

MYASTHENIA GRAVIS FOUNDATION OF AMERICA, INC.®

Myasthenia Gravis Foundation of America 2013 Annual Report

MGFA Mission

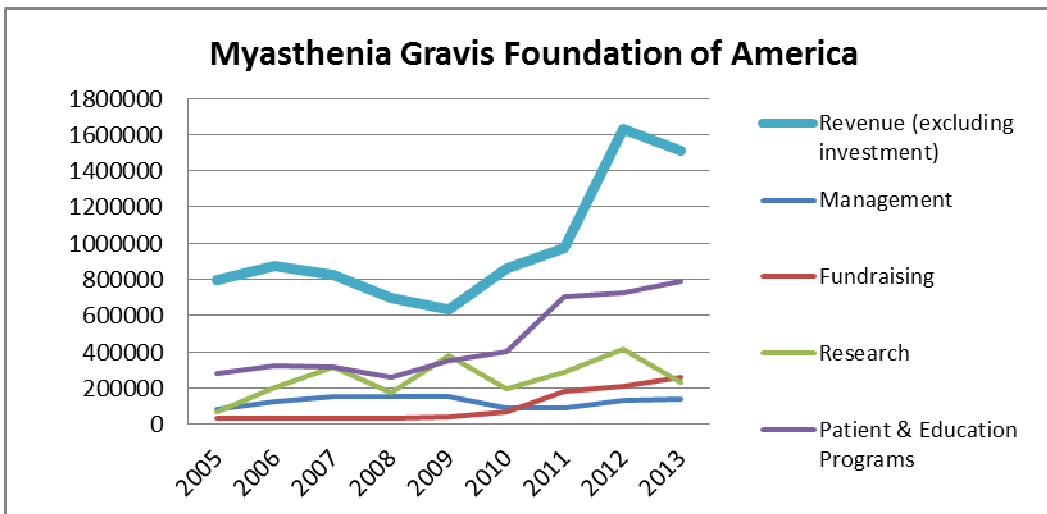
Myasthenia Gravis Foundation of America (MGFA) is committed to finding a cure for myasthenia gravis and closely related disorders, improving treatment options and providing information and support to people with myasthenia gravis through research, education, community programs and advocacy.

MGFA Vision

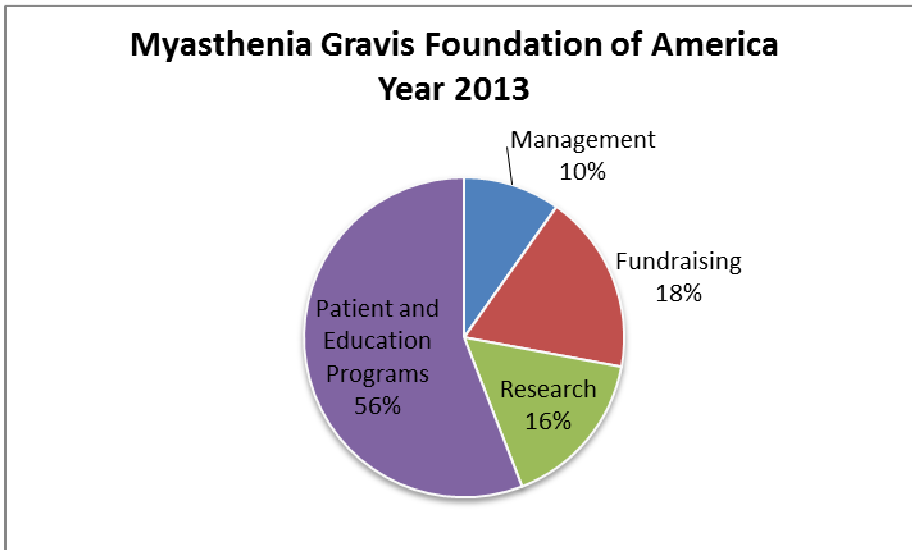
A world without Myasthenia Gravis

Overall Performance

2013 was another strong year in terms of revenue with both the MG walks and individual contributions showing significant increases over previous year (see financial schedules in the back). This positive trend was negated by a decline in legacies. This is being addressed with the development of new planned giving programs.



In 2013 the Foundation program expenses for Patient and Education Programs amounted to 56% of total expenses with Research and Fundraising at 16% and 18% respectively. MGFA meets all financial ratios and governance requirements set by BBB Wise Giving Alliance and the National Health Council's Standards of Excellence Certification Program.



2013 MG Walks Raise More Than \$700,000

The 2013 National MG Walk Campaign was a success for the MGFA. Since its inception in 2010, the walks have raised more than \$1.75 million to help fund critical research, education, community programs and advocacy. In 2013, the 32 MG Walks had nearly 5,000 participants raising more than \$700,000 and generating media attention from coast to coast. Through the MG Walk, patients along with families and friends unite their voices to say; "MG must be stopped. We need your help to find a cure!"

More Than 2,700 MG Patients Have Downloaded the New App "myMG"

More than 2,700 Myasthenia Gravis patients have downloaded the "myMG" software application designed to run on smartphones, tablet computers and other mobile devices. With "myMG", the MG patient records symptoms and their impact on daily activities. The app allows the user to record notes with each survey.

National Conference in Miami, Florida

MGFA's 2013 national conference in Miami was a successful gathering of people who have MG, their families and caregivers, as well as medical professionals and researchers who are treating and trying to conquer MG. The meeting consisted of presentations by healthcare professionals and educators on topics such as MG101, current research and how best to live with MG. Videos of conference presentations are available at www.myasthenia.org.

The conference included the Annual Awards Dinner where MGFA recognized dedication and commitment to the foundation's mission and bestowed the following honors:

Lifetime Achievement: Coleen Shinn, Jack and Elaine Schumacher

Young People of the Year: Kourtney Davis and Jasmine Snow

Caregiver of the Year: Jack Schumacher

Volunteer of the Year: Tommy Santora

Chairman's Award: Robert Pascuzzi, MD

Nurses of the Year: London (Ontario) University 7th Floor Nurses

Doctor of the Year: Janice Massey, MD

Publications

In 2013 MGFA published a brochure on “Effects of Myasthenia Gravis on Voice, Speech and Swallowing” written by two experts at the Medical University of South Carolina Evelyn Trammel Institute for Voice and Swallowing. The brochure is a significant addition to the foundation’s collection of educational materials. Understanding how MG may influence voice, speech and swallowing is important for persons who have MG, as well as those who care for them on a professional or personal level.

MGFA Receives Advocacy Award from the Child Neurology Foundation

MGFA was the recipient of The Child Neurology Foundation Advocacy Award of Merit, created in 2002 through the efforts of its Board of Directors and the Foundation’s Advocacy Committee to recognize patient support organizations that make outstanding achievements on behalf of patients and families with neurologic and developmental disorders.

MG Patient Registry Launched

The launch of the MG Patient Registry exceeded our expectations with a total of 1,140 MG patients having registered in the first year.

The registry is patient driven and is a confidential means to provide information to an active database of persons with MG and was developed for the purpose of research, treatment and patient information.

It provides a system for researchers to gauge the potential for recruiting patients for clinical trials and communicating with them in a manner that respects their privacy. The registry also can be used to provide education about MG to patients, care givers, non-expert health care providers and funding sources.

The Registry is fully funded by the MGFA and is open to any patient with MG.

Funding High Impact Pilot Projects on Myasthenia Gravis and Related Neuromuscular Junction Disorders

MGFA funded the following projects: *Study the disease-related quality of life (MG-QOL15) and symptoms and activities (MG-ADL) of patients with MG who download and complete the free “myM” ® phone app and the Efficacy of Prednisone in the Treatment of Ocular Myasthenia*. The key criteria for this program is that the projects must be highly focused and innovative with a clear plan that will lead to new federal, pharmaceutical or private foundation supported investigations.

Nurses Clinical Practice Guidelines

MGFA fully funded the development and publishing of “Clinical Practice Guidelines (CPG), *Care of the Patient with Myasthenia Gravis*”, in partnership with the American Association of Neuroscience Nurses (AANN). The MG CPG provides timely and pertinent information for practitioners across all levels of care.

Financial Management

What follows is a partial statement of activities for the year ending December 31, 2013, with comparative totals for the year ending December 31, 2012. The complete independent auditor’s report is available at the MGFA website, www.myasthenia.org.

Public Support and Revenue

	2013 Total All Funds	2012 Total All Funds
Public Support:		
Individuals	\$ 221,178	\$ 176,867
Corporations	32,017	28,259
Foundations	56,903	7,433
Legacies	245,671	704,167
Chapters	92,666	5,051
Public Agencies	49,129	47,464
MG Walk	708,902	553,754
Total Public Support	\$ 1,412,688	\$ 1,522,995
Revenue:		
Chapter Assessments	\$ 61,011	\$ 71,587
Fundraising Event	-	8,111
Merchandise	1,898	2,243
Meetings and Conventions	36,781	25,650
Other	-	155
Investment Income (Loss)	<u>848,712</u>	<u>558,728</u>
Total Revenue	<u>\$ 948,402</u>	<u>\$ 666,474</u>
Total Support and Revenue	\$ 2,361,090	\$ 2,189,469

Program Expenses and Supporting Services

	2013 Total All Funds	2012 Total All Funds
Program Expenses:		
Chapter & Patient Services	340,818	316,094
Annual Conference	97,610	77,240
Public Information	340,636	321,744
Medical and Nurse Advisory Boards	11,479	9,881
Research	<u>228,716</u>	<u>412,413</u>
Total Program Expenses	<u>\$ 1,019,257</u>	<u>\$ 1,137,372</u>
Supporting Services:		
Management and General	\$ 138,458	\$ 150,829
Fundraising	256,705	211,157
Total Supporting Services	<u>\$ 395,163</u>	<u>\$ 361,986</u>
Total Expenses	\$ 1,414,420	\$ 1,499,358
Net Assets	<u>2013 Total All Funds</u>	<u>2012 Total All Funds</u>
	\$ 6,608,214	\$ 5,661,544

Board of Directors

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 Robert Ruff, MD, Chair-elect, Medical/Scientific Advisory Board
 Wilma Koopman, RN (EC), BScN, MScN, TCNP, CNN(C) Chair Nurses Advisory Board

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MGFA Staff

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 Martha Jones, Patient/Chapter Services Manager
 Karimah Day, Patient Services Coordinator



Samuel Schulhof
 MGFA, Chairman



Tor Holtan
 MGFA, CEO

