

# Foundation Focus

News about myasthenia gravis for patients, family and friends • Summer 2007

## MGFA: moving forward

As the leadership of the Foundation passed from Esther Land to Sam Schulhof at the Annual Meeting, it was a good time to reflect on our recent successes and turn our focus towards future goals. 2005 was the year of listening and learning, 2006 was the year of assessment and adjustment, and 2007–2009 are the years of accelerating change.

Significant progress has already been made in the areas of chapter and patient support, communication and education, research, fundraising, and management. It is only through the collaborative efforts of the national office, national board, the chapters, and donors that we have realized positive change.

Chapter support has been improved, enhancing the services chapters can provide to MGFA members. Patient services have also been improved with the unveiling of MGFA's new Web site ([www.myasthenia.org](http://www.myasthenia.org)), the announcement of the establishment of a partnership with the Foundation for Financial Service Professionals to provide pro-bono financial services to chapter members (see insert for details), and the partnership with CaringBridge (see details on page 15).

Looking forward in a rapidly- and ever-changing healthcare environment, our goals include refining membership demographics, cultivating and developing

the next generation of national board members and chapter leaders, and the further development of patient service programs.

Communication and education efforts have been far-reaching and include the redesigned and updated MGFA Web site, production of the "Double Vision, Scrambled Voice" DVD, distribution of



the "Clinical News Alert" on myasthenia gravis, development and distribution of MG Awareness Month materials, and co-sponsorship of the 11th International Conference on MG with the NY Academy of Science.

MGFA's research endowment has been established, and initial fundraising has started. The endowment received a major boost with



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## MGFA: moving forward

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the establishment of the Cummings Research Endowment Fund (see article below). MGFA has increased the number of fellowships funded and is supporting the thymectomy trial by providing funding along with our Maryland/DC/Delaware Chapter. Our Medical/Scientific Advisory Board and our Nurses Advisory Board have been tasked with developing a multi-year, focused research agenda that leverages the research efforts of other organizations and MGFA funds with others from both the public and private sectors.

We continue to look at ways to improve and increase the quality and value of patient services while increasing professional and public awareness about MG.

In the words of Oliver Wendell Holmes, Jr.:

*“It’s not so much where we start, but what direction we are moving: we must sail sometimes with the wind and sometimes against it, but we sail and not drift, nor lie at anchor.”*

We’ve hoisted the anchor and are sailing into the future. Are you on board? ■

## MGFA receives significant bequest

The Foundation has received a \$3.5 million bequest from the estate of David Cummings to establish the Cummings Research Endowment Fund. The purpose of the endowment is to provide funding for research into the cause(s) of and/or cures for myasthenia gravis.

The fund will enable the Foundation to provide seed funding for the development of research protocols and pilot studies for clinical research. It is expected that this strategy will enable MGFA to participate in much larger multi-center studies, including National Institutes of Health funded projects.

Robert Pascuzzi, Chair of the Foundation’s Medical/Scientific Advisory Board, said, “The Cummings bequest will make a significant difference in the Foundation’s ability to provide ‘start-up research funding’ that is critical to finding new and effective treatments for MG patients.” Sam Schulhof, chair of the MGFA national board of directors, said, “The Cummings Research Endowment provides us with a great opportunity to expand our research support towards finding a cure for MG.”

Dr. Cummings, a myasthenic, was born in New York on February 11, 1932, and died September 5,

2006, in Los Angeles, CA. He earned his B.S. and M.S. degrees from City College of New York and his Ph.D. in 1962 from Michigan State University. He worked for the U.S. Geological Survey from 1962 to 1977, when he resigned to accept a tenured professorship in the Geology Department at Occidental College. He remained at Occidental College until the end of 1983, when he went to work

*“[This] provides us with a great opportunity to expand our research support towards finding a cure for MG.”*

for Science Applications International Corporation. Dr. Cummings was appointed to the California Licensing Board for Geologists and Geophysicists in 1998 by the Governor of California. He served as its president from 2000-2001. ■

## Changes in the MGFA national board of directors

**Marc Kalish, Esq.**, a member of MGFA's Jim L. Walker Arizona Chapter, was elected to a three-year term on the MGFA national board of directors and was also elected treasurer of MGFA. He served as president of the Arizona Chapter from 1986-1992, chairperson of the MGFA national board of directors from 1992-1996, and chair of the Audit Committee from 1997-2000. During this past year, he served on both the Finance and Bylaws/Policies and Procedures Committees.



Marc graduated from Purdue University and received his law degree (magna cum laude) from Georgetown University Law Center in 1980. Between college and law school, he achieved the rank of captain, serving as a fighter pilot in the United States Air Force. He practices law in Phoenix, specializing in mediation, arbitration, and private judging. Marc and his wife, Ginny, have two grown children, Jason and Mandy.



**Nancy Law** was elected to a three-year term on the MGFA national board of directors and is a member of MGFA's Chapter Relations Committee and Resource Development Committee. She is the Executive Vice-President

of Programs and Services for the National MS Society, where she has worked since 1986. During this past year, she served as a member of MGFA's Resource Development Committee.

Nancy graduated with a degree in speech/communications from Ohio Wesleyan University and received her social work license in Ohio in 1986. She currently lives in Denver, CO.

**Janet A. Myder, MPA**, a member of MGFA's Maryland/DC/Delaware Chapter, was elected to a three-year term on the MGFA national board of directors and is a member of MGFA's Communications Committee. She is a board member of the Maryland/DC/Delaware Chapter and co-chair of the Bethesda Support Group. During the past year, she has also served as an alternate delegate representing MGFA at National Health Council meetings.



Janet retired from her position as Director of Regulatory Systems for the American Health Care Association (AHCA) last year. She is currently a self-employed consultant specializing in federal regulations governing nursing facility participation in Medicare, Medicaid, and related survey, certification, and enforcement policy development and implementation to the long-term care community.

Janet earned a Master of Public Administration degree from the American University and a Bachelor of Science degree in physical therapy from the University of Connecticut. Prior to joining AHCA, she was Deputy Director of the National Council of Senior Citizens' Office of Legislative Liaison and Research. Before entering the public policy arena, she practiced physical therapy in hospitals, home health, and physician office settings and served four years as administrator of the physical medicine department in a 300-bed community hospital.

Two current board members were re-elected for three-year terms: **Ronald McFarlane, R.Ph.** (Raleigh, NC), who was also elected board vice-chairperson; and **Michael Rusinko** (Minneapolis, MN).

The board gratefully acknowledges outgoing directors **Melissa Noble**, who completed one three-year term, and **Stanley Way**, who served on the board for the past nine years. ■



From left to right: Board Chair Sam Schulhof, Board Chapter Liaison Officer Marie Ronnlof, and Chapter/Patient Services Manager Mat Spaan (photo courtesy of Janet Myder)

## 2006 Chapter Challenge results

MGFA's 2006 Chapter Challenge had a number of goals: to increase the number of research fellowships that could be awarded in the event MGFA received even more applications than last year; to increase the interest in myasthenia gravis research; and to encourage up-and-coming doctors, nurses, and students to focus their interest on MG.

The 2006 Challenge raised a total of \$66,214! Our chapters participated in this effort by contributing to the Challenge over and above the research assessments for which all chapters are responsible. The amount raised by the challenge resulted in the MGFA national board of directors awarding one more research fellowship than it could have without this effort.

The following chapters deserve special recognition for their participation in the 2006 Challenge:

- Carolinas Chapter
- Connecticut Nutmeg State Chapter
- East Central Florida Chapter
- Garden State Chapter
- Georgia State Chapter
- Greater Florida Chapter (formerly West Central Florida)
- Myasthenia Gravis Foundation of Illinois
- Massachusetts/New Hampshire Chapter
- Metro New York Chapter
- Pacific Northwest Chapter
- Minnesota Chapter
- Oklahoma Chapter
- South Florida Gold Coast Chapter
- Wisconsin Chapter

In addition, late in the year, the chapters challenged our Medical/Scientific Advisory Board and Nurses Advisory Board to join in raising an additional \$500.

Many thanks to all of the participants in the 2006 Challenge for their commitment to MGFA's research fellowship program. Great things are happening! We are proving that **together, we are stronger!** ■

*(Turn to page 6 for a photograph of representatives of the chapters participating in the 2006 Chapter Challenge.)*

## MGFA meets BBB Wise Giving Alliance Standards for Charity Accountability and receives NHC Standards of Excellence Award

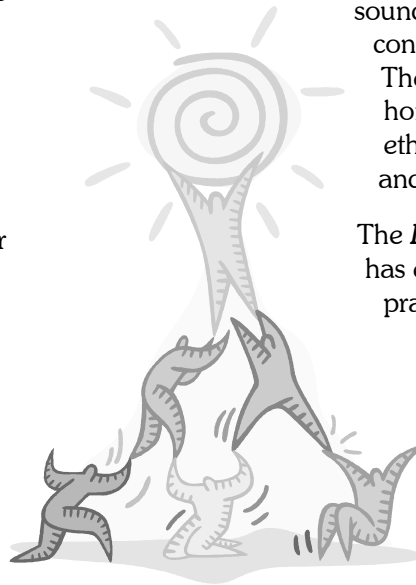
MGFA is proud to have received recognition from both the BBB and the NHC for meeting their highest standards of organizational effectiveness and public stewardship.

The **Better Business Bureau (BBB)** has established standards for nonprofit organizational accountability "to assist donors in making sound giving decisions and to foster public confidence in charitable organizations. The standards seek to encourage fair and honest solicitation practices, to promote ethical conduct by charitable organizations and to advance support of philanthropy."

The **National Health Council (NHC)** has established a set of good operating practices to ensure that its voluntary health agency (VHA) members maintain the highest standards of organizational effectiveness and public stewardship. The standards cover the areas of governance, personnel policies, programs, fundraising, finance, accounting, and reporting and evaluation.

The principle of the BBB and the NHC is full disclosure to donors and potential donors at the time of solicitation and thereafter. As voluntary standards, they go beyond the requirements of local, state, and federal laws and regulations. The BBB and the NHC help donors make informed giving decisions and advance high standards of conduct among organizations that solicit contributions from the public.

(To learn more about the BBB Wise Giving Alliance and MGFA, go to [www.give.org](http://www.give.org).) ■



## MGFA national board approves funding of planning grant for new clinical trial of CellCept® in MG

*In the spring 2007 Foundation Focus, we published an article by our Medical/Scientific Advisory Board Chair, Robert Pascuzzi, MD, discussing the results of two clinical trials to evaluate the role of mycophenolate (CellCept®) in the treatment of MG. Many clinicians feel strongly that CellCept® is an excellent drug for the treatment of myasthenia gravis even though these two studies did not demonstrate a benefit. The full article is available online at [www.myasthenia.org/atf\\_mgfaneews.cfm](http://www.myasthenia.org/atf_mgfaneews.cfm).*

Over the past four months, the Medical/Scientific Advisory Board (M/SAB) CellCept® Study Group has been studying the results of the two recently-completed clinical trials. Thorough analysis of the two trials and their results have led to a series of discussions and considerations regarding the role of CellCept® in MG and reconciliation of the study results with the common experience of the clinicians who have been using this drug over the past five years.

Clearly, there are patients and clinicians who are firmly convinced of the value of this drug in treatment of MG and the importance of continuing to use the drug in appropriate scenarios. On the other hand, there is a need to explain the lack of documented benefit in the two recently-completed trials and to

clarify for physicians and patients how well this drug really works in MG.

The CellCept® Study Group has discussed the design of new trials of CellCept® in MG that would address the unanswered questions above and has developed several different models for further potential clinical investigation. These options have led to the M/SAB recommending the first steps toward a new clinical trial of CellCept® in MG.

To further this effort, MGFA has approved funding for a planning grant to create the protocol for a further trial of CellCept®. The investigators will use the funding to complete the development of a proposal for a clinical trial, including detailed work on study design, methodology, statistical analysis, feasibility, potential study sites, and potential funding for the conduct of the trial.

“...there is a need to ... clarify for physicians and patients how well this drug really works in MG.”

The M/SAB CellCept® Study Group will present its recommendations for funding recipients at the October 2007 meeting of the MGFA national board of directors. ■

### calendar

#### **MGFA National Board of Directors meeting**

October 5, 2007  
Washington, D.C.

#### **MGFA Medical/Scientific Advisory Board presents the “Scientific Session”**

October 6, 2007  
Marriott Wardman Park Hotel  
Washington, D.C.

#### **MGFA National Board of Directors meeting**

January 19, 2008  
Tampa, Florida

#### **Myasthenia Gravis Foundation of America, Inc. Annual Meeting**

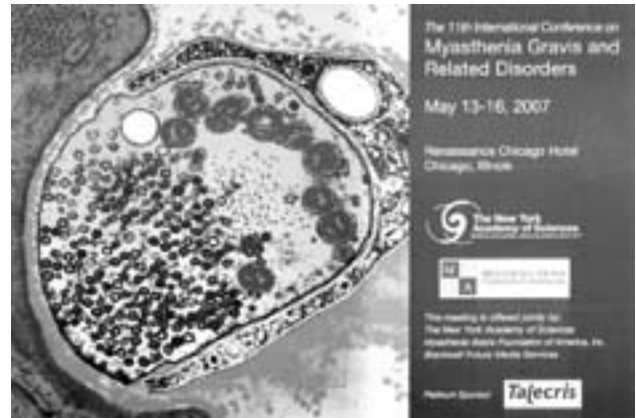
June 12–14, 2008  
Milwaukee, Wisconsin

## 11th International Conference draws record presentations and attendance

The 11th International Conference on Myasthenia Gravis and Related Disorders was held May 13-16, 2007 at the Renaissance Hotel in Chicago, Illinois. Presented jointly by the Myasthenia Gravis Foundation of America, Inc., the New York Academy of Sciences, and Blackwell Futura Media Services, the conference was organized and co-chaired by MGFA Medical/Scientific Advisory Board members Richard J. Barohn, MD (Chair of the Department of Neurology at the University of Missouri, Kansas City) and Henry J. Kaminski, MD (Chair of the Department of Neurology at the St. Louis University Medical Center).

Research investigators and professors from Canada, France, Germany, Greece, Israel, Italy, Japan, The Netherlands, Norway, Spain, Taiwan, the United Kingdom, and the United States presented the latest advances in:

- Structure and function of the neuromuscular junction (NMJ)
- Structure and function of the acetylcholine receptor (AChR)
- Muscle specific kinase (MusK) and MG
- Congenital myasthenic syndromes (CMS)
- Immunology of autoimmune disorders involving neuronal and glial channel proteins
- Autoimmune pathogenesis in MG: current concepts
- Clinical trials
- Treatments on the horizon for MG
- Recent developments
- Thymectomy for MG



With more than 225 participants from twenty-five countries, this was the most successful gathering of this prestigious conference since its inception in Philadelphia in 1954.

Attendees included junior and senior university faculty members from interest areas such as biochemistry, structural biology, cellular and molecular neuroscience, pharmacology, immunology, and clinical neurology.

Over the intense three-day meeting (which included more than 50 speakers and session chairs and 100 poster displays), nearly all attendees participated in intense discussions of the NMJ and treatment of autoimmune diseases.

The conference created excitement and renewed commitment as colleagues shared and learned. We look forward to the next International Conference in five years. ■

*Representatives of chapters participating in the 2006 Chapter Challenge (L-R):* Dr. Pulley, East Central Florida; Dr. Weiss, Greater Florida; Carolyn Golz, Myasthenia Gravis Foundation of Illinois; Marilyn Buckner, Massachusetts/New Hampshire; Denise Delpratt-Sampson, Metro New York; Jim Holland, Pacific Northwest; Barbara Corner, Minnesota; Patricia Lamp, Wisconsin



(photo courtesy of Janet Myder)

## Highlights from the 2007 MGFA Annual Meeting

The Myasthenia Gravis Foundation of America, Inc. held its annual meeting April 19-21, 2007 at Doubletree Crystal City in Arlington, Virginia. Attendance was the best it has been in several years, with 20 chapters represented and 160 attendees from 27 states, the District of Columbia, two Canadian provinces, and Pakistan. Attendees included medical professionals, chapter leaders, and myasthenics and their families and friends.

MGFA is grateful for the support provided by its sponsors, Athena Diagnostics, Critical Care Services, CSL Behring, IgG America, and MedPro Rx.

This year's General Assembly was opened by **Janet Golden**, MGFA's Chief Executive, followed by immediate past chair **Esther Land**, who reflected on her tenure. Chair **Sam Schulhof** presented the State of the Foundation, and **Beth Tabak, CPA, CVA** of Ulbrich & Co., MGFA's outside auditor, reviewed MGFA's financial statements.

**Nancy Law**, a myasthenic, Executive Vice President of the National Multiple Sclerosis Society Program and Services, and a newly elected MGFA national board member (see page 3), discussed the advantage of federated structures such as MGFA and highlighted how best to work within that structure.



Georgiann Davis, Virginia Chapter; Gwen Hancock, Virginia Chapter; Patricia Lamp, Wisconsin Chapter (photo courtesy of Janet Myder)

MGFA Medical/Scientific Advisory Board (M/SAB) chair **Robert Pascuzzi, MD**, Chair of the Department of Neurology at the University of Indiana, provided an update on current research initiatives and the 2007-2008 Post-Doctoral Research awards.

Thursday afternoon provided an opportunity for newly-diagnosed MG patients to get basic information on MG and various treatment options. These interactive sessions were moderated by MGFA's Nurses Advisory Board (NAB) members, led by our NAB chair **Wilma Koopman, RN**, Assistant Professor of the School of Nursing at the University of Western Ontario. Panel



### Make a gift to MGFA

It has always been simple—and we just made it even easier! MGFA is now using Acceptiva™, a secure, simple-to-use, online donation service specifically for nonprofit organizations.

Visit [www.myasthenia.org](http://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.” You may also wish to consider a one-time tax deductible gift—see “tax savings” on page 13.

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!**

## Highlights

(continued from page 7)



members included **Arlene Stuckey, RN** and **Madeleine Batenjany, RN, MSN, ANP-C**.

Concurrently, chapter leaders participated in interactive workshops on budget and financial reporting (led by **Beth Tabak, CPA, CVA**), the Society of Financial Service Professionals' Financial Education Partnership program (led by **Mike Elder, MSW**, Director of Financial Education Partnership; see insert for details), and board development, recruitment, and retention (led by **Sam Schulhof**, MGFA national board chair; **Robyn Spearot**, chair of MGFA's Board Development Committee; and **Marilyn Buckner**, chair of the Massachusetts/New Hampshire Chapter).

**Myrl Weinberg, CAE**, president of the National Health Council (NHC), opened the day on Friday by summarizing NHC's activities on behalf of the approximately 100 million people with chronic diseases and/or disabilities. She discussed progress being made on the use of Electronic Personal Health Records and NHC initiatives in advocating drug safety legislation and regulations.

A review of the current use of IVIG therapy and supporting research was presented by **Marinos Dalakas, MD**, Chief of the Neuromuscular Diseases Section at the National Institute of

Neurological Disorders and Stroke. His discussion included IVIG's side effects, expense, and access.

The recipient of MGFA's first annual Young Person of the Year Award and a member of our Wisconsin Chapter's board of directors, **Lindsay Knudsen, MS**, shared the results of her study on the "Psychosocial Aspects of Living with Myasthenia Gravis".

"A Pragmatic Approach to the Treatment of Myasthenia Gravis" was presented by **Allan S. Weiss, MD**, a clinician with the St. Petersburg Neurology Clinic and member of MGFA's M/SAB. He reviewed the general approach to the treatment of myasthenia gravis and the side effects of the various treatments. His final thoughts emphasized individualized treatment, that there is no cookbook for the treatment of MG, and that the only thing predictable about MG is its unpredictability!

Friday evening included MGFA's annual awards banquet (see page 12 for details). This banquet offered participants the opportunity to reflect on MGFA's accomplishments over the past year, as well as be entertained by the evening's motivational speaker and "sit-down" standup comic, Brett Leake. Brett Leake, a nationally renowned comedian born with muscular dystrophy, spoke to attendees on the use of humor to overcome life's daily challenges.

## 2008 MGFA Annual Meeting

The 2008 MGFA Annual Meeting will be held in Milwaukee, Wisconsin, on June 12–14, 2008. Watch for more information as it becomes available! ■

Photos on this page, from left to right:

- Dr. Weiss and Dr. Pulley, M/SAB panelists
- Brett Leake, "sit-down" standup comic
- Janet Golden, MGFA Chief Executive

Photos courtesy of Janet Myder

On Saturday, distinguished experts in the treatment and understanding of MG and members of MGFA's M/SAB shared their expertise and answered questions from the floor. Members of MGFA's M/SAB who participated were:

- **Marinos Dalakas, MD**, Chief of the Neuromuscular Diseases Section at the National Institute of Neurological Disorders and Stroke
- **Daniel Drachman, MD**, Professor of Neurology and W.W. Smith Charitable Trust Professor of Neuroimmunology at the Johns Hopkins University
- **Henry Kaminski, MD**, Chair of the Department of Neurology at the St. Louis University Medical Center

- **Audrey Penn, MD**, Special Advisor to the Director of the National Institute of Neurological Disorders and Stroke
- **Michael Pulley, MD, PhD**, Director of the EMG Laboratory at the University of Florida – Jacksonville, College of Medicine
- **Donald Sanders, MD**, Co-Director of the EMG Laboratory Division of Neurology at Duke University
- **Allan Weiss, MD**, St. Petersburg (FL) Neurology Clinic

Dr. Penn moderated the session on the latest treatments used for MG. Dr. Dalakas talked about the role IVIG plays as a treatment modality. Dr. Drachman briefly discussed the cholinesterase



Photos on this page, left to right:

- Esther Land, outgoing MGFA Chair, and Sam Schulhof, incoming MGFA Chair
- Dr. Dalakas, NINDS (National Institute of Neurological Disorders and Stroke)
- Dr. Drachman, M/SAB member
- Marika Bates, Maryland/DC/Delaware Chapter; Marie Ronnlof, Greater Florida Chapter; and Tammy Murphy, Pennsylvania Chapter
- Attendees enjoy lively lunch conversation

Photos courtesy of Janet Myder

## Highlights

*(continued from page 9)*

inhibitors and immunosuppressant drugs currently in use and potential use of the “rebooting” strategy, primarily for refractory cases, using high-dose cyclophosphamide. Dr. Sanders provided an update on the results of the recently-completed CellCept® clinical trials in treating MG. Dr. Kaminski provided an update on the National Institute of Neurological Disorders and Stroke funded thymectomy and prednisone clinical trial that is currently in the recruitment and readiness stage with approximately 70 centers in 22 countries.

The Q&A session, moderated by Dr. Kaminski, brought a wide variety of questions from patients and their families. The panel poignantly discussed their differing opinions while adding humor to the seriousness of the issues being discussed.

The Saturday afternoon program, designed for chapter leaders, consisted of interactive work sessions focused on chapter and support group management, fundraising, and advocacy.

The above summary is a mere sketch of three full and exciting days that provided education and insight into the changing direction of MGFA. ■



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 Photos on this page, from top to bottom, left to right:

- Attendees get ready for another informative session
- Myrl Weinberg, President of NHC (National Health Council)
- Lindsay Knudsen, Wisconsin Chapter
- Steve Borski, Jim L. Walker Arizona Chapter, and Esther Land, Great Lakes Chapter
- Stan and Laurie Way, Maryland/DC/Delaware Chapter
- Ron McFarlane, Vice President of the MGFA national board of directors, and Janet Golden, MGFA Chief Executive

Photos courtesy of Janet Myder





### Esther Land steps down as chair

Esther Land of Grand Rapids, MI, stepped down as chairperson of the MGFA national board of directors at the April 2007 Annual Meeting.

Esther served as chair of the board of directors for the past several years. Esther was elected to the chair position upon the untimely death of Barry Gold in 2002, and subsequently was elected to a full three-year term in 2004.

She has been an active and vital part of the Foundation since being diagnosed with MG in 1959. Esther helped organize our Great Lakes Chapter in 1976 and was first elected to the MGFA national board of directors in 1986. This is Esther's fifth term on the board, and she remains a member of the Executive Committee of the board. Sam Schulhof, the current chair, told the Annual Meeting attendees that "Esther's philosophy of life is what MGFA is all about: nothing is impossible if you believe." Sam added that "Esther has contributed much to MGFA over the years and will continue to do so in the future."



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Photos on this page, from top to bottom, starting on the left:

- Dr. Kaminsky, M/SAB member, and Marika Bates, Maryland/DC/Delaware Chapter
- Drs. Sanders, Penn, and Drachman, M/SAB panelists
- Dr. Weiss, M/SAB member
- Nancy Law, national board of directors member
- Visitors from Pakistan: Khalid Zia and Syed Baehah
- Irv Beck, Connecticut "Nutmeg" Chapter, and Esther Land, Great Lakes Chapter

Photos courtesy of Janet Myder

## Awards and recognitions

**Stanley H. Way** of Rockville, MD received MGFA's prestigious **Lifetime Achievement Award** for his more than two decades of service to MGFA. Stan has been actively involved with MGFA since his diagnosis in 1980. He has just completed nine consecutive years of service on the national board and, in addition, still serves as a member of our Maryland/DC/Delaware Chapter board of directors. Stan is best known and loved by many for his interest in the



Internet and its potential for promoting awareness of myasthenia gravis. He has been integral to MGFA's Web presence, having served as MGFA's webmaster from 1998 to 2006 and as a co-founder of our premier

online chapter, MGNet. With his keen eye for finding anything related to myasthenia gravis on the Internet, Stan continues to be a resource to MGFA.

**Rahman Pourmand, MD** of Stony Brook, NY was named as MGFA's **2007 Doctor of the Year** for his extraordinary assistance to individuals and families affected by MG. Dr. Pourmand is a Professor of Neurology, Director of the Neuromuscular Disease Center, and Chief of the EMG Laboratory at Stony Brook University Medical Center in New York. He earned his MD in 1973 from Ferdowsi University, Meshed, Iran. He completed his internship at Youngstown Hospital Association in 1976, and completed his neurology residency at Southside Medical Center, Ohio, and the University of Tennessee Hospital. For the past eight years, he has served as editor of the *Journal of Clinical Neuromuscular Diseases*.



Dr. Pourmand is a member of numerous professional organizations, including the American

Academy of Neurology, the American Association of Electrodiagnostic Medicine, and the American Clinical Neurophysiology Society. He has also been an active member of the Myasthenia Gravis Foundation of America, Inc. since 1994.



Dr. Pourmand was instrumental in establishing the Suffolk support group of the Metro New York Chapter. He frequently attends support meetings, provides valuable information to MG patients and their families, and furthers awareness by encouraging MG patients to participate in lectures and seminars for medical students at Stony Brook University. His dedication and work with the Metro New York Chapter and the support group earned him the chapter's Physician of the Year Award in 2003 and 2006.

### **Wilma Koopman, RN, MScN, ACNP, CNN(C)**

of London, Ontario was named the 2007 **Nurse of the Year** for her extraordinary efforts to assist individuals and their families affected by MG, her



commitment to furthering the goals and mission of MGFA, and her significant efforts in the areas of patient and family services and professional and lay education. Wilma is a nurse practitioner/clinical nurse specialist with the Neuromuscular Clinic of the London Health Sciences Centre in Canada. In addition, she is an assistant professor at the School of Nursing at the University of Western Ontario. She earned her initial Registered Nursing degree from Hamilton Civic Hospitals and then pursued further nursing education at both the graduate and postgraduate levels. She completed an Acute Care Nurse Practitioner degree in 2000 and also received certification in neuroscience nursing in 2002. As current chair of MGFA's Nurses Advisory Board (NAB), Wilma has provided the leadership and inspiration necessary to revitalize the Nurses Advisory Board.

**Lindsay Knudsen, MS, RADC1** of Milwaukee, WI received MGFA's inaugural **Young Person of the Year Award** for her demonstrated commitment and leadership in furthering the goals and mission of MGFA. Ever since she was diagnosed with myasthenia gravis in her early college years, Lindsay has been educating others about the disease and



serving as a role model as she lives with the ups and downs of MG. Lindsay earned her BS in Education and graduated *magna cum laude* from the University

of Wisconsin - Oshkosh and received her MS in Educational Psychology and Community Counseling at the University of Wisconsin - Milwaukee in May 2006. Lindsay was the recipient of MGFA's Student Fellowship Award in 2005 for her research on "The Psychological Aspects of Myasthenia Gravis." In addition, she received the Student Leadership Award in 2003 from the University of Wisconsin - Oshkosh and was named to the National Dean's List and Who's Who Among Students In American Colleges and Universities in 2003-2004. ■

Photographs courtesy of Janet Myder.

## Thank you to our 2007 Annual Meeting sponsors:



## Tax-savings opportunities for donors aged 70½+

On August 17, 2006, President Bush signed into law new tax incentives for charitable gifts from donors who are 70½ or older. The **Pension Protection Act of 2006** encourages financial support of qualified charitable organizations such as MGFA.

Previously, if you had taken a distribution from your IRA or Roth IRA to make a gift to MGFA, you would have been required to pay income tax on the distribution, and then you would have been entitled to a charitable deduction for the gift amount. Under the new law, you can make a lifetime gift using these funds without undesirable tax effects.

### **You can benefit from this new law if:**

- You are age 70½ or older.
- The gift is \$100,000 or less each year.
- You make the gift on or before December 31, 2007, for the 2007 tax year.
- You transfer funds directly from an IRA, Rollover IRA, or a Roth IRA to MGFA.

Please consult a tax professional if you are contemplating a gift under the new law. ■

## Post-Doctoral Fellowships awarded

The Myasthenia Gravis Foundation of America, Inc. has awarded three new Post-Doctoral Fellowships for 2007-2008. This twelve-month fellowship is awarded for clinical or basic research related to MG or related neuromuscular disorders. Research may be concerned with the neuromuscular transmission, immunology, molecular, or cell biology of the neuromuscular synapse or the etiology/pathology or diagnosis of MG.

The Research Committee received and reviewed nine applications. While all nine applications were meritorious, the Research Committee awarded three \$50,000 recipients.

**Jianrong Sheng, PhD** of the University of Illinois is investigating the use of a specific growth factor (GM-CSF) to induce a specialized type of immune cell (T regulatory lymphocytes) as a treatment for mice with MG. Previous work in this area has shown this strategy to be effective in preventing

mice from acquiring experimentally-induced MG. The desired outcome of this current research is to use the immune system's own regulatory network to establish immune balance, eliminating the need for chronic immunosuppression.

Dr. Sheng will be working with Dr. Bellur Prabhakar and Dr. Matthew Meriggioli.

### **Shalini Muhherjee, PhD**

will be working with Dr. Steven Verino at Texas Southwestern University to investigate 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.



## MGFA family member mourned

Patricia Ellsworth Wilson (whose mother, Jane Dewey Ellsworth, founded MGFA) mourns the loss of her husband Laurence H. Wilson, who died of lung cancer on March 28, 2007, at age 78.

Larry was born in Johnston, PA, and earned his PhD in organic chemistry from New York University.

After his marriage to Pat in 1980, Larry became a passionate supporter of MGFA and was a familiar face at many annual meetings of the Foundation. He served on the MGFA national board of directors, as well as on the board of trustees for our Great Lakes Chapter.

He was a loyal and compassionate caregiver and an enormous source of encouragement for Pat. Larry will be missed by many, particularly by Pat, as she continues her battle with MG and myositis. ■

**Jennifer Anderson, PhD** will be investigating 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. Dr. Anderson will be working with Dr. Ricardo Maselli at the University of California Davis.

The MGFA and the myasthenic community look forward to hearing the results of these exciting research programs. ■

## Friends and families stay connected with CaringBridge

Today, families can be spread out across the country, or even around the world. This makes it challenging for families and friends to stay connected, to know how you are doing, or perhaps how a loved one is coping with a new treatment or how he or she is recovering from surgery. Sometimes it may take too much precious energy to let everyone know that you are doing okay.

MGFA is collaborating with CaringBridge to help patients stay connected with family and friends during a health crisis, treatment, and recovery.

Founded in 1997, CaringBridge is a nonprofit national voluntary health agency and, like MGFA, is a member of the National Health Council. Its mission is to bring together a global community of care powered by the love of family and friends in an easy, accessible, and private way.

CaringBridge is a Web service that connects more than 15 million people each year. The service is always free, private, and personalized, and it takes just a few moments to set up your own CaringBridge Web site.

**To set up your own Web site**, visit [www.caringbridge.org/MGFA](http://www.caringbridge.org/MGFA) and follow the simple steps.

Keeping in touch with loved ones during difficult times is important. **Together, we are stronger.** ■

## A sample of MGFA advocacy activities in May 2007

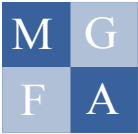
### **National Coalition of Autoimmune Patient Groups Rally and Health Fair in Washington, DC, May 22, 2007**

Twenty-seven organizations, including MGFA (represented by Janet Myder), attended the rally and health fair on Capitol Hill to coincide with the U.S. Senate's designation that May is National Autoimmune Diseases Awareness Month (ADAM), with the goal of raising congressional and public awareness of autoimmune diseases.

The rally included patients with autoimmune diseases and their friends and family members. Signs stating "24 Million Americans with Autoimmune Disease Need Your Help" were held, along with a banner listing more than 100 autoimmune diseases. Key speakers included Robert Goldberg, Executive Director of the Myositis Association; U.S. Representative Steve Israel (D-NY); Dr. Noel Rose, Director, Autoimmune Disease Research Center, Johns Hopkins University; U.S. Representative Patrick Kennedy (D-RI); "Brave Dave" Gearing, a multiple sclerosis patient; and Virginia Ladd, President and Executive Director, American Autoimmune Related Diseases Association.

### **Centers for Medicare & Medicaid Services (CMS) Holistic Health Fair, May 9, 2007**

Approximately 100 organizations participated in the Health Fair. MGFA was represented by Janet Myder, member of the MGFA and Maryland/DC/Delaware Chapter boards of directors, and Bunny Krause, member of the Maryland/DC/Delaware Chapter board of directors. ■



MYASTHENIA GRAVIS  
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**MGFA is proud to be  
a member of the  
following associations:**



**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.

**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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# *Financial Counseling and Planning Assistance*

## ***How can MGFA help me with my Financial Planning?***

MGFA and the Foundation for Financial Service Professionals have created a partnership that provides access to free, sound and practical financial advice to members of myasthenia gravis community. These services are offered by the Financial Education Partners (FEP) program, a national initiative supported by the Foundation for Financial Service Professionals, the charitable arm of the Society of Financial Service Professionals (SFSP).

## ***What is Financial Counseling and Planning?***

Financial planning and counseling includes:

- Insurance analysis, claims assistance
- Basic budgeting and bill paying strategies
- Credit card management
- Employee benefits analysis: retirement planning, medical plans, disability coverage and life insurance.
- Retirement planning: analysis of adequacy and tax effectiveness
- Estate planning: strategies to maximize inheritances
- Legal planning: wills, special needs trusts, living trusts, etc.
- Pros and cons of various financial instruments

## ***What FEP cannot do:***

FEP is not a source of emergency funding, loans or cash assistance. It does not specialize in public assistance programs (except Social Security and Medicare) and is unable to assist in referring clients to these programs. Participants should not expect an FEP volunteer advisor to act as their long-term financial advisor.

## ***Are the FEP volunteers trying to sell anything?***

Absolutely not. As volunteer advisors, members of SFSP are providing information on a totally pro bono basis under the program. FEP volunteer advisors participate in the program because they want to share their financial knowledge with those who are in need. FEP volunteer advisors have the capacity to help with purchase of a financial product but that is not their purpose in participating in FEP.

## ***How can I arrange a meeting with the FEP Volunteer in my area?***

To take advantage of this benefit you must first contact your chapter or the chapter serving your area. Requests can only be considered for enrollment in the FEP program if endorsed by a chapter. And remember this is a no-cost benefit through your MGFA membership.

## ***What is the Society of Financial Service Professionals?***

Founded in 1928, the Society of Financial Service Professionals is a professional association whose members have broad exposure to all aspects of financial planning and their professional network gives them ready access to members who have strengths in different areas of expertise. Many MG patients and their families have special financial planning needs and partnering with FEP allows access to financial and health benefit counseling.

FEP is providing service to members of:  
National Multiple Sclerosis Society  
American Cancer Society  
Habitat for Humanity