

MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.

2008
ANNUAL
REPORT



LETTER FROM THE CHAIRMAN OF THE BOARD AND THE CHIEF EXECUTIVE

2008 was a tough year and we expect 2009 to be even tougher. The economy officially entered a recession in December 2007. Despite the difficult economy, in 2008 MGFA managed to maintain the same level of services and support to the MG community as in 2007.

2008 was also a year of change for the Foundation, changes that we believe will position us to better meet the evolving needs of the community we serve. The MGFA Board of Directors decided that upon the expiration of our management contract with Nonprofit Solutions (NPS) in December 2008, we would make a change in management companies. This was a difficult decision, as NPS had helped to stabilize and focus MGFA. It became clear, however, that to achieve its full potential, MGFA would have to move to a broader and more diversified management company. Therefore, at the end of 2008 we bid goodbye to our friends at NPS who had helped us reach this point, and, effective January 1, 2009, began a new relationship with the Kellen Company, an Atlanta-based professional services and association management company.

With Kellen Company managing the day-to-day operations of MGFA, the Board will be free to focus on strategic issues such as the creation and implementation of a coordinated international-research agenda/program. The agenda will include a goal of finding a cure for myasthenia gravis; improving the daily lives of individuals with myasthenia; increasing public awareness and advocacy programs on behalf of the MG community; developing and implementing capacity-building initiatives; and enhancing delivery of programs and services at the national and local levels.

In 2008, under the leadership of Wilma Koopman, R.N. (E.C.), B.Sc.N., M.Sc.N., T.C.N.P., C.N.N.(C.), the Nurses Advisory Board offered its first accredited continuing education program in myasthenia gravis. This event attracted more than 125 nurses. Under the leadership of James “Chip” Howard, M.D., the Foundation published “Myasthenia Gravis a Manual for the Health Care Provider” for distribution to health care professionals.

In the coming year we will continue to manage the Foundation in a conservative manner while meeting the needs of the MG community and building on the foundation for change initiated in 2008. We look forward to reporting to you next year on the progress we are making in meeting our strategic goals.

Sam Schulhof
Chair, Board of Directors

Tor Holtan
Chief Executive



PUBLIC AWARENESS & EDUCATION

ANNUAL MEETING

The 2008 MGFA Annual Meeting was held June 12-14 at the Hilton Milwaukee City Center in Milwaukee, WI. Sessions included:

- **Long- and Short-term Treatment Strategies**
Suraj Ashok Muley, M.D., associate professor and director, Myasthenia Gravis Program at the University of Minnesota, Minneapolis, MN
- **Medical and Surgical Treatment Therapies**
Alexandra Barboi, M.D. and William B. Tissol, M.D., Medical College of Wisconsin, Milwaukee, WI
- **The impact of MG on Women's Health**
Margherita Milone, M.D., Ph.D., Mayo Clinic, Rochester, MN

- **The Role Positive Thinking and Lifestyle Habits Play in a Person's Overall Health**

Bhupendra Khatri, M.D., medical director of the Regional MS Center at Aurora St. Luke's Medical Center, Milwaukee, WI.

PUBLICATIONS

As part of its continuing education and awareness campaign, MGFA published a comprehensive manual for health care professionals and emergency respondents: "Myasthenia Gravis: A Manual for the Health Care Provider."

CONTINUING EDUCATION FOR NURSES

The Nurses Advisory Board, in conjunction with the Wisconsin Chapter, conducted a continuing education program (CEU) for nurses. 120 nurses participated in the program.



AWARDS & FELLOWSHIPS

AWARDS

Founder's Award: David Grob, M.D.

The Founder's Award was bestowed posthumously on Dr. David Grob who passed away on March 23, 2008 at the age of 89. Dr. Grob, chair of the department of medicine at Maimonides Medical Center and director of the Maimonides Research Foundation in Brooklyn, NY, was internationally recognized for his groundbreaking work on neuromuscular diseases, particularly myasthenia gravis. Dr. Grob was a co-founder and chairman of MGFA's Medical/Scientific Advisory Board as well as the organizer of the 5th and 6th International Conferences on Myasthenia Gravis in 1975 and 1980, respectively.

International Lifetime Achievement Award: John Newsom-Davis, M.D.

Dr. John Newsom-Davis, who passed away on August 24, 2007 at the age of 75, was posthumously awarded the MGFA International Lifetime Achievement Award for his groundbreaking work in auto-immune diseases of the nervous system, particularly for his revolutionary discovery that MG is caused by a defect in the immune system and can be treated by drugs or other procedures. Dr. Newsom-Davis spent much of his career researching the causes and treatments for MG and similar diseases. He was a professor of clinical neurology at Oxford University until his retirement in 1998, and edited *Brain*, the U.K.'s premier neurology journal, until 2004. In 2006 Dr. Newsom-Davis, in conjunction with colleagues in the U.S., began recruiting for the MG Thymectomy Clinical Trial (MGTX Trial), funded by the U.S. National Institutes of Health. The MGTX trial is a multi-center trial focused on determining whether thymectomy procedures – the removal of the thymus gland – should play a role in treatment of patients with non-thymomatous MG.

2008 Doctor of the Year:

Charlene Hafer-Macko, M.D.

Dr. Charlene Hafer-Macko was named MGFA's 2008 Doctor of the Year for her personal commitment and contributions in supporting the work and vision of MGFA. Nominated by the Maryland/Delaware/Washington, DC chapter of MGFA, Dr. Hafer-Macko is an associate professor of neurology with secondary appointments in geriatrics and physical-therapy rehabilitation medicine at the University of Maryland School of Medicine in Baltimore, MD, where she is also the director of the Neuromuscular Fellowship, the Myasthenia Gravis Center and the Neurology Infusion Center. Dr. Hafer-Macko also serves as the director of the Baltimore Veterans Administration Medical Center's Neuromuscular Division.

FELLOWSHIPS

MGFA awarded second-year funding to two post doctoral research projects in 2008.

Shalina Mukherjee, Ph.D.,
The University of Texas Southwestern
Medical Center, Dallas, TX

Dr. Mukherjee's project, titled "Antibody Mediated Modulation of Neuronal Nicotinic Acetylcholine Receptors," investigates the relationship between two antibody-mediated diseases that involve an attack on acetylcholine receptors (AChRs): autoimmune autonomic neuropathy (AAN) and myasthenia gravis (MG). In MG, the antibodies reduce the amount of AChR available to the muscle and damage muscle membrane, whereas in AAN the antibodies attack AChRs on the nerve cell, impairing communication between nerve cells. This research expects to yield important information about the process that occurs in antibody-mediated diseases such as myasthenia gravis.

Jennifer Anderson, Ph.D.
University of California, Davis, CA
Dr. Anderson's project, titled "Allele-Specific RNAi Treatment for Slow-Channel Syndrome Caused by M2 Acetylcholine Receptor Mutations," investigates the potential treatment for slow-channel syndrome (SCS), a form of congenital myasthenic syndrome (CMS). This strategy involves developing gene therapy that will silence the abnormal gene, which contributes to the development of slow channel syndrome. The protocol is currently concluded in the in-vitro (test tube) phase and will proceed to in-vivo research in mice.

JOHN NEWSOM-DAVIS MEMORIAL AWARD FOR NEUROLOGY RESIDENTS-IN-TRAINING

MGFA established an award for residents-in-training in honor of Dr. Newsom-Davis. The award commemorates Dr. Newsom Davis' life and dedication to improving treatment of patients with MG. The award is open to registrars, residents or fellows who wish to present their MG-related research at a recognized professional event or who would like to attend a meeting that will significantly further an understanding of MG and related autoimmune diseases.

AWARDS & FELLOWSHIPS





STATEMENT OF FINANCIAL POSITION

The audited financial statements are available at the MGFA website www.myasthenia.org, or by contacting MGFA directly at (800) 541-5454.

PUBLIC SUPPORT AND REVENUE

	2008	2007
	Total All Funds	Total All Funds
Public Support		
Individuals	\$128,472	\$141,368
Corporations	27,445	25,617
Foundations	21,735	57,229
Boards	5,580	11,122
Legacies	211,696	319,367
Chapters	93,770	95,946
Public Agencies	53,088	48,892
Total Public Support	\$541,786	\$699,541
Revenue		
Chapter Assessments	\$94,454	\$203,595
Merchandise	3,461	2,724
Meetings and Conventions	62,445	34,015
Other	1,595	1,034
Investment Income (Loss)	(992,162)	88,124
Total Revenue	\$(830,207)	\$329,492
Total Support and Revenue	\$(288,421)	\$1,029,033

PROGRAM EXPENSES AND SUPPORTING SERVICES

	2008	2007
	Total All Funds	Total All Funds
Program Expenses		
Patient Services	\$61,715	\$98,556
Annual Meeting	77,901	94,768
Scientific Session	6,320	84,820
Chapter Development	79,679	80,964
Public Information	27,879	37,286
Medical and Nurse Advisory Boards	14,133	7,396
Research	171,176	227,917
Total Program Expenses	\$438,803	\$631,707

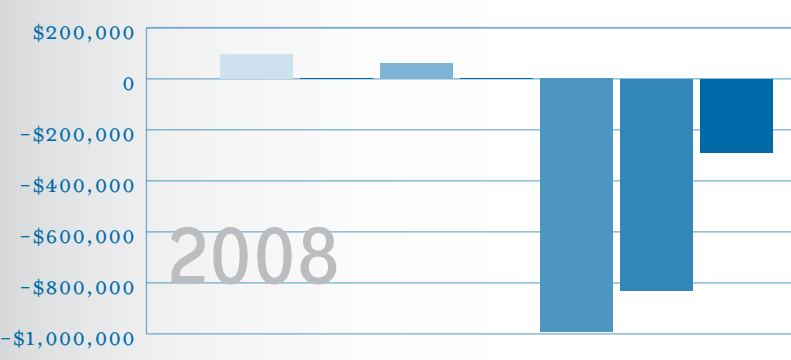
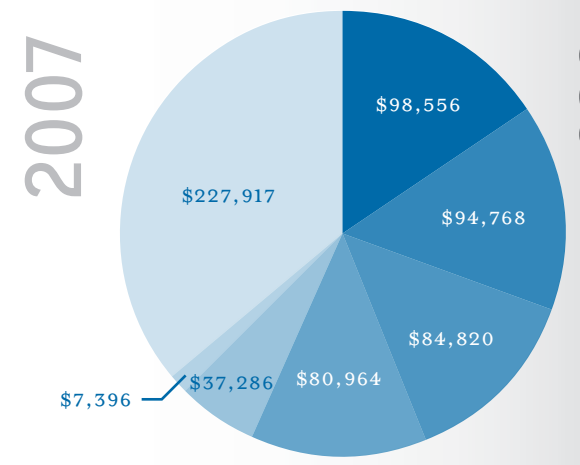
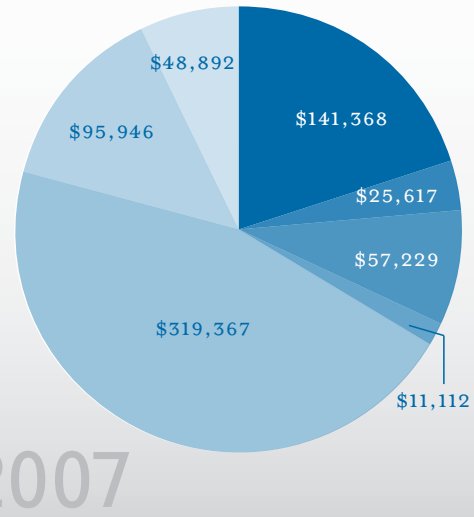
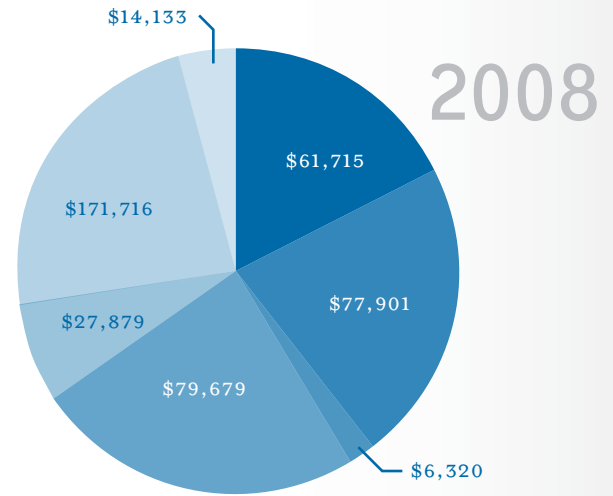
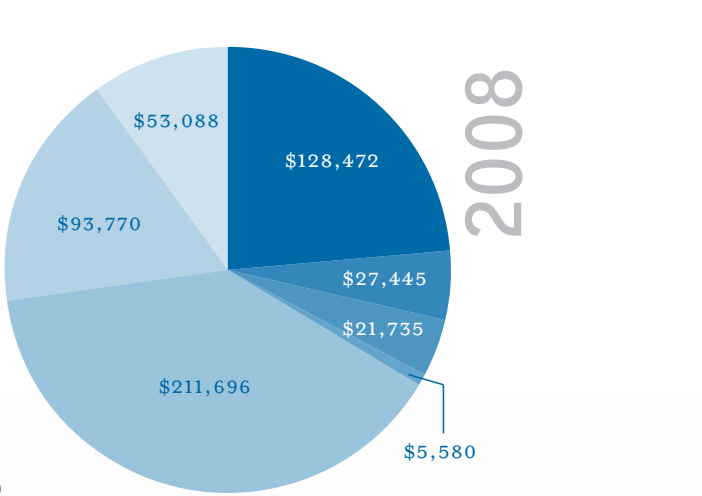
Supporting Services

Management and General	\$153,572	\$156,082
Fundraising	36,422	34,677
Total Supporting Services	\$189,994	\$190,759
Total Expenses	\$628,797	\$822,466

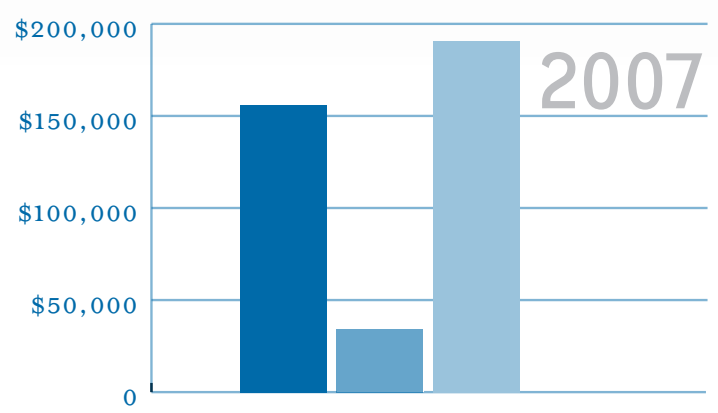
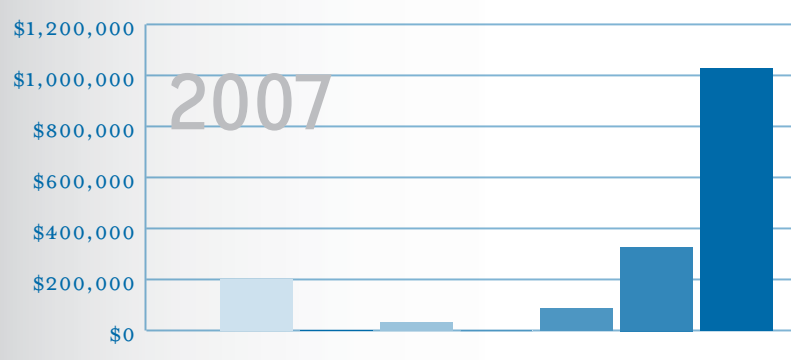
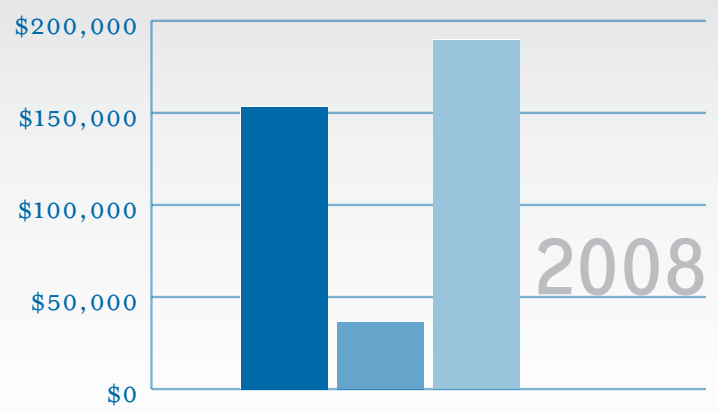
Net Assets

2008 Total All Funds	2007 Total All Funds
\$4,473,593	\$5,390,811

Program Expenses



Supporting Services



Revenue

BOARD OF DIRECTORS

Samuel Schulhof,
Chair

Marc Kalish, J.D.,
Treasurer

Ronald McFarlane, R.Ph.,
Vice-Chair

Marie Ronnlof,
Acting Secretary, Chapter Liaison

Marcia S. Lorimer, R.N., M.S.N., C.P.N.P.,
Audit Committee Chair

Richard Barohn, M.D.,
Chair, Medical/Scientific Advisory Board

Henry J. Kaminski, M.D.,
Chair-elect, Medical/Scientific Advisory Board

Wilma Koopman, R.N., M.Sc.N.,
Representative, Nurses Advisory Board

Esther M. Land

Nancy Law

Janet Myder, M.P.A.

Louis Nemtsov

Robert Ruff, M.D., Ph.D.

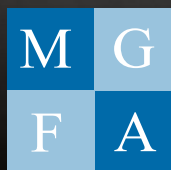
Michael Rusinko

MGFA STAFF

Janet Golden, Chief Executive

Matthew Spaan, Patient/Chapter Services Manager

Jenny Weber - Patient Services Coordinator



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