Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient. 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.

News about myasthenia gravis for patients, family and friends

Fall 2010

Message from Chairman Sam Schulhof ........................................ pg 2
Advocacy Update ................................................................. pg 3
Monarsen (EN101) .............................................................. pg 5
Traveling with Myasthenia Gravis .......................................... pg 6
MG and Pregnancy: Things to Consider ................................ pg 9
Chapter Updates ............................................................... pg 10
New Board Members ........................................................ pg 11
Genes Underlying Myasthenia Gravis: (GWAS update) ........ pg 13
2010 MGFA National Conference Highlights ...................... pg 14

Calendar

Board Meeting
January 22, 2011
Tampa, Florida

2011 National Conference
May 4–6, 2011
Baltimore, Maryland

Thank you

...to all of our wonderful donors!

Your generosity brings us closer to a world without MG.
The MGFA National Conference held in May in St. Louis was a tremendous success and a positive precursor to a productive, although hot, summer.

The chapters elected eight new national Board members, which substantially increases the diversity of the Board (read about the new Board members on page 11). The Board said goodbye to two strong and dedicated members as Ron McFarlane, Board Vice-Chair, and Marc Kalish, Treasurer, completed their terms.

Thanks to the leadership of Wilma Koopman, Chair of the Nurses Advisory Board (NAB), and all those who participated, the third annual Run/Walk/Sit-a-Thon was a great success. This year’s event honored Madeleine Batenjany, a member of the NAB and a former Board member. The Run/Walk/Sit-a-Thon attracted twice as many participants as last year and contributions increased by $3,000.

In an effort to show what MGFA is doing at the national level and to better appreciate what is being accomplished at the chapter level, we are visiting chapters. In May, June, and September, I had the opportunity to attend and speak at the Wisconsin, Great Lakes, and Maryland/DC/Delaware Chapter’s annual meetings. I met many inspirational and positive people, including patients and caregivers, who are the backbone of MGFA. I also heard first hand about the service these chapters provide to their communities. In October, I will attend the Ohio Chapter’s annual meetings. Marie Ronnlof, Chapter Liaison Officer and Board member, attended the Oklahoma Chapter’s annual meeting in the spring and the Minnesota Chapter’s annual meeting in September. Tor Holtan, MGFA’s CEO attended the Connecticut Nutmeg Chapter meeting in September.

MGFA’s annual Scientific Session was held October 6, in conjunction with MGFA’s fall Board meeting and the annual meeting of the American Association of Neuromuscular & Electrodiagnostic Medicine. There were more than 150 people in attendance at the Scientific Session, where 11 abstracts and posters on current research were presented.

With Labor Day behind us, the promise of cooler weather is around the corner. There is much work left for the Chapter and National teams to do in order to accomplish our vision of “A World without MG.”

Please think of MGFA when you consider workplace giving this fall

Many workplaces throughout the country launch employee giving campaigns in the fall. You can choose to support the MGFA through your workplace giving campaign, including the United Way and Combined Federal Campaign. Please consider designating your contribution to the MGFA. Our Combined Health Charities identification number is 11240.

Please check with your human resources department to ask if your company will match your contribution. Our work to improve treatment options and provide information and resources to people with myasthenia gravis depends on your support. Many thanks!
Health Care Reform
On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act of 2010 (Affordable Care Act/the Act). This complex collection of mandates is intended to expand health insurance options for individuals and groups and make access to health care services more affordable. Although its full effects will not be known for some time and implementation of the main provisions of the Act will take four years, the Act contains several provisions that will be implemented in 2010. Many of these are significant for people with chronic illnesses and disabilities.

This article highlights the mandates that are the most likely to affect people with chronic illnesses such as Myasthenia Gravis and those with disabilities. It is not intended to be an exhaustive listing or analysis of all such provisions. Future issues of Foundation Focus and MGFA’s E-Newsletter will feature key developments as the Act is implemented.

The Act does not require individuals to give up their current health insurance. Plans in effect as of March 23, 2010, are “grandfathered” and are not subject to all of the new requirements under the Act. Grandfathered plans must have the mandatory protections such as restrictions on annual coverage limits or lifetime caps, but they are not required to cover certain preventative services without charge. Over time, the number of plans that are grandfathered is expected to decrease as plans change their benefit packages or employers consciously choose to give up the grandfathered status of their plans.

Unless otherwise noted, the provisions listed below are effective for plan years beginning on or after September 23, 2010. This means that an individual’s current health insurance coverage will not be required to comply with the provisions below until the annual renewal date for individual coverage or the new plan year for group health coverage.

Denial of coverage based on pre-existing conditions. New individual plans and existing group plans cannot deny coverage to children under age 19 based on a pre-existing condition. Starting in 2014, the prohibition applies to any age, and plans also cannot charge higher premiums for pre-existing conditions.
Insurance for individuals with pre-existing conditions. Effective on July 1, 2010, individuals who have not been insured for at least six months due to a pre-existing condition can purchase coverage through a new Pre-Existing Condition Insurance Plan that is available until 2014. States can run this program, or if they choose not to, the U.S. Department of Health and Human Services (HHS) will establish a plan in those states. After 2014, health insurance will be available through new “Exchanges.” These may vary among states depending on whether states continue their existing high risk insurance pools with funding through the Act or choose federal government provided coverage. Premiums in the exchanges are expected to be high initially and lower when subsidies take effect in 2014.

Coverage for early retirees. Employment-based plans may apply for funding to help them continue providing access to coverage until 2014 for people who retire between age 55 and 65 and who otherwise would lose employer-sponsored insurance and are not yet eligible for Medicare.

Reversal of coverage. Insurers may not rescind coverage except for cases of non-payment or fraud. They cannot deny payment if a customer uses a high amount of health care services or makes a mistake on an application for coverage.

Appeals of insurance company decisions. Individuals can appeal coverage determinations or claims to their insurance company. All health plans will be required to allow an appeal by outside, independent decision makers.

Medicaid. Effective April 1, 2010, states can receive federal matching funds for covering some additional low-income individuals and families for whom federal funds were not previously available.

Medicare. Starting in June 2010 beneficiaries who reach the “donut hole” in Part D prescription coverage will receive a $250 rebate. Over several years, the donut hole will be eliminated. In 2011, Medicare patients will be eligible for an annual wellness exam and certain preventive services with no co-payments or deductibles.

Long-term care. A new voluntary program called CLASS (Community Living Assistance Services and Supports) will provide cash benefits to adults who need services and support to remain in their communities. The HHS Secretary is to designate a benefit plan no later than October 1, 2012.

Limits on Insurance Coverage. Insurers may not impose lifetime dollar limits on “essential health benefits,” as defined in the Act. The Act provides that “essential health benefits” include ambulatory and emergency services, hospitalization, maternity and newborn care, mental health, prescription drugs, lab services, chronic disease management, pediatric services, and other benefits as defined in regulations issued by the Department of Health and Human Services. To date, the regulations defining other “essential health benefits” have not been released. Effective January 1, 2014, insurers may not impose annual lifetime dollar limits for “essential health benefits.” Annual and lifetime limits may still be imposed on non-essential health benefits.

Information for Consumers. The Act requires HHS to establish a website for consumers to obtain information, compare health insurance coverage options and select coverage. It became effective July 1, 2010. www.healthcare.gov

Preventive Care. All new plans must cover certain preventive services such as mammograms and colonoscopies without charging a deductible, co-pay or co-insurance.

The depth and breadth of the Act reinforces the need for persons with a chronic disease such as MG to be advocates — to take an active role in their own care and become knowledgeable consumers of medical care services. Persons with a chronic disease are encouraged to know at least the basics of the law that will affect their particular circumstances. This knowledge refers both to knowing about the sources and extent of their insurance coverage as well as advocating on their behalf and that of others in similar situations before state and federal officials. Web sites are available to help in this endeavor. A great deal of information is available through internet sites of reputable organizations that represent people with disabilities and specific diseases, sponsor coalitions, or conduct research and analyze public policy.

The following websites provide comprehensive details and updates on the Act and its implementation.

HHS official site providing reform law details, state information, updates, forums, etc.: www.healthcare.gov
Kaiser Family Foundation description of provisions, implementation developments, and analysis: http://healthreform.kff.org

Flu season is upon us! As with all medications, MGFA encourages you to consult your physician before getting a flu shot.
Monarsen (EN101)  Robert L. Ruff, MD, PhD

This brief text addresses Monarsen (also known as EN101). Monarsen is an orally available preparation of nucleic acids (DNA and RNA are made of long strings of nucleic acids) that is designed to interfere with the production of acetylcholine esterase (AChE). This is a novel approach to inhibiting AChE. Mestinon is a medication that is commonly used by people with MG and it acts by inhibiting AChE. Monarsen would take longer to act then Mestinon, but could be taken once a day. Consequently, Monarsen has the potential to be an alternative to Mestinon for people with MG. An additional possible benefit of Monarsen is that it may act to suppress the immune system through its action on a form of AChE that may modulate the action of white cells.

Monarsen was developed by basic researchers in Israel. These researchers sold the international production rights for Monarsen to an Israeli company, Ester. The Israeli Company then sold the rights to a British company, Amarin Corp (UK). Amarin has chosen not to continue with the development of Monarsen. Specifically, Amarin is not planning to pursue with phase II or phase III clinical trials of Monarsen. As the rights to Monarsen are owned by a private company, researchers are not able to independently study this preparation. It is MGFA policy not to invest money in private companies, such as Amarin. The Medical/Scientific Advisory Board (M/SAB) of MGFA has communicated with a researcher in the United Kingdom who is trying to negotiate with Amarin to be able to use Monarsen. To date, Amarin has not been willing to allow others to use Monarsen in research studies nor have they moved Monarsen through the process of getting this preparation approved for clinical use with patients.

The M/SAB will continue to explore new strategies to improve the lives of people with MG and to pursue research on treatment for MG. Unfortunately, the M/SAB and other researchers are currently blocked from studying Monarsen.

---

The annual Scientific Session of the Myasthenia Gravis Foundation of America provides neurologists and others doing basic or clinical research relating to the neuromuscular junction an informal opportunity to discuss their work in progress. The following abstracts were selected for discussion at the 2010 Scientific Session:

- **Incidence of MG Based on Screening Data of MGTX Study**  
  **Author:** Inmaculada B. Aban, Department of Biostatistics, Birmingham, AL

- **Detection of Muscle Specific Tyrosine Kinase Antibodies in Myasthenia Gravis: Comparison of an ELISA and Radioimmunoprecipitation Assay**  
  **Author:** Jennifer Brealy, University of British Columbia

- **The MG-QOL15 for Following the Health-Related Quality of Life of Patients with Myasthenia Gravis**  
  **Author:** Ted M. Burns, MD, University of Virginia

- **Rituximab in Refractory Generalized Myasthenia Gravis**  
  **Author:** Mazen M. Dimachkie, University of Kansas Medical Center

- **The OBFR is a Useful Tool to Assess Bulbar Function in MG**  
  **Author:** Dr. Maria Elena Farrugia, Institute of Neurological Sciences, Glasgow, UK

- **The Cost of Misdiagnosis in Myasthenia Gravis**  
  **Author:** Guptill JT, Duke University Medical Center

- **Outcomes in a Large Cohort of MuSK Antibody Positive Patients**  
  **Author:** Guptill JT, Duke University Medical Center

- **Relationship Between the Quantitative Myasthenia Gravis Scale and Clinical, Immunological and Electrophysiological Markers of Disease Status in Myasthenia Gravis**  
  **Author:** Katzberg HD, Toronto General Hospital

- **MG-ADL: Is it Still a Relevant Outcome Measure?**  
  **Author:** Srikanth Muppidi, MD, University of Texas, Southwestern

- **Increasing Incidence of Anti-AChR Seropositive Myasthenia Gravis in British Columbia, Canada**  
  **Author:** Zahra Pakzad, University of British Columbia

- **How Myasthenia Gravis Alters the Safety Factor for Neuromuscular Transmission**  
  **Author:** Robert L. Ruff, M.D., Ph.D., Case Western Reserve University
Myasthenia Gravis (MG) is a chronic neuromuscular disease that affects the strength and stamina of voluntary muscles. Symptoms within muscle groups can vary from person to person and can fluctuate by the day or month. Sometimes the illness can worsen for no apparent reason. Unexpected changes in a patient’s condition present a special challenge for patients who need or wish to travel. This leaves individuals and families of people who have MG to question, “Is it safe to travel with MG?” and if so, “What do I need to consider before traveling?”
Traveling is not impossible, however individuals with MG may require a more thoughtful plan and scrutiny of their itinerary. There are helpful tips that can assist individuals with MG to prepare for trips and special activities. These are intended to help you travel wisely, remain safe, and ensure you enjoy your time away.

**Planning**

First, it is recommended to think about your overall medical condition and treatments. Consider how stable your myasthenia gravis has been in the last year. Are you prone to fluctuations in symptoms? If so, how sudden and severe are these fluctuations? Have you required a change in medications or treatments? It is important to realize that psychological stress, infections, and changes in weather conditions may exacerbate MG symptoms. Answering questions about your overall health, your MG condition, and your response to changes in conditions may prove to be helpful in planning your trip.

Consider discussing your travel plans with your family physician and/or MG specialist. They may be able to provide you with a realistic comprehensive medical view on your condition. They can assist you with a careful risk assessment based on where and how long you plan to travel and environmental factors such as weather and infectious diseases that can challenge people with MG.

Ask your physician(s) for a copy of the most recent consultation note that summarizes your MG condition and includes a list of your medications, dosages and other treatments. This will be helpful to health care providers should you require assistance while traveling. Consider asking your MG specialist about possible medical contacts they may have around your travel destination. They may know of physicians who specialize in MG or a neurologist who may be contacted for emergency services.

Another option is to consider discussing your destination and plans with a travel medicine physician. Many cities have Travel Clinics that are staffed by travel medicine physicians and nurses who specialize in travel medicine. Some are infectious disease specialists. They are aware of current conditions and travel warnings for foreign countries. Depending on your destination, they will be able to provide answers to specific travel concerns. They may charge a small fee for their services.

There may be some areas of the world that will not be safe for you. If your MG is active and you are taking immunosuppressive drugs, a risk assessment by trained health care professionals may suggest that you not travel to a particular area. This is intended to reduce potential harm especially if it is “absolutely contraindicated and the patient is at high risk of infection or when the clinical condition of a patient may worsen because of travel.” (Travel Medicine and Infectious Disease 2007 5, 7-17) If traveling locally, people with MG often choose not to travel during the peak flu season or when there is an outbreak of other contagious diseases.

MG is a relatively rare disease. While there are hospitals and medical clinics accessible in foreign countries, the health care professionals may not be well trained in caring for people with MG. Advanced treatment options may be unavailable. It would be prudent to research health care facilities in advance to establish exactly what services are available, the location, and hours of operation. Consider the following questions – How far away is the medical facility from where you are staying? Do they have adequate medical facilities to manage MG and provide the care you need should symptoms worsen? It may be helpful to contact the local Embassy or Consulate at your destination. They may be able to offer contact information of medical providers who practice Western style medicine and are familiar with MG and standard treatments.

Research websites such as the International and Overseas Medical Clinics or the International Association for Medical Assistance for Travelers (IAMAT) are available for medical contact information.

It is advised that you closely research your destination. Location, duration, reason for travel and accommodation should be considered. It is important to remain realistic about what you can and cannot do.

Is your travel for business purposes or pleasure? How will the trip challenge your abilities for activity? Will it allow for rest periods? Travel plans should be realistic. Perhaps going for a relaxing cruise is a better choice than an excursion requiring more physical exertion. Traveling to exotic areas away from medical facilities or areas that require certain immunizations may not be possible. How long do you intend to be gone? Will this interfere with regular treatments for MG?

By asking in-depth questions in advance you will have a better chance for a safe and enjoyable travel.

See the MGFA website for the full Traveling with MG article. 

While there are hospitals and medical clinics accessible in foreign countries, the health care professionals may not be well trained in caring for people with MG.

**Traveling to exotic areas away from medical facilities or areas that require certain immunizations may not be possible.**
Myasthenia Gravis (MG) is common in women of child-bearing age. The effects of MG on women and their newborns should be carefully considered and monitored during and following pregnancy. Below are some questions that women often ask in this situation.

**Will my baby be healthy?**
Overall the risk of birth defects is not increased for women with MG and is comparable to pregnancies of women without MG. A rare birth defect that has been linked to MG is arthrogryposis, which refers to muscle weakness and joint deformities that are present at birth. Women who have large amounts of a specific type of antibody that targets the infantile form of the acetylcholine receptor are more likely to deliver babies with arthrogryposis. The fortunate feature is that women who deliver babies with arthrogryposis usually do not have clinical MG. The subset of antibodies that cause arthrogryposis do not cause symptoms in adults. Consequently, women who have MG are not likely to have babies with arthrogryposis. Severe arthrogryposis can be recognized by ultrasound prior to delivery.

One health concern that women with MG and their doctors must consider is transient neonatal MG (TNMG). TNMG occurs when MG antibodies are transferred from the mother to the baby and can be effectively addressed if anticipated. The baby will need treatment, perhaps for several days to a week, until the MG antibodies from the mother have been removed from the baby or spontaneously broken down. Babies who have had TNMG have grown to be normal children.

**How will my MG treatment complicate my ability to get pregnant?**
Women need to consider several issues and have extensive discussion with their physicians and other women who have been pregnant before they attempt pregnancy. As pregnancy advances, women frequently feel fatigued. Fatigue can be more prominent in women with MG. Treatment with anticholinesterase medications, such as pyridostigmine (mestinon®), does not affect the ability of an individual to become pregnant nor is it known to appreciably complicate a woman’s ability to carry a pregnancy. There is slight risk of anticholinesterase medication triggering or enhancing uterine contractions. Many people with MG are treated with medications that alter the immune system, immunosuppressive agents. Immunosuppressive agents include glucocorticoids, such as prednisone, azathioprine, mofetil mofetate (CellCept®), cyclosporine and other agents. It is essential if you are taking a medication or treatment to alter your immune system that you discuss the risks associated with getting pregnant when using that treatment. In general glucocorticoids can be continued during pregnancy.

**How will pregnancy affect my MG?**
About a third of women with MG will have a flare of their MG during the first trimester of pregnancy. In general, MG symptoms, with the exception of general fatigue, tend to decline during the second and third trimesters of pregnancy. As pregnancy advances, breathing during sleep can be compromised in any pregnant woman. Because disorders of sleep, particularly sleep apnea, are often under-recognized in people who have MG, women contemplating pregnancy should discuss with their caregivers whether they should have a sleep study to evaluate their breathing when asleep. The usual treatment for sleep apnea, continuous positive airway pressure (CPAP), does not complicate pregnancy.

**Reference**
Carlayne E. Jackson The effect of myasthenia gravis on pregnancy and the newborn. Neurology 2003; 61; 1459-1460 [The online version of this article, along with updated information and services, is located on the World Wide Web at: http://www.neurology.org/cgi/content/full/61/10/1459]
See the MGFA website for the full article on Pregnancy and MG or contact National at 800-541-5454 for a copy of the brochure.
Chapter Updates

Carolinas Chapter
A Carolinas Chapter Support Group arranged a group of MG supporters to attend a local semi-pro baseball game in Winston-Salem, North Carolina. The group of 36, many of whom wore MGFA t-shirts, were announced over the PA system as well as displayed on the large scoreboard.

Ohio Chapter
The Ohio Chapter will hold its annual meeting and luncheon on Saturday, October 23, from 12:30-3:00 PM at Dimitris Restaurant in Parma, Ohio. This year’s meeting will feature a question and answer session with Drs. Robert and Suzanne Ruff. The meeting is open to all members and friends. For more information, contact the chapter at 330-834-9066.

Garden State Chapter
The 13th annual Myasthenia Gravis (MG) Walk-A-Thon in memory of Tracy Lynn Allen was another great success! A brief rain shower did not deter more than 200 walkers from braving the weather and participating. Janine Strafaci from News 12 New Jersey, Mayor Christopher Vergano from Wayne Township, and Father Daniel Kelly from Immaculate Heart of Mary Church cut the ceremonial ribbon to officially kick off the event. Contributions climbed to $27,000 and continue to come in.

This is a special year for the MG Walk, as this year, the fundraiser was dedicated in memory of Tracy Lynn Allen, the daughter of Board members Bob and Diana Allen. Tracy Lynn passed away due to complications of Myasthenia Gravis in 1995, but her loving spirit is still alive in her beautiful parents. Their strength and dedication to this cause is beyond measure. Henceforth, the MG Walk-A-Thon will continue to be in her honor. Every Step Counts!

Once again, Governor Christie issued an important proclamation declaring June as Myasthenia Gravis Awareness Month. Looking ahead, the Garden State Chapter is in the midst of planning the 18th annual Helen & Leonard A. Golden Memorial Golf Classic.

Pacific Northwest Chapter
The Pacific Northwest Chapter obtained State Proclamations from Washington, Oregon, Idaho, and Alaska declaring June as Myasthenia Gravis Awareness Month. The cities of Seattle and Auburn, Washington also issued Proclamations. Washington held a meeting on June 13, where Dr. Steve Hamilton, Chairman of the Chapter’s Medical Advisory Board, gave a talk on MG 101 as well as current research. The Chapter celebrated its 25th anniversary on October 18, 2009 with a meeting and reception honoring Marian Forschler, RN, BSN for her founding of the Chapter in 1984. Dr. Robert Miller, a consultant and Clinical Associate Professor at the University of Washington, spoke about swallowing and speech problems encountered by myasthenics.

Massachusetts/New Hampshire Chapter
For the fifth year in a row, the Massachusetts/New Hampshire Chapter received a Governor’s Proclamation and a Legislative Resolution declaring June as Myasthenia Gravis Awareness Month in Massachusetts. This is a result of the outstanding effort of Board member and past Chapter President, Bob DeBoer. Proclamations were also received in the towns of Hull, Marshfield, and Sutton, Massachusetts.
Chapter Updates Continued

Oklahoma Chapter

The Oklahoma Chapter received a proclamation from Oklahoma’s Governor Brad Henry declaring June as Myasthenia Gravis Awareness Month. The Chapter held a “Picnic in the Park” in Oklahoma City and Tulsa to celebrate June Awareness Month. Hamburgers, hot dogs, good food and fellowship were enjoyed by all who attended.

New Board Members

One of the highlights of MGFA’s annual meeting in St. Louis in May was the election of new members to the national board of directors. The process of identifying energetic and motivating people for possible election began late last year when the Board Development and Nominating Committee sought help from key members of the MGFA community. In early December a call for nominations package was sent to all chapter board members and the MGFA board, as well as the Medical Scientific/Advisory Board and the Nurses Advisory Board. Members were asked to submit nominations to the national office by the end of January. During the May 7th General Assembly meeting, the voting members (or their proxies), including chapter chairs, unanimously elected members who were up for re-election and eight new members to the national board. We are pleased to introduce the new board members.

Judith Boder has extensive marketing experience including direct and interactive marketing. She most recently served as Senior Vice President - Marketing Director, Citi Cards, where she was responsible for improving the customer experience and building customer loyalty through optimization of communication strategies and channels such as e-mail, websites and direct mail. Judy holds a B.A. in English from Brooklyn College (1975) and an MBA in Finance from the Stern School of Business at NYU (1979). Judith serves on the Communications and Resource Development Committees and the two new special committees - Outreach/Programs and Web Redesign.

Jennifer Faucett is an associate attorney with the law firm of Bryan Cave, LLP, in Atlanta, Georgia. Jennifer’s expertise is in the area of employee benefits and executive compensation. She has experience with health and welfare plans and privacy issues (including HIPAA). Jennifer is an MG patient and a member of the Georgia State Chapter of MGFA and is building a local support group. Jennifer has a particular interest in, and has previously worked for non-profit organizations in Montana, exploring funding and grant opportunities. Jennifer holds a B.A in Political Science from Furman University (2001) and a Juris Doctor, Magna Cum Laude, University of Alabama School of Law (2005). Jennifer serves on the Communications and Chapter Relations Committees and the two new special committees – Outreach/Programs and Web Redesign.

Nancy Kuntz, MD, is Medical Director of the Mazza Foundation Neuromuscular Disorders Program at Children’s Memorial Hospital in Chicago. Nancy’s specialty is Pediatrics and Child Neurology. She received her A.B from Boston College (1972), M.D. from Boston University School of Medicine (1975). Graduate Medical Education in Pediatrics at John Hopkins Hospital (1975-1977) and Child Neurology (1977-1980) and Clinical EMG (1982) at the Mayo Graduate School of Medicine. Nancy serves on the Communications Committee and the Outreach/Programs Committee.

Steve Merusi is currently Senior Director, Application Development & Support, Group RCI Wyndham Worldwide and President of Merusi Management Consulting, L.L.C. Steve has worked in traditional and consulting organizations, where he helped transform businesses by providing technology solutions for business problems. Steve
has more than 20 years of development and management experience with expertise in process engineering, software architecture and development. Steve completed the Leadership and Management Program at the Massachusetts Institute of Technology, Sloan School of Management (2008) and received his Diploma in Computer Science from the Chubb Institute in 1995. Steve serves on the Communications Committee and the two new special committees – Outreach/Programs and Web Redesign.

**Jeffrey Pilgrim** is a founding partner in the law firm of Grady Pilgrim Christakis Bell LLP, in Chicago. He is a graduate of the University of Iowa (1993) with a B.A. in Business Administration and Finance. He earned his J.D with High Honors in 1999 from the Chicago–Kent College of Law, Illinois Institute of Technology. Jeff has MG and has organized successful fundraising events for the MG Research Program at the University of Illinois at Chicago. Jeff serves on the Bylaws/Policies & Procedures and Resource Development Committees.

**Arthur Phillips Sultan** is a Financial Systems and Accounting Manager with 45 years of experience in both the for-profit and non-profit sectors. Arthur has worked for such diverse organizations as Citibank, Xerox, Yale University, Louis Dreyfus and Pepsi Cola. He held a variety of senior management positions such as: Chief Financial and Information Officer and Controllerships both domestically and internationally. His non-profit experience includes Board Member and Finance Chair for Fraunces Tavern Museum and the New Canaan Nature Center. In addition he has served as board Member and Budget Chairman for the New Canaan Board of Education. Arthur earned his B.A. from the University of Bridgeport and MBA from Hofstra University in Finance and Management where he earned the distinction of being number one in his class. Arthur suffers from Post Polio Syndrome, a degenerate nerve disorder. Arthur co-chairs the Audit/Risk Management Committee and serves on the Executive, Board Development/Nominating and Resource Development Committees.

**Jurgen Venitz, MD, PhD** is an Associate Professor of Pharmaceutics, School of Pharmacy, Medical College of Virginia at Richmond. He is a clinical pharmacologist, involved in drug research and teaching. His expertise in drug development and translational sciences has led to appointments on FDA Advisory Committees and NIH review panels. Jurgen was diagnosed with refractory MG in 2005 and has been a member of the Virginia/West Virginia Chapter for the last four years. Jurgen received his M.D. from the Universitat des Saarlandes, West Germany (1981) and his Ph.D in 1986. Jurgen serves on the Communications Committee.

**Edward Walsh** is a senior executive with 30 plus years of international, financial and operating experience in corporate and consumer financial services. Since retiring from Citibank/Citicorp were he was Executive Vice-President (EVP), Chief Administrative Officer, Consumer Lending he has gotten involved with several start up ventures as both a board member and investor. As EVP he was responsible for all asset product offerings other than credit cards for Citibank/Citigroup and accountable for the management of $222B in assets. Ed earned a B.S. in Finance and Accounting from Fordham University (1975) and is a CPA. Ed serves on the Executive and the Finance Committees.

-----

**Rare and Neglected Diseases Caucus**

The National Organization for Rare Disorders (NORD) announced the establishment of the Rare and Neglected Diseases Congressional Caucus, co-chaired by U.S. Representatives Joseph Crowley (D-NY) and Fred Upton (R-MI). Members of congress form caucuses to provide forums for issues or legislative agendas and draw attention to issues of importance to their membership. The new caucus will focus on:

- Bringing Congressional attention to the 6,800 known rare diseases that currently have no approved therapies
- Ensuring sufficient funding for research and orphan product development
- Exploring ways to give companies incentives to create new drugs, biologics, and humanitarian use devices
- Providing an opportunity for members of congress, families and advocacy groups to exchange ideas and policy concerns

Encourage your Representative to join the caucus. For details go to: [http://www.rarediseases.org/news/Diseases_Caucus](http://www.rarediseases.org/news/Diseases_Caucus)
Genes Underlying Myasthenia Gravis: GWAS update

Daniel B. Drachman, MD

There is a great deal of evidence that genetic influences predispose individuals to Myasthenia Gravis (MG), and play important roles in its clinical features. To analyze the genes that are related to MG, a Genome Wide Association Study (GWAS) is being conducted with support from MGFA. The ultimate goal of the study is to understand the genetic factors underlying MG and be able to target the relevant genes to provide new and effective treatments for MG.

This study involves analysis of a very large number of genes from more than 1,000 MG patients. In collaboration with 14 MG centers throughout North America, we are collecting DNA from saliva samples and clinical information (kept confidential) that includes factors likely related to the individual’s genetic makeup, such as gender, age of onset of MG symptoms, severity, association with other autoimmune diseases, family history of MG or other autoimmune diseases, and response to treatments. The collection of DNA and information began at the end of January 2010. We have obtained more than 500 DNA specimens and related clinical information and have found that about 6 percent of these patients have a family member who is also affected by MG. 26 percent of the patients have additional autoimmune disorders and 30 percent have a family member with an autoimmune disorder. These numbers are far higher than expected for the non-MG population, and support the idea that genetic factors are involved.

When the DNA and clinical information collection is completed, the material will be analyzed by collaborators at the National Institutes of Health, under the direction of Dr. Bryan Traynor. They will analyze 700,000 genes from each patient’s DNA. The genetic information will be processed by computers, using bioinformatic methods, to determine which genes are associated with MG.

The fall appeal featured a story by Edwin L. Kennedy, Jr. who shared his story with MGFA of how a diagnosis of MG didn’t stop his son from fulfilling his dream of becoming a United States Army parachutist. We invite you to read the full story online at www.myasthenia.org where you can also make a donation to show your support.

MGFA is busy working on a website redesign. Check out its new and improved look when it launches this October at www.myasthenia.org.
The Myasthenia Gravis Foundation of America, Inc. held its annual conference May 5–7, 2010, at the Sheraton Clayton Plaza Hotel in St. Louis, Missouri. More than 100 people traveled from different parts of the United States, Canada, and Spain to attend. Chairman Sam Schulhof welcomed everyone on Wednesday evening at the Town Hall Meeting and Reception. Attendees had the opportunity to meet each other and spend time with friends made at previous conferences.

The conference sessions were facilitated by twenty distinguished speakers and covered a wide range of topics, some of which included: State of the Art Treatment, Adverse Drug Events and Interactions in Myasthenia Gravis, Experimental Therapies; What The Future May Have in Store, Medical and Surgical Management of MG, Quality of Life, and the Ask the Professionals Panel, which allowed attendees to ask questions of a panel of doctors.

Members of the Nurses Advisory Board led the third annual Run/Walk/Sit-a-Thon on Thursday morning. Participants wore matching MGFA t-shirts and helped raise awareness and funds for MGFA. The annual Awards Dinner on Thursday evening provided guests time to socialize and enjoy an authentic St. Louis BBQ. MGFA honored Dr. Michael Nicolle as the 2010 Doctor of the Year, Anne Williams as the Nurse of the Year, Marie T. Ronnlof as the Volunteer of the Year, and John Ronnlof as the Caregiver of the Year. Dr. Arthur J. L. Strauss was awarded MGFA’s Lifetime Achievement Award.

On Friday afternoon, Sam Schulhof made the closing remarks and announced the date and location of the 2011 National Conference. It will be held May 4–6, 2011 at the Tremont Plaza Hotel in Baltimore, Maryland. MGFA is grateful for the support provided by its 2010 sponsors, ARJ Infusion Services, Athena Diagnostics, Impax Laboratories, Inc., Mayo Clinic, and MedPro RX, Inc. For more information on the presentations given at the 2010 National Conference, visit www.myasthenia.org.
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.

Foundation Focus is published by the Myasthenia Gravis Foundation of America, Inc. If this issue was mailed to you, you are on our subscriber list. If you would like to add, remove or update a subscription, or request that you receive future issues by e-mail, please contact the MGFA national office.

If you would like to receive Foundation Focus by email only, please email mgfa@myasthenia.org.

Save The Date

2011 National Conference, May 4-6
Tremont Plaza Hotel
Baltimore, Maryland