calendar

Board Meeting
January 23, 2009
Tampa, FL

Board Meeting
May 6, 2009
Charlotte, NC

MGFA Annual Meeting
May 7-8, 2009
Charlotte, NC

Thank you...to all of our wonderful donors!

Your generosity brings us closer to a world without MG.

fall 2008

Comments from Chairman Sam Schulhof ................................................................. pg 2
More than 150 people attended MGFA’s 2008 annual meeting. Chairman Sam Schulhof set the stage...

Ask the doctor ........................................................................................................ pg 2
Are there any precautions I should take before visiting the dentist or while at the dentist?
I need to have oral surgery. What types of anesthetics are safe for people with MG?

Health insurance—be aware! ................................................................................ pg 3
One of the most important concerns to anyone with a chronic illness is having the proper health insurance to cover the major costs of any potential issue.

MGFA advocacy update ......................................................................................... pg 3
For the first time in recent history, MGFA’s member advocacy efforts resulted in a special message from President Bush acknowledging June Awareness Month.

Myasthenia Gravis: A Manual for the Health Care Provider ................................ pg 4
We are pleased to announce the publication of Myasthenia Gravis: A Manual for the Health Care Provider.

Proposed research agenda ..................................................................................... pg 4
MGFA has asked the M/SAB to propose a research agenda in order to target MGFA’s funding more effectively.

Alert to patients experiencing problems with medications ................................. pg 4

Highlights from the 2008 Annual Meeting .............................................................. pg 5

MGFA welcomes three new board members ....................................................... pg 9

Dr. David Grob recognized by Foundation .......................................................... pg 10
This year, MGFA has bestowed upon Dr. David Grob the honor of Founders Award.

MGFA joins NORD coalition to end Medicare waiting period ......................... pg 10
MGFA and NORD believe that no one with disabilities severe enough to qualify for SSDI should be without insurance.

2008 Doctor of the Year ....................................................................................... pg 11
Dr. Charlene Hafer-Macko was named as MGFA’s 2008 Doctor of the Year.

Across the country: calendar of MGFA chapter events ....................................... pg 11

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs and should not be used as a basis for decision-making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient.
Comments from Chairman Sam Schulhof

More than 150 people attended MGFA’s 2008 annual meeting. The meeting was held June 12-14 at the Hilton Milwaukee City Center in Milwaukee, WI. Sponsors included Mayo Clinic, Amarin, Accredo, Talecris Biotherapeutics, MedProX, and CSL Behring.

Chairman Sam Schulhof set the stage at the annual meeting’s general assembly with a review of the Foundation’s accomplishments over the past year. He also outlined the exciting year ahead, labeling 2008-2009 as the year of accelerating change.

MGFA will continue to work toward achieving its strategic goals through 2009 to build a sustainable foundation with a diversified and stable funding base; increase public awareness about MG and MGFA; continue to increase the MGFA endowment; broaden and strengthen our board of directors; focus and strengthen our committees; and broaden our donor database.

We have made many strides toward our strategic goals over the past year, including the addition of three new members to the board: Steve Hawco, Louis Nemtsov, and Sue Klinger. (Learn more about them on page 8.)

Our Nurses Advisory Board (NAB) and Medical/Scientific Advisory Board (M/SAB) have been working together more than ever to help raise awareness for MG. The NAB hosted an MG continuing education program for nurses in Milwaukee, which drew more than 100 registrants. The NAB also organized their inaugural walk/run fundraiser. The M/SAB and NAB are in discussion with the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institute of Health, organizing an MG summit to develop a multi-year research agenda.

As we move towards 2009, we continue to focus on raising awareness, enhancing programs, and strengthening our chapters with the goal of improving the lives of individuals with MG.

Ask the doctor

Robert Ruff, MD, PhD

Are there any precautions I should take before visiting the dentist or while at the dentist?

In general, MG does not lead to dental disease. However, having MG may compromise your ability to swallow and, if you’re taking Mestinon®, you may produce more saliva. Jaw weakness may lead to jaw misalignment.

If your condition is unstable, consultation with your neurologist is recommended prior to dental treatment in order to ascertain the extent of neuromuscular weakness and frequency of neuromuscular exacerbations or crises, and to discuss the need for medical management to optimize the treatment outcome.

The dentist should know that you have MG and what medications you’re taking. This information enables the dentist to adjust dental treatment so you have the best experience possible. Regardless of your condition, it’s helpful to give your dentist the MGFA brochure on dental treatment. The dental treatment brochure can be found at http://www.myasthenia.org/docs/MGFA_Brochure_DentalTreatment.pdf. You may also request this information from the national office at 1-800-541-5454.

I need to have oral surgery. What types of anesthetics are safe for people with MG?

Patients with MG are excessively sensitive to neuromuscular blocking agents. These agents are sometimes used to produce muscle weakness, and their use can lead to prolonged post-anesthesia weakness. The neuromuscular blocking agents include succinylcholine and medicines related to curare. There is also potential exaggerated weakness associated with local anesthetics; procaine should be avoided.

The table below indicates medications that may produce exaggerated weakness.

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<tr>
<th>Relatively Contraindicated</th>
<th>Use with Caution</th>
<th>Safe</th>
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<tr>
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<td>Vancomycin¹</td>
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<tr>
<td>Penicillin &amp; derivatives</td>
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</tr>
<tr>
<td>Other drugs</td>
<td>Corticosteroids¹</td>
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</tbody>
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Key:
1 = drugs which may acutely potentiate myasthenic weakness
2 = use with caution in patients with respiratory difficulty or depression
3 = may induce an exacerbation of MG
4 = significant drug interaction with cyclosporine
Health insurance—be aware!
Susan Klinger

Having a chronic illness like myasthenia gravis presents many kinds of life changes and issues. One of the most important concerns to anyone with a chronic illness is having the proper health insurance to cover the major costs of any potential issue.

There are a lot of questions to be asked and answered. For example, do you have the right insurance? Is it a plan provided by your employer, your union, your school? Are you eligible to be covered as a dependent by a spouse? Does it cover your MG treatments, medications, hospitalizations, second opinions, or other serious illnesses? Is your insurance a PPO or an HMO? Do you have in-network and out-of-network coverage? What happens if you change or lose a job? What happens if you are a student and you “age out” of your parents’ insurance?

These are only some of the many questions asked by anyone who needs what in today’s world can only be described as expensive medical care. There is no universal health care in the US today except for those who are Medicare eligible. Health insurance plans are all over the map when it comes to what they do and don’t cover. Even those who enroll in Medicare Advantage plans find out that all coverage is not equal. Almost 50 million people in the US are without health insurance, and you don’t want to be one of them.

What to do, then, to ensure that you, as an MG patient, don’t get stuck with inadequate health insurance? The best advice is to check your plans and know your health insurance coverage so you will be prepared for any health care contingency. If you have health insurance from an employer or union plan, make sure you understand exactly what your plan covers. Read the booklets, go on the Internet sites, or ask your human resources department. Many plans only provide coverage if you use a plan-specific network of providers and facilities. If you go out of the plan’s network, you could wind up with hefty out-of-pocket expenses. Make sure you select the insurance that works for you and your family’s health needs.

If you or a child loses coverage, you will be eligible for COBRA coverage for at least 18 months. (Beware: COBRA coverage was only meant as a stopgap and is very expensive.) Ask for a certificate of insurability from your previous insurance so you will have no pre-existing condition issues with any new insurer. This is a provision of HIPPA, the Health Insurance Portability and Privacy Act, which protects patient’s health records. If you have regular Medicare, you may need a supplemental insurance plan.

MGFA advocacy update
Janet Myder

Grassroots Efforts for June Awareness Month

For the first time in recent history, MGFA’s member advocacy efforts resulted in a special message from President Bush acknowledging June Awareness Month. MGFA requested that members and friends ask their congressional representatives to urge President Bush to declare June 2008 MG Awareness Month. Congressional members followed through and MGFA received a signed “President’s Message” dated May 29, 2008. In part, this message read:

“I send greetings to those observing Myasthenia Gravis Awareness Month… One of America’s greatest strengths is the compassion our citizens have for their neighbors… I appreciate the tireless work and compassion of the MGFA and all those who are dedicated to improving lives and finding a cure for MG.”

This was the clear result of the efforts of all of our members, chapters, national board, and national office, and is evidence that “together, we are stronger!”

Many of our chapters requested and received official proclamations from various counties, states, and cities across America proclaiming June as MG Awareness Month. This effort provided an opportunity to broaden public awareness of MG and resulted in several newspaper, radio, and television interviews.

Advocacy Program

The Communications Committee continues to refine MGFA’s Advocacy Program, a coordinated program of actions and strategies at the national, chapter, and individual levels. Further program development will focus on helping chapters build on their own advocacy activities. While MGFA will guide the program, it will seek chapters’ input and action.

We again urge you to contact your local chapter to volunteer to help with this program. Web site enhancements are planned to enable two-way communication. For example, bulletins at the national level would inform users about timely issues and recommended action. Chapters would be able to share information about their activities, successes, and examples.

Support for Americans with Disabilities Act (ADA)

On September 17, the House of Representatives approved by voice vote a major civil rights bill that protects people with disabilities. MGFA advocated passage of the bill when it joined the National Health Council’s campaign asking congressional leaders to support H.R. 3195, the ADA Restoration Act (later titled the ADA Amendments Act of 2008). The act redefines “disability” and protects people with chronic diseases and disabilities from workplace discrimination.
Advocacy update
continued from page 3

MGFA considers these amendments to be vital for people with MG. The courts have narrowed the definition of disability so much since the ADA was enacted 17 years ago that people with conditions such as MG, epilepsy, diabetes, and heart disease who manage their disabilities with medication or other treatment are viewed as “too functional” to be protected under the law.

The House approved H.R. 3195 on June 25 by a vote of 402 to 17, and on September 11 the Senate approved its version, S3406, by unanimous consent. The House approved the final bill by voice vote on September 18, clearing the way for the President’s signature.

MGFA is asking chapters and friends to thank their members of Congress for supporting the legislation. Go to www.myasthenia.org for information.

Myasthenia Gravis: A Manual for the Health Care Provider

We are pleased to announce the publication of Myasthenia Gravis: A Manual for the Health Care Provider. It is the first comprehensive manual on myasthenia gravis specifically written for health care professionals involved in the care and management of people with MG. The manual addresses various aspects of evaluation, diagnosis, and management of MG. Sections address issues related to:

- Nursing
- Anesthesia
- Emergency Care
- Psychosocial: From Diagnosis to Lifetime Management
- Physical Therapy
- Occupational Therapy
- Speech Pathology and Swallowing
- Dental Care
- Guidelines for the Pharmacist

We would like to thank Dr. James Howard (M/SAB member who spearheaded the efforts to write the manual) for his dedication and contribution to the MG community in developing this tool for health care providers. We would also like to thank the Wisconsin Chapter for their generous support and patience throughout this project.

If your health care provider is interested in receiving a copy of the manual, please have him/her contact the national office at mgfa@myasthenia.org or 1-800-541-5454.

Proposed research agenda

Henry J. Kaminski, MD, Medical/Scientific Advisory Board vice chair, presented an update on research and the board’s proposed research agenda at this year’s annual meeting.

Dr. Kaminski pointed out that typical clinical trial grants funded by the NIH cost several million dollars. While MGFA is “an important, but small area of funding...”, we cannot even come close to funding grants of that magnitude. Therefore, the M/SAB recognizes the necessity of leveraging the Foundation’s resources to insure the funding of successful MG research. The research agenda was proposed as a way of leveraging our funds into specific areas of study.

The major focus areas include etiology (finding the cause of MG), detection/early diagnosis, and treatment. Treatment is further broken down into the areas of:

- Application of drugs
- Combination therapy
- The thymus gland
- Less expensive ways to administer plasma exchange and IVIG therapy
- New therapies for known targets
- New therapeutic targets
- New strategies
- Quality of life aspects
- Collateral effects of MG

Alert to patients experiencing problems with medications

We have received several complaints from members who are experiencing problems with pyridostigmine bromide crumbling or disintegrating in the original packaging. It is recommended that you return those tablets to your pharmacist and request that they be replaced with a different batch or a different manufacturer. It is also recommended that you file a MedWatch Report with the Federal Drug Administration at www.fda.gov/medwatch/report/consumer/consumer.htm. Once you have filed a MedWatch Report, please report your problem to the MGFA office at mgfa@myasthenia.org or 800-541-5454.
This year’s meeting was unique with the addition of the Foundation’s inaugural one-mile walk/run fundraiser on Friday morning. People of all ages and abilities participated by walking, running, and chair-exercising. Together, we raised a total of $2,365 to benefit our Nurses’ Program.

Chairman Sam Schulhof opened this year’s general assembly with the State of the Foundation report, reflecting on the accomplishments of the past year and the goals of greater awareness and sustainability through improved infrastructure. Board member Nancy Law delivered an inspiring speech on developing a unified vision for MGFA and the necessity for all of MGFA’s chapters to work together for a stronger and more focused organization.

MGFA’s Nurses Advisory Board hosted a wide variety of highly-attended patient sessions on everything from the basics to nutrition and lifestyle.

Sessions for chapter leaders were held (concurrently with patient sessions) on various topics, including budgeting, completing the new 990, and audit and risk management.

Medical/Scientific Advisory Board vice chair Henry Kaminski, MD shared the board of directors’ proposed research agenda. (See page 4 for more information on the research agenda.)
Suraj Ashok Muley, MD, an associate professor of neurology and the director of the Myasthenia Gravis Program at the University of Minnesota, presented on various treatment strategies. Dr. Muley lectured on the goals of treatment and the differences between long-term immune-directed and short-term immune-directed treatment. He also shared the results of several clinical trials.

Alexandru Barboi, MD and William B. Tisol, MD discussed medical and surgical therapies as well as their work with the MGFA-sponsored Thymectomy Study at the Medical College of Wisconsin in Milwaukee.

“Social Security Disability: Change and Confusion” was presented by Jeffrey Rabin, JD. Mr. Rabin humorously outlined the different Social Security programs and qualifications for eligibility, as well as information about returning to work.

Dr. Robert Pascuzzi opened the Awards Dinner with a retrospective view of MGFA. In addition, he called out the significant contributions by the late Drs. David Grob and John Newsom-Davis. Dr. Grob was posthumously awarded the MGFA Founder’s Award in recognition of his contributions to the Foundation. Dr. Newsom-Davis was awarded the International Lifetime Achievement Award.
A crowd favorite was the presentation “Thirty Years of Caring for MG” with Bhupendra Khatri, MD, who stressed the role of positive thinking in regards to a person’s overall health and well-being. Dr. Khatri showed videos of some seemingly miraculous recoveries by some of his patients who, with his guidance, changed their attitudes and thoughts to focus on the positive and what they could do. He pointed to several lifestyle habits—such as meditation and therapeutic massage and relaxation, researched by Dr. Richard Davidson of University of Wisconsin-Madison—that can help improve immunity.

Esther Land commemorated the life of Pat Wilson (1931-2007), the daughter of MGFA’s founder, with pictures of Pat’s life and work with the foundation.

“Myasthenia Gravis and Women’s Health” was presented Saturday morning by Margherita Milone, MD, PhD from the Mayo Clinic. This presentation focused on MG and pregnancy, transient neonatal MG, the menstrual cycle and sex hormones, and potential complications from immunotherapy.
Annual Meeting
continued from page 7

This year, the popular “Ask the Doctor” session (a panel of Medical/Scientific Advisory Board members) was led by MGFA’s Doctor of the Year Charlene Haefer-Macko, MD. Members of the panel included Bhupendra Khatri, MD, Margherita Milone, MD, PhD, and Brian Crum, MD. Attendees submitted questions beforehand and panelists provided responses during the session.

Lindsay Knudsen, MS, chair of the Wisconsin Chapter, and new board member Steve Hawco presented on the “Changing Face of MG.” They stressed the importance of the Internet for expanding outreach to a more diverse MG community.

The Wisconsin Chapter celebrated its 50th anniversary Saturday night with a dinner on The Edelweiss.

Save the date!

MGFA Annual Meeting

May 7-8
2009
Charlotte, NC
Marriott City Center

Back by popular demand: in-depth patient programs provided by the MGFA Nurses Advisory Board.

Registration and more information will be available soon at www.myasthenia.org.
As we reach the end of the year, make a gift to MGFA

Please consider making a tax-deductible donation to MGFA. Visit www.myasthenia.org and click on “How can I help.” You can make a donation by using the Acceptiva™ secure payments process or by sending in a check (make checks payable to Myasthenia Gravis Foundation of America, Inc.). Other ways that you can support MGFA and its mission financially can be found by selecting “Planned Giving.”

Your dollars will help support medical research about myasthenia gravis, provide printed material to those struggling with myasthenia gravis, keep the lights on in the home office, and so much more.

Your gift is tax-deductible to the fullest extent of the law. Thank you for your support!
Comments on the early history of MGFA, Dr. David Grob in the 1950s, and Dr. Grob in 2008

This year, MGFA bestowed upon Dr. David Grob the honor of Founder’s Award. Along with Dr. Henry Viets, Dr. Grob was one of the original founding members of the Medical/Scientific Advisory Board and one of the founding members of MGFA. Dr. Grob was also instrumental in the coordination of the first International Symposium on myasthenia gravis.

Dr. Grob has made a huge and unique contribution to the overall understanding of the clinical manifestations of MG, the spectrum of clinical presentations, and the all-important natural history data. Dr. Grob has presented and published a remarkable series of reports on the natural history of MG in several thousand patients. Some of the observations cover six decades. Fittingly, Dr. Grob’s last publication was published in Muscle and Nerve shortly before his death and served to summarize six decades of observations on myasthenia gravis. I cannot think of a set of data that I have used more consistently in my day-to-day practice in dealing with MG patients as the collection of clinical and natural history data provided over the years by Dr. Grob.

Dr. Grob was born in New York City in 1919. He finished high school at age 14 and graduated from the City College of New York at 18. He graduated from Johns Hopkins University in 1942 with his MD degree.

While on staff at Johns Hopkins, he devoted much of his professional skill on the evaluation, management, and research of patients with myasthenia. From 1958 to 1989, Dr. Grob chaired the department of medicine at Maimonides, and from 1989 to 2006, he was medical director of the Maimonides Research Foundation.

A full version of Dr. Grob’s work and contribution to MG can be found at www.myasthenia.org.

Members of Dr. Grob’s family (Susan Lichtenfield and Charles Grob) accept the Founder’s Award on his behalf.

MGFA signs on with the National Organization for Rare Disease’s coalition to end the two-year waiting Medicare period for people with disabilities

People with MG who are under the age of 65 and qualify for Medicare must wait two years from the date they are deemed eligible for Social Security Disability Insurance (SSDI) to receive Medicare coverage. During this two-year wait, many people are uninsured or underinsured and may be forced to forego care they cannot afford.

MGFA and NORD believe that no one with disabilities severe enough to qualify for SSDI should be without insurance. In the coming months, the Foundation will play a role in the creation of an action plan for the next Congress to ensure that this issue is a priority for lawmakers and the new administration. Look for an update on this important issue in our spring Foundation Focus.
MGFA chapters are busy planning or recently have held events for our members. The following events are a look at just some of the activities around the country. We encourage you to contact your local chapter to find out what’s going on in your local area. To locate your local chapter, please call 1-800-541-5454 or visit www.myasthenia.org and click on MGFA Local Chapters.

**Connecticut**

October 5, 2008 – Connecticut Nutmeg State Chapter’s 2008 Annual Meeting and 35th Anniversary Party, Waterbury, CT. For more information, contact the Connecticut Nutmeg State Chapter at 203-926-9910, 866-329-8784 (toll free), or via e-mail at conn@myasthenia.org.

**Florida**

December 3-7, 2009 – 2nd Annual Anchors Aweigh with MGFA!, four-day cruise; leaves from Tampa, FL with ports of call in Key West, FL and Cozumel, Mexico. For more information, contact the Greater Florida Chapter at 727-596-1491, 877-596-1491 (toll free), or via e-mail at tromnlof@verizon.net.

**Maryland/Washington DC/Delaware**

September 6, 2008 – Maryland/DC/Delaware Chapter’s 2008 Annual Meeting, Baltimore Washington Medical Center. For more information, contact the Maryland/DC/Delaware Chapter at 410-432-6193, 866-437-2881 (toll free), or via e-mail at maryland@myasthenia.org.

**Massachusetts**

November 2, 2008 – Massachusetts/New Hampshire Chapter’s 2008 Annual Meeting, Sheraton Framingham, Framingham, MA. For more information, contact the Massachusetts/New Hampshire Chapter at 508-435-3808 or via e-mail at massachusetts@myasthenia.org.

**Minnesota**

September 21, 2008 – Minnesota Chapter’s 2008 Annual Meeting, Hampton Inn, Shoreview, MN. For more information, contact the Minnesota Chapter at 218-562-4594 or via e-mail at mgcorn@uslink.net.

**New York**

October 2008 – Annual Awards Luncheon, New York, NY. For more information, contact the Metro New York Chapter at 516-538-0738 or MetroNY@myasthenia.org.

**Wisconsin**

October 4th, 2008 – Wisconsin Chapter’s Annual Pancake Breakfast, West Allis, WI. For more information, contact the Wisconsin Chapter at 262-938-9800 or via e-mail at wisconsin@myasthenia.org.

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**2008 Doctor of the Year**

Dr. Charlene Hafer-Macko was named as MGFA’s 2008 Doctor of the Year. Dr. Hafer-Macko is an associate professor of neurology and medical director of the Myasthenia Gravis Center at the University of Maryland School of Medicine. She also serves as the co-director of the Neuromuscular Fellowship and the director of the Baltimore Veterans Administration Medical Center Neuromuscular Service.

Nominated by the Maryland/Delaware/DC Chapter of the Myasthenia Gravis Foundation of America, Inc., Dr. Hafer-Macko is recognized for her personal commitment and contributions in supporting the work and vision of MGFA.

» Dr. Charlene Hafer-Macko… has been a “rock” for so many of our members and has been a great supporter of our MG Chapter. Despite a very demanding schedule teaching and researching, she is always available when we have concerns. She places herself on the “patients’” level, never talking down and quick with a hug if needed. If you are having a test done at the hospital, and she knows you are concerned, it is not uncommon to have her show up to offer moral support.

» Dr. Macko is one of the “rare” doctors who is also a friend.

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**Across the country: calendar of MGFA chapters’ events**

Dr. Charlene Hafer-Macko (2nd from left) with the members of the Maryland/Delaware/DC Chapter.
Myasthenia gravis is an autoimmune neuromuscular disorder. Symptoms may include double vision, drooping eyelids, slurred speech, difficulty chewing and swallowing, weakness in arms and/or legs.

**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.

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