



MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.

News about myasthenia gravis for patients, family and friends

FOUNDATION FOCUS

Fall 2004



by *Esther M. Land*

As its name implies, MGFA's Medical/Scientific Advisory Board is comprised of patient care physicians as well as research scientists with a keen interest and

involvement in myasthenia gravis. These world-class scientists continue to monitor what is being done at major research centers across the country and, in fact, around the world. Within the M/SAB Board are the Research and Grants Committee and the Henry R. Viets Fellowship Committee. These seasoned research scientists are experts in myasthenia gravis, experimental myasthenia gravis and/or immunology and use the expertise within the Foundation as well as go outside of the organization when the review of a particular topic is beyond their current expertise.

The Viets Fellowships are primarily geared for students in the healthcare profession to expose them to MG through short-term research projects with a stipend of \$3,000. The Osserman/Sosin/McClure Fellowships provide support for post-doctorial training in basic science or clinical research in MG with a stipend of \$50,000.

Submitted applications are forward to the Chairperson of the Research & Grants Committee or the Henry R. Viets Fellowship Committee chair, who disseminates them to each committee member. Adhering to strict NIH-accepted standards, members independently review each applicant and submit written evaluation to the committee chair. Applicants are ranked and awarded in accordance to the number of applicants approved by the MGFA Board of Directors at its fall meeting. At the conclusion of their

chairperson update

research, each Fellowship recipient submits to MGFA the outcome of his or her research efforts in a written report in lay terms.

The M/SAB also organizes the annual MGFA Scientific Session, at which Viets and Osserman/Sosin/McClure Fellowship recipients and other interested scientists from around the world present their findings. The next Scientific Session will be October 2, 2004 at the Sheraton Toronto Hotel.

MGFA has a long-standing record of research sponsorships and is dedicated to providing funds to underwrite these programs. Over the past five years, we have supported an average of three Osserman/Sosin/McClure and three Viets Fellowships per year. This year, three Viets Fellowships (all underwritten by chapters) were awarded but, sadly, due to funding limitations, we were able to support only one Osserman/Sosin/McClure Fellowship applicant out of the nine very promising candidates.

We are all looking for a cure for MG and we know it will come only through consolidated efforts. With research costs increasing and MGFA's available research dollars dwindling, the Board of Directors adopted an Investment Policy Statement at its May meeting that paves the way to establish an endowment fund to provide on-going funding for our research programs.

Endowments are created when funds from a variety of sources are consolidated to build a large pool of monies. These funds are acquired from bequests, outright gifts, revocable charitable trusts, insurance policies, life income gifts and charitable lead trusts. Expenditures from the fund are dispensed only on interest/dividends earned in the previous year, never dipping into the capital investment. Gifts into the endowment fund

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by LJ Taugher

The national office is continually working to improve and enhance the services we provide in an effort to minimize time and expenses while increasing the quality of service to the MG community and chapters. To this end, we have been active in data management, medical brochure content updates, planning for the 2005 Annual Meeting and fundraising.

For any organization, data is key. With this in mind, the national office is about to begin development of a new database to centralize all the national office data in one tailor-made database. Our expectation is that this database will enhance our ability to communicate with people who request information, current patients with MG, chapters and donors—resulting in a long-term savings for the organization as a whole.

As part of our mission “to improve... lives through programs of patient services,” our Medical/Scientific Advisory Board and Nurses Advisory Board have reviewed and updated the brochures on mycophenolate mofetil (CellCept®), azathioprine (Imuran®) and cyclosporine. If you would like to see the updated brochures, please visit www.myasthenia.org/information/.

We are happy to announce that the 2005 Annual Meeting will be held April 21-23 in Grand Rapids, Michigan. More information will be forthcoming.

We will be kicking off our annual appeal mailing in the coming month to help us raise funds for research, patient services and our new endowment (mentioned in Esther Land’s cover article). Please keep an eye out for the annual appeal in your mail and help us continue the fight for better treatment for MG and the search for a cure. ■

chairperson update *continued*

may be earmarked or named in honor or memory of a specified donor—perpetuity that will create a legacy. By living on in perpetuity, endowment funds will guarantee continued success in research and constant funding until we find a cure.

The board, national office and M/SAB will be working as a team to accomplish this—the board identifying and soliciting donors, the national office providing expertise in the infrastructure and the M/SAB providing expertise for the best expenditure of the funds. As the chair of the M/SAB, James (Chip) Howard, Jr., MD wrote to me, “It is only through these combined efforts that we will continue making strides in the understanding of MG, its treatment and ultimately the ability to allow each and every patient with this illness to experience a respite from its clutches and a quality of life second to none.”

Can we count on your support in this endeavor to create an endowment fund? ■

Welcome!

Marinos C. Dalakas, MD from NIH/NINDS, Bethesda, Maryland, was voted onto the Medical/Scientific Advisory Board in October 2003.

Emma Cifaloni, MD from the University of Rochester Medical Center, Rochester, New York and Melissa Noble from Valeant Pharmaceuticals International, Costa Mesa, California, were elected to the National Board of Directors in May 2004. ■

Great things are happening!

by Jennifer Heidelberger,
Patient/Chapter Services Coordinator

Each June is Myasthenia Gravis Awareness Month, and chapters throughout the country were active in promoting awareness about myasthenia gravis in June 2004. Here are some samples of what was accomplished.

The **Detroit Chapter** and the **Great Lakes Chapter** each received a proclamation from the State of Michigan for “June as Myasthenia Gravis Awareness Month.”

The **Great Lakes Chapter** designs a display case about myasthenia gravis in the local library each June to coincide with their annual meeting held at the same location. This year, they also printed and distributed posters to members to be displayed in locations throughout the chapter’s territory.

The **Garden State Chapter** promoted awareness of MG by urging all 566 New Jersey municipalities to declare June as Myasthenia Gravis Awareness Month. As a result, more than 100 townships and Governor James McGreevey issued the proclamation. Additionally, the Chapter created awareness of MG with several stories in highly-circulated newspapers, Web sites and broadcast spots.

The **Dallas/Fort Worth Chapter** received proclamations from the Texas cities of Roanoke and Fort Worth proclaiming June as MG Awareness Month. Frank Temple, Chairperson, represented the chapter at both cities’ council meetings and received the proclamations. Mayor Randy Corn of Roanoke and Mayor Mike Montcrief of Fort Worth issued the proclamations. The chapter received a mounted proclamation from Fort Worth signed by the Mayor and Council members.

In June, the **Illinois Chapter** sent out PSAs to 27 radio stations in metro Chicago. They also sent a press release to 28 newspapers throughout the state of Illinois. They received a

proclamation from the State of Illinois, the City of Chicago and Calumet City. Gerry Tarka, Executive Director, distributed information about MG at the Calumet City Council meeting. The chapter also held a successful membership drive in June.

Mayor Norm Archibald proclaimed June 2004 as Myasthenia Gravis Awareness Month in the city of Abilene, Texas. The proclamation was presented to Lajuana Miller, Abilene Support Group Leader and Chairperson of the **Northwest Texas Chapter**. Each member of the city council and those in the audience of the council meeting were given several copies of the Abilene Support Group brochure, which includes basic facts of MG, and were challenged to help promote MG awareness by sharing these brochures with their co-workers, families and friends.



Lajuana Miller receives the June 2004 Myasthenia Gravis Awareness Month proclamation from the Abilene City Council

Also honored on the same day was Beatrice Takacs for 25 years of service in the Abilene Public Library. Beatrice has worked with the chapter to add books about MG at the public library—another great way to promote MG awareness.

The **Oklahoma Chapter** celebrated June with proclamations by both Tulsa’s Mayor Robert Lafortune and Oklahoma’s Governor Brad Henry declaring June as Myasthenia Gravis Awareness Month. Chapter members, their families, the chapter board and office staff gathered at Lafortune Park in Tulsa on Sunday, June 6th for a fun, old-fashioned picnic. Good food, friendly conversation and great weather were experienced by all!

The **Alabama Chapter** held its 10th Annual “All Eyes on Myasthenia” conference for nurses on June 19. The training was co-sponsored by the University of Alabama Neurology Department and St. Vincent’s Hospital.

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Can a person with myasthenia gravis compete in the Olympics?

YES! **James Carter** overcame the obstacles of having myasthenia gravis to compete in the 400-meter hurdles for the 2004 Olympics—and finished fourth! See his pictures competing in the U.S. Olympic Team Trials Track and Field in San Francisco at www.usatf.org/events/2004/OlympicTrials-TF/photos/day3/m400mHF/. For more information about James Carter, visit www.usatf.org/athletes/bios/Carter_James.asp. James is a “Gold Medal Winner” in our myasthenic community—an inspiration to us all! ■

Foundation Focus introduces e-mail version

With the summer 2004 issue of *Foundation Focus*, the MGFA national office introduced an e-mail version of the newsletter.

More than 500 newsletter subscribers elected to receive the new version, which is sent as a Web-page-like HTML e-mail directly to the subscriber’s e-mail address.

A follow-up survey was sent to the e-mail version recipients following the inaugural issue. The 42 survey respondents were unanimous in their responses: They liked the e-mail format and found it easy to access, navigate and read. Here are a few comments from the survey responses:

“It saves me time—I can automatically print it and copy for other members of [our chapter]. I don’t have to go to another ‘site’ to retrieve it.”

“I read this e-mail issue more thoroughly than I ever have a printed version.”

“I liked it. Easier to use than the paper version.”

Would you like to receive future issues of *Foundation Focus* by e-mail instead of mail? Simply contact the national office at 1-800-541-5454 or info@myasthenia.org and let us know! ■

MG awareness idea

by Donna Whittaker,
Public Relations Committee Chair

When you hear or see an MGFA public service announcement (PSA), call, write or e-mail the publication or station who ran it to thank them. Occasionally, national radio networks run MGFA public service announcements in the middle of the night. If appreciation is shown, it is possible that these public service announcements will be run in more advantageous time slots. Everyone appreciates being thanked, and the publication or station will be more likely to use our PSAs in the future.

The media is required to do a certain number of public service announcements. Contact the radio stations, television stations, cable companies and newspapers in your area with PSAs from the Myasthenia Gravis Foundation of America, Inc. You will be helping them by providing material they can use to meet their requirement. And, of course, thank them when they use our PSAs! ■

MG Internet community

In June 2003, a group of MGers from across the world-wide Internet community met in Branson, Missouri, for an MG Retreat to meet each other face to face and share some good times as a break from the daily grind of living with MG. Calling themselves “Snowflakes,” they shared a blizzard of fun snowflake gifts

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Ephedrine sulfate update

MG patients are currently experiencing difficulties in obtaining prescription ephedrine sulfate. The MGFA Medical/Scientific Advisory Board is aware of the problem and working towards a solution. Watch the MGFA Web site for news as it becomes available.

What you need to know about generic medications

by Kristen Jefferies, PharmD,
University of Utah Hospitals and Clinics



What is a generic drug?

A generic drug is an identical reproduction of a brand name drug in dosage, safety, strength, quality, intended use and how it is taken.

Generic drugs also must work in the body the same way as the original brand name products. Manufacturers can apply to the Food and Drug Administration (FDA) to sell generic versions when the patent of the brand name medication is close to expiration.

What are the FDA requirements for generic drugs?

The Food and Drug Administration (FDA) takes many steps to ensure that generic drugs are safe to use in place of the brand name versions, including the following.

- The generic medication must contain the same active ingredient. The dosage form and route of administration must be identical. For example, if the brand name drug is a capsule, the generic version must also be a capsule. The generic version must also be the same dose strength as the brand name drug.
- The generic version of the medication must be “bioequivalent” to the brand name version. This means that the amount of active drug that reaches the bloodstream and the amount of time for the drug to reach the bloodstream cannot be “significantly” different in patients who take the generic version compared to patients who take the brand name version.
- The generic medication must have the same labeling as the brand name medication.
- The manufacturer must prove to the FDA that the generic medication and the raw materials used to produce it meet the United States Pharmacopoeia (USP) standards for purity. The USP is the organization that sets standards for drug purity.

- The manufacturer must prove that the generic version is stable and that the drug’s container will not interact with the drug.
- The manufacturer must show that the facilities used to make the generic drug meet federal regulations about good manufacturing practices and pass an inspection by the FDA.

How are generic drugs and brand name drugs different?

Generic drugs must look different than brand name drugs because of patent laws. The colors, flavors and inactive ingredients of generic drugs may be different from those in the brand name version. Patients who have allergies or side effects from dyes may react differently to generic products.

When should I not switch from generic to brand name medications?

If you take a medication that requires checking drug levels in the blood, you should not switch between the generic and brand name versions. Some medications that require this type of monitoring are warfarin (Coumadin), digoxin (Lanoxin) and several medications used to treat seizures such as phenytoin, carbamazepine, valproate and phenobarbital. The slight variations between the generic and brand name versions may increase or decrease the drug levels, making it difficult to adjust the dose correctly.

How can I tell if my medication is generic or brand name?

Your doctor can specify whether the pharmacist is allowed to dispense a generic version of the medication you are prescribed. The pharmacist should tell you if a generic medication has been dispensed in place of a brand name product. The names of both medications are included on the label of the prescription bottle. Ask your pharmacist if you have any questions about which version you are getting. ■

The slight variations between the generic and brand name versions may increase or decrease the drug levels.

Retraction

The article entitled “Is the Generic or Brand Name Version for You?” has been removed from the electronic version of the Fall 2004 *Foundation Focus*. Please see the retraction below for further details.

– *MGFA National Office*

It has come to our attention that the information supplied in the article “Is the Generic or Brand Name Version for You?” from the Fall 2004 *Foundation Focus* newsletter contained information that was cited out of context or which could be misinterpreted. The statement that “generic pyridostigmine bromide tablets may not be as reliable as the trade brand Mestinon®” was incorrectly attributed to Louise O’Donnell. The article may have given the impression that the generic versions of pyridostigmine bromide are not as good or reliable as the brand name of pyridostigmine bromide (Mestinon®).

This is not the case. The intention was not to imply that one product is superior or inferior to another. There are reasons why a physician may prescribe either the generic or brand name version of pyridostigmine bromide.

We apologize for any confusion or difficulties the article may have caused. ■

What you can do if the generic doesn’t work for you

If your health insurance pharmaceutical supplier has substituted generic pyridostigmine bromide for your Mestinon® prescription and you find that your myasthenia gravis symptoms are not as well controlled, contact your prescribing neurologist to have your prescriptions marked “Brand Name Only; No Substitutions Allowed.”

Be sure to have your neurologist contact the pharmaceutical company to have them send you the brand name to replace the generic you were unable to take. Do not wait until a three-month supply is taken if you find the generic does not work for you. ■

First endowed chair in the U.S. devoted to myasthenia gravis

Please join us in congratulating **James F. (Chip) Howard, Jr., MD** for the newly created endowed chair in his honor from the Broyhill family. Dr. Howard has been giving exceptional care to a family member for the past several years. The family has agreed to express their gratitude through the creation of an endowed professorship named after Dr. Howard. The chair will be called the James F. Howard, Jr. Distinguished Professorship. It will reside in the Department of Neurology in perpetuity to support Dr. Howard’s clinical and research efforts devoted to myasthenia gravis and/or neuromuscular disorders. This is the first endowed chair in the U.S. devoted to myasthenia gravis. ■

great things *continued*

Two board members of the **East Central Florida Chapter**, Jim Burke and Ashley Bermeo, along with her twins, who both have myasthenia gravis, regularly give presentations to students at St. Augustine University Colleges of Physical and Occupational Therapy. The students are given information about MG and are asked to devise therapy strategies.

If you're not currently affiliated with a chapter in your area, please visit our Web site at www.myasthenia.org/chapters for current contact information or call the national office at 800-541-5454. ■

Internet community *continued*

with each other. Attendees came from several states and Israel to enjoy seeing Internet friends in person.

This MG Retreat was so much fun that another MG Retreat was held in Branson in June 2004. Other retreats in Ohio and Florida were planned. In 2005, the Snowflakes will return to Branson in June and add MG Retreats in other regions. Although many of these "Snowflakes" are members of MGnet, the MGFA Internet Chapter, these retreats are not sponsored by MGnet. For information on upcoming MG Retreats, check Bette's Club of Hearts Yahoo! Group at <http://health.groups.yahoo.com/group/bettesmyastheniagravissupport/> or join mgmail and post a message at <http://pages.prodigy.net/stanley.way/myasthenia/mgmail.htm>. Meeting MG friends from our Internet community face to face is a thrilling experience! ■

MGFA Scientific Session

October 2, 2004
Sheraton Center Toronto Hotel
123 Queen St W
Toronto, Ontario, M5H 2M9 Canada
1-414-361-1000

More information: Visit www.myasthenia.org or contact the national office at 800-541-5454 or mgfa@myasthenia.org.

MGFA Annual Meeting

April 21-23, 2005
Amway Grand Plaza Hotel
187 Monroe NW
Grand Rapids, Michigan
www.amwaygrand.com

Hosted by: Great Lakes Chapter

More information: Visit www.myasthenia.org or contact the national office at 800-541-5454 or mgfa@myasthenia.org.

Would you like to donate to MGFA?

It's simple! Mail your donation to the national office. Make checks payable to Myasthenia Gravis Foundation of America, Inc. Your gift is tax-deductible to the fullest extent of the law.

Unable to leave home to attend support group meetings?

MGnet, the Internet chapter of MGFA, has weekly support chats on a number of topics. Everyone interested in myasthenia gravis is welcome to "come."

A chat for family members and friends is still forming. Interested people can contact Irv Beck at irv@mgfa-mgnet.org.

To join the MGnet Chat Room, visit:
www.mgfa-mgnet.org



MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.

1821 University Ave W, Ste S256
St. Paul, MN 55104-2897
(800) 541-5454
(651) 917-1835 fax
mgfa@myasthenia.org
www.myasthenia.org

officers and directors

The MGFA mission is to facilitate the timely diagnosis and optimal care of individuals affected by Myasthenia Gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy and patient care.

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