MG community as a member of MGNet and has committed $250,000 of funding ($50,000 for each year) to support the project. This commitment from MGFA, as well as that of Illinois-based Conquer MG, was instrumental in demonstrating the support of the MG community for the project—an essential component of the criteria for funding established by the NIH.

The grant will fund research into the underlying pathophysiology of the disease, provide fellowships in MG for young investigators, and fund pilot grants. This funding will also ensure that the serum bank created by the MGFA's transformative grant will continue. Henry Kaminski, MD, chair of the Department of Neurology and Meta Amalia Neumann Professor of Neurology at the George Washington School of Medicine and Health Sciences (SMHS), is a world-renowned expert in myasthenia gravis and has spent decades studying the disease. He is joined by Linda Kusner, PhD, associate research professor of pharmacology and physiology at GW SMHS, and Alison Hall, PhD, associate dean for research workforce development at GW SMHS, in leading this grant. "Myasthenia gravis is a chronic autoimmune disease that affects how well the nerves and muscles communicate with each other. Often patients experience extreme weakness, struggle with their vision, and are even hospitalized because of difficulty breathing," said Kaminski. "This grant will give the researcher community the needed infrastructure to study this rare disease in order to develop new therapies."

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NOW!
2019 NATIONAL CONFERENCE
Connect. Learn. Empower.

THE MGFA NATIONAL CONFERENCE CONTINUES TO GROW AND CONNECT THE MG COMMUNITY

Our National Conference is the world's largest meeting of the MG Community, bringing together people with MG, their families and caregivers, as well as a number of clinical and scientific experts and industry partners. Thanks to the amazing leadership of our Atlanta Support Group and invaluable contributions of our National Conference Planning Committee, our three day event was filled with education, support and social connections that endure beyond the conference dates.

Here are some highlights:

- **This year's conference had record attendance**, with more than 300 attendees: nearly 200 patient and family members, 40 expert speakers, and 21 representatives from industry.
- **Nearly 350 people attended our National MG Walk**, hosted by our Atlanta Support Group and community.
- **Nearly 40 MG community leaders and peer support volunteers**, both new and experienced, participated in a half-day training and networking session. These leaders attended the full conference, taking the education gained and connections built back to people with MG in their community. Whether through in-person support groups or through MGFA's peer counseling program, MG Friends, learning and insight gained can now be shared across the US and Canada.
- Popular sessions included "MG Pipeline: What's New in Clinical Trials & Treatment?" from Dr. Michael Pulley and Dr. Shruti Raja – our newest post-doctoral fellowship recipients.
- A session on the "Importance of Clinical Trials" followed, with representatives from seven different industry partners. Information provided helped to de-mystify the clinical trials process, while allowing each company to share their unique experience in working towards FDA approval of their treatment.
- The exhibit hall was bursting with information and interactive activities from **17 sponsors and exhibitors**, allowing partners to connect with attendees.

- New volunteer, and recently retired Administrative Law Judge, Elaine Deloach presented on “Navigating SSDI: Applying & Appeals”, preparing attendees with important information about Social Security Administration eligibility and benefits. Dr. Ricardo Roda and Dr. Michael Rivner also dived into the complex issue of the role of antibodies in their “Understanding Antibodies & MG” general session, making it understandable for attendees.
- Dr. Rudrani Banik and Dr. Raghav Govindarajan presented a hugely popular session on “MG & Overall Wellness”, which featured information on functional medicine, nutrition and more. Attendees gained important information on how to be proactive about their health while living with MG.
- While the conference was happening, several people with MG and their family members participated in video interviews, sharing their stories about living with MG. These touching stories will be featured on our new website (same address — myasthenia.org), and will help develop public service announcements and more to raise awareness of MG.

KEY MGFA LEADERS AND VOLUNTEERS RECOGNIZED WITH ANNUAL AWARDS

As part of our Annual National Conference, the MGFA recognizes the amazing volunteers, community members, and medical professionals who help drive our mission forward and make life better for the entire MG Community. We are happy and excited to have announced these awards.

CORPORATIONS OF THE YEAR:
Alexion, argenx, Catalyst, BriovaRx

FAMILY OF THE YEAR:
The Gershwin Family

PHILANTHROPIST OF THE YEAR:
Susie Johnson

OUTSTANDING BOARD MEMBERS OF THE YEAR (for 3 terms on Board of Directors):
Jennifer Faucett-Cote
Jurgen Venitz
Jeffrey Pilgrim

YOUNG PERSON OF THE YEAR:
Anaya Mitchell

VOLUNTEER OF THE YEAR:
Alexis Rodriguez

FOUNDERS AWARD:
Celia Meyer
Roger Morse

DOCTOR OF THE YEAR:
Jeffrey Guptill, MD

MGFA PLAYS A LEADERSHIP ROLE IN RARE DISEASE CLINICAL RESEARCH NETWORK

MGFA plays a major role in supporting the Rare Disease Research Network (RDCRN) project, with a position on the Executive Committee and participation in the Council of Patient Advocacy Groups. The launch meeting took place on November 20, 2019. One of the primary goals and requirements for this project is **to share key data and information across disease groups to learn about synergies and potential patterns in rare disease groups**. There are only 25 disease networks at any given time who are a part of this network and key milestones will be communicated and promoted in the years ahead.

REGIONAL CONFERENCES HELP EDUCATE OUR COMMUNITY IN VARIOUS U.S. REGIONS

This fall, we have had conferences in the **Pacific Northwest**, **Houston** and **New England**. Next year, we are already looking to expand to other areas. For members of the community who cannot travel to our National Conference, our MGFA Regional Conferences enable community members to hear from medical experts in their own regions – a short drive or flight to a location that is geographically closer to their homes. Attendees learn about services and resources in their local areas while connecting with friends and members of the MG Community who live close by. **Our support group network is more than 90 groups strong nationwide!**

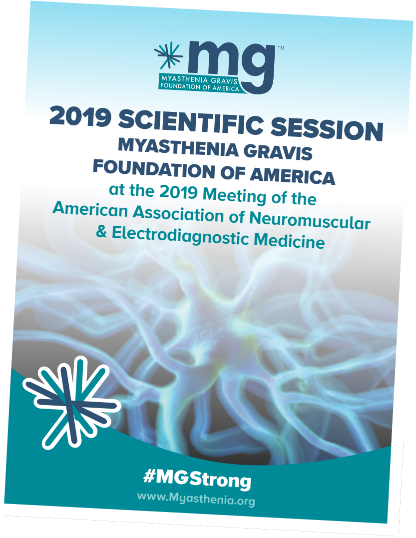
MG COMMUNITY HITS THE HILL FOR RARE DISEASE WEEK

Rare Disease Week on Capitol Hill took place from February 24 to February 28. **More than 800 rare disease advocates** traveled from across the nation to raise their voice on issues important to the rare disease community! **Approximately 450 advocates participated in 298 meetings with members of Congress**. Members of the MG Community were among the many advocates, representing California, Maryland, Connecticut, Philadelphia, New Jersey, Montana and North Carolina! Our special thanks to Lisa Douthit for helping to organize. The week kicked-off with advocates joining in-person for the Legislative Conference, with an additional 100 participating remotely via livestream. Experts from Capitol Hill and patient advocacy organizations discussed 2019 legislative priorities. Advocates learned how to build effective relationships with members of Congress and how to introduce their own legislation.

450 RARE DISEASE ADVOCATES CONVERGED ON CAPITOL HILL, PARTICIPATING IN MEETINGS WITH MEMBERS OF CONGRESS, MAKING IT THE BIGGEST LOBBY DAY EVER!

MGFA SCIENTIFIC SESSION SHOWCASES NEW RESEARCH PATHWAYS

The 2019 annual Scientific Session provided medical professionals the opportunity to learn from colleagues about current, pre-publication research in the field of myasthenia gravis. The session is always geared towards medical professionals, but is open to the public. The meeting was held in conjunction with the AANEM Annual Meeting of similar professional societies of physicians who focus on neuromuscular medicine. The event took place on Wednesday, October 16 2019 at the JW Marriott. Key presenters included Dr. Cutter discussing what to expect from registries, Dr. Hehir highlighting treatment adverse affects, and other medical professionals including MGFA chair of the Medical Advisory Board. **A series of posters and "data blitzes" focused on new research and study outcomes as well as highlights in new scientific research.**



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MYASTHENIA GRAVIS FOUNDATION OF AMERICA

2019 SCIENTIFIC SESSION
MYASTHENIA GRAVIS FOUNDATION OF AMERICA
at the 2019 Meeting of the
American Association of Neuromuscular
& Electrodiagnostic Medicine

#MGStrong
www.Myasthenia.org

RESEARCH GRANTS AND MILESTONES IN 2019

We support research that will improve the lives of patients with myasthenia gravis and related neuromuscular junction disorders. The committee has identified five broad research priorities:

- **BIOMARKERS**: facilitate early diagnosis, predict clinical outcomes and immunosuppressive therapy response and utilize in clinical trials
- **DISEASE MECHANISMS**: understand basic mechanisms and self-tolerance loss throughout course of disease
- **TARGETED THERAPIES**: develop new therapeutic targets, prevent widespread immunosuppression and off-target side effects, optimize treatment strategies with existing therapies
- **PATIENT OUTCOMES**: understand the full impact of disease on daily living and patient treatment priorities, understand collateral effects of disease; related medical conditions, side effects and financial impact
- **PEDIATRIC TREATMENT**: identify strategies, safety concerns, and long-term outcomes

In 2019, MGFA provided four research grants to the following projects and recipients:

2019 High Impact Pilot Project Grant Award: Amanda C. Guidon, M.D., Massachusetts General Hospital, Neuromuscular Diagnostic Center, “Evaluation of automated techniques for decoding speech and movement abnormalities in myasthenia” **$55,000**

2019 High Impact Pilot Project Grant Award: Jeffrey T. Guptill, M.D., Duke University, “Metabolic pathways of pathogenic Th17 Cells in myasthenia gravis” **$55,000**

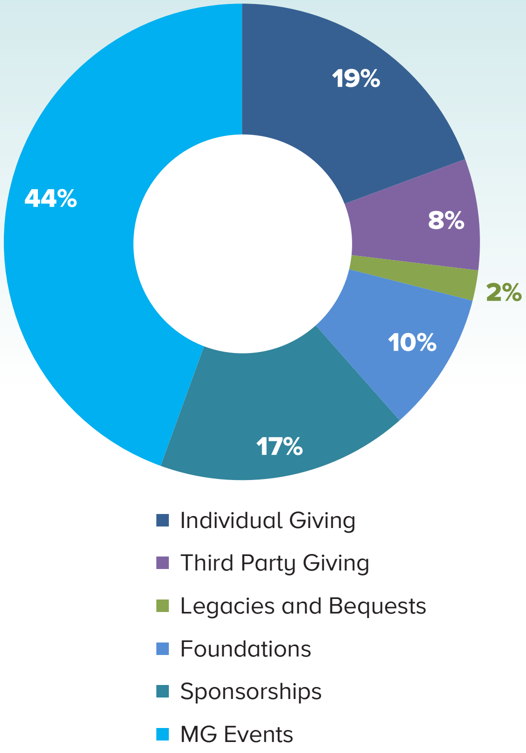
2019 High Impact Pilot Project Grant Award: Ricardo A. Maselli, M.D., University of California Davis, “CSF Delivery of AAV9-mediated gene therapy of congenital myasthenic syndrome due to CHAT mutations” **$55,000**

2019 Second year extension for **Dr. David Richman’s 2018 award**.

2020-2022 Research Contract: University of Alabama at Birmingham, “MG Patient Registry” **$329,827**

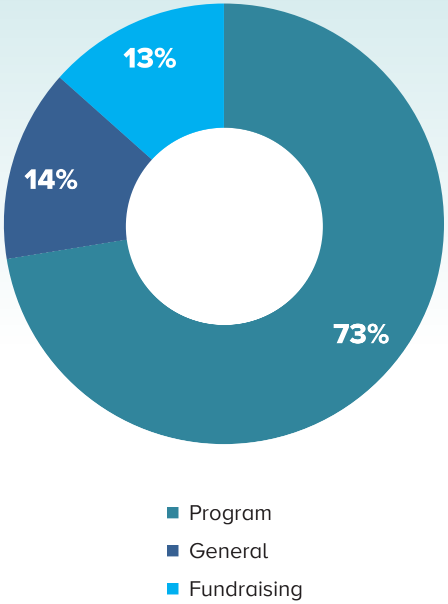
MYASTHENIA GRAVIS FOUNDATION OF AMERICA FINANCIAL INFORMATION — 2019

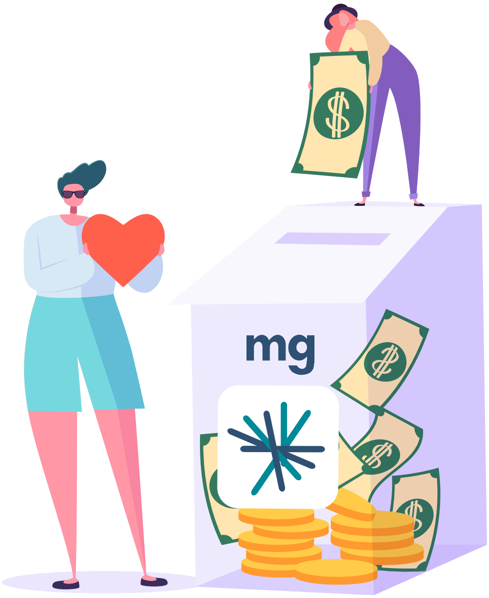
PUBLIC SUPPORT:	**2017**	**2018**	**2019**
Individual Giving	385,498	412,240	413,818
Third Party Giving	32,090	116,431	161,481
Legacies and Bequests	43,217	163,049	44,067
Foundations	114,220	140,849	203,146
Sponsorships	87,500	159,250	365,050
MG Events	858,997	1,055,762	950,367
Total Public Support	**1,521,522**	**2,047,581**	**2,137,929**
REVENUE:			
Research studies	248,069	188,670	106,360
Conference and Other Fees	34,597	30,127	71,075
Total Revenue	**282,666**	**218,797**	**177,435**
Total Support and Revenue	**1,804,188**	**2,266,378**	**2,315,364**



MYASTHENIA GRAVIS FOUNDATION OF AMERICA FINANCIAL INFORMATION — 2019

PROGRAM EXPENSES:	**2017**	**2018**	**2019**
Community and patient services	316,174	320,047	539,490
National conference	134,010	134,356	189,274
Awareness and Advocacy	518,534	543,703	356,965
Research	871,174	521,629	636,901
Total Program Expenses	**1,839,892**	**1,519,735**	**1,722,630**
Management and general	230,723	233,028	336,136
Fund raising	262,387	346,012	319,175
Total Supporting Services	493,110	579,040	655,311
Total Expenses	**2,333,002**	**2,098,775**	**2,377,941**
Nonoperating Income	1,089,451	(474,341)	1,264,287
Net Change in assets	560,637	(306,738)	1,201,710
Net Assets	**7,645,668**	**7,338,929**	**8,540,640**





2019 MGFA BOARD OF DIRECTORS
(served on Board for all or part of 2019)

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Darin Conselyea

Jennifer Cote, JD.

Kim Eldridge

Brian Gladden

Dr. Jeffrey Guptill
(Incoming Chair MSAB)

Susie Johnson

Linda L. Kusner, PhD
(Outgoing Chair of MSAB)

Michael Lifshitz

Charlene Hafer-Macko, MD

Celia Meyer, RN

Jeffrey D. Pilgrim, JD.

Denise Rossi, PhD

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Suzanne Ruff, PhD

Katherine Ruzhansky, MD

Tommy Santora

Michael Ursic

Jurgen Venitz, MD, PhD

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Allan Weiss, MD

Annette Zampelli, MSN,CRNP, IgCN
(Chair NAB)

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Beth Ulbrich, CPA, CFO

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Susan Klinger

Marcia S. Lorimer, CPNP, RN

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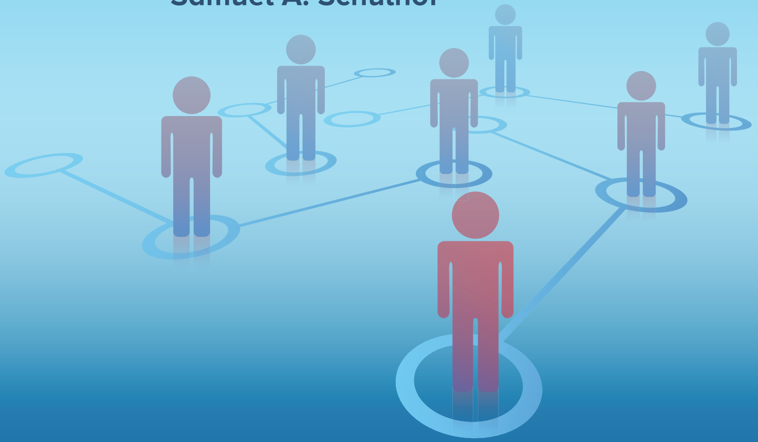

CORPORATE SUPPORT LIST

ALEXION
argenx
BIOCURE
briova Rx
Catalyst pharmaceuticals
CSI PHARMACY Clinical Specialty Infusions, LLC.
InfuCare Rx
IMMUNOVANT
KabaFusion Patient-Focused Infusion Therapy
Kroger
Momenta
RARE PATIENT Voice
SOLEO HEALTH Innovators in Specialty Infusion
The Assistance Fund
ucb Inspired by patients. Driven by science.
HPC

Nancy Law

Nancy Law, CEO

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