



**MYASTHENIA GRAVIS**  
FOUNDATION OF AMERICA, INC.®

## **2012 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**

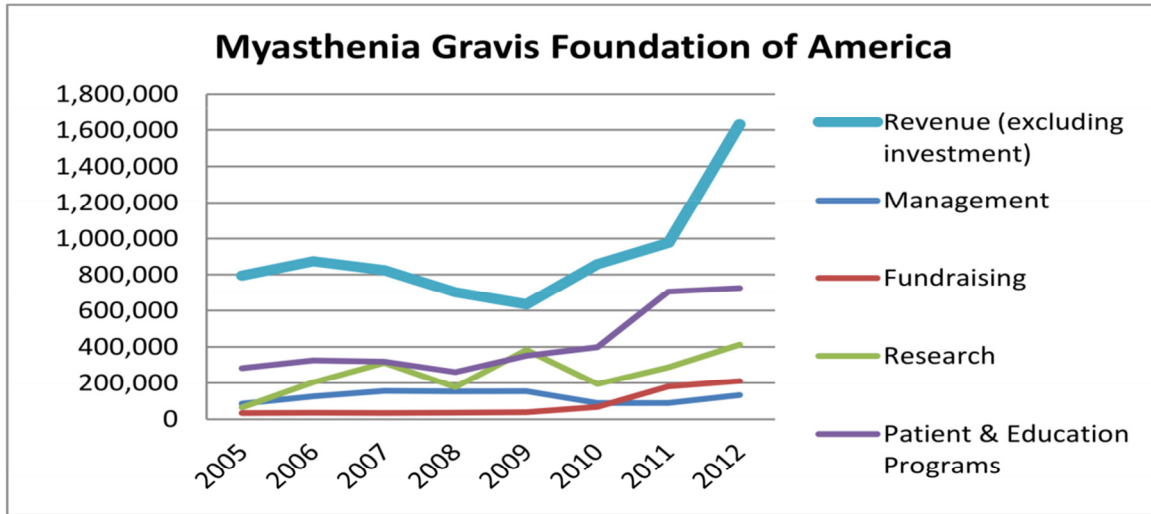
A world without Myasthenia Gravis

### **Letter from the Chairman and the Chief Executive**

To assess how the foundation is doing, one needs to take a longer perspective than just over the past year. As one can see below, the revenue has increased significantly over the last four years while the expenses were held in check. We did experience an expected increase in fundraising expenses due to the MG Walks, but that was more than offset by the awareness and revenue generated by this national event.



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This positive increase in the net revenue has enabled us to consistently increase the level of funding for research with the goal of achieving the MGFA vision of *A World Without MG*.

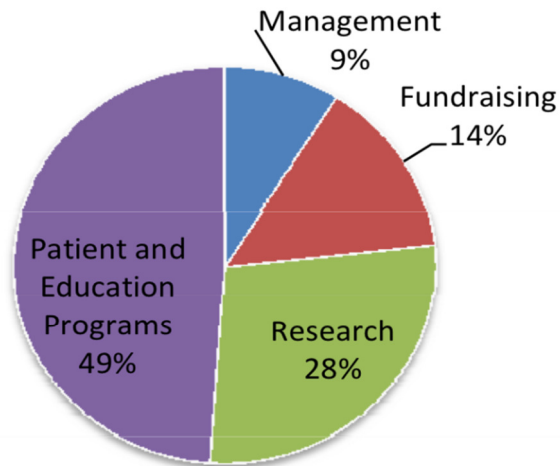


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**\$3,178,068**  
↑  
Research 1993 - 2012

In 2012 the Foundation program expenses for Patient and Education Programs amounted to 49% of total expenses followed by Research at 28%. MGFA meets all financial ratios set by BBB Wise Giving Alliance and the National Health Council's Standards of Excellence Certification Program.





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### **MGFA Celebrates its 60th Year**

The MGFA was founded in 1952 by Jane Ellsworth a concerned mother of a 16- year old daughter diagnosed with MG. Her aim was to raise funds for research into the cause and cure of MG. Within one year, Mrs. Ellsworth created the Myasthenia Gravis Foundation, Inc. (MGF), formed a governing board, and sought out the most talented experts in the medical community to form a medical advisory board. Within two years the MGF sponsored the first International Symposium on MG. Mrs. Ellsworth's commitment and drive ultimately led to a 60-year span of research, education and patient care and the evolution of the Myasthenia Gravis Foundation of America, Inc. as we know it today. To celebrate the anniversary and commemorate the foundation's early history, MGFA published a special edition of *Foundation Focus*.

### **International Symposium**

The 12<sup>th</sup> International Conference on Myasthenia Gravis and Related Disorders was held May 21-23, 2012, in New York City at the New York Academy of Sciences (NYAS). Held every five years, the meeting helps to keep the MG scientific community abreast of the latest developments and fosters interactions, especially for younger investigators. As has been the case since the first conference held in 1954, the meeting was co-sponsored by the NYAS and Myasthenia Gravis Foundation of America (MGFA). Support was provided by MGFA, the National Institutes of Health (NIH), the National Institute of Neurological Disorders and Stroke (NINDS), the National Center for Advancing Transitional Sciences (NCATS), the Office of Rare Diseases (ORD) and several corporate sponsors.

Nearly 300 scientists and clinicians from around the world attended the meeting--- a 30 percent increase over the 2007 conference. The plenary sessions included 50 presentations; more than 100 abstracts were presented during two poster sessions

### **MG Walk: \$1 million raised in first 2 years!**

The MG Walks have raised \$1 million dollars to fund research and patient support over the last two years. The Campaign has raised awareness, renewed hope and worked to build a connected and caring community of those affected by myasthenia gravis.

Through the MG Walk, patients and their families have connected as never before. Those whose lives have been touched by MG have a way to reach out to their circle of influence and invite them to join in creating a better future for all with MG. The MG Walk has quickly become a central part of our mission delivery.

### **myMG Smartphone App**



In December 2012, MGFA launched “my MG,” an innovative mobile application for individuals to track their MG. The new app is available free by downloading from the Google App Store or iTunes.

### **Publications**

In 2012 the Foundation published three new brochures; *“Caring for Children and Supporting Adolescents with Myasthenia Gravis, Emergency Management I, “Important Information for Medical Personnel and Emergency Management II,” “ Important Information for Patients, Families, and Caregivers”*.

### **MG Patient Registry**

The foundation provided \$100,000 for the development of an “MG Patient Registry”. The Registry will be an active database of persons with MG, developed for the purposes of research, treatment, patient information, and to raise awareness of the prevalence of MG to the public and the medical community. The registry is being developed in conjunction with the Coordinating Center of the University of Alabama at Birmingham (UAB), and with oversight by the MGFA Patient Registry Committee. The MG Patient Registry will be launched the summer of 2013.

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

Through this program, MGFA funded for the third year in a row two 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 “myMG” app and the “ Efficacy of Prednisone in the Treatment of Ocular Myasthenia*. The key criteria for evaluating proposals in 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.

### **FINANCIAL MANAGEMENT**

What follows is a partial statement of activities for the year ending December 31, 2012, with comparative totals for the year ending December 31, 2011. The complete independent auditor’s report is available at the MGFA website: [www.myasthenia.org](http://www.myasthenia.org).



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## Public Support and Revenue

	2012 Total All Funds	2011 Total All Funds
<b>Public Support:</b>		
Individuals	\$ 176,867	\$ 161,932
Corporations	28,259	20,004
Foundations	7,433	34,896
Legacies	704,167	126,977
Chapters	5,051	52,804
Public Agencies	47,464	44,238
MG Walk	553,754	418,124
<b>Total Public Support</b>	<b>\$1,522,995</b>	<b>\$ 858,975</b>
<b>Revenue:</b>		
Chapter Assessments	\$71,587	\$57,073
Fundraising Event	8,111	16,233
Merchandise	2,243	1,894
Meetings and Conventions	25,650	42,415
Other	155	35
Investment Income (Loss)	<u>541,006</u>	<u>(278,615)</u>
<b>Total Revenue</b>	<b><u>\$648,752</u></b>	<b><u>\$(160,965)</u></b>
<b>Total Support and Revenue</b>	<b>\$2,171,747</b>	<b>\$698,010</b>



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**Program Expenses and Supporting Services**

	<u>2012 Total All Funds</u>	<u>2011 Total All Funds</u>
<b>Program Expenses:</b>		
Patient Services	\$71,540	\$89,884
Annual Conference	77,240	80,133
Chapter Development	244,554	280,126
Public Information	321,744	235,128
Medical and Nurse Advisory Boards	9,881	19,645
Research	<u>412,413</u>	<u>287,714</u>
<b>Total Program Expenses</b>	<b><u>\$1,137,372</u></b>	<b><u>\$992,630</u></b>
<b>Supporting Services:</b>		
Management and General	\$133,107	\$89,920
Fundraising	211,157	180,800
<b>Total Supporting Services</b>	<b><u>\$ 344,264</u></b>	<b><u>\$ 270,720</u></b>
<b>Total Expenses</b>	<b>\$1,481,636</b>	<b>\$1,263,350</b>



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<b>Net Assets</b>	<b><u>2012 Total All Funds</u></b>	<b><u>2011 Total All Funds</u></b>
	<b>\$ 4,971,433</b>	<b>\$5,536,773</b>

#### **BOARD OF DIRECTORS**

Samuel Schulhof, Chair

Edward Walsh, Treasurer

Steven Hawco, Vice-Chair

Janet Myder, Secretary

Jennifer Faucett, Chapter Liaison

Marcia S. Lorimer, RN, MSN, CPNP, Audit Committee Chair

Gil Wolfe, MD, Chair, Medical/Scientific Advisory Board

Ted Burns, MD, Chair-Elect, Medical/Scientific Advisory Board

Wilma Koopman, RN (EC), BScN, MScN, TCNP, CNN, Chair MGFA's Nurses Advisory Board

Charlene Hafe-Macko, MD

Carl Hansson

Nancy Kuntz, MD

Nancy Law

Jeffrey Pilgrim

Denise Rossi

Robert Ruff, MD, Ph.D.

Suzanne Ruff, Ph.D.

Arthur Sultan

William Sauerwine

Jurgen Venitz, MD, Ph.D.

Allan Weiss, MD

#### **MGFA STAFF**

Tor Holtan, Chief Executive

Martha Jones, Patient/Chapter Services Manager

Dana O'Donnell, Patient Services Coordinator





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Samuel Schulhof  
MGFA, Chair

Tor Holtan  
MGFA, Chief Executive