



by *Esther M. Land*

It was during the summer of 1982 that I had the privilege of meeting Edith Williams, a very dear friend of Jane Dewey Ellsworth, MGFA's founder. These two women were

visiting Patricia (Pat) Ellsworth Wilson and her husband, Laurence, in Holland, Michigan. One day, over lunch, I was fascinated by the stories told about the days after Pat was diagnosed with myasthenia gravis.

Mrs. Ellsworth shared her frustration in locating medical help for Pat and, through inquiry, located physicians interested in the disease, resulting in the formation of the Medical Advisory Board with Dr. Henry R. Viets of Boston serving as chairman. I also learned about Sylvia Lawry, founder of the MS Society, and how these two women shared their knowledge and resources. Branching off the knowledge gained from Ms. Lawry, in 1952 Mrs. Ellsworth forged ahead to organize the Myasthenia Gravis Foundation. Recently, Pat shared additional information with me about the encouragement and support the Ellsworth family received from Edith Williams and her husband, Edward J., special friends they met during their years in Greenwich, Connecticut. As the Foundation was forming, it was particularly the business expertise Mr. Williams possessed that triggered Mrs. Ellsworth to ask him to serve as the first MGFA Board President. He assisted in this capacity for several years. The bond of friendship between the two families continued even after the Ellsworths moved to California and the Williamses to Pennsylvania in pursuit of career opportunities.

By that time (the late 1950s), MG Chapters were being organized, and for many years Edith Williams was very active with the

chapter in Pittsburgh. In later years, after each of the women had become a widow, they continued to have weekly phone chats, even though Mrs. Ellsworth resided in California and Mrs. Williams had moved back home to West Virginia to be with family.

Last November, Edith Williams passed away at the age of 97. To show their concern and support of Pat, the Williamses had included the MGFA in their will, and recently the Foundation gratefully received a generous donation from their estate. The bequest was the Williamses' gift to Pat through MGFA. They realized that the greatest gift they could give her was to provide the Foundation with funds so that successful programs would be available for Pat and all MG patients today and into the future, and so that research would continue until the desperately-desired cure was found. What a poignant way to honor Pat and her mother!

If you, a friend, or family member have been helped by the Foundation during a critical time, or have been an active member of the organization, what better way to keep those efforts ongoing than to include MGFA in your will, trust or estate planning? You may not be a philanthropist, but we all have the power to plan, whether resources are large or small. If you have already made that commitment, be sure that the information is current. It is recommended that planned giving portfolios be reviewed periodically. If you are giving to the national Foundation, the named recipient should be The Myasthenia Gravis Foundation of America, Inc. (include address). If you are giving through an MGFA chapter, remember to include the Chapter name and address in the designation.

Please contact LJ Taugher at our national office (800-541-5454) if you have questions about planned giving. Thank you for considering leaving a legacy to the Myasthenia Gravis Foundation of America, Inc. ■

NIH Approves Funding

by James F. Howard, MD, M/SAB Chair

The Executive Committee of the Thymectomy Clinical Trials study is pleased to announce that the National Institutes of Health (NIH) recently approved funding for an international multi-center thymectomy trial. The study will determine the optimal role of thymectomy in the treatment of myasthenia gravis. Enrollment is anticipated to begin in late spring 2006. Further information will be forthcoming as events unfold.

This funding is the direct result of the arduous five-year efforts of the organizing committee: Drs. John Newsom-Davis, Gil Wolfe, Henry Kaminski, Gary Cutter and Alfred Jaretzki III. ■

MG/Autoimmune Progress Report released by NIH

by Joe Powers, Virginia Chapter Chair

Following the Autoimmune Research Plan issued in December 2000, the National Institutes of Health (NIH) has just now released its first biennial Progress Report as required by Congressional legislation. Congress instructed NIH to “expand, intensify and coordinate autoimmune research” and to establish priorities “to reflect input from a broad range of scientists, patients, and advocacy groups.”

To develop the initial Plan and the present Progress Report, an Autoimmune Diseases Coordinating Committee (ADCC) was established with the participation of every NIH Institute, three federal agencies (CDC, FDA, and HHS) and 10 patient advocacy groups. Nearly 50 scientists and physicians participated in developing the reports.

The report identifies \$591.2 million expended by NIH in FY2003—happily, an increase of 36% over FY2000, yet still less than 2% of the total NIH budget of \$28 billion. Expenditures

for MG research also increased from \$1.7 million in FY2000 to \$5 million in FY2003. Expenditures for FY2004 and 2005 were not provided, nor expected projections for 2006 and beyond.

Autoimmunity (AI) is outlined in the report as a composite of many different disorders. *Just as there are many different forms of cancer or heart disease, there are nearly 80 different forms of autoimmune disease; one of which is MG.* The impact of these disorders is described by the report in very stark language: “Collectively autoimmune diseases affect 14.7 to 23.5 million people in this country—and for reasons unknown—their prevalence is rising... they are also a leading cause of death among young and middle aged women”.

Although the cause of autoimmune disease remains unknown, and is not thought to be directly inherited, the report emphasizes that genetic factors play a major role in susceptibility and may be “triggered” by infections or an exposure to a wide range of environmental agents. The seriousness of having any one of 80 different autoimmune diseases was emphasized by the report: “Overlapping genetic traits enhance susceptibility to many of the diseases, so that a patient may suffer from more than one autoimmune disorder, or multiple autoimmune disorders may occur in the same family.”

Access the report on the Internet at: http://www.niaid.nih.gov/dait/pdf/ADCC_Final.pdf. Print copies are available from the National Institutes of Health. ■

International MG news

by Stanley Way, Member, MGFA Board of Directors

Two myasthenia gravis organizations, one halfway around the world in Pakistan and the other in Northern Africa, became connected through the wonderful world of the Internet and e-mail. It is an amazing story of large-scale assistance that took place this past spring.

Pakistan is a country wherein myasthenics are supported by the Pakistan Myasthenic Welfare Organization (PMWO). Morocco, on the northwest coast of Africa, benefits from the Association of the Friends of Moroccan Myasthenics (AAMM). Both organizations have strong leadership and are working hard for myasthenics, especially the poor and uninsured. In this case, the Pakistan PMWO was able to provide very significant aid to many—maybe hundreds of—myasthenics in Morocco with the gift of over 40,000 pyridostimine (generic Mestinon®) tablets (which they have branded Amygra®).

The PMWO has been an active participant in the worldwide effort to find better treatments through research and has provided medical services to many myasthenics in Pakistan. Khalid Mehmood Zia is founder and Secretary

General of the PMWO—and is a myasthenic himself. In Morocco, Dr. My Ahmed Idrissi is chairman of the AAMM effort and personally treats many myasthenics.

I first met Khalid Zia about eight years ago by way of the mgmail e-mail listserv. In those early years of e-mail, I learned quickly that a major issue of the PMWO was obtaining supplies of Mestinon® for many myasthenics in Pakistan who could not afford the high cost. In recent years, because sufficient supplies of Mestinon® have become increasingly more difficult to obtain, the PMWO began to push for development of the generic drug, pyridostigmine. The resulting drug, Amygra®, is now manufactured in Pakistan, and through it the PMWO is helping others.



Khalid Mehmood Zia, Secretary General of the PMWO

A recent e-mail posting on behalf of Moroccan myasthenics to the Myasthenia Mail List (MML) asked for help in finding affordable supplies of Mestinon® and led to a mention of the Amygra® in Pakistan. Khalid Zia read that posting and started the involved process of assistance. Zia arranged for the shipment of 2,100 boxes (each box with 20 tablets) of Amygra® tablets to the Moroccan AAMM in care of Dr. Idrissi, who immediately dispatched them to several neurology wards in Moroccan hospitals to treat myasthenic patients who could not afford to pay for the medication. Tablets were distributed to patients through individual neurologists. The shipment of Amygra® was made from Pakistan to Morocco with some difficulty, but between the Pakistani Ministry for Health and the Moroccan Health Ministry, an agreement for tax- and duty-free shipment was obtained.

Some concerns were voiced by patients over switching from Mestinon® to Amygra® but, for the most part, there were no reported instances of less-than-normal response. Dr. Idrissi stated that one patient returned the Amygra®, preferring to stay on Mestinon®. Dr. Idrissi felt



...to help the Myasthenia Gravis Foundation of America strive for a world without MG. Contact your chapter or the national office to find out how.

that this was “probably a psychological side-effect.”

Dr. Idrissi, in a letter to Khalid Zia, stated: “Please allow me to thank you personally, Mr. Zia, as well as all the doctors, specialists, pharmaceutical laboratories and generous donors from your great country, Pakistan, the ally and friend of Morocco, for your commitment to exporting human values of solidarity and brotherhood throughout the world.”



Dr. Idrissi accepts the shipment of 2,100 boxes of Amygra® on behalf of myasthenics in Morocco.

The PMWO, with its direct assistance to the myasthenics of Morocco, is a great example of how effective the Internet and e-mail are in connecting myasthenics around the world. In a final message, Dr. Idrissi asked me to “transmit to all myasthenics and their friends in America, warm greetings from their friends of Morocco.”

Web Links:

- PMWO:
<http://www.myastheniagravispk.com>
- Myasthenia Gravis E-mail Lists:
http://www.myasthenia.org/links/#PATIENT_SUPPORT_LINKS

E-Mail Addresses:

- Khalid Zia:
pmwo@yahoo.co.uk
- Dr. My Ahmed Isrissi:
maidoc@caramail.com ■

Student with MG plays college football

by Kendra Myers, Senior Communications Coordinator, MGFA National Office

Brandon Cox starts this year as quarterback for the Auburn University Tigers (Alabama). The season looks promising: Brandon was named the MVP of the A-Day game after completing 13 of 22 passes for 226 yards.

Brandon joined the Auburn team in December 2002. In 2004, he played as backup quarterback and was named the MVP of the A-Day game after completing 12 of 13 passes for 206 yards and two touchdowns.

In high school, Brandon set a state record with his football career. He was selected for all-state and was ranked one of the top 20 quarterbacks in the nation by ESPN.com. (He also received high rankings from a variety of other sports publications.) In addition to football, Brandon played on his school's basketball and baseball teams, achieving all-state in baseball as the second-team pitcher.

What makes all this more remarkable than the track record of an outstanding athlete is that Brandon was diagnosed with myasthenia gravis at the age of 16.

If you're watching college football this year, keep an eye out for this Tiger! ■

Sources:

- Player roster/bios page, <http://www.auburntigers.com/football/>
- “Tough Tiger” by Christina Turner, July 31, 2005, *Ledger-Enquirer*, <http://www.ledger-enquirer.com>

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Research results published

Two MGFA post-doctoral research fellowship recipients, Drs. Huan Yang and Erdem Tuzun, and their preceptor, Dr. Premkumar Christadoss, University of Texas Medical

Branch, Galveston, TX, are the respected authors of a research paper that appeared in the reputed *Journal of Immunology*, August 2005 issue. The technical article discusses the positive results of IL-1 receptor antagonist (IL-1ra) administered in animal models as potential nonsteroidal drug for the treatment of myasthenia gravis. ■

New Advocacy and Government Affairs Committee being developed

by Damon Wainscoat, Chair of the Advocacy and Government Affairs Committee

During MGFA's Annual Meeting in April, 2005, the Board of Directors established a committee for advocacy and government affairs. Newly-elected board member Damon Wainscoat will chair the committee.

Nine members have volunteered or been selected for positions on the committee:

- Mechelle Genigeski, Great Lakes Chapter
- Lisa Sackuvich, ARJ Infusion Services, Inc., Kansas City
- Carol Golz, Illinois Chapter
- Dale Wurtenberger, Pennsylvania Chapter, MGnet Chapter
- Jerry Smith, Minnesota Chapter
- John Powers, Virginia Chapter
- Joe Powers, Virginia Chapter
- Esther Land, MGFA Board Chair
- LJ Taugher, MGFA Chief Executive Officer

The Board of Directors is reviewing a proposed advocacy action plan for approval. Additionally, various materials are being prepared to support committee members in their work. The committee will support the Board of Directors, Chapters and committees in presenting the MGFA position on present and future Congressional funding of health issues, related resolutions, and bills pending in Congress that affect the MG autoimmune community. ■

Stay tuned—Discovery Channel MG program to air

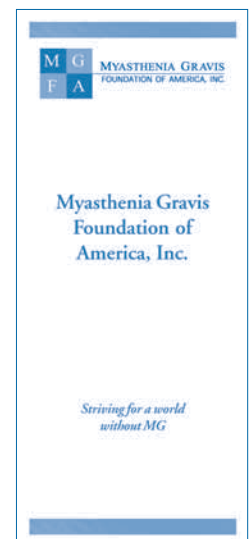
As reported in our Summer 2005 issue, Chairman of the MGFA Medical/Scientific Advisory Board, James Howard, MD, recently worked with Discovery Channel to produce a television show on a patient's difficult time in getting a diagnosis of myasthenia gravis. Discovery Channel has not yet scheduled the program for air time; they tell us it could be six months to a year. We'll keep you posted. ■

Brochures in Spanish are available

Thanks to Dr. Claudio Mazia of the Miastenia Gravis Foundation of Argentina, MGFA has added Spanish translations of four more brochures to the Web site: thymectomy, home injury prevention, emergency management, and pyridostigmine. For these and other informational brochures in Spanish, please visit the "Information" page of the MGFA Web site at www.myasthenia.org, or contact the national office to request that copies be sent to you by mail. ■

Updated "About MGFA" brochure available in mid-September

We've been working hard on updating our brochure about the Foundation and its activities, and we're almost ready to go to press. The updated brochure includes primarily the same information as the previous one, but contains more specific information about MFGA's programs and events. ■



Great things are happening!

by *Mat Spaan, Chapter/Patient Services Manager*

Throughout the year, our chapters remain very active maintaining and developing their support groups, events, and awareness activities. However, since June is Myasthenia Gravis Awareness Month, our chapters end up being even busier than normal during this important outreach month. Well, this year was no different. I have included just a few of the many activities that happened across the country.

Our **Great Lakes Chapter** was instrumental in getting the month of June declared "Myasthenia Gravis Awareness Month" in the city of Olivet, MI. The city's mayor maintains a particular interest in MG awareness, as her father is a myasthenic.

Our **Northwest Texas Chapter** held a very successful Walk-a-Thon on June 11th that netted over \$4,000. This Chapter has been working hard to serve a very large area of Texas, and will be holding an MG awareness event on September 17th in El Paso, TX. For more information, please contact the Chapter at (806) 749-3126.

Our **Maryland/DC/Delaware Chapter** had a great article published in the *The Capital* newspaper of Annapolis on June 19th. The article focused on the MG experiences of Marika Bates, the Chapter's Chair, and provided readers with a very frank description of what it means to live with the disease.

Our **Pacific Northwest Chapter** had awareness pieces published in *The Seattle Times* and the *King County Journal*. They also had an article published within a Bellevue, WA paper. The article described the MG experience of Jim Holland, a member of the Chapter.

Our **Upstate New York Chapter** was declared the Schenectady, NY Charity of the Month for June. This honor allowed the Chapter to get a TV spot aired on June 1st, along with some great promotion for MG Awareness Month.

Finally, although not exactly an MG Awareness Month activity, our **Garden State Chapter** held a Walk-a-Thon in May. The event raised over \$25,000 and had more than 300 participants.

As further examples of the great work our Chapters do throughout the year, I would like to let everyone know about the following chapter happenings:

Our **Utah Chapter** is actively looking for volunteers, board members and Chapter/support group participants throughout the state. If you are interested in meeting with other MG patients, giving back to your community, and helping to provide much-needed support in fulfilling MGFA's mission, this is a great time to start working with us in Utah. For more information or to volunteer, please contact the Chapter/Patient Services Manager in the national office at (800) 541-5454.

Our **Oklahoma Chapter** is starting a new support group in the southeast Oklahoma area. It will take place in McAlister, OK. For more information, contact the chapter at (918) 494-4951.

Although there is no longer an MGFA Chapter located within the **Houston, TX area**, there are several support groups either active or starting up within the area. For more information, please call the national office at (800) 541-5454.

Remember, nearly all of our chapters are staffed completely by volunteers, and all of them are led by volunteers. For more information on how you can make your area's chapter even stronger, please contact the national office at (800) 541-5454. ■

ICE your cell phone!

by Donna Whittaker, Chair of the Public Relations Committee

Myasthenics in crisis often cannot talk, and so cannot tell emergency first responders important medical information. ICE could have a critical impact on your medical emergency outcome.



In Case of Emergency (ICE) is the key to your emergency contact information. Enter the phone numbers of family members or friends who know your medical needs (including your medications, dosages, and allergies) with ICE as the entry name. If you have more than one, you can designate ICE 1 Mom, ICE 2 husband, ICE 3 Mary Doe, etc. First responders and law enforcement will be able to use your cell phone to quickly call your emergency contact(s) if you are unable to communicate.

Missouri is one of many states and municipalities officially participating in the ICE initiative, which was started by the East Anglian Ambulance Trust in England in order to provide better care for citizens.

Encourage your friends and relatives to ICE their cell phones, too. Anyone could be involved in an accident that could make him or her unable to communicate their medical needs. ■

Board of Directors Meeting

September 23, 2005
Wyndham San Diego at Emerald Plaza
San Diego, California

2005 Scientific Session

September 24, 2005
San Diego Marriott Hotel and Marina
San Diego, California

2006 Annual Meeting

May 3-6, 2006
Wyndham Buttes Resort
Tempe, Arizona

More information about these events will be published on the MGFA Web site (www.myasthenia.org) and in upcoming issues of *Foundation Focus* as it becomes available.



Would you like to donate to MGFA?

It's simple! Just mail your donation to the national office. Make checks payable to Myasthenia Gravis Foundation of America, Inc. Your dollars will help support medical research about myasthenia gravis, providing printed material to those struggling with myasthenia gravis, keeping 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!

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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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