

## Myasthenia Gravis Foundation of America 2014 Annual Report

### MGFA Vision



A world without Myasthenia Gravis

### 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.

*To All of Our Supporters & Friends:*

*Thank you for your involvement with the Myasthenia Gravis Foundation of America (MGFA). MGFA is the only national volunteer health agency in the United States dedicated solely to the fight against myasthenia gravis. MGFA serves patients, their families and caregivers through a network of chapters, support groups and programs. The foundation made great strides in 2014 and could not have done it without you. Each donor and volunteer is critical to MGFA's success in the continued effort to accomplish our mission: finding a cure, improved treatment options and education. Your support along with the increased awareness generated by the MG Walks® has enabled the Foundation to make progress across all pillars of the mission, all of which are reviewed in this report.*

*Detailed financial information including the IRS 990 and full audit report can be found on the MGFA website [www.myasthenia.org](http://www.myasthenia.org).*

*Thanks again all for your support in 2014!*

## Overall Performance

2014 Was another strong year in terms of revenue with both the MG walks and individual contributions performing well (see financial schedules in the back). The MG Walks set another revenue record growing by 11% year over year. However, this positive trend was negated by a decline in legacies a revenue source that is difficult to forecast. Too offset this, going forward. two new Planned Giving programs are being developed and we continue to look at ways to improve our current fundraising programs For example, we believe one of the ways to improve our fundraising programs is to do a better job of communicating with the donor community on how we leverage our resources and insure our programs meet the changing needs of the MG community.

In 2014 the Foundation program expenses for Patient, Education and Research Programs amounted to 75% of total expenses with Administration and Fundraising at 9% and 16% respectively. The Foundations spending on fund raising has enabled it to increase its revenue stream and thus provide more resources for program development and delivery while at the same time increasing awareness. MGFA's expenditures meet all financial ratios and governance requirements set by BBB Wise Giving Alliance and the National Health Council's Standards of Excellence Certification Program.

## 2014 MG Walks® Raise More Than \$780,000

The 2014 National MG Walk® Campaign was a huge success for the MGFA. Since its inception in 2010, the walks have raised more than \$2.55 million to help fund critical research, education, community programs and advocacy.

In 2014, the 30 MG Walks® had more than 5,000 participants raising close to \$800,000 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!"

## National Conference in Philadelphia, Pa.

The 2014 National Conference was held at the Lowe's Hotel in downtown Philadelphia, April 16 -18. Two days of programs offered presentations by experts involved in treatment and research.

Interactive discussions on pertinent topics gave attendees an opportunity, in small discussion groups, to talk about their particular needs, hear how others in similar situations deal with their struggles, fears and obstacles, and better understand and plan for living with MG.

The interactive sessions and the informal time between meetings offered attendees opportunities to communicate with a larger community of MG patients their families and the medical professionals who provide care and conduct research.

A huge benefit of attending the annual conference is the chance to meet many other people who have MG. Many first-time attendees are newly diagnosed or have struggled with MG without the support of others. Attending the meetings enables them to experience a "new world" of MG as they discover that they are not alone. They learn that there is a large community of individuals who care about MG and the people that it affects.

## 2014 MGFA Award Recipients

MGFA was pleased to recognize some of the many volunteers who have made exceptional contributions to the MG Community. The awards were announced at the National Conference Awards Dinner.

**Marika Bates - Lifetime Achievement Award** – Marika Bates has made tremendous contributions to the MG Community, her Chapter and MGFA. She calls herself bossy, but really she is a helper, a doer, a hands-on person with exceptional foresight and caring.



**Kathy and Ray Bibeau - Volunteer of the Year Award** – Kathy and Ray are the dynamic duo of the Pacific Northwest! Traveling throughout the region the two have helped set-up support groups from Oregon to Idaho. With passion and caring they have been there for patients and caregivers.

**Herb Johnson, Carolinas Chapter Chairman - Volunteer of the Year Award**

Herb Johnson has had a major impact on the quality and scope of services available to MG patients in the Carolinas in a very short time. With passion and know-how he has expanded support groups, created *The MG Phone Circle of Friends* project and much, much more.



**Jonathan Goldstein, M.D. - Doctor of the Year Award** – Jonathan's down-to-earth style and commitment to the care of MG patients has endeared him to MG patients and caregivers in both Connecticut and New York. He has unstintingly shared his time, knowledge and caring with patients and caregivers.



**Paul Heule - Lifetime Achievement Award** – From a chance meeting on a plane to 22 years as an active, effective and devoted Chairman for the Great Lakes Chapter, Paul has had a major positive impact for the MG Community in Michigan.

**Victor Mendevil - Young Person of the Year Award** – Victor Mendevil was diagnosed with MG at 5 years of age. Today, Victor is an active, accomplished 14 year old, who is a role model for those who wish to rise above the limitations that MG can place on your life. His active participation in the 2013 MG Walk® was one highlight of his triumph over MG.



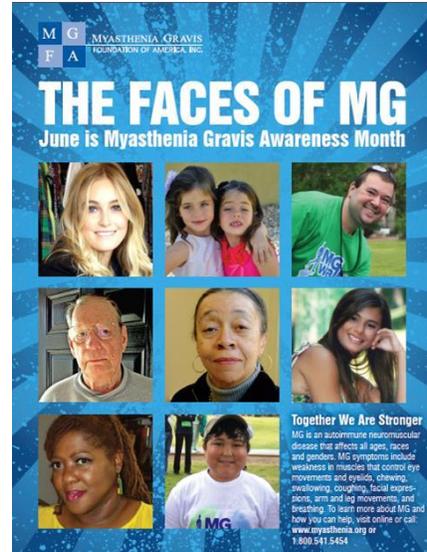
**Donald Sanders, M.D. - Chairman's Award** – Don has directed the MG Clinic at Duke University Medical Center for 25 years. He has authored more than 200 scientific publications on the diagnosis and treatment of neuromuscular disorders. Don has organized and led MGFA's efforts over the last several years to update MGFA's internationally accepted standards for Clinical Trials and the development of internationally accepted Treatment Standards.

**William V. Lorimer, M.D. - Caregiver of the Year Award** – Bill has been married to Marcia for 43 years. They met when Bill was in medical school and Marcia was in nursing school. When they were dating, Marcia told Bill all about the challenges that she had faced since being diagnosed with myasthenia at age 10. Learning about these challenges did not dissuade him. Bill's love and support through their years together have made living a full and productive life with myasthenia possible. With Bill's support Marcia, who is a full time Assistant Professor of Nursing at the Duke School of Nursing, has devoted a great deal of her time and energy to the Foundation. Marcia has served as Chairperson of two of MGFA's Chapters, Chair of the Foundations Nursing Advisory Board and Board Member and Chair of the Foundation's Board of Directors.



## 2014 June Awareness Month Features Several MG Awareness Proclamations by Major U.S. Cities

During MGFA's "June is MG Awareness Month," the national office, as well as chapters and volunteers throughout the country, were involved in a variety of activities to promote awareness. These activities included obtaining proclamations from local and state officials, providing information about MG to the media, holding MG awareness events, disseminating information via social networks, and distributing MGFA's "Uniting for A Cure; A World without MG" June Awareness Month posters. The MGFA's "Create Your Own June Awareness Poster" Facebook contest, allowed the MG community to participate and create an awareness poster of their own. The winner's poster was displayed on the MGFA's Facebook page during the month of June.



## Capacity Building

To better serve the MG Community, a National Program Director, Kathleen Brown, MPA, was added to the national office. This key position will enhance MGFA's ability to deliver new national program and services.

## 2014 MGFA/ABF Clinician Scientist Development Award in Myasthenia Gravis

MGFA in conjunction with the American Brain Foundation (formally AANF) sponsored another three-year fellowship award. These fellowships are designed to train the next generation of clinical researchers. Dr. Ricardo Roda was the 2014 winner of the award, which will grant him \$240,000 over the course of three years to conduct research and provide new insights into new therapies for Myasthenia Gravis. His study is "Clinical Significance and Pathogenic Mechanisms of LRP4 Antibodies in Myasthenia Gravis."

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

MGFA again in 2014 funded two projects: 1 - Anti-apoptotic Mechanisms in Persistence of Autoimmune Myasthenia Gravis and 2 - Generate pilot polychromatic flow cytometry data on the role of B10 cells in a broad population of MG patients . The key criteria of 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.

## 2014 MGFA Scientific Session

The 2014 MGFA Scientific Session took place in Savannah, GA. This annual event provides neurologists and others doing basic or clinical research relating to the neuromuscular junction an informal opportunity to discuss their work in progress.

This year's meeting saw another record attendance with close to 200 listening to 10 abstract presentations. The MGFA Scientific Session is run in conjunction with the American Association of Neuromuscular & Electrodiagnostic Medicine.

## Consensus Conferences

During 2014: two significant consensus conferences took place bringing together MG experts from around the world. These conferences will set the standards for both pre-clinical trials and the treatment of MG.

**Pre-Clinical Trials** - The conference was held at the National Institute of Neurological Disorders and Stroke in Rockville, MD. The twenty-four participants, experts in preclinical research design and animal models of MG, came from 11 countries including the United States and represented 20 universities. In a process of knowledge sharing, discussion and consensus building, these experts developed standards aimed at optimizing preclinical therapeutic development research for MG. especially animal models that encompass the induction of the disease, longitudinal assessment measurements, and evaluations to determine efficacy. The participants possess extensive, practical experience in the field of animal models of myasthenia gravis with early studies dating back to 1975.

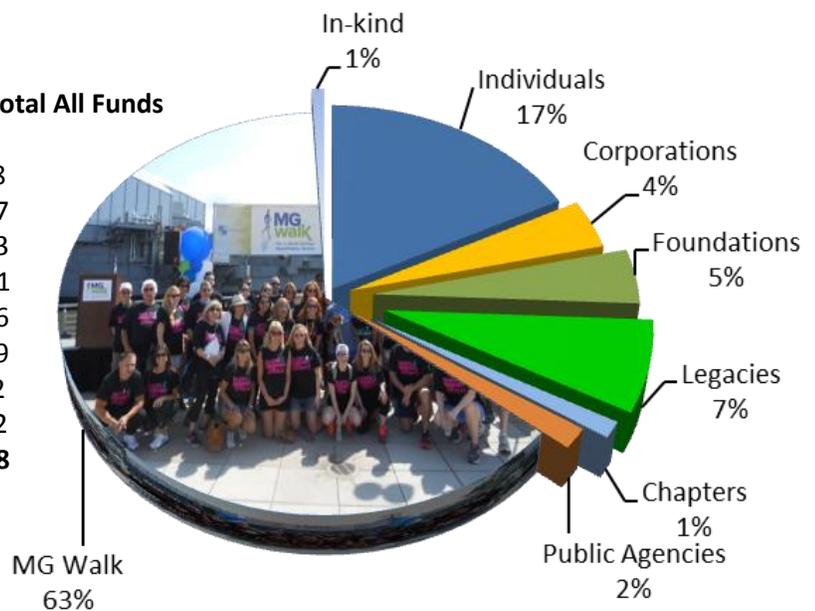
**Treatment Guidelines** - The MGFA Task Force on International Treatment Guidelines for Myasthenia Gravis met in Durham, NC, under the joint leadership of Drs. Donald Sanders and Gil Wolfe. The purpose of the Task Force was to develop guidelines for treating acquired autoimmune myasthenia gravis based on consensus of international experts. Task Force membership included 14 physicians from the US, Europe and Asia who are recognized experts in treating myasthenia gravis, plus the consensus process coordinator.

## Financial Management

What follows is a partial statement of activities for the year ending December 31, 2014, with comparative totals for the year ending December 31, 2013. The complete independent auditor's report is available at the MGFA website, [www.myasthenia.org](http://www.myasthenia.org).

### Public Support and Revenue

	2014 Total All Funds	2013 Total All Funds
<b>Public Support:</b>		
Individuals	216,093	\$221,178
Corporations	49,094	32,017
Foundations	54,705	56,903
Legacies	91,458	245,671
Chapters	16,232	92,666
Public Agencies	20,568	49,129
MG Walk	784,258	708,902
In-kind contributions	10,469	6,222
<b>Total Public Support</b>	<b>1,299,395</b>	<b>1,427,688</b>



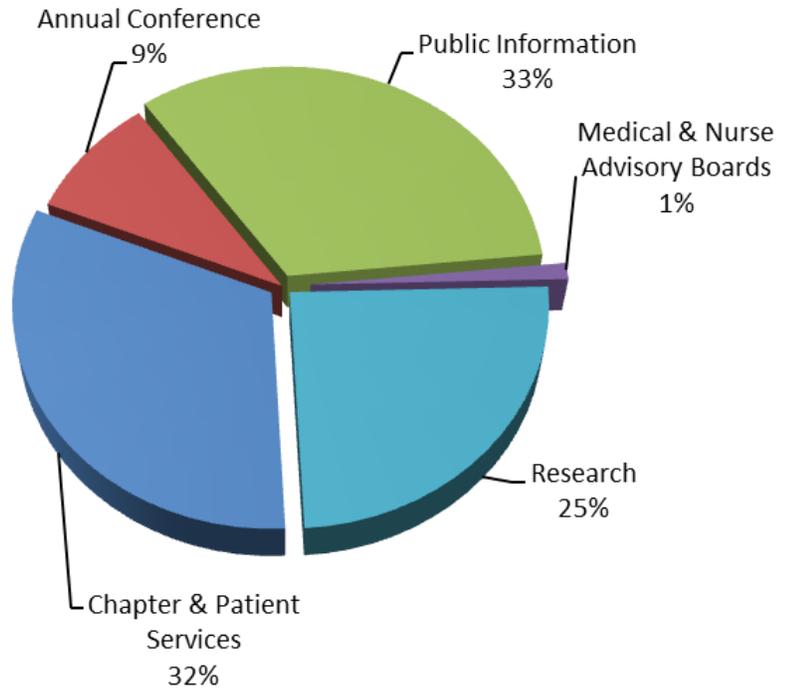
**Revenue:**

Chapter Assessments	33,162	61,011
Merchandise	2,082	1,898
Meetings and Conventions	23,988	21,781
Investment Income (Loss)	286,522	<u>848,712</u>
<b>Total Revenue</b>	<b><u>\$345,754</u></b>	<b><u>\$933,402</u></b>

<b>Total Support and Revenue</b>	<b>\$1,645,149</b>	<b>\$2,361,09</b>
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**Program Expenses and Supporting Services**

	<u>2014 Total</u>	<u>2013 Total</u>
	<u>All Funds</u>	<u>All Funds</u>
<b>Program Expenses:</b>		
Chapter & Patient Services	427,992	340,818
Annual Conference	120,575	97,610
Public Information	445,496	340,636
Medical & Nurse Advisory Boards	15,680	11,479
Research	<u>328,765</u>	<u>228,716</u>
<b>Total Program Expenses</b>	<b><u>\$1,338,508</u></b>	<b><u>\$1,019,257</u></b>



**Supporting Services:**

Management and General	\$157,442	\$138,458
Fundraising	279,012	256,705

<b>Total Supporting Services</b>	<b><u>\$436,454</u></b>	<b><u>\$ 395,163</u></b>
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<b>Total Expenses</b>	<b>\$1,774,962</b>	<b>\$1,414,420</b>
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<b>Net Assets</b>	<b><u>2014 Total All Funds</u></b>	<b><u>2013 Total All Funds</u></b>
	<b>\$6,478,401</b>	<b>\$6,608,214</b>

## **BOARD OF DIRECTORS**

Samuel Schulhof, Chair

Sue Klinger, Vice-Chair

Edward Walsh, Treasurer

Denise Rossi, Secretary

Jennifer Faucett, Chapter Liaison

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

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

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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Charlene Hafer-Macko, MD

Steven Hawco

Nancy Law

Michael Lifshitz

Jeffrey Pilgrim

Robert Ruff, MD, PhD

Suzanne Ruff, PhD

Tommy Santora

Arthur Sultan

William Sauerwine

Jurgen Venitz, MD, PhD

Allan Weiss, MD

Gil Wolf, MD

## **MGFA STAFF**

Tor Holtan, Chief Executive

Kathleen Brown, MPA, CAE, National Program Director

Martha Jones, Patient/Chapter Services Manager

Karimah Day, Patient Services Coordinator

## **ADD SIGNATURES**

Samuel Schulhof    Tor Holtan MGFA, Chairman    MGFA, CEO