

2017 ANNUAL REPORT:

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

2017: LIVING YOUR BEST LIFE WITH MYASTHENIA GRAVIS



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.

2017: A LANDMARK YEAR FOR THE MG COMMUNITY

It was the year that many had thought might never happen. We had been waiting for such a long time. Since the approval of Mestinon in 1955, no new FDA-approved treatments for myasthenia gravis (MG) had surfaced in more than six decades. In 2017, our wait was over. Treatment Soliris (eculizimab), a drug previously approved for two other rare conditions was now FDA-approved for myasthenia gravis. By blocking the terminal complement cascade, a part of the immune system that triggers damage to muscle cells, the medication showed promising results in the clinical trial phase for people with autoimmune MG. It was particularly exciting that this treatment worked for people who had been refractory to other treatments for MG. Looking back to 2010, MGFA is particularly proud to have paved the way for promising research on role of complement inhibitors in MG through our pilot grant award to Dr. Linda Kusner.

While research never moves as quickly as we would like, there is often a tipping point, when the years of scientific discovery and dedication come together towards new understanding and treatment. 2017 was that year for MG. With one drug approved, we saw increasing interest in others—some with similar mechanisms and others that identified different pathways. That interest peaked at an incredible gathering in May 2017.

Every 5 years, in partnership with the New York Academy of Sciences, MGFA sponsors the premiere international meeting on MG. In 2017, at the 13th International Conference on Myasthenia Gravis and Related Disorders, 300 of the top MG experts from around the world gathered at the



Freedom Tower in New York City. The meeting featured 60 presenters and more than 100 posters. Representatives from the pharmaceutical industry also attended, propelling even more trials in MG treatment. It was clear to all who attended — we are getting closer to a world without MG.

We are moving forward on our commitment to help people with MG and their families, helping them live their best lives with MG. Based on survey feedback, the MG community identified three priorities for MGFA: connections, information and research.

We are proud to provide a forum for people with MG to share and help each other in their journey. In 2017, we decided to take our community support efforts one step further with the launch of our tele-support program, MG Friends. Thanks to our amazing group of dedicated and knowledgeable volunteers, every person with MG has the opportunity to connect with a friend via phone, providing support in every corner of the country, year-round.

We are proud to provide crucial resources and information to help people better understand and manage their MG. In 2017, we continued our work on re-branding MGFA, ensuring that information was more accessible, robust and up-to-date. We strengthened our local presence and awareness efforts through networking and training opportunities for support groups. At our 2017 National Conference, themed "Living Your Best Life with MG," more than 250 people gathered in New Orleans, many at our conference for the first time. It was wonderful to watch people connect in person with friends they made on social media.. The conference also gave light to a new idea; that MGFA would serve as a hub for the MG community, embracing all who are working to improve the world for people living with MG and related disorders.

We are proud to be supporting innovative research that brings us closer towards a cure for MG. In 2017, our Medical and Scientific Advisory Board revised the research agenda to incorporate a wider reach for people of all ages with MG. We also funded a number of pilot grants as well as extended promising research grants throughout 2017, ensuring continued momentum in scientific discovery and treatment options for MG.

OVERALL PERFORMANCE

While 2017 revenue experienced a decrease of \$375,000 from 2016, it was largely due to an influx of unanticipated bequests in 2016, which totaled nearly 1.3 million. In 2017, MGFA revenue succeeded 2016 revenue in almost every category, with the exception of bequests.

The MG Walk had its most successful year to-date, with fundraising efforts yielding a total of \$859,000, an increase of more than \$65,000 from 2016. In 2017, the MG Walk raised MG awareness in more than 35 communities around the country, in addition to serving as a rallying point for people with MG to connect with each other. MG Walk revenue, robust investment growth and gifts from individuals and foundations allowed MGFA to fulfill important research obligations and launch new programs in 2017. We exceeded revenue goals for 2017, with an increase in net assets of more than \$560,000 at the conclusion of the year.



RESEARCH



MG research continued to accelerate in 2017, as demonstrated by the presentations at the 13th International Conference on Myasthenia Gravis and Related Disorders. To read summaries of the presentations, please see here.

The Medical and Scientific Advisory Board revised our Research Agenda, adding research for pediatric myasthenia gravis as a priority.

The Research Agenda priorities identified in 2017 are as follows:

- Identifying biomarkers
- · Mechanisms of the disease
- · Therapeutic strategies
- · Improving patient outcomes
- · Pediatric treatment strategies, safety concerns, and long-term outcomes.

To see our complete Research Agenda, please see <u>here</u>.

In 2017, 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.

The following projects, including multi-year, were ongoing or newly awarded grants during 2017:



Principal Investigator: Ricardo Maselli, M.D.

Institution: University of California, Davis

Project Name/Description: **Stem-cell treatment of congenital myasthenia associated with endplate acetylcholinesterase deficiency**

Amount: \$50,000

Year & Award Type: 2016 Extension Research
Opportunity Grant Award

Principal Investigator: Jeffrey Guptill, M.D.

Institution: Duke Clinical Research Institute

Project Name/Description: **B10 Cells in MG/ Generate pilot polychromatic flow cytometry data on the role of B10 cells in a broad population of MG patients**

Award Amount: \$50,000



Principal Investigator: Ruksana Huda, Ph.D

Institution: University of Texas, Medical Branch

Project Name/Description: **Novel cell specific**

therapy for autoimmune myasthenia

Amount: \$50,000

Year & Award Type: 2016 Extension
Research Opportunity Grant Award

Principal Investigator: Linda L. Kusner, Ph.D.

Institution: George Washington University

Project Name/Description: **GWU/Anti-apoptotic**

Mechanisms in Persistence of Autoimmune Myasthenia Gravis Award

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Amount: \$50,000



Year & Award Type: 2016-2018 Transformative
Research Award for Myasthenia Gravis and
Related Neuromuscular Junction Disorders

Awarded to: Jeffrey Guptill, M.D.

Institution: Duke Clinical Research Institute

Project Name/Description: Role of CD4 T cell

subsets as drivers of MG diseases

Amount: \$275,000



Awarded to: Jon Lindstrom, Ph.D.

Institution: University of Pennsylvania

College of Medicine

Project: **Determining the Best Adjuvant Usable**

in Humans for Specific Immunosupressive

Therapy in MG

Amount: \$50,000



Awarded to: David Richman, M.D.

Institution: University of California, Davis

Project: Targeted Therapy of Myasthenia
Gravis with Chimeric Autoantibody Receptor

to T Cells

Amount: \$50,000

Year & Award Type: 2016-2018 Research Opportunity Fund Award

Institution: University of Alabama at

Birmingham (UAB)

Project: MG Patient Registry

The MG Patient Registry is a data gathering and analysis tool designed to expand our understanding of MG and allow for further study of MG and its impact on people with MG.

Amount: \$312,952

PROGRAMS AND COMMUNICATIONS

2017 National Conference: Living Your Best Life with MG

We held our largest National Conference to-date in New Orleans, Louisiana, will more than 250 attendees. The program included a line-up of outstanding speakers ranging from health professionals to community leaders, to people affected by MG. Recordings of plenary sessions for the 2017 National Conference are available on our website **here**.

Our keynote speaker was Dr. Vickie Petz Henderson, who captivated the attendees with her personal story about MG. As a speaker, author and motivator, she shared her "Right Side Up Life" philosophy and her presentation entitled, "Unwrapping the Gift."











Renowned MG experts, Dr. Robert Ruff, Dr. Gil Wolfe, Dr. Gary Cutter, Dr. Richard Nowak and Dr. Jon Lindstrom participated in a panel on MG research. Other sessions ranged from exercise to treatment options to strategies to take charge of your MG; a broad range of topics for people of all ages and abilities with MG. Share & Care sessions in addition to other opportunities encouraged both conference veterans and newcomers to share their experiences and coping strategies in a supportive environment.

June Awareness Month

Our 2017 June Awareness theme, MGStrong, achieved great success among the MG community. The Twibbon launched via social media outlets, reaching almost 50,000 people on Facebook. Nearly 10,000 people re-posted the Twibbon on their individual Facebook page, multiplying our awareness reach even further. In June 2017, MGFA's Twitter page alone had nearly 11,000 impressions.











Our infographic, developed to educate and increase awareness around MG, reached approximately 30,000 people, thanks to social media and grassroots outreach of our robust volunteer network. Twibbon and Infographic efforts combined, 6,000 people clicked to learn more about MGFA, re-directing them to information on our website.

A large portion of our awareness efforts in 2017 focused on informing the larger MG community and the public about groundbreaking research presented at the 13th International Conference on Myasthenia Gravis and Related Disorders. To ensure wide dissemination of this critical information for those that were unable to attend in person, we conducted video interviews with nearly a dozen presenters at the conference. These videos were posted on our website, Facebook page and on YouTube.

Information and Referral Services

In 2017, the MG community voiced the need for community connections as a top priority. To



meet this need, we launched first nationwide peer-to-peer tele-support program for people with MG. Looking forward, we will continue to innovate and deliver high-quality programs for the MG community and expand our network of support services.



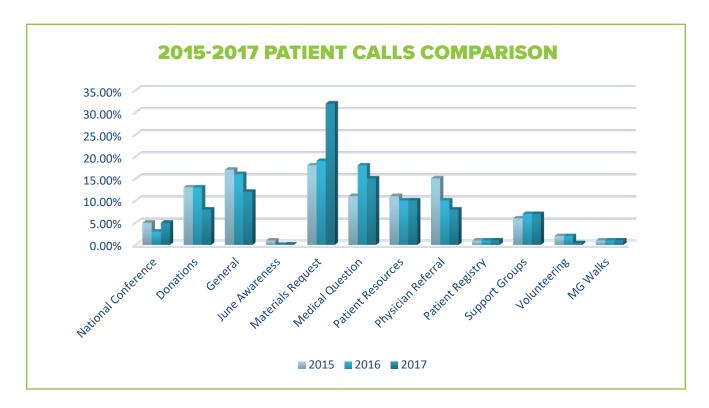
 With the help of our Medical and Scientific Advisory Board's Education Committee and our 2017 Doctor of the Year, Dr. Yuebing Li, we embarked on a project to audit more than 20 different educational brochures. This project has a three-fold goal: 1) update critical information about MG, treatment and support resources; 2) explore needs for new brochures and content; and 3) re-design and re-brand brochures to increase organizational visibility. We made significant

progress on this project; more than half were complete by the end of 2017, with the remainder slated for completion in 2018. As a result of our efforts, we experienced an increase in requests for brochures from nationwide support groups and physicians' offices.

Information and resource requests remain a priority for 2017. In comparing the volume of calls to MGFA's Help Line over the past three



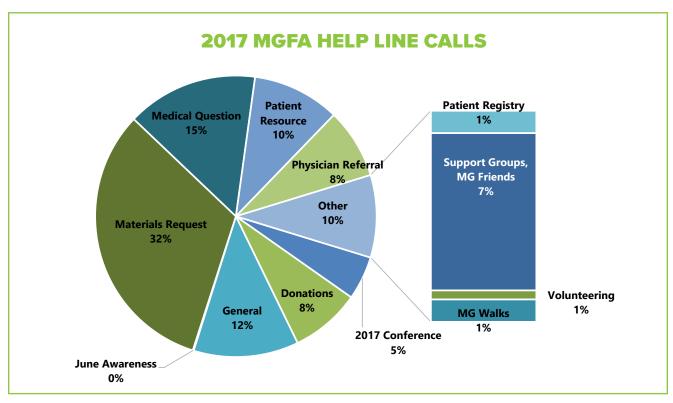
years, we experienced increased call volume in the following areas: materials requests, National Conference and support groups. We attribute the significant increase in materials requests during 2017 to our efforts around our brochure audit project. Please see a chart below that shows call volume comparison across all areas, for the period between 2015 through 2017.



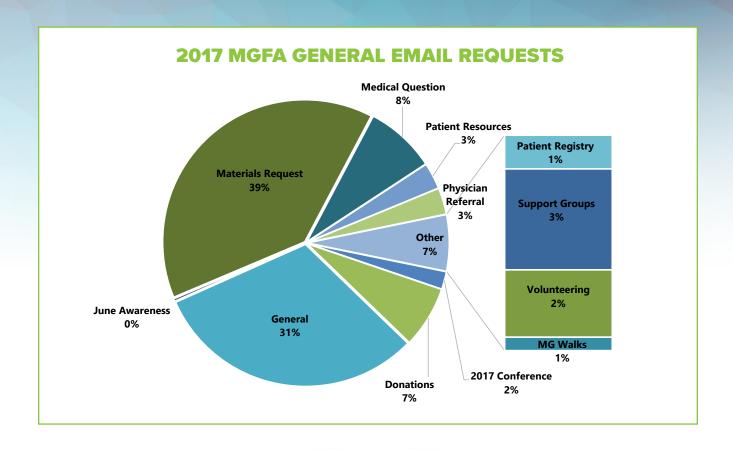


In 2017, we received approximately 850 calls to our national MGFA Help Line. We received approximately 1,000 emails to our general email address inbox, MGFA@myasthenia.org. We disseminated approximately 520 information packets via mail and email to people affected by MG and health professionals. Please see the following charts that breakdown the nature of requests received via phone and email.

- 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







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 2017, featuring the following important topics:

- Patient Questions Answered, presented by Sami Khella, M.D. and Jonathan Goldstein, M.D.
- <u>Living Your Best Life with MG</u>, presented by Suzanne Ruff, Ph.D. Robert Averack and Rachel Higgins
- Falls & MG, presented by Charlene Hafer-Macko, M.D. and Julia Naumes, OTD, OTR/L
- MG Drugs in Development, presented by Robert Ruff, M.D., Ph.D. and James Howard, M.D.

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 2017, the MG Patient Registry continued to grow, finishing the year with 2,280 active members.



2017 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 2017 Scientific Session took place at the Annual Meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) on Wednesday, September 13, 2017, in Phoenix, Arizona. Dr.

Jeffrey Guptill, Dr. Michael Hehir and Dr. Amanda Guidon chaired the session. Both Dr. Guptill and Dr. Hehir were recipients of Clinician-Scientist Development Awards, which are jointly funded by MGFA and the American Academy of Neurology.

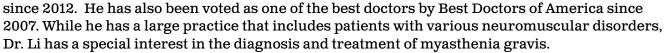
2017 Award Recipients

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.

Yuebing Li, MD: Doctor of the Year

Dr. Li gives tirelessly to MG Community, not only as a compassionate clinician and participant in research studies, but also as an active member of the Education Committee of the Medical and Scientific Advisory Board. In 2017, Dr. Li helped us launch a two-year project to review and revise all of our educational brochures. He also became the first Medical Chair for the MG Walk helping to bring in participants from the patient and professional communities, diversifying our efforts in the Cleveland area. Dr. Li has served as a staff neurologist in the Neuromuscular Center at the Cleveland Clinic Foundation since 2012. He has also been voted as one of the best doctors by Best Doctors of





Sally O'Meara is an amazing example of perseverance, generosity of spirt and commitment to learning. After four years of struggling in finding a proper diagnosis for her symptoms, she was diagnosed with MG. Soon after being diagnosed, she joined our Nurses Advisory Board. Sally has been a powerhouse in educating both health professionals and patients about MG. She is a nursing educator at Oakland

University School of Nursing. After some unfortunate personal experiences, Sally became passionate about a critical but often overlooked aspect of MG management, recognizing and managing MG



Center: Sally O'Meara, MSN, RN

crisis. Sally has created materials for people affected by MG and health professionals, with a focus on emergency room personnel. Her educational efforts have saved lives.



Steven Hawco: Outstanding Service Award

Steven Hawco did not have a personal connection to myasthenia gravis when former Chair Sam Schulhof recruited him to our Board, but he soon became a dedicated leader. Steven brought needed skills to our Board as a smart, skilled digital marketing and e-commerce executive. Steven has served as leader and creative thinker with over twenty years of transforming companies and brands to achieve their goals; having worked with the LEGO Group; Wyndham Worldwide and Maidenform. Steven served on the Board of Directors Finance Committee, while also providing

invaluable expertise on MGFA's web and social media communications. Despite completing three terms on the Board, Steven has continued to support MGFA's work. Steven has been the chief advisor for the re-design project of MGFA's website, to be launched in 2019. Steven also still lends his expertise to our Finance Committee.

Susan Klinger: Outstanding Service Award, Volunteer of the Year



Right: Susan Klinger

Susan Klinger is a name known to many in the MG community. A person with MG herself, Sue is a passionate advocate for people with MG. Sue has helped hundreds of patients with MG navigate the complex health care system, in addition to helping them adjust to the challenges of living with MG. Susan started the New York Support Group several years ago and continues to serve as its stalwart leader. As a former Vice President for Human Resources with Citi Bank, she brings nearly 30 years' experience in helping people with complex issues. Since her retirement from Citi Bank, Susan has volunteered with the Medicare Rights Center as a Health Advocate. She has also served as a Board Member and Human Resources Chair for the Human Development Services of Westchester, a social services organization focused on mental

health and housing. Despite her busy schedule, MGFA remains a top priority. Susan has given exemplary service on the Board of Directors, serving as its Vice Chair, for more than a decade. Through her Board recruitment efforts, she has made a profound impact in diversifying and expanding MGFA's expertise.

Marilyn Cohen: Lifetime Achievement

Marilyn Cohen has lead her South Florida Support Group for more than 14 years. Marilyn received a diagnosis of MG more than 17 years ago, having spent 3 years in an out of intensive care. Despite a long and arduous journey with MG, Marilyn goes above and beyond to help others in their MG journey. As a friendly face in the hospital or a patient advocate, she is always there to lend a hand or an ear.

Marilyn is a devoted mother, grandmother, and now great-grandmother. She has also helped fundraise to support people with MG through the MG Walk.



Center: Marilyn Cohen

Robert Ruff, M.D, Ph.D.: Lifetime Achievement

Dr. Ruff has been involved in MG research and treatment for over 30 years. Dr. Ruff is a leader in the community and a member of our Board of Directors. He serves as the Chair of our Medical and Scientific Advisory Board. Dr. Ruff brings his experience, wisdom and willingness to roll up his sleeves and work to help the MG community, as our resident medical expert. Dr. Ruff is the retired Chief of Neurology at the Cleveland VA Medical Center and National Director of Neurology for the Department of Veterans Affairs. He is a neurologist and biophysicist. Dr. Ruff is also a professor of Neurology and



Right: Robert Ruff, M.D., Ph.D.

Neurosciences at Case Western Reserve University School of Medicine and Acting Director of Rehabilitation Research and Development Science for the Department of Veterans Affairs. He also serves as a member of our Communications Committee. Dr. Ruff always puts patients first, and he is a tireless advocate for patient rights.

Nicolette Hoffman: Young Person of the Year



Right: Nicolette Hoffman

Even though a junior in high school, Nicolette helped organize a MG walk in her hometown of Tallahassee, Florida. The Tallahassee MG Walk is now approaching its seventh year, with Nicolette and her team raising over \$94,000. She also contributed to an MGFA public service announcement in 2011. While attending the University of Florida, she was dedicated to service, working with causes such as Girls Scouts of the USA, Gators March for Babies and Prevent Child Abuse America. Nicolette has since graduated, earning a public relations degree with honors. She is now pursuing a career in communications and public relations with a focus on sports, hospitality and nonprofits.

Alexion Pharmaceuticals: President's Award

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 2017 National Conference and the 13th International Conference on Myasthenia Gravis and Related Disorders. 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. In 2017, Alexion's contributions total more than \$150,000. 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

The Snow/ Goldstein Family: Family of the Year

In 2009, Jasmine Snow learned that she had MG. After an initial year of confusion, fear and getting to acclimating to her "new normal", Jasmine decided to become part of the MG community. After attending support group meetings in New York City and hearing about the MG Walk, she knew that she had to get involved. Competitive by nature, Jasmine knew that she could use her extensive contacts to raise money for the MG Walk, easily surpassing other members' fundraising efforts.

Inspired, Jasmine left that meeting and immediately put together an MG benefit to raise money for the Tri-State MG Walk. Her team, "Jas and the Riverside Rockstars," raised over \$90,000 that year, gaining the confidence and momentum to continue the benefit for six more years!

Meanwhile, Jasmine's mother, Mary Beth, started the "Knock the Socks Off of MG" campaign. Every year, she sends several hundred letters to family, friends and colleagues asking for donations. With each letter, she includes a pair of socks for them to take to the Tri-State MG

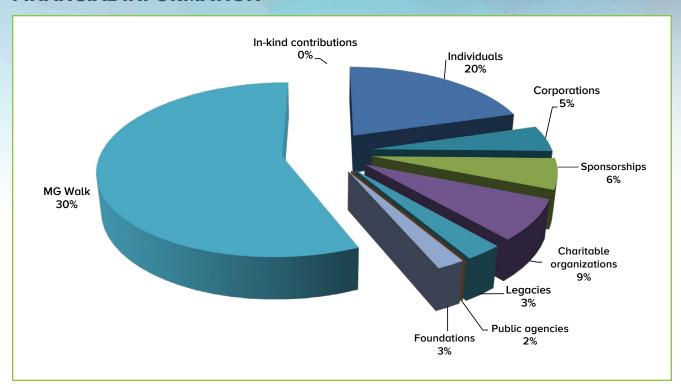
Walk. Mary Beth and her husband Russell have since raised nearly 1.5M to benefit MGFA.

There is so much hope out there for MG patients and Jasmine is a true testimony of how life goes on and gets better. Through both the highs and lows of MG, and now as parents to little Isla Blake Goldstein, Jasmine and her husband Paul have become passionate about living life to the fullest. They both hope to continue supporting MGFA, funding critical research towards a world without MG.



The Snow/ Goldstein Family

FINANCIAL INFORMATION



2017 TOTAL	ALL FLINDS	2016 ΤΟΤΔΙ ΔΙΙ	FIINDS

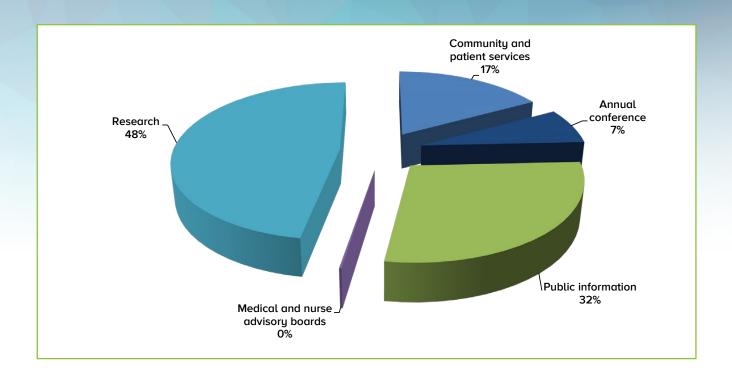
PUBLIC SUPPORT:

Individuals	\$311,206	\$321,184
Corporations	74,291	56,598
Sponsorships	87,500	35,000
Foundations	114,220	46,000
Legacies	43,217	1,129,483
Charitable organizations	-	241,067
Public agencies	32,090	48,412
MG Walk	858,997	793,632
In-kind contributions	-	-
TOTAL PUBLIC SUPPORT	1,521,522	2,671,376

REVENUE:

Research studies	\$248,069	\$136,500
Merchandise sales	1,153	1,514
Meeting and convention fees	30,533	25,212
Investment income (loss)	1,089,451	433,399
Other income	2,911	817
TOTAL REVENUE	1,372,117	597,442
Total Support and Revenue	2,893,639	3,268,818





PROGRAM EXPENSES:

Community and patient services	\$312,694	\$374,794
Annual conference	134,010	73,251
Awareness and Advocacy	518,534	576,361
Medical and nurse advisory boards	3,480	13,954
Research	871,174	556,400
TOTAL PROGRAM EXPENSES	1,839,892	1,594,760
SUPPORTING SERVICES:		
Management and general	230,723	217,194
Fund raising	262,387	240,406
Total Supporting Services	493,110	457,600
Total Expenses	2,333,002	2,052,360
Net Assets	7,645,668	7,085,032

2017 CORPORATE SUPPORT

Support totaling \$1,000 or more

Alexion Pharmaceuticals, Inc.	\$125,000
BioTek ReMedys, Inc.	\$1,000
Catalyst Pharmaceuticals	\$10,000
Florida Power and Light Company	\$2,500
Kroger Specialty Infusion CA (formerly Biofusion)	\$13,000
Louis Mohana Furniture	\$2,500
Neuroscience Group	\$1,000
Northside Hospital	\$3,000
NuFactor Specialty Pharmacy	\$7,500
Ochsner Health System	\$1,000
OptumRx- Briova (formerly AxelaCare)	\$20,000
Receivable Recovery Services, LLC	\$1,000
Soleo Health Holdings, Inc.	\$5,500
United HealthCare Services, Inc.	\$1,000
WWL-TV	\$1,000



BOARD MEMBERS

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Steven J. Hawco

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Michael Lifshitz

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