

# 2018 ANNUAL REPORT:

## MYASTHENIA GRAVIS FOUNDATION OF AMERICA



# 2018 ANNUAL REPORT



## VISION:

A World Without Myasthenia Gravis.

## MISSION:

The Myasthenia Gravis Foundation of America (MGFA) is committed to finding a cure for myasthenia gravis and closely related disorders, improving treatment options and providing information and support to people with myasthenia gravis through research, education, community programs and advocacy.



**250+** attendees at our 2018 National Conference



**Nearly 200** people attended our webinars in 2018



**200+** clinicians and scientists attended our 2018 Scientific Session

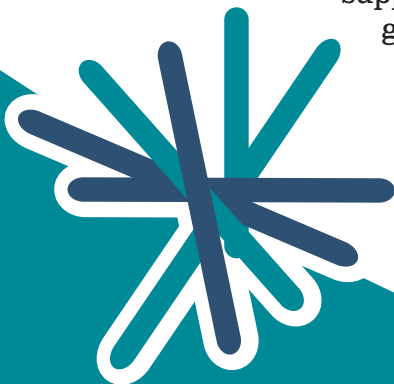


June Awareness efforts reach **more than 50,000** people annually via social media

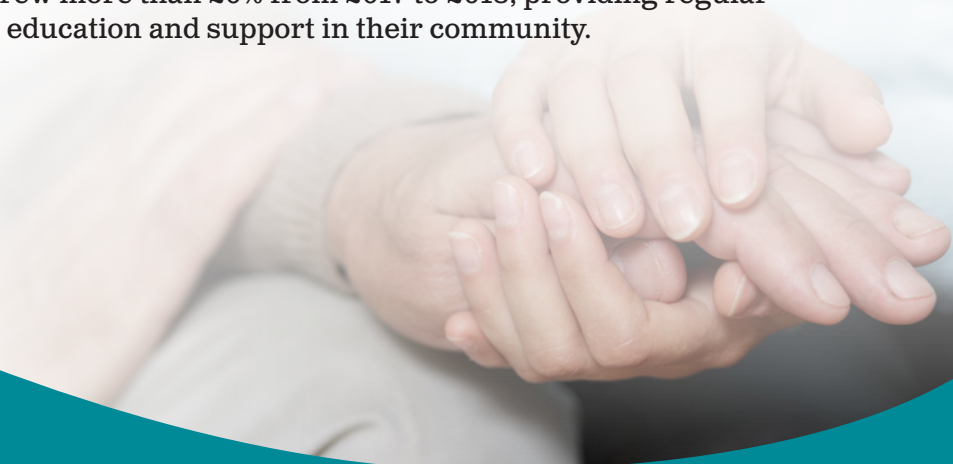
## 2018: PAVING THE WAY FOR PATIENT EMPOWERMENT

With exciting advances in research and treatment in 2017, the year ahead was one filled with renewed hope for people with MG. Building on the feedback of our MG community survey, we strengthened our commitment to help people with MG and their families in the areas of connections, information and research. Through our expanded programs, resources and research towards creating a world without MG, we can help those with MG stay #MGStrong and Be the Change!

**Strengthen Connections:** We strengthened community connections through our tele-support, peer-to-peer *MG Friends* program. This program helps those newly diagnosed with MG better navigate their care and daily challenges. In 2018, our *MG Friends* program grew more than 70% from 2017, connecting more people with MG around the nation. Our in-person support groups grew more than 20% from 2017 to 2018, providing regular gatherings for education and support in their community.

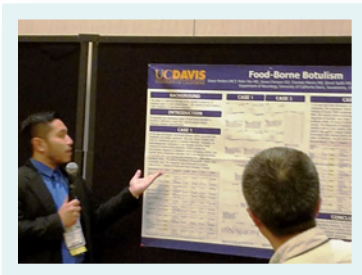


**#MGStrong**





**Strengthen Resources & Information:** We increased educational offerings and information to help people better understand and manage their MG. In 2018, we solidified our re-branding efforts and expanded our educational materials to improve education around emergency care and MG treatments. Our 2018 National Conference, themed “Be the Change!” brought together medical professionals and patients as co-presenters on topics ranging from “Crisis & Emergency Management”, “Starting a Family” to “Helping Your Child with MG Succeed”. In 2018, we increased the frequency of our digital newsletter, MG News, from quarterly to monthly to help people with MG stay connected to the latest information in advocacy, community programming and research.



**Strengthen Work Towards A World Without MG:** We experienced record-breaking attendance at our 2018 Scientific Session, with more than 200 clinicians, researchers and health professionals in attendance. More than 12 posters were displayed from scientists and clinicians around the globe. We also continued to fund a wide variety of pilot grants within the basic and clinical sciences to help people of all ages with MG.

## OVERALL PERFORMANCE

Despite the organization’s best fundraising year in history, 2018 net assets experienced a sharp decrease due to a downturn in investments at year-end. Robust public support and revenue helped offset unrealized losses due to market activity. The organization had ample cash in reserve and was able to take the calculated distribution from the research endowment while maintaining balance above corpus.

Despite the downturn in investments, 2018 public support increased nearly 35% from 2017, with fundraising efforts yielding a total of \$2,047,581. In 2018, the MG Walk experienced its most successful fundraising year-to-date, generating \$981,774 in funding support. An increase in MG Walk revenue, legacy gifts, social media fundraising and sponsorship allowed MGFA to fulfill important research obligations and launch new programs in 2018.





## RESEARCH



The Research Agenda priorities identified in 2018 are as follows:

- **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 2018, MGFA funded innovation in MG research through pilot grants to help discover new pathways to treatment and understanding of MG. We also continued to support promising research through multiple continuation grants. Research funding was under budget for 2018 as only one pilot grant application was recommended for funding. The unexpended funds will carry into 2019, allowing us to fund an expanded portfolio of promising research proposals.

The following projects, including multi-year, were ongoing or newly awarded grants during 2018:

### ✱ 2018 High Impact Pilot Project Grant Award

Principal Investigator: Andrew Engel, M.D.

Institution: Mayo Clinic

**Project Name: Genetic Basis of Unsolved Congenital Myasthenic Syndromes and the Role of the AChR-CYS Loop Length in AChR Activation**

Amount: \$50,000

### ✱ 2016-2018 Transformative Research Award for Myasthenia Gravis and Related Neuromuscular Junction Disorders

Principal Investigator: Jeffrey Guptill, M.D.

Institution: Duke University

**Project Name: Role of CD4 T cell Subsets as Drivers of MG Disease**

Amount: \$275,000

### ✱ 2016-2019 Clinician-Scientist Development Award

Principal Investigator: Michael Hehir, M.D.

Institution: University of Vermont Medical Center

**Project Name: Immunosuppressive Cost Unit: A Novel Method to Assess the Value and Cost of Immunosuppressant Side Effects**

Amount: \$160,000

### ✱ 2016-2018 Research Opportunity Fund Award

Institution: Duke University

**Project Name: PROMISE-MG Study meeting to expand research sites under Patient-Centered Outcomes Research Institute (PCORI) grant**

Amount: \$30,270

### ✱ 2016-2018 Research Contract

Institution: University of Alabama at Birmingham

**Project Name: MG Patient Registry**

Amount: \$312,952





## PROGRAMS AND COMMUNICATIONS

### 2018 National Conference: Be the Change!

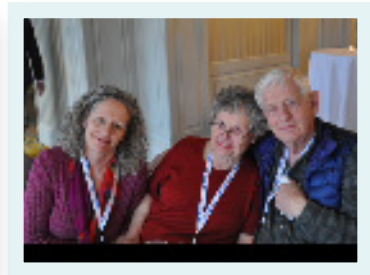
Our 2018 National Conference was held from April 15 to 17 in Kansas City, Missouri. International bestselling author and MG patient, Andrew E. Kaufman, opened the conference as keynote speaker. Andrew shared his experience about receiving an MG diagnosis and the tremendous impact it had on his life. Andrew gave an honest reflection on his experience with MG; sharing his fears as well as his journey to finding a “safe place” and strength. He spoke about the importance of “finding your tribe”; connecting with others that can support you in navigating life with MG.

With topics ranging from “New Treatment Pathways in MG”, to “Patient-Centered Outcomes Research” to “Supporting One Another”, the conference provided a forum for medical experts and community leaders to come together. Other sessions ranged from exercise to advocacy to the latest advances in surgical treatment for MG. We also hosted “Share & Care” sessions to facilitate connections among the MG community, as well as a session on staying positive with MG. Recordings of plenary sessions for the 2018 National Conference are available [here](#).



### 2018 MG NATIONAL CONFERENCE

Kansas City, MO | April 15-17, 2018  
Intercontinental Kansas City at the Plaza



### June Awareness Month

Our 2018 June Awareness theme, #MGStrong, achieved great success among the MG community. In June 2018, our Facebook post reach from non-paid sources reached nearly 181,000 people. MGFA's Twitter page alone had nearly 11,000 impressions in June 2018.

June Awareness Month in 2018 was our strongest to-date, with building lightings, proclamations and our first-ever satellite media tour. In June 2018, we secured 10 city and state proclamations, participated in nearly 25 media interviews and raised nearly \$200,000 at our New York City MG Walk.





## Information and Referral Services



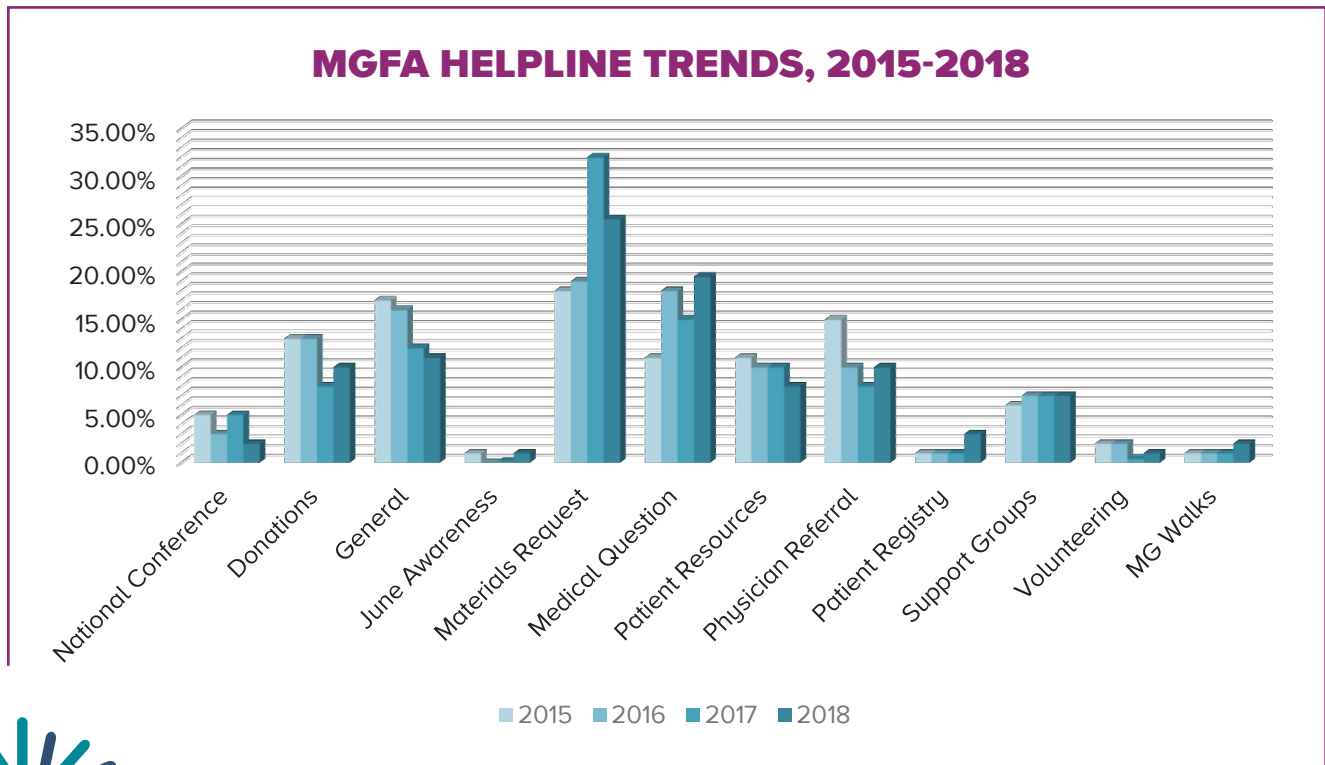
As a top priority for 2018, we strengthened our community programming to increase access to support services. Through significant growth in our MG Friends program and our Support Groups around the nation, more people than ever are supported in their MG journey.

We are also building our resources for our Partners in MG Care program, which was launched in fall 2017. This program aims to build a robust directory of MG medical experts from around the nation to help people access quality MG care. As part of our efforts to grow this program, we are launching a multi-faceted physician outreach effort, leveraging community presence as well as staff resources in targeted regions. We are also developing a physician outreach packet and web-based forms to increase patient referrals to MGFA for support resources.



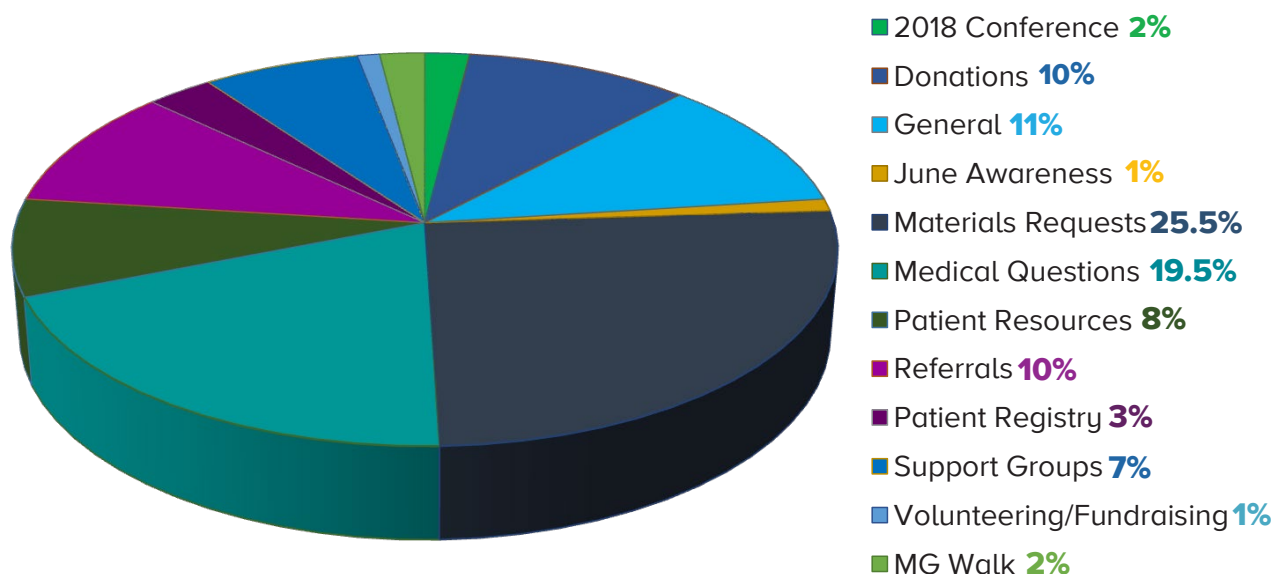
Information and resource requests continue to be a priority for MGFA. In comparing the volume of calls to MGFA’s Help Line over the past four years, we experienced increased call volume in the following areas: materials requests, medical questions, physician referrals, the MG Patient Registry and Support Groups. As we have digitized more of our materials and made them available via our website and communications channels, we have been able to take a more proactive approach to disseminating information, reducing helpline calls for National Conference, donations and general resources.

Please see a chart below that shows call volume comparison across all areas, for the period from 2015 to 2018.



In 2018, we received approximately 937 calls to our national MGFA Help Line. We received approximately 1,000 emails to our general email address inbox, [MGFA@myasthenia.org](mailto:MGFA@myasthenia.org). We disseminated approximately 2,000 information packets via to people affected by MG and health professionals. Please see the following charts that breakdown the nature of requests received via phone and email.

## MGFA HELPLINE ACTIVITY BY CATEGORY, 2018



**National Conference:** registration, agenda inquires, hotel accommodations, etc.

**Donations:** how to donate, donation processing, etc.

**General:** calls to specific staff, requests to be on mailing list

**June Awareness:** how to secure proclamations, request posters / infographic

**Materials Request:** requests for educational brochures, manuals, CDs, patient packets

**Medical Questions:** requests for information around diagnosis, treatments, medications, etc.

**Patient Resources:** requests for prescription assistance, durable medical equipment and assistance with government benefits

**Physician Referral:** requests for information about local MG medical experts

**Patient Registry:** requests on how to register, reset passwords, etc.

**Support Group/MG Friends:** requests on how to find a support group, how to start a support group; requests for one-on-one tele-support

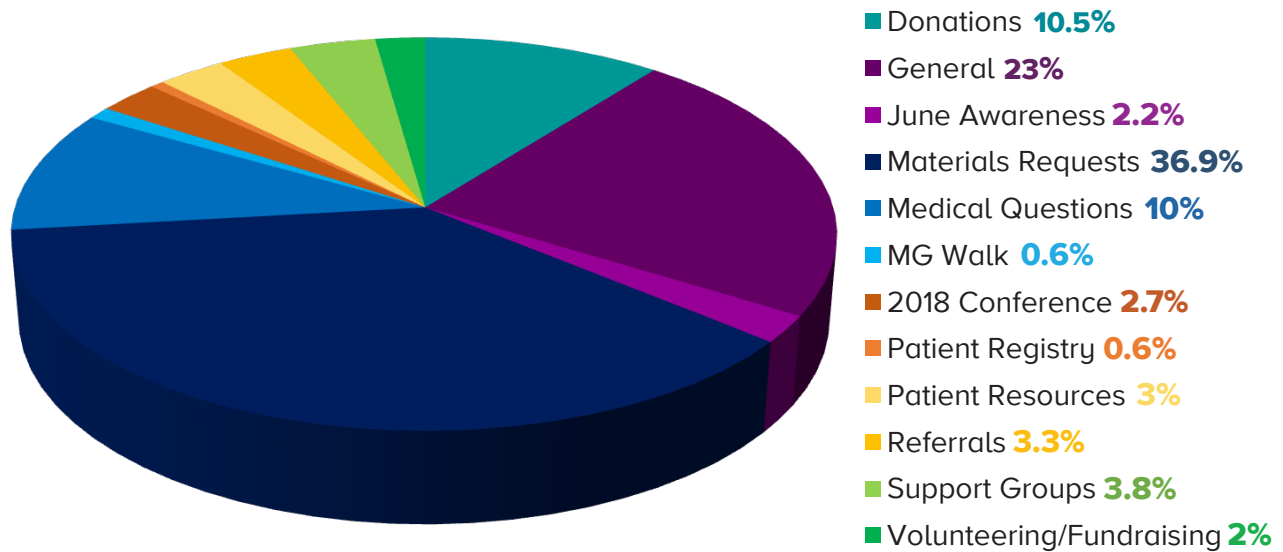
**Volunteering:** interest in volunteering and fundraising

**MG Walks:** inquiries on MG Walks





## MGFA GENERAL EMAIL ACTIVITY BY CATEGORY, 2018



### Educational Webinars

Our live webinar series allow people in the MG community to interact in real time, allowing participants to ask questions directly to experts in the field. We record and post many of our webinars to the MGFA website to ensure wide access to the information discussed. MGFA continued its ongoing webinar program series in 2018, featuring the following important topics:

- [Ocular MG](#), presented by Rudrani Banik, MD
- [MG & You](#), presented by Raghav Govindarajan, MD

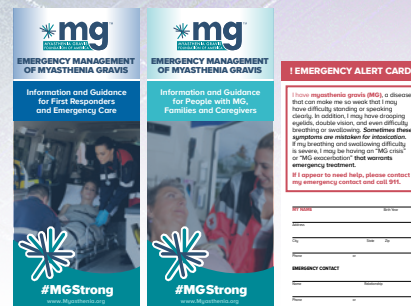
### MG Emergency Management Education & Resources

In 2018, we created a multi-faceted program to better serve the needs of the MG community when it comes to myasthenic crisis, a potentially life-threatening complication of myasthenia gravis. As many healthcare providers and first responders may be unfamiliar with MG, it may easily be mistaken for other neuromuscular diseases or the effects of substance abuse among other diagnoses. If a myasthenic crisis goes unrecognized, it can be possibly exacerbated by medical personnel unfamiliar with MG.





With the leadership of our Medical and Scientific Advisory Board Education Committee, we created a Certified Nurse Educator (CNE)-accredited webinar training. This training, available on our website [here](#), is geared towards nurses and first responders. The webinar educates health professionals regarding the symptoms, proper assessment and treatment of myasthenic crisis. As part of our work, we also created brochures for emergency management personnel, family members and caregivers. In addition, a wallet card was created to help patients communicate critical information during an emergency if they are unable to speak clearly or breathe due to respiratory muscle weakness. These materials are available on our website [here](#) and provided in print form to the public free-of-charge.



## MG Patient Registry

In an effort to understand and serve the MG community more effectively, we developed the MG Patient Registry. The MG registry incorporates general and medical information as well as diagnostic tools to gauge a patient's quality of life with MG. Information gathered from this registry will serve to drive research, expand treatment options and better understand the full impact of MG.



In 2018, the MG Patient Registry continued to grow, finishing the year with nearly 2,700 active members.

## 2018 Scientific Session

The Scientific Session provides a venue for young investigators to present data through talking and traditional posters. Posters provide an opportunity for investigators to present their work through one-on-one conversations rather than large public presentations, helping to foster research innovation from various levels within the medical community.

The 2018 MGFA Scientific Session was held on October 10 in Washington, DC. Our Scientific Session is held in conjunction with the annual meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) to bring together the brightest minds in neuromuscular medicine. With nearly 200 attendees, it was our largest Scientific Session to-date. Dr. Michael Hehir, Dr. Amanda Guidon and Dr. Araya Punwanant chaired the Session. Before the presentations began, Edward Walsh, Chair of the MGFA Board of Directors, thanked the MGFA Content Development and Review Committee, led by Dr. Yuebing Li, for his committee's work reviewing and updating our medical information literature for patients. We would like to take this opportunity to acknowledge the members of this committee for their work:

- Eugene R. Casagrande, DDS
- Emma Ciafaloni, M.D.
- Jonathan Goldstein, M.D.
- Amanda Guidon, M.D.
- Charlene Hafer-Macko, M.D.
- Michael K. Hehir, M.D.
- Vern C. Juel, M.D.
- Henry Kaminski, M.D.
- Sami Khella, M.D.
- Yuebing Li, M.D., Ph.D. (Committee Lead)
- Marcia S. Lorimer, MSN, RN, CPNP
- Janice M. Massey, M.D.
- Sally O'Meara, RN
- Michael T. Pulley, M.D., Ph.D.
- Jay S. Raval, M.D.
- Katherine Ruzhansky, M.D.
- Gil Wolfe, M.D., FAAN
- Annette Zampelli, MSN, CRNP, IgCN



Nancy Law, Chief Executive Officer of the MGFA, welcomed care providers attending the session to join the Partners in MG Care program.



## 2018 Award Recipients

MGFA is grateful for the many talented and dedicated volunteers and donors who give so much to support our mission.

We are glad to honor some of these remarkable contributors.

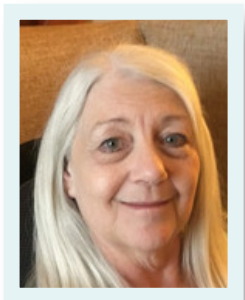


### Linda Kusner, PhD: Doctor of the Year

Dr. Kusner obtained a Ph.D. from Case Western Reserve University in the Department of Physiology and Biophysics. After a postdoctoral fellowship position in Neurology studying myasthenia gravis, she became an Assistant Professor at Saint Louis University in the Department of Ophthalmology in 2007. Due to her interest in skeletal muscle, she joined the Research Center for Genetic Medicine at Children's National Medical Center. Her research interests focused on the understanding of extraocular muscle physiology and response to disease. As the Chair of MGFA's Medical and Scientific Advisory Board, Dr. Kusner, along with Dr. Ted Burns of the University of Virginia, organized the 13th International Conference on Myasthenia Gravis and Related Disorders that was held in 2017 with the support of the New York Academy of Sciences, the National Institute of Health, and the Myasthenia Gravis Foundation of America.

### Rebecca Molitoris, Volunteer of the Year

Rebecca is a retired Chemical Engineer and Technical Communicator. She spent over 30 years working as a Research and Development Chemist, ISO 9000 Consultant, Technical Writer, and Trainer. Rebecca was diagnosed with MG in 1982 after 26 years of undiagnosed myasthenic symptoms. She served as the Facilitator of the MGFA Wooster, Ohio Chapter from 1983 - 1989. She has been the facilitator of the Greater Cleveland Area Myasthenia Gravis Support group since 2013 along with her husband Jerry (coffee man) Molitoris. Together they publish a monthly newsletter for the 100+ members of the Greater Cleveland Area MG group.



### Julia Naumes, OTD: Young Person of the Year

Julia Naumes, OTD, OTR/L, is an Occupational Therapist practicing in an outpatient hand therapy clinic in Bremerton, Washington. She was diagnosed with MG in 2011 while completing her pre-requisite coursework for her doctorate in OT. She was not aware of the MGFA until her insurance company denied treatments in 2014. Since then she has been an active member of the Pacific Northwest support groups and presented at support groups in Oregon, Washington, and Maryland. Additionally, she has attended and presented at the MGFA annual conference multiple times, has conducted and published research on MG, and was the 2016 Portland MG Walk Hero. She has a Bachelor's of Science in Exercise Science Motor Behavior and a Doctorate of Occupational Therapy. During her Doctoral Experiential Internship, working alongside Dr. Charlene Hafer-Macko at the University of Maryland and the Baltimore VA, their team conducted, analyzed, and published various research projects on the topics of promoting fitness and





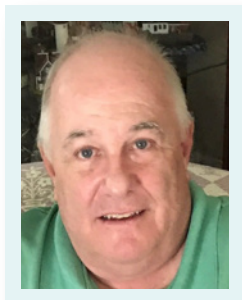
functional performance in the MG population. She is very passionate about improving quality of life and engagement in exercise in the MG population. She and Dr. Macko are currently in the process of analyzing and publishing research on prevalence of falls within the MG population.

### Celia Meyer: Chairman's Award

Celia Meyer is a RN and a Navy veteran. Celia is a graduate of Columbia College with a B.S. in Information Science. She received her nursing degree from Motlow College. Celia was diagnosed with myasthenia gravis in 2013 after being symptomatic for many years. As a member of the MGFA's Board of Directors, Celia currently serves on the MG Patient Registry Committee and the Communication Committee. Celia also assists the MGFA with their Facebook page and social media. Celia is a tireless advocate for the MG Patient Registry, and her work in promoting the importance of the Registry to MG patients has been a driver in doubling the number of participants.



*Left to Right: Julia Naumes, OTD; MGFA CEO Nancy Law; Celia Meyer, RN; Roger Morse*



### Roger Morse: Chairman's Award

Roger is a lifetime resident of Maine who spent 43 years in the insurance industry prior to retirement in October 2018. Before being diagnosed with MG in September 2012, he was an avid runner, a certified long distance running coach and also spent 12 years coaching high school hockey.

Since his diagnosis, he has battled to get back to running while continuing to coach adult beginner runners. Along with MGFA Board Member Celia Meyer, he has worked to promote the MG Patient Registry in an attempt to increase the number of registrants.

He firmly believes that a positive attitude combined with humor can make life with MG easier. That belief led to the creation of the Curing Myasthenia Gravis with Duck Tape Facebook group.

### Alexion Pharmaceuticals: Corporation of the Year

We are so grateful for the investment Alexion Pharmaceuticals has made in myasthenia gravis and in supporting the activities of MGFA. Alexion is the presenting sponsor for the MG Walk, the 2018 National Conference and the 2018 Scientific Session. They have also provided support for patient services, educational webinars and have conducted focus groups to learn more about the experiences of people with refractory

MG. As a thoughtful, kind and patient-first company, Alexion is helping to serve a great need. In 2017, their FDA-approved medication, Soliris, provided a treatment option for people with MG when other therapies failed. Soliris was the first new drug for MG in more than 60 years.



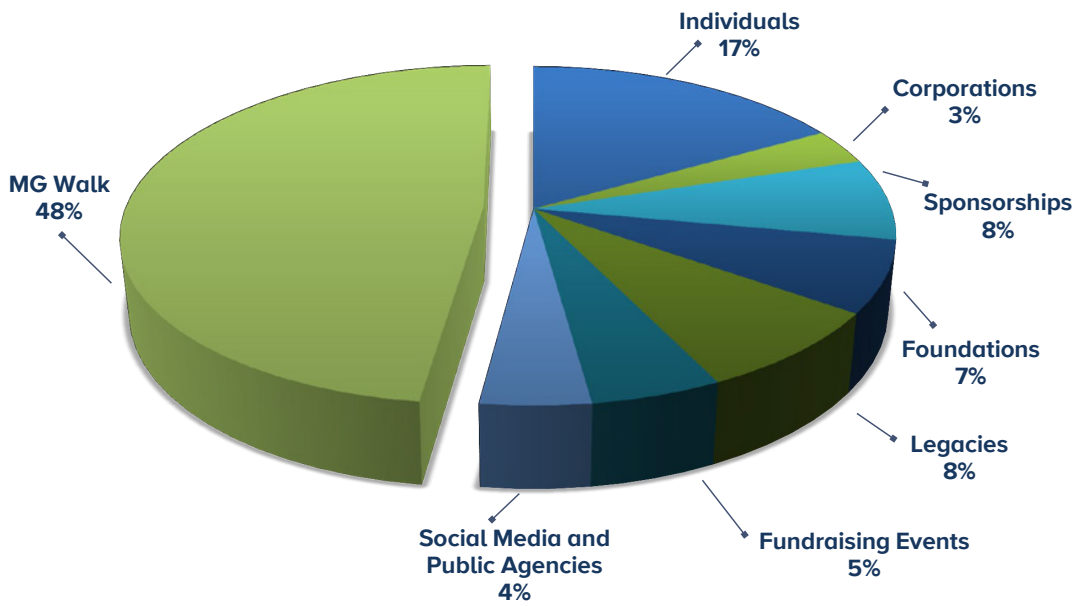
*Left: Roisin Armstrong, Ph.D., Vice President Global Team Development, Alexion Pharmaceuticals*





# FINANCIAL INFORMATION

## PUBLIC SUPPORT BY CATEGORY, 2018



### 2018 TOTAL ALL FUNDS

### 2017 TOTAL ALL FUNDS

#### PUBLIC SUPPORT:

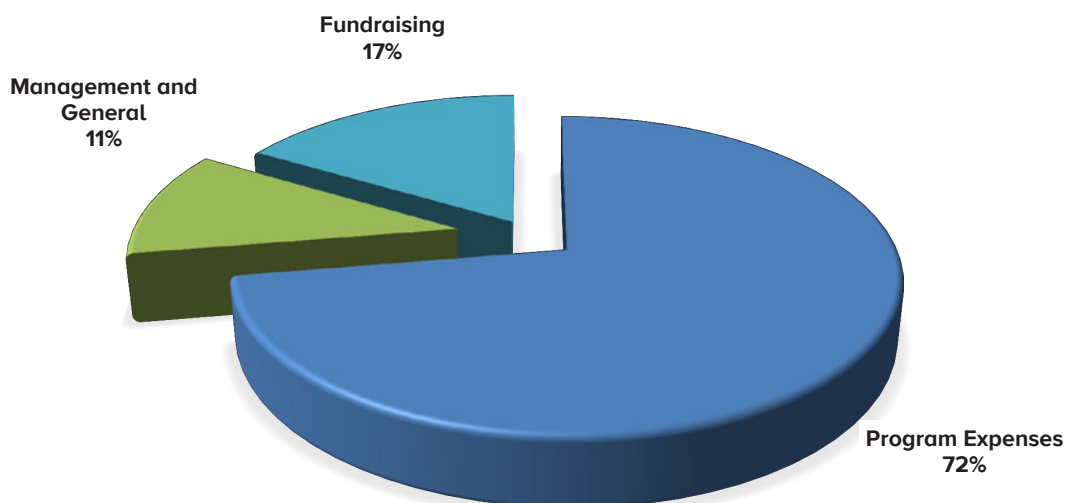
|                                |                  |                  |
|--------------------------------|------------------|------------------|
| Individuals                    | \$342,875        | \$311,206        |
| Corporations                   | 69,365           | 74,291           |
| Sponsorships                   | 159,250          | 87,500           |
| Foundations                    | 140,849          | 114,220          |
| Legacies                       | 163,049          | 43,217           |
| Fundraising Events             | 103,441          | -                |
| Social Media & Public agencies | 86,978           | 32,090           |
| MG Walk                        | 981,774          | 858,997          |
| In-kind contributions          | -                | -                |
| <b>TOTAL PUBLIC SUPPORT</b>    | <b>2,047,581</b> | <b>1,521,522</b> |





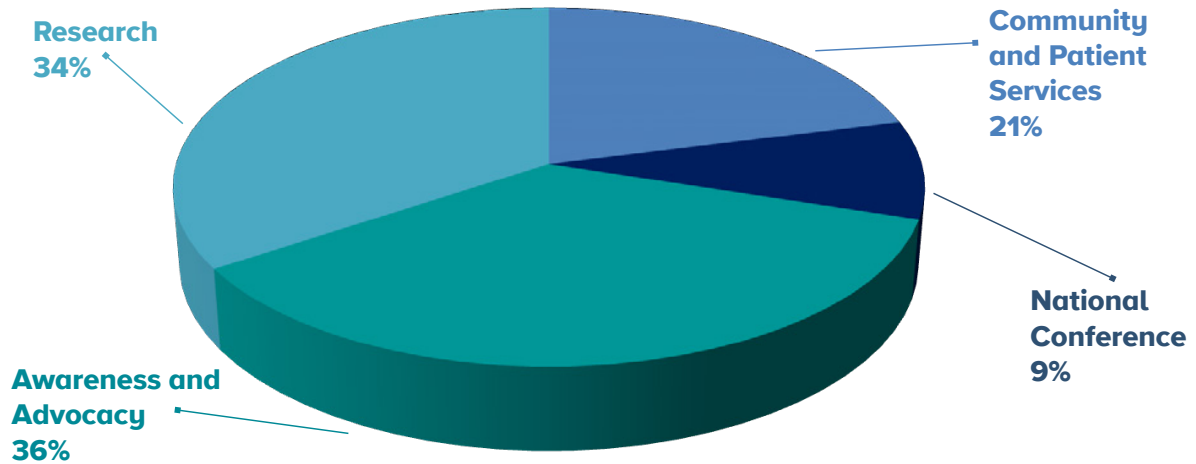
| <b>REVENUE:</b>                  | <b>2018</b>      | <b>2017</b>      |
|----------------------------------|------------------|------------------|
| Research studies                 | \$188,670        | \$248,069        |
| Merchandise sales                | 1,657            | 1,153            |
| Meeting and convention fees      | 27,554           | 30,533           |
| Investment income (loss)         | (536,091)        | 1,089,451        |
| Other income                     | 62,665           | 2,911            |
| <b>TOTAL REVENUE</b>             | <b>(255,545)</b> | <b>1,372,117</b> |
| <b>Total Support and Revenue</b> | <b>1,792,036</b> | <b>2,893,639</b> |

### EXPENSES BY FUNCTIONAL CATEGORY, 2018





## PROGRAM EXPENSES BY CATEGORY, 2018



| <b>PROGRAM EXPENSES:</b>          | <b>2018</b>      | <b>2017</b>      |
|-----------------------------------|------------------|------------------|
| Community and patient services    | \$320,047        | \$312,694        |
| Annual conference                 | 134,356          | 134,010          |
| Awareness and Advocacy            | 543,703          | 518,534          |
| Medical and Nurse Advisory Boards | -                | 3,480            |
| Research                          | 521,629          | 871,174          |
| <b>TOTAL PROGRAM EXPENSES</b>     | <b>1,519,735</b> | <b>1,839,892</b> |
| <b>SUPPORTING SERVICES:</b>       |                  |                  |
| Management and general            | 233,028          | 230,723          |
| Fund raising                      | 346,012          | 262,387          |
| <b>Total Supporting Services</b>  | <b>579,040</b>   | <b>493,110</b>   |
| <b>Total Expenses</b>             | <b>2,098,775</b> | <b>2,333,002</b> |
| <b>Net Assets</b>                 | <b>7,338,929</b> | <b>7,645,668</b> |





## 2018 CORPORATE SUPPORT

*Support totaling \$1,000 or more*

|  |           |
|--|-----------|
| Alexion Pharmaceuticals, Inc. ....                       | \$116,140 |
| argenx.....  | \$60,000  |
| ARJ Infusion .....                                       | \$3,000   |
| AVASA RX.....  | \$1,000   |
| BioRx, LLC .....   | \$3,500   |
| BioTek ReMedys, Inc.....                                 | \$8,500   |
| Catalyst Pharmaceuticals .....                           | \$25,000  |
| HPC Specialty Pharmacy .....                             | \$1,000   |
| Infucare RX, Inc. ....                                   | \$1,000   |
| Kroger Specialty Infusion CA (formerly Biofusion) .....  | \$9,000   |
| Momenta Pharmaceuticals, Inc.....                        | \$10,000  |
| NuFactor Specialty Pharmacy.....                         | \$6,000   |
| Optum Services, Inc. — Briova (formerly AxelaCare) ..... | \$35,000  |
| Ra Pharmaceuticals.....                                  | \$12,000  |
| Soleo Health Holdings, Inc. ....                         | \$11,000  |
| Superior Biologics NY, Inc. ....                         | \$3,000   |
| Terumo BCT.....  | \$3,030   |





## 2018 BOARD MEMBERS

**Allan Weiss, MD**

**Charlene Hafer-Macko, M.D.**

**Denise Rossi**, Treasurer

**Edward T. Walsh**, Chairperson

**Jeffrey Pilgrim**

**Jennifer Faucett Cote, J.D.**

**Jurgen Venitz, M.D., Ph.D.**

**Robert L. Ruff, M.D., Ph.D.**

**Susan Klinger, Vice Chair**

**Suzanne Ruff, PhD**, Secretary

**Tommy Santora**

**Michael Lifshitz**

**Celia Meyer, RN**

**Katherine Ruzhansky, M.D.**

**Phil Cogan**

**Darin Conselyea**

**Kim Eldridge**

**Linda Kusner, Ph.D.**

**Michael Ursic**

**Annette Zampelli**

**Ex Officio: Nancy Law**, Chief Executive

**Ex Officio: Beth Ulbrich**, Chief Financial Officer

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**Nancy Law**, Chief Executive

*Nancy Law*

**Edward Walsh**, Chairman

*Edward T. Walsh*

**Susan Klinger**, Vice Chair

*Sue Klinger*

