

2016 Myasthenia Gravis Foundation of America Annual Report

Do You Have Muscle Weakness?

These symptoms can be caused by **MYASTHENIA GRAVIS**

Drooping Eyelids

Slurred Speech

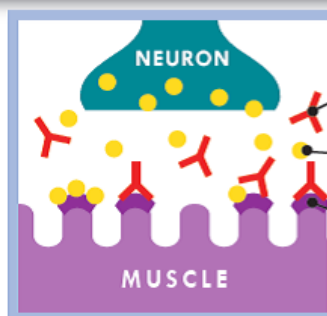
Blurred/Double Vision

Weakness in Neck, Arms & Legs

Limited Facial Expressions

Myasthenia Gravis Is...

...a disorder causing *extreme* muscle weakness and can impact a person's ability to see, smile, walk, talk and breathe. In MG, the body's immune system attacks the connection between the nerves and the muscles, limiting the ability of the brain to control muscle movement.



Antibodies block the **neurotransmitters** from connecting to **receptors**

Who Gets MG?

MG affects people of all races, genders and ages. Like snowflakes all MG cases are unique.



MGFA Can Help

If you or someone you know is experiencing sudden or gradually increasing symptoms of muscle weakness, it could be a sign of MG or another serious condition. Talk to your doctor if you are short of breath, have difficulty smiling, talking or swallowing, or cannot walk any distance without having to rest.

#MGStrong

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 www.facebook.com/myasthenia-gravis-foundation-of-america-inc

www.myasthenia.org



2016 Annual Report

TOGETHER WE ARE STRONGER

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.

2016: A YEAR OF UNIFICATION

2016 was the MGFA's first year with a unified governance structure. As with any major change, there were challenges, and some losses, which made it all the more inspiring to see how the MG Community came together to make 2016 one of the best years in history for the MGFA.

We said farewell to Chief Executive Tor Holtan and thanked him for his 6 years of service and leadership as we wished him well in retirement. Experienced non-profit executive, Nancy Law, an MGFA Board member and a person with MG, was recruited to succeed Tor. Nancy, Tor and other staff worked closely with key leadership volunteers to ensure a smooth transition.

We began the process of rebranding MGFA—to be a more proactive and relevant organization, engaging and listening to the MG community. This included outreach to other organizations, and an increased presence in social media.

Volunteers from around the country worked with staff to build a new infrastructure to ensure that MGFA continued to strengthen its local presence and grow connections with vital resources. Supporting the community leaders who facilitate support groups and awareness activities was a top priority for MGFA in 2016. Thanks to a generous grant from AxelaCare Health Solutions, we were able to offer travel subsidies to those key support group leaders to attend the national conference and a first-ever workshop for support group leaders to learn from each other and share ideas. This was a huge success, and has helped to grow long-term connections among these key volunteers.

The 2016 National Conference focused on the theme “Together We Are Stronger!” and served as the launch for the “new” MGFA—an organization that could serve as a “hub” for the MG Community, embracing all who are working to change the world for people living with myasthenia gravis and related disorders.

OVERALL PERFORMANCE

2016 was a landmark year in so many ways. Revenue was up from 2015 in almost every category: **The MG Walk** continued to be the cornerstone of fund raising efforts, with revenue increasing by more than \$66,000 to \$793,632, while also raising awareness in more than 35 communities nationwide. Gifts from individuals were up from \$207,224 to \$321,184, and investments were up more than \$400,000. In addition to all of this good news, MGFA was the beneficiary of several legacies, totaling \$1.129 million. This revenue allowed MGFA to fulfill research obligations and invest in new programs, and still finish the year with an increase in net assets of more than \$1.2 million.

RESEARCH

2016 was a year of unprecedented research breakthroughs in knowledge and understanding of myasthenia gravis.

The results of the *Randomized Trial of Thymectomy in Myasthenia Gravis*, a 6 year study funded collaboratively by MGFA, MDA and the National Institutes of Health, showed that thymectomy is an effective treatment for many people with MG.

These long-awaited study results were published in the *New England Journal of Medicine*. This study, compared patients who received a thymectomy plus prednisone to a group which received only prednisone. Those who received surgery plus prednisone had an overall reduction in muscle weakness and required lower daily doses of prednisone, 44 mg versus 60 mg for those taking prednisone alone. You can find the *New England Journal of Medicine* [article here](#). In addition, visit this video summarizing the key findings [here](#). The NIH has also done a [summary announcement](#). This trial has provided strong support for thymectomy a result that's been many years in coming.

The study was led by Gil Wolfe, MD, and Henry Kaminski, MD, former chairs of the MGFA Medical/Scientific Advisory Board.

The paper, *International Consensus Guidance for the Management of Myasthenia Gravis*, was published in *Neurology*—providing the first guidelines for clinicians for treating MG. The consensus task force, led by Don Sanders, MD and Pushpa Narayanaswami, MD, was appointed and funded by MGFA, and the organization also paid to create open access for the public (not just to *Neurology* subscribers) so patients and physicians can use this information in decision making about treatment, and advocacy for access and reimbursement for treatments from payers. We are grateful for the diligent work of the members of the consensus task force and believe this is an important step forward in better understanding the management and treatment of MG.

For the full scientific article, please [click here](#). For a summary article, please [click here](#).

Results of the REGAIN phase 3 trial of Soliris (eculizumab) were released by Alexion Pharmaceuticals. While the drug narrowly missed achieving statistical significance in the primary endpoint, the totality of the evidence was convincing, and the drug was submitted for approval in the United States, as well as in Europe and Japan. It is the first drug moved forward for approval for treating MG since Mestinon in 1955. MGFA funded early research in complement inhibition in MG--the mechanism of action for Soliris.

Due to new scientific discoveries the MGFA Medical and Scientific Advisory Board revised the *MGFA Research Agenda*. Key priorities are:

- Identifying biomarkers
- Discovering mechanisms of the disease
- Developing therapeutic strategies
- Improving patient outcomes

To see the full Research Agenda, [click here](#).

The following grants and projects (including multi-year) were funded during 2016:

**2015 Continuation MGFA RFA
Grant—\$50,000**

Ricardo Maselli, MD
University of California, Davis

“Stem-cell treatment of congenital myasthenia associated with endplate acetylcholinesterase deficiency”

**2015 Continuation MGFA RFA
Grant—\$50,000**

Ruksana Huda, Ph.D, Assistant Professor
University of Texas Medical Branch

“Novel cell specific therapy for autoimmune myasthenia”

**2016 One Year Extension Award
MGFA RFA Grant—\$50,000**

Jeffrey Guptill, MD
Duke Clinical Research Institute

“B10 Cells in MG/Generate pilot polychromatic flow cytometry data on the role of B10 cells in a broad population of MG patients.”

**2016 One Year Extension Award
MGFA RFA Grant—\$50,000**

Linda L. Kusner
George Washington University

“Anti-apoptotic Mechanisms in Persistence of Autoimmune Myasthenia Gravis”

**2013-2016 ABF-MGFA Clinician Scientists
Development Award—\$149,506**

American Brain Foundation/MGFA collaboration to provide grants to support clinician/scientists.

Post-doctoral Fellowship to Ricardo Roda, MD, PhD, Johns Hopkins University School of Medicine

“Clinical Significance and Pathogenic Mechanisms of LRP4 Antibodies in Myasthenia Gravis.”

**2016-2019 ABF-MGFA Clinician Scientists
Development Award—\$160,000**

American Brain Foundation/MGFA collaboration to provide grants to support clinician/scientists

Post-doctoral Fellowship to Michael Hehir, MD, University of Vermont Medical Center

“Immunosuppressive Cost Unit: A Novel Method to Assess the Value and Cost of Immunosuppressant Side Effects”

2016-2018 Transformative Grant—\$275,000

Jeffrey Guptill, MD
Duke Clinical Research Institute

“Role of CD4 T cell subsets as drivers of MG diseases”

2016-2018 MG Patient Registry—\$312,952

University of Alabama at Birmingham (UAB)

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 myasthenia gravis.

Programs and Communications

National Conference

MGFA held its annual National Conference in Raleigh, NC, May 2 & 3, 2016 with over 150 attendees. The program included a line-up of outstanding speakers with both health professionals and patients. The program consistently scored high with attendees --94% of plenary presentations received a score of 4 out of 5. The plenary sessions are available for viewing on the [MGFA website](#).



There was genuine excitement and a sense of comradeship when Keynote Speaker and professional actor Lenny Banovez inspired attendees with his MG Story. Henry Kaminski, MD shared the MG Thymectomy study trial results while Jeff Guptill, MD & Sally O'Meara, RN spoke on *Understanding MG Crisis*. Many other excellent talks helped to make the program rich with information and ideas as well as socially rewarding as participants got to share their MG experiences with one another in a supportive environment.

June Awareness

SNOWFLAKES IN JUNE!
Like snowflakes people with myasthenia gravis (MG) are:

- ✧ Each completely different
- ✧ Beautiful
- ✧ Stronger sticking together

WHAT'S MG?
MG is a disorder that causes extreme muscle weakness that can impact a person's ability to see, walk, talk, breathe, and even smile. Many times patients suffer without any visible symptoms. The degree of muscle weakness can vary from person to person, and day to day. Due to the high number of misdiagnoses, the precise number of people with MG is unknown, but MG is estimated to affect approximately 100,000 Americans of all ages, races and genders. There are effective treatments, but there is currently no cure for MG.

June is **MYASTHENIA GRAVIS AWARENESS MONTH**

M G F A MYASTHENIA GRAVIS FOUNDATION OF AMERICA, INC.
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To learn more about MG and how you can help, visit us online at www.myasthenia.org or call 1-800-541-5454

Snowflakes in June! was the headline for the June is MG Awareness Month poster which featured patients in all their individuality while informing the reader about "What is MG?"

Press results included 35 calendar listings and 11 original stories. These news items allowed MGFA to reach an audience of nearly 6 million. The press release was picked up by 204 outlets and there were 5,660 direct views of the press release.

An infographic was developed to provide an "MG at a Glance" tool to educate the general public and those newly diagnosed.

In addition, MGFA created its first Twibbon, #IHaveHeardofMG, which was used by 5,000 people as part of their social media profiles.

The delivery of high quality programs and services for the MG Community is a top priority for MGFA, and in 2016 we focused first on three key areas for growth:

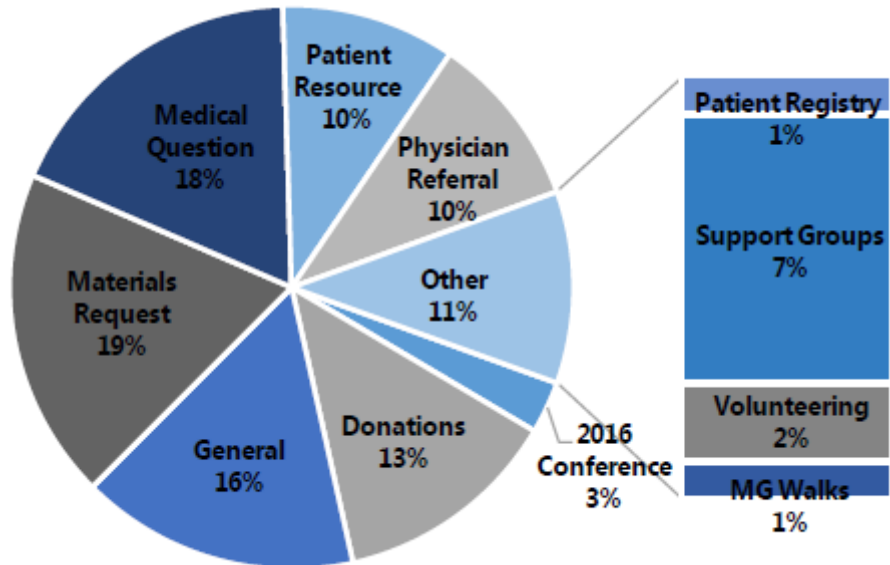
1. Upgrading the experience of those calling or emailing with questions or requests for assistance
2. Connecting people living with MG to others for learning and emotional support
3. Education for patient, professionals and industry



Information and Referral

With the change to a unified organization, the nationwide helpline became even more important than before. We used the year to collect data to better understand who was reaching out to MGFA—and why. We changed some processes to ensure that those calling and/or emailing MGFA receive a timely response and had a positive experience—no matter where they lived. Call volume increased for 552 calls in 2015 to 1035 in 2016. The chart below shows the nature of calls received in 2016.

2016 MGFA Call Log



Webinars

MGFA continued its ongoing program of webinars with these two important topics:

Thymectomy or Not? – Dr. Gil Wolfe, MD, Irvin and Rosemary Smith Chair of Neurology, Buffalo General Medical Center, lead author of “Randomized Trial of Thymectomy in Myasthenia Gravis” reported on the groundbreaking trial in this important webinar.

MG Treatment Guidelines – Dr. Don Sanders, MD, Professor of Neurology, Duke University presented the results of a 3 year effort to develop agreement among an international group of MG experts on the use of various treatments for people with MG. This effort is expected to improve treatment for MG patients and support insurance appeals when patients are denied coverage for treatments.

Spanish Language Brochures

We moved closer to our goal of serving ALL who live with MG by translating materials into Spanish. Nine brochures were translated and made available on the MGFA website:

- [*Síndromes Miasténicos Congenital*](#)
- [*Miastenia Gravis Ocular*](#)
- [*Consideraciones si tiene MG y esta Pensando quedar embarazada*](#)
- [*Cuidado para Niños*](#)
- [*Fundación de Miastenia Gravis de America, Inc*](#)
- [*Manejo de Emergencias II*](#)
- [*Manejo de Emergencias I*](#)
- [*Miastenia Gravis Autoimmune*](#)
- [*Efectos de Miastenia Gravis en la Voz, el Habla y al Tragar*](#)

Support Group Development

MGFA established eight new support groups in 2016, and also reached out to form collaborative alliances with several state and local MG organizations. Most sent representatives to the national conference. Webinar trainings were established to train new leaders and travel subsidies were provided for leaders to attend the National Conference, including the first nationwide meeting for MG support group facilitators where these highly valuable volunteers were able to learn, network and hone their skills.



Intermountain Summit:



Utah volunteers Kelly Odermott and Theresa Collins led MGFA's first regional educational summit as a unified organization. Registration was handled through the MGFA website, and funding through sponsorship, nominal fees for attendees, and support from the MGFA budget was managed centrally. The dedicated local

volunteers did the rest! CEO Nancy Law attended and spoke about a unified organization and working with communities. There were about 60 in attendance, from 5 states. This regional education program will serve as a model for more local and regional education efforts.

MG Patient Registry

MGFA has enhanced its recruiting efforts for the MG Patient Registry, led by volunteers Roger Morse and Celia Meyer. A new contract was agreed upon by both UAB and MGFA, beginning October 1, 2016.

The Registry was used to identify patients for a focus group in support of a grant application from Duke University to the Patient Centered Outcomes Research Institute (PCORI). Alexion Pharmaceuticals also used the Registry to better understand the experiences of those with refractory generalized myasthenia gravis.

2016 Scientific Session

The MGFA Scientific Session was held Sept 14, 2016 at the annual meeting of the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM). There were 11 platform presentations, and 19 posters, 5 of which were chosen as "talking" posters where the investigator had an opportunity to talk about their work. The program was attended by approximately 150 scientists and clinicians.

Impact of MG Survey

More than 670 people with MG completed a survey to help MGFA better understand the impact of MG on people's lives. The results showed the variability of experiences that people have with MG: from those whose symptoms are well under control or are even in remission, to those for whom MG has had a devastating impact on nearly all aspects of their lives. Many provided their stories, expressing a mix of frustration, sadness and hope as they cope with the impact of MG on their lives. The data and commentary have been used to help make MGFA's programs and services more responsive and sensitive to patient needs.

2016 Award Recipients

MGFA is grateful for the many amazing volunteers and donors who give so much to support our mission. We were glad to honor some of these remarkable contributors.

Philanthropist of the Year

Mona Roth is a person with myasthenia gravis who wanted to give back to the scientists and clinicians who she credits for saving her life. MGFA was honored to present the organization's 2016 Philanthropist of the Year award to Mona Roth, of Syosset, Long Island, NY. The award was presented to Mrs. Roth by MGFA's Medical/Scientific Advisory Board Chair, Robert Ruff, MD, PhD, with many of her children and grandchildren in attendance, at the 13th *International Conference on Myasthenia Gravis and Related Disorders*.



In 2016, Mrs. Roth gave an exceptionally generous gift of \$50,000 to support research, and in her acceptance speech she recognized those physicians and scientists who saved her life. The audience of 300 clinicians and scientists were honored to meet this remarkable woman, whose gift was not only a generous show of support for others who live with MG, but also a demonstration of her appreciation for their life's work. To learn more about Mona's remarkable story in the Fall 2017 *Focus on MG* magazine, [click here](#) and go to page 8.



Lifetime Achievement

Sam Schulhof is a remarkable individual who has served the MG Community with exceptional dedication. With drive, determination and imagination, Sam took the leadership of MGFA as Chairman of the Board in 2007. Back then MGFA was a much different organization -- it was struggling in many ways. Sam took up the challenge to re-create MGFA for the future. He brought his skills and experience as a former executive with General Electric Company and the University of Pittsburgh as well as in senior level political appointments with the U.S. Environmental Protection Agency, U.S. Department of Health, Education and Welfare and as deputy special assistant to two U.S. Presidents. Over ten years Sam worked tirelessly with the board to bring in new leaders, new ideas and new ways of accomplishing our mission. And Sam never lost sight of the goal – making MGFA not a good organization but a great one. He lived and breathed MGFA every day. Sam Schulhof helped lead MGFA to a new beginning. He is more than worthy of a Lifetime Achievement Award.

Young Person of the Year

Niki Grossheim is a young mom, a support group leader, and in 2016 was a member of the MGFA Community Volunteer Committee, which has been expanded to the Patient and Community Services Committee. Niki is a super fundraiser and even collected funds for MGFA at her wedding reception! Niki's perspective has been a tremendous addition in helping MGFA ensure that our groups and local programs are relevant to younger people living with MG. Niki has supported other women with MG who were considering pregnancy, and those dealing with the challenges of toddlers. Niki's baby, Brock, has been an honorary MGFA volunteer as at lots of meetings he has been right in her lap—contributing to the conversation in his own way.



Volunteer of the Year

Janet Myder is a person of many talents—and the MG Community is the beneficiary. Janet is the editor of the *MGFA E-Update*, a former MGFA board member; leads the Low Country Support Group in Mt. Pleasant S. Carolina, and is an active member of the MGFA Communications Committee. Janet is an indefatigable fighter for the MG Community. She can always be counted on to review any MGFA publication with a close eye to detail and an incisive intelligence. Janet is always at the ready to work, to stand up and be counted. She has been a strong leader in helping MGFA to engage in public and private sector advocacy. She would be an outstanding asset to any organization. We are lucky she has chosen MGFA! MGFA honors Janet for all her hard work, high standards and commitment to improving life for all those who live with MG.



Nurse of the Year

Vilija Rasutis (Vil-e-ah Ra-su-tis) is a member of the MGFA's Nurses Advisory Board. Vilija always puts herself forward to work. She is never in the background, always in the forefront-- helping to get things done. She's presented many MG sessions and written articles for the MGFA newsletter, *Foundation Focus*. She's helped create content for patients and helped to edit the parents' program materials about helping youngsters with MG. Vilija is the volunteer's volunteer and the nurse's nurse. We heartily thank her for all her contributions.

Doctor of the Year

Dr. Michael Hehir, of the University of Vermont Medical Center/the Lamer College of Medicine and the MGFA Medical/Scientific Advisory Board, is an exemplary champion for the MG community. Dr. Hehir was the 2016 recipient of the **Clinician-Scientist Three-Year Award in Myasthenia Gravis – Cosponsored by the American Academy of Neurology, the American Brain Foundation, and the Myasthenia Gravis Foundation of America**. The Research Project is: **Immunosuppressive Cost Unit: A Novel Method to Assess the Value and Cost of Immunosuppressant Side Effects**. Dr. Hehir, working with Dr. Jeff Guptill, Duke University, leads the planning of the MGFA Scientific Symposium which has grown to be a major educational and networking event for clinicians and researchers interested in MG. Mike is always at the ready to help provide information, ideas and support to MGFA and to the MG community. He's lent his support to the New England Walk and encouraged his patients to become involved with MGFA.



President's Award

AxelaCare Health Solutions, one of the top home infusion companies in the country, was very, very generous to the MGFA and to the MG Community in 2016--serving as presenting sponsor for the MG Walk, sponsoring the 2016 annual meeting; providing travel subsidies and meeting costs for the very first meeting of MGFA Support Group Leaders; and providing a grant to print the MGFA Support Group Leader Manual. AxelaCare staff also helped with issues regarding IVIg denials—providing advice and resources for MG patients. They have been caring partners for MGFA, and their support is appreciated.

Financial Information and Stewardship

The MGFA meets all of the standards of BBB Wise Giving Alliance, Community Health Charities, and the National Health Council, and is a careful steward of donations received. Seventy-eight percent (78%) of every dollar expended in 2016 went to support the MGFA's mission.

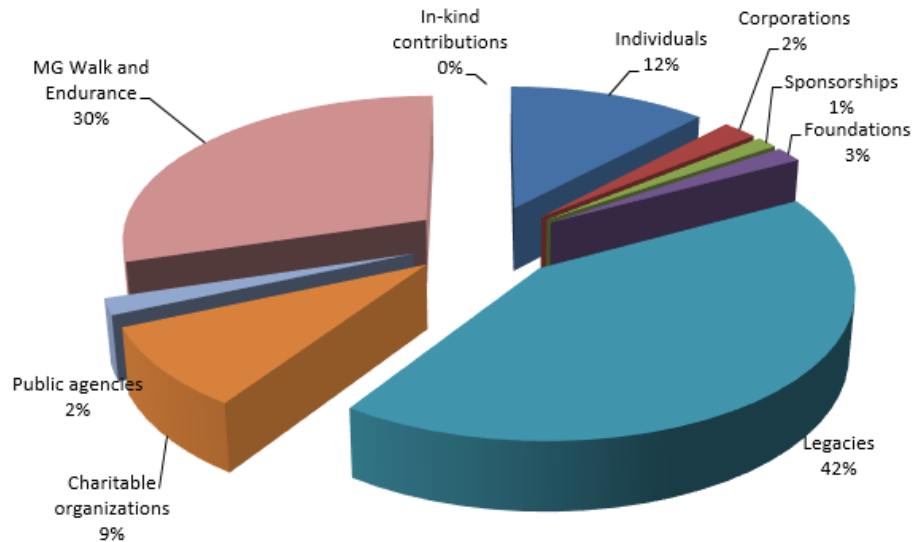
The MGFA is generously supported by donations from individuals, Walkers and Walk Teams, charitable organizations and others as shown in the pie charts on the next page.

	2016 total All Funds	2015 total All Funds
Public Support:		
Individuals	\$ 321,184	\$ 207,224
Corporations	56,598	45,500
Sponsorships	35,000	79,201
Foundations	46,000	40,204
Legacies	1,129,483	154,699
Charitable organizations	241,067	125,544
Public agencies	48,412	39,824
MG Walk and Endurance	793,632	727,520
In-kind contributions	-	-
Total Public Support	2,671,376	1,419,716
Revenue:		
Research studies	136,500	-
Merchandise sales	1,514	1,692
Meeting and convention fees	25,212	27,990
Investment income (loss)	433,399	(287,081)
Other income	817	6,653
Total Revenue	597,442	(250,746)
Total Support and Revenue	3,268,818	1,168,970
Program Expenses:		
Community and patient services	374,794	465,435
Annual conference	73,251	126,063
Awareness and Advocacy	576,361	433,990
Medical and nurse advisory boards	13,954	22,890
Research	556,400	288,127
Total Program Expenses	1,594,760	1,336,505
Supporting Services:		
Management and general	217,194	186,436
Fund raising	240,406	255,856
Total Supporting Services	457,600	442,292
Total Expenses	2,052,360	1,778,797
Net Assets	7,085,032	5,868,574

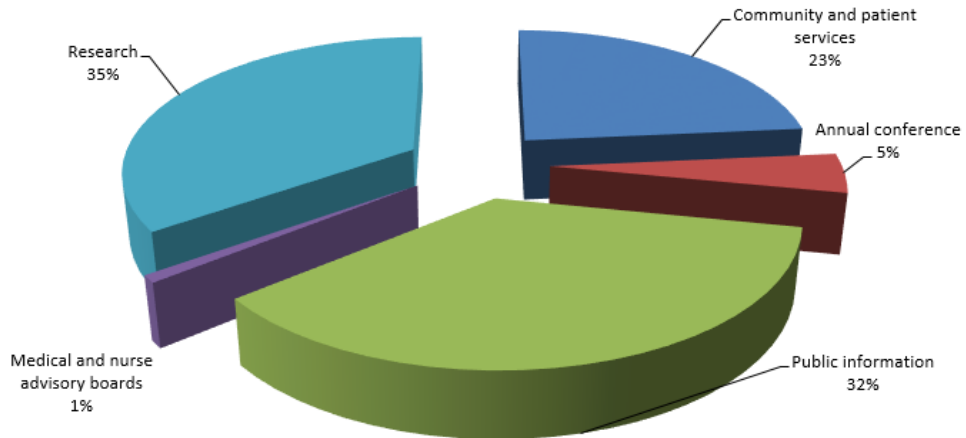
Financial Information and Stewardship cont.

The MGFA conducts a variety of programs in support of the MG community. The following pie charts shows the distribution of Public Support and Program Expenses.

2016 Public Support



2016 Program Expense



2016 MGFA Sponsors (\$1,000 or more)

The total amount of corporate support from pharmaceutical, biotechnology, and medical device companies in 2016 was 5.26% of total revenue.

\$40,000	Alexion Pharmaceuticals, Inc.	\$36,000	Option Care Enterprises, Inc.
\$15,000	Biofusion, LLC	\$70,000	Optum Services Inc.
\$3,000	Florida Power & Light Company	\$1,000	Receivable Recovery Services LLC
\$2,000	Louis Mohana Furniture	\$5,000	Soleo Health Holdings, Inc.
\$6,000	NuFactor Specialty Pharmacy	\$1,000	Rare Patient Voice
\$1,000	Ochsner Health System	\$2,000	The Home Depot Store Support

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Beth Ulbrich, CPA, Finance Director

Nakeshia Betsill, Volunteer Program Manager

Lawrence McClean, Patient Services Coordinator

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Nancy Law, CEO