2015 Annual Report:
Myasthenia Gravis Foundation of America

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.

2015: A YEAR OF CHANGE: 2015 was a memorable and extraordinary year in the history of MGFA. After extensive discussion, examining the risks and benefits, on April 30th, the MGFA General Assembly voted to approve changes in MGFA's governance structure. This decision changed the organization from a federated model, with chapters, to a unified structure. The motion to approve the proposed changes to the MGFA by-laws was approved by a vote of 21 for, 9 against, and 1 abstention becoming effective January 1, 2016.

At this same meeting 3 term board chairman, Sam Schulhof handed the gavel to incoming chairman, Edward Walsh. The volunteers thanked Sam for his dedication through nine years of service, which included developing a strategic plan and expanded research agenda, enhancing nationwide programs and services, launching a new website, and shepherding the previously described organizational changes. Sam's strong leadership through a time of change is deeply appreciated.

These structural and organizational changes meant that some functions that had been managed by chapters would now be centrally administered. Chapter leaders, support group leaders, national board members, staff and volunteers all worked together tirelessly to implement these changes and to make sure that MGFA's mission and the patients we serve were well cared for as we transitioned. To ensure continuity and essential support for local community volunteers and support groups, the MGFA Board also approved the addition of a full time staff position dedicated to working with MGFA volunteers. A Community Volunteer Committee was also organized to guide the organizational transition.

OVERALL PERFORMANCE: 2015 was a challenging year from a funding standpoint despite an increase in public support, as lower return on investments resulted in a modest decline in net assets—a trend which we hope to see reversed in 2016.

2015 MGFA Board of Directors

MYASTHENIA GRAVIS
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The MG Walk continued to be the cornerstone of fund raising efforts, and while revenue was slightly lower than 2014, we saw an upturn in participation from both individuals and teams, and the Walks raised more than $700,000—and raised awareness of MG in 35 communities nationwide. We anticipate growth in our Walks in 2016 with planning for several new sites and building on momentum in others.

And there were many highlights and accomplishments to celebrate in mission delivery----starting with our investments in research, which included both new and ongoing grants, the maintenance of the MG Patient Registry, and an educational scientific session. We also saw tremendous progress in our efforts in awareness and communications, new patient services and educational materials, and a very successful national conference.

RESEARCH AND SCIENTIFIC DISCOVERY

The Transformative Research Program was launched in 2015. This program was initiated with a goal of "supporting investigations that are focused, innovative, and highly likely to produce fundamental alterations in the understanding of myasthenia gravis and related disorders." In year one the following award was given:

2015 MGFA Transformative Research Grant—$275,000

Dr. Jeffrey Guptill
Duke Clinical Research Institute
Transformative Research /Role CD4 T cell subsets
as drivers of MG diseases

MGFA also awarded the following two new grants as well as continued others previously awarded:

2015 MGFA RFA grant—$50,000

Ricardo Maselli, MD
University of California, Davis

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

2014 MGFA RFA grant—$50,000

Dr. Jeffrey Guptill
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"

2014 MGFA RFA grant—$50,000

Linda L. Kusner
George Washington University

"GWU/Anti-apoptotic Mechanisms in Persistence of Autoimmune Myasthenia Gravis"

2015 MGFA RFA grant—$50,000

Ruksana Huda, Ph.D, Assistant Professor

University of Texas Medical Branch

"Novel cell specific therapy for autoimmune myasthenia"

2014 ABF-MGFA Clinician Scientists Development Award—$149,506

American Brain Foundation

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

2012 MGFA RFA grant—$50,000

Hans D. Katzberg

Toronto General Hospital/UHN

"UHN/Nicotinic Acetylcholine Receptor PET Radiolabeling in Patients with Myasthenia Gravis"

MGFA Patient Registry continued to grow and was listed on the NIH NINDS Clinical Trials and You website.

The 2015 Scientific Session was held at the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM) conference with 12 presenters and 4 posters. The program attracted nearly 200 participants helping to expand knowledge, inspire research thinking and ideas as well as helping to make connections among MG researchers. The content was published in the medical journal, ***Muscle & Nerve,*** further expanding the program's reach.

AWARENESS AND COMMUNICATIONS

June Awareness Program: MGFA's 2015 June Awareness program provided a vehicle for educating the public about myasthenia gravis and its impact on lives. The 2015 effort had a variety of exciting and gratifying results:

35 participants from NY, CT, PA and MD appeared at the Today Show Plaza holding signs and getting on camera. Photos were posted to social media.

Social Media

- Referrals from Social Networks to the Website tripled from June 2014 (954) to June 2015 (2,712).
- Website traffic rose from 35,760 Sessions in June 2014 to 47,161 in June 2015.
- 300,000 people were reached with MGFA messaging via Facebook
- 1,617 new page likes (approximately 200% increase in like acquisition over previous quarter)
- 15,419 engagements (approximately 600% increase in engagements over previous quarter)

Print & Broadcast Media

Print & broadcast media reached an audience of 4.9 million people.

Syndicated news article: As of June 30, the article garnered **1,106 online placements** for an estimated **ad value of more than $317,000** and a potential audience of **approximately 55.4 million** individuals. Media included:

- *KOTATV.com* – Rapid City, SD *(June 16, 2015) – reaches* 78,830
- *Good Morning KOTA Territory* – Rapid City, SD *(June 16, 2015)* Audience: 8,663
- *Today Show* - NBC National *(June 23, 2015)*-- Audience: 4.756 million-- MGFA volunteers from CT, MD, NJ and NY participated
- *Arizona Foothills Magazine* Online – Scottsdale, AZ (*July 9, 2015*)-- *reached* 221,332 along with Twitter Followers: 52,000
- *Atlanta Jewish Times* –An *Internal Struggle: MG Lurks in Some Who Appear Healthy*- 55,000
- WZZM-13, ABC Covers MG 5K Run/Walk, MI
- News release picked up by over 1100 websites including *The Los Angeles Times* website; *San Francisco Gate* website; the *Chicago Tribune* website and the *Orlando Sentinel* website.

Looks can be deceiving; people with Myasthenia Gravis, an autoimmune neuromuscular disease, often look normal to others even while they may be suffering in many ways. More than 100,000 people of all ages, races and genders, are coping every day with the debilitating and potentially life-altering effects of MG.

PROUD TO CELEBRATE MYASTHENIA GRAVIS AWARENESS MONTH

TO LEARN MORE ABOUT MG AND HOW YOU CAN HELP, VISIT ONLINE AT **WWW.MYASTHENIA.ORG** OR **CALL 1-800-541-5454.**

EDUCATION, PROGRAMS AND SERVICES FOR PEOPLE WITH MG AND THEIR FAMILIES.

Hattie Ewing

Helping people who live with MG to manage the day to day challenges of the disease is a high priority. The National Conference brought 151 people together in San Diego, CA, to hear from scientists and clinicians, and to learn from each other. After the meeting, key presentations were posted to the MGFA website, extending the important information to people with MG worldwide.

MGFA continued to work to grow our network of community based support groups, as well as increasing our presence in social media. A training webinar for new leaders was developed, and our leader manual revised and distributed.

The Foundation also launched a new initiative to support a very special population: families who have a child or teen with MG through our **Parents' Program – When Your Child Has MG** – the following materials were developed and posted to the MGFA website.

- Understanding Your Child's Myasthenia Gravis
- Your Child and Exercise
- A Parent's Guide—Steering Your Child with MG to School Success
- Resources – Compilation of Resources and Links
- Tracking Chart

In addition, the following existing items were posted to the Parents webpage:

- Caring for Children and Supporting Adolescents with MG
- Congenital Myasthenia
- Emergency Management 1 & 2
- Informational Materials Page

A webinar was produced on November 7th with Dr. Nancy Kuntz as speaker and is available on the website:

Other educational webinars reached a broader audience on topics important to people living with myasthenia gravis

- The Role of Exercise in Taking Control of Your MG – Dr. Charlene Hafer Macko, May 15, 2015
- Ocular MG – Dr. Donald Sanders, May 21, 2015
- Understanding Myasthenia Gravis and Your Child – Dr. Nancy Kuntz, November 7, 2015

2015 MGFA Awards:

The MG Community is privileged to include many exceptional individuals who contribute their time, energy, expertise and resources. In 2015, MGFA was pleased to recognize some of these wonderful volunteers and leaders for their contributions.

2015 LIFETIME ACHIEVEMENT AWARD RECIPIENT

Audrey Penn, MD, is the retiring deputy director of the National Institute of Neurological Disorders and Stroke (NINDS). Dr. Penn has spent her career working to understand and find therapies for MG and has made a major contribution that has made a difference in the lives of patients. Penn was an NINDS special fellow early in her career and her studies of muscle proteins led to her interest in MG, producing many papers advancing the understanding of MG. She was also dedicated to the development of the MGFA. She is a former president of the American Neurological Association (ANA) and a director of the American Board of Psychiatry and Neurology.

CHAIRMAN'S AWARD

Marilyn Ricci, RN, MS, CNS, CNRN is the chairperson of the MGFA Nurses Advisory Board and has been a Neuroscience Clinical Nurse Specialist for over 35 years. Marilyn is an educator who has shared her knowledge and expertise locally, nationally and internationally. She is a leader both for her support group, and professionally as the past president of the American Association of Neuroscience Nurses (AANN), founding member and past president of the American Board of Neuroscience Nurses (ABNN) and a founding member and past president of the Accreditation Board for Specialty Nurses Certification (ABSNC).

DOCTOR OF THE YEAR AWARD

Gil I. Wolfe, MD, Professor and Chair of the Department of Neurology at Buffalo School of Medicine and Biomedical Sciences at SUNY was awarded the Doctor of the Year Award. Gil has been an essential leader in the MG community, shepherding the groundbreaking, multi-year, Thymectomy Trial to conclude in November 2015. Gil served as the chairman of the MGFA Medical Scientific Advisory board and organized the twelfth 2012 International Symposium on Myasthenia Gravis and Related Disorders supported by the MGFA and the New York Academy of Sciences. Gil has been and is a tireless supporter of the MG Community and his MG patients.

VOLUNTEER OF THE YEAR AWARD

Whitney Miller winner of Fox's 1st Master Chef competition has given her time and her celebrity status to MGFA including donating a portion of the proceeds from her cookbook, *Modern Hospitality: Simple Recipes with Southern Charm (Rodale),* and proceeds from her line of popsicles to MGFA. Whitney has also shared her expertise as a chef with healthy eating and cooking tips at MGFA conferences including the 2015 National Conference in San Diego, CA. Whitney's dad has MG.

VOLUNTEER OF THE YEAR AWARD

Jennifer Fisher – MGFA is pleased to recognize Jennifer Fisher for her efforts to establish and build the MGFA Stanford University Medical Center MG Support Group. Jennifer is a tireless and enthusiastic supporter of the MGFA and is always eager to help MG patients. With a broad knowledge base in community resources, Ms. Fisher is dedicated to building relationships with community partners, patients and their families. Jennifer has gone out of her way to build the MGFA-Stanford University Medical Center Support Group, bringing important new resources to people with MG and their families in Northern California.

YOUNG PERSON OF THE YEAR AWARD

Mike Ursic of Morgantown, West Virginia came to the 2011 MGFA National Conference and quickly made his mark on MGFA and the MG Community. He quickly became a leader helping to involve and support young people in the MGFA. He presented the Young People's podcast and is an active member of the MGFA Outreach Committee.

Financial Information What follows is a partial statement of activities for the year ending December 31, 2015, with comparative totals for the year ending December 31, 2014. The complete independent auditor's report is available at the MGFA website, www.myasthenia.org.

	2015 total All Funds	2014 total All Funds
Public Support:		
Individuals	207,224	216,093
Corporations	45,500	49,094
Sponsorships	79,201	56,500
Foundations	40,204	54,705
Legacies	154,699	91,458
Charitable organizations	125,544	16,232
Public agencies	39,824	20,586
MG Walk and Endurance	727,520	784,258
In-kind contributions	-	10,469
Total Public Support	**1,419,716**	**1,299,395**

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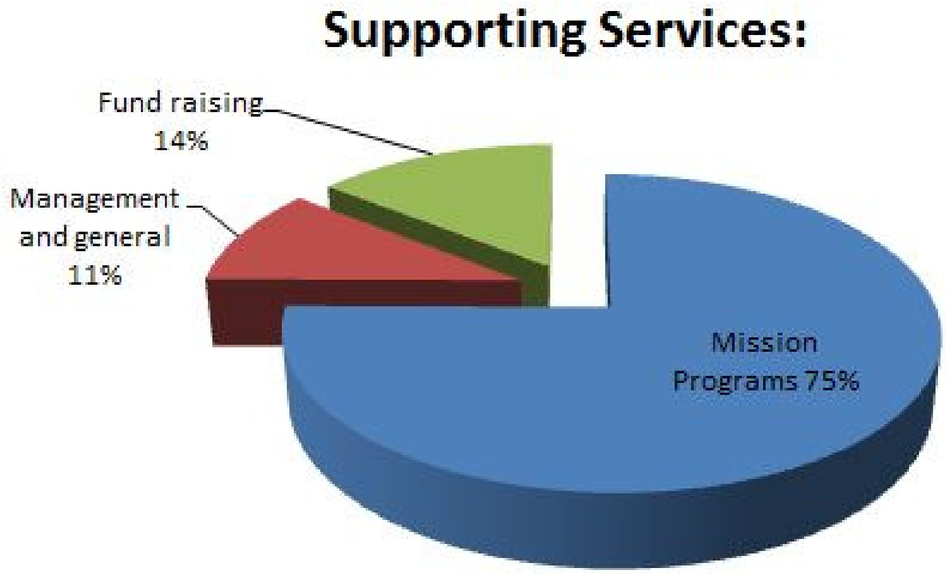
Supporting Services:	2015	2014
Management and general	186,436	157,442
Fund raising	255,856	279,012
Total Supporting Services	**442,292**	**436,454**
Mission Programs	**1,336,505**	**1,338,508**
Total Expenses	1,778,797	1,774,962
Net Assets	5,868,574	6,478,401



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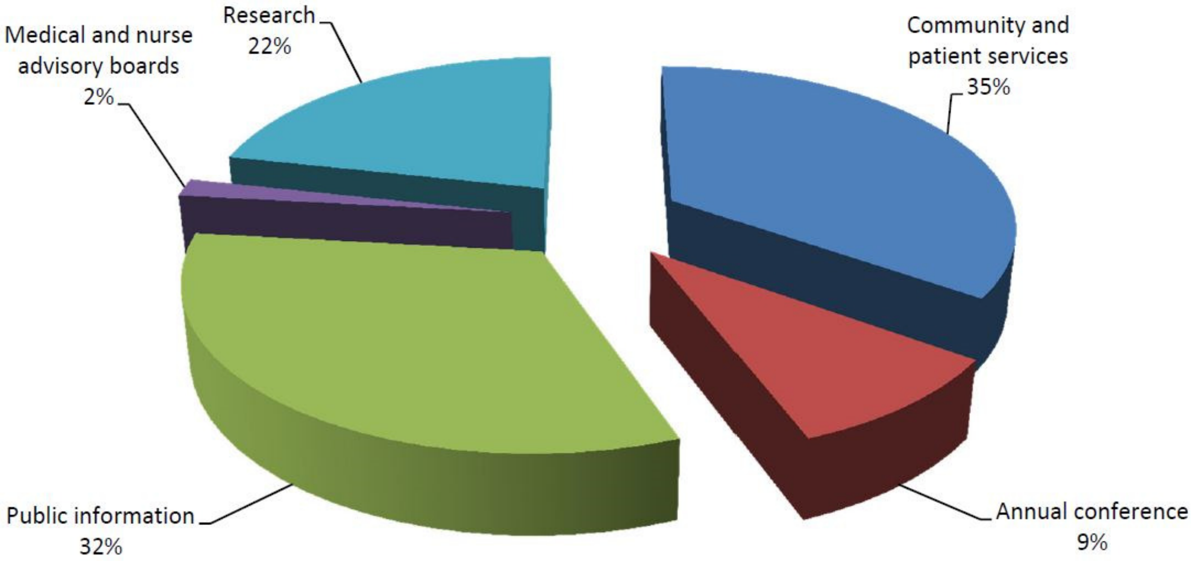
Revenue:	**2015**	**2014**
Chapter assessments	4,095	33,162
Merchandise sales	1,692	2,082
Meeting and convention fees	27,990	23,988
Investment income (loss)	(291,176)	286,522
Other income	6,653	-
Total Revenue	**(250,746)**	**345,754**
Total Support and Revenue	1,168,970	1,645,149
Program Expenses:		
Community and patient services	465,435	427,992
Annual conference	126,063	120,575
Public information	433,990	445,496
Medical and nurse advisory boards	22,890	15,680
Research	288,127	328,765
Total Program Expenses	**1,336,505**	**1,338,508**

Program Services



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