Patient Support Group Meetings

- **April 15, 2012 – 2:00 pm** – **Oklahoma City Support Group** – The film “Exercise & Myasthenia Gravis: Beyond Neuromuscular Junction” with Richard Macko, MD will be shown, with a caring/sharing time following.

- **June 2, 2012 – 12:30 pm** – **Tulsa** — A Chapter Picnic in the Park will be held in Tulsa’s La-fortune Park, 61st & Yale where we will be celebrating “June as MG Awareness Month.” Hot dogs, hamburgers and beverages will be provided. RSVP to Peggy at the OKMGF office at 918-494-4951.

- **June 9, 2012 – 11:00 pm** – **Oklahoma City** – A Chapter Picnic in the Camp will be held in OKC’s Camp DaKaNi, 3309 E. Hefner, Oklahoma City, where we will once again celebrate “June as MG Awareness Month.” Hot dogs, hamburgers and beverages will be provided. Camp DaKaNi is located at 3309 E Hefner, which is .6 miles west of I-35 N. Please RSVP to Jeanmarie Carper at 405-285-9445 or email her at jemmariecarper@yahoo.com if attending.

- **July 15, 2012 – 2:00 pm** – **Tulsa Support Group** – The film “Myasthenia Gravis and the Eyes” with Christopher Glisson, D.O., Neuro-Ophthalmologist will be shown. A caring/sharing time will follow.

- **August 12, 2012 – 2:00 pm** – **Oklahoma City Support Group** – Our guest speaker will be Pam Forducey, PhD., from Integris Health, Director, IT Applications. She will be talking on “how to handle stress in living with a chronic illness.”

- **September 9, 2012 – 2:00 pm** – **Tulsa Support Group** – a film from the 2011 Annual meeting of the Myasthenia Gravis Foundation of America, Inc. will be shown, with a caring/sharing time following.

- **November 4, 2012 – 2:00 pm** – **Oklahoma City Support Group** – a film from the 2011 Annual meeting of the Myasthenia Gravis Foundation of America, Inc. will be shown, with a caring/sharing time following.

No RSVP unless noted is necessary to attend the meetings. Light snacks will be provided.

Please feel free to bring a snack item to share with others.

Oklahoma City Patient Support Group meetings, unless otherwise noted, are held in the Central Oklahoma Cancer Conference Center, at SW 44th St. & S Western Ave., which is next to Integris Southwest Medical Center. Do not enter the Cancer Conference Center at the front doors, enter through the garden area that is to the right of the front doors, look for our MG chapter’s red arrow signs pointing the way to our meetings.

Tulsa Patient Support Group meetings, unless otherwise noted, meet at Saint Francis Hospital, 61 & Yale Ave., in the Education Center (on east side of the hospital). Park in the employee parking garage that is near the meeting area. Look for our MG chapter’s red arrow signs pointing the way to our meetings.
Who the Oklahoma MG Chapter Served in 2011

We serve Oklahoma MG patients in 84% of the 77 counties in Oklahoma.

OKMGF presence broken down by geographic area:

- Adair - 7
- Alfalfa - 1
- Atoka - 2
- Beaver - 1
- Beckham - 1
- Blaine - 2
- Bryan - 8
- Caddo - 3
- Canadian - 28
- Carter - 5
- Cherokee - 4
- Choctaw - 4
- Cimarron - 2
- Cleveland - 26
- Coal - 1
- Comanche - 10
- Cotton - 3
- Craig - 1
- Creek - 6
- Custer - Ø
- Delaware - 8
- Dewey - Ø
- Ellis - 2
- Garfield - 7
- Garvin - 5
- Grady - 4
- Grant - Ø
- Greer - 2
- Harmon - Ø
- Harper - 1
- Haskell - 3
- Hughes - 2
- Jackson - 5
- Jefferson - 1
- Johnson - Ø
- Kay - 9
- Kingfisher - 1
- Kiowa - 4
- Latimer - 1
- LeFlore - 10
- Lincoln - 8
- Logan - 6
- Love - Ø
- Major - 1
- Marshall - Ø
- Mayes - 6
- McClain - 5
- McCurtain - Ø
- McIntosh - 3
- Murray - Ø
- Muskogee - 24
- Noble - 1
- Nowata - 4
- Okfuskee - 1
- Oklahoma - 137
- Okmulgee - 4
- Osage - 4
- Ottawa - 7
- Pawnee - 4
- Payne - 11
- Pittsburg - 14
- Pontotoc - 2
- Pottawatomie - 8
- Pushmataha - 2
- Roger Mills - Ø
- Rogers - 10
- Seminole - 3
- Sequoyah - 4
- Stephens - 6
- Texas - 2
- Tillman - 1
- Tulsa - 211
- Wagoner - 5
- Washington - 16
- Washita - 1
- Woods - 2
- Woodward - 2

We also serve MG patients in the following areas:

- Kansas – 43
- Missouri – 11
- Arkansas – 18
- Texas – 22
- Others Served – 52

MG Chapter Picnics Planned

Tulsa’s MG Support Group is planning a Chapter Picnic in the Park for Sunday, June 2nd, 11:00 pm – 2:00 pm in Tulsa’s Lafortune Park to celebrate “June as MG Awareness Month.” Hot dogs, hamburgers and beverages will be provided. Those attending are asked to bring a picnic type food dish to share with others in attendance. Lafortune Park is located at 61st St & Yale Ave. in Tulsa. We will be in a covered shelter just north of the baseball fields batting cage. Park in the baseball area parking lot. Please RSVP to Peggy Foust at the Oklahoma Chapter office at 918-494-4951 if planning on attending.

The Oklahoma City Support Group will also be hosting a Chapter Picnic in the Camp that be held in OKC’s Camp Fire’s Camp DaKaNi on Saturday, June 9th, 11:00 am—2:30 pm, where we will once again celebrate “June as MG Awareness Month.” Hot dogs, hamburgers and beverages will be provided. Those attending are asked to bring a picnic type food dish to share with others in attendance. Camp DaKaNi is located at 3309 E Heffner, which is .6 miles west of I-35 N. Please RSVP to Jeanmarie Carper at 405-285-9445 or email her at jeammariecarper@yahoo.com if attending.

MG—THE SNOWFLAKE DISEASE

MG is a neurological disorder. It causes fluctuating weakness of the voluntary muscles of the body and can include a drooping eyelid, blurred or double vision, slurred speech, difficulty chewing and swallowing, weakness in the arms and legs, and difficulty breathing.
Are there any precautions I should take before visiting the dentist or while at the dentist?
In general, MG does not lead to dental disease. However, having MG may compromise your ability to swallow and, if you're taking Mestinon®, you may produce more saliva. Jaw weakness may lead to jaw misalignment.

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

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

I need to have oral surgery. What types of anesthetics are safe for people with MG?
Patients with MG are excessively sensitive to neuromuscular blocking agents. These agents are sometimes used to produce muscle weakness, and their use can lead to prolonged post-anesthesia weakness. The neuromuscular blocking agents include succinylcholine and medicines related to curare. There is also potential exaggerated weakness associated with local anesthetics; procaine should be avoided.

The table below indicates medications that may produce exaggerated weakness.

<table>
<thead>
<tr>
<th>Relatively contraindicated</th>
<th>Use with caution</th>
<th>Safe</th>
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<tbody>
<tr>
<td>Local Anesthetics</td>
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<tr>
<td>Procaine</td>
<td>Lidocaine</td>
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<td>Mepivacaine</td>
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<td>Bupivacaine</td>
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<td>Prilocaine</td>
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<tr>
<td>Analgesics</td>
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<td>Morphine &amp; derivatives</td>
<td>Acetaminophen</td>
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<td>Narcotics</td>
<td>NSAIDS</td>
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<td>Aspirin</td>
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<td>Anxiolytics/Sedatives/Hypnotics</td>
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<td>Benzodiazepines</td>
<td>N₂O/O₂ sedation</td>
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<td>Hypnotics</td>
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<td>Barbiturates</td>
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<td>Antibiotics</td>
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<td>Erythromycin</td>
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<td>Gentamicin</td>
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<td>Neomycin</td>
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<tr>
<td>Polymyxin B</td>
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<tr>
<td>Bacitracin</td>
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<tr>
<td>Clindamycin</td>
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<tr>
<td>Other drugs</td>
<td>Corticosteroids</td>
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</tbody>
</table>

Key: * = drugs which may acutely potentiate myasthenic weakness
§ = use with caution in patients with respiratory difficulty or depression

Myasthenia Gravis Foundation of America, Inc.
Medications to “Boost Immune System”:
Benefits and Implications in Myasthenia Gravis

Mamatha Pasnoor, MD, Assistant Professor, Department of Neurology, The University of Kansas Medical Center

Myasthenia Gravis (MG) is an autoimmune condition in which weakness is caused by circulating T-cell-mediated antibodies that block the receptors at the neuromuscular junction, the area where nerve endings communicate with skeletal muscles. Infections may exacerbate existing myasthenia by provoking a T-cell-mediated immune response.

The function of the human immune system is to defend the body against invaders like microbes (germs or microorganisms), cancer cells, and transplanted tissues or organs. Various ways have been suggested to boost immune system including sleep (chronic insomnia causes immune deficiency), moderate exercise, stress reduction (stress releases cortisol which alters immune system), fruits (berries are rich sources of organic acids and phenolics, which have antimicrobial activities) and vegetables (contain flavonoids that have anti-bacterial and anti-viral activity).

The immune system is incredibly complicated and while certain aspects of it may be enhanced by certain medications and dietary supplement, another aspect of it may be harmed. There are many supplements and nutrients that have been reported as supporting or boosting immune system. However, the research in this area is very limited.

Multivitamins formulations usually contain a combination of vitamins and minerals, some of which function as antioxidants and antimicrobial agents and are usually safe for myasthenics. Recent research shows that vitamin D may upregulate ability to fight infections by helping produce antimicrobial peptides. Vitamin K also decreases the pro-inflammatory cytokine interleukin-6 (Reddi K et al 1995) which is involved in myasthenia gravis pathogenesis. Some reports mention that B vitamin complex is also highly involved in cellular function and acetylcholine production and may help boost acetylcholine levels. However, it must be remembered that excessive use of some vitamins, such as vitamin A can actually reduce immune function.

Active Hexose-Correlated Compound (AHCC) a mushroom extract from agaricus, has been tested as an immune enhancing, liver protective and anti-cancer agent. Other mushrooms that have been considered to have medicinal value include Maitake, Reishi, Shitake, Cordyceps, Chaga and some of these have been reported as having an immune enhancing properties. It has been suggested, but not scientifically proven, that Reishi mushroom (Ganoderma lucidum) may help treat myasthenia gravis. However, the effects of most of these mushrooms or extracts, on myasthenia gravis is unknown as there is no published data or research trials. Therefore safety of their use in myasthenia gravis cannot be determined.

Ginseng and Salviae herbs have been shown to play a role as immune activators and modulate immune response during influenza virus infection (Fu Shi Quan, 2006). Ginsenosides are the active compounds in ginseng. A randomized, double-blind study showed that an extract of American ginseng reduced influenza cases in the elderly when compared to placebo (McElhaney JE et al. 2004). Large doses of Ginseng and Astragalus combination was recommended for Myasthenia Gravis treatment by Chinese herbal experts (Zhang Wentao et al, 1982). Ginko is another herb derived from one of the oldest trees and is used in traditional Chinese medicine for centuries. It has powerful antioxidant properties. However, the literature is limited in relation to MG and there is no clear information on the safety of these in MG.

Huperzine A, an active component of Chinese club moss (Huperzia serrata) is a potent immune modulator and is a reversible, highly effective, and highly selective inhibitor of the acetylcholinesterase enzyme (Wang R et al 2006). Experiments have demonstrated that huperzine A can intensify muscular contractions (Lin JH et al 1997). In one study, 128 cases of MG indicated that 99 percent of the clinical symptoms were controlled or improved after treatment with huperzine A (Cheng YS et al 1986). However, randomized control studies are necessary to establish its efficacy in MG. Side effects include seizures and cardiac rhythm abnormalities.

Many people report that dietary modification helped their Myasthenia Gravis. These claims aren’t supported in peer-reviewed studies. More randomized controlled studies are required to establish the efficacy of these supplements and herbal medications as immune modulators and safety in Myasthenia Gravis.

Dr. Mamatha Pasnoor is a neurologist & Assistant Professor at the University of Kansas Medical Center and sees patients at the KUMC MG-Clinic and serves on the Myasthenia Gravis Association (which is located in Kansas City) Medical Advisory Committee.

Permission to reprint this article was given by Dr. Pasnoor and the Myasthenia Gravis Association, Kansas City, MO.
The Oklahoma MG Chapter is seeking myasthenia gravis patients or their family members to serve as board members to help guide our organization. If you think strategically and creatively, and care about those with myasthenia gravis, call us at 1-918-494-4951. We meet about eight times year in the OKMGF Tulsa office on the fourth Thursday of the month at 5:00 pm.

Podcast Educational Series Available

The Myasthenia Gravis Foundation of America, Inc. produces patient-oriented Podcasts (*Podcasts are digital audio or video files that can be downloaded over the Internet or through services such as iTunes) with information on the diagnosis, treatment, and management of myasthenia gravis (MG) to further its mission of increasing awareness and providing information on MG to the community.

Podcasts that can be viewed at http://myasthenia.org/LivingwithMG/PodcastEducationalSeries.aspx are: Living Healthy and Active Lives: The Patient Perspective; Myasthenia Gravis and Pregnancy; A discussion about therapies for MG; Top 5 lists of what a patient needs to know about living with MG; What the patient and caregiver should know about prescription drugs and MG; A brief overview of myasthenia gravis; Clinical manifestations and diagnosis of MG; Review of the cause of MG; Brief overview of treatments and Vaccines and MG.

Development of a twin study for MG

Nicole Kerlero de Rosbo, PhD

Scientists with world-wide expertise in MG are carrying out research that should help explain the relative contribution of the environment and the genetics to the development of MG. Part of the research will involve the biological comparison between identical twins, with one or both twins affected with MG. If you and your identical twin are willing to participate in this project, please contact Nicole Kerlero de Rosbo, PhD at nicole.kerlero-de-rosbo@upsud.fr. MGFA and the M/SAB have agreed to support this research. At present, we want to establish a list of willing participants whom we can contact for further information and possible enrollment in the survey. Your personal details will be kept confidential. In the future, we hope to contact you for additional medical history and a 50 ml (3 and half tablespoons) blood sample. Myasthenia gravis is a rare disease and this research can only be carried out with your help and active participation. We thank you in advance for your interest in this important endeavor and we look forward to hearing from as many patients as possible.

Board Members Needed

The Oklahoma MG Chapter is seeking myasthenia gravis patients or their family members to serve as board members to help guide our organization. If you think strategically and creatively, and care about those with myasthenia gravis, call us at 1-918-494-4951. We meet about eight times year in the OKMGF Tulsa office on the fourth Thursday of the month at 5:00 pm.

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs, and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advise of a physician or health care professional who is directly familiar with the patient. The information contained in this publication reflects the views of the authors, but not necessarily those of the Myasthenia Gravis Foundation of America (MGFA) and the Oklahoma Chapter of the Myasthenia Gravis Foundation of America, Inc. Any reference to a particular product, source, or use does not constitute an endorsement. MGFA, its agents, employees, Directors, chapters, its Medical/Scientific Advisory Board, and its Nurses Advisory Board or their members make no warranty concerning the information contained herein, and assume no responsibility for any damage or liability resulting from the use of such information.
Ask the Doctor

- Robert Ruff, MD, PhD, Elena Luchanok, MD, Henry J. Kaminski, MD

**Are there special considerations MG patients should make in the summer?**

Dr. Ruff answers:

There are some precautions that folks with MG should take so that summertime heat does not lead to worsening of manifestations of MG. One of the features of MG is that raising body temperature can increase weakness. Therefore, it is essential for folks with MG to remain cool. Do not stay in the sun for prolonged periods of time. Sun block will protect you from sunburn, but not from overheating.

Another concern in the summer is dehydration. Some of the medications used to treat the symptoms of MG—specifically pyridostigmine (Mestinon®) and related drugs—enhance the risk of dehydration. Medical/Scientific Advisory Board member Dr. Henry Kaminski described some of the risks of dehydration (www.netwellness.org/question.cfm/24231.htm, or call the MGFA national office at 1-800-541-5454 for more information). It is important to maintain adequate intake of water to compensate for water loss caused by sweating and other causes.

A third concern is that the warm weather can entice people to become more active—which is good, provided that one is adequately conditioned. Stanley Way, a former member of the MGFA Board of Directors, provided a personal description of the importance of conditioning to prevent muscle strains (http://pages.prodigy.net/stanley.way/myasthenia/stanstor.htm). One key point is that it is important not to overdo it when the weather gets warm in the summer.

**Does MG affect a patient’s cognition and cause a mental fatigue?**

Drs. Luchanok and Kaminski answer:

Slightly more than one half of MG patients complain of memory loss that they believe is associated with their disease. Although there is no evidence that MG affects the central nervous system, several studies suggest that memory function is affected in people with MG. MG patients may have subtle difficulties with learning of new information, but it does not affect patients’ attention and retention of already learned information. Such problems, in our opinion, relate to coping with the symptoms of MG. It is important to note that the problems of MG patients are much different than those with dementia (such as Alzheimer’s Disease), who have difficulties remembering previously learned information. Many MG patients report experiencing feelings of mental fatigue in addition to the symptoms of physical fatigue, and there is a strong correlation between mental fatigue and cognitive problems in MG patients. The exact reasons for mental fatigue are likely related to coping with chronic disease and medication side effects.

**Does mental health affect MG or cause exacerbations?**

Drs. Luchanok and Kaminski answer:

MG patients often experience more severe symptoms during times of emotional distress or depressed mood, but there is no data that unequivocally indicates that psychological stress affects the onset or the severity of MG. Emotional stresses (like a death in the family, divorce, or other trauma) will make the quality of any human being’s life worse, and that can lead to the feeling, that a disease is affecting them more. It is important to appreciate that all humans suffer emotional traumas, but that does not necessarily mean that a disease is directly caused by them.

The Myasthenia Gravis Foundation of America, Inc.
DONATIONS – HONORARIUMS – MEMORIALS

The following are the names of those who have paid their Chapter memberships or have made contributions to the Chapter from February 20, 2012 — March 26, 2012.

In Memory of Kay Estes
John & Donna Gibson
Shannon & Gary Lorenz
Connie Brandon

In Honor of Dr. Kay Northcutt
Frances Oney

Donations & Dues
Eva & Paul Armer
Jamie Kaczmarek
Ananta Kirikera
Norma Thomas
Mark Swift
Gene Drake, DDS
Eugene Griswold
Harold Landrum
Barbara Chastain
Harvey & Rochelle Jantzen
Beulah Watkins
Tianna Rogers
Ray & Doris Vanscoy
Lyndl Jacquemot
Dorothy Mansfield

A great way to remember a family member’s or a friend’s birthday, graduation, anniversary, or memory is with a donation to the OKMGF. Our chapter will send an OKMGF Birthday, Honor or Memorial card to let them know that you care.

May no myasthenic ever feel alone in their disease.

Contact Information

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Office Staff: - Peggy Foust, Executive Director & Margret Feller

OKMGF Board Members
President - Peggy Foust, Vice President/Treasurer/Secretary—Margret Feller
DeAnna Cooper, Ed. D., Kay Northcutt, D. Min., Tianna Rogers, Carolyn Staubach, RN, & Rick Weigel

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Monday – Friday 8:00 a.m. – 5:00 p.m. mgfa@myasthenia.org
webpage: http://www.myasthenia.org
"The Disease Nobody Knows"

MYASTHENIA GRAVIS

It can strike anyone at any age. MG is a highly misdiagnosed autoimmune disease in which communication between nerve and muscle is impaired, causing weakness. Its primary symptoms are erratic. The most common symptoms, alone or in any combination are: droopy eye lid(s), weak arms, hand, neck, face or legs, difficult chewing, smiling, swallowing, talking, or breathing or shallow respiration, blurred or double vision, sense of balance difficulty or undue fatigue. MG can masquerade as over work, under-rest, anemia, vitamin deficiency, disease of the involved organ(s), or even emotional disturbances.

MG’s cause is unknown. There is no cure. As a result of research financed by the Myasthenia Gravis Foundation, diagnosis and treatment procedures have markedly improved. The MGFA, a charitable non-profit organization, was formed to serve patient needs, promote public awareness and provide for research. The Oklahoma Chapter of the Myasthenia Gravis Foundation of America, Inc. is the only organization in the state of Oklahoma that works exclusively for Myasthenics.