Oklahoma Chapter Myasthenia Gravis Patient Support Group Meetings Planned

- **April 7, 2013 – 2:00 pm** - **Oklahoma City Support Group** – program to be “Healthy Eating & MG.”

- **June 2, 2013 – 12:30 pm** - **Tulsa** — A Chapter Picnic in the Park will be held in Tulsa’s Lafortune Park, SE Shelter, 61st & Yale where we will celebrate “June as MG Awareness Month.” Hot dogs, hamburgers and beverages will be provided.

- **July 14, 2013 – 2:00 pm** - **Tulsa Support Group** - We will be showing the film “MG in Young People” with Nancy Kuntz, MD, Medical Director of the Mazza Foundation, Neuromuscular Disorders Program, Children’s Memorial Hospital, Chicago.

- **August 4, 2013 – 2:00 pm** - **Oklahoma City Support Group** – Pamela Forducey, Ph.D., ABPP Director of INTEGRIS Telehealth and Jim Thorpe Clinical Development will be our guest speaker.

- **September 15, 2013 – 2:00 pm** – **Tulsa Support Group** – program to be announced later.

- **November 3, 2013 – 2:00 pm** - **Oklahoma City Support Group** – Our guest speaker will be Dr. Eduardo DeSousa, neurologist, with University of Oklahoma Health Sciences Center; Director, Neuromuscular Disorders/ EMG Lab will be speaking to us “What is an MG Crisis and how is a crisis treated?” We will have a caring /sharing time following his talk.

No RSVP unless noted is necessary to attend the meetings.

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. We have changed our meeting location inside the hospital. We will now be meeting in a meeting room inside the food court located on the B Level of the hospital. You should park in the employee parking garage on the east side of the hospital, either walk across the drive or cross the skywalk, to enter the education center. Go to the B Level, then go right. The exit of the food court will be on your left, enter here. Meeting room is inside food court on your left. Please look for our MG chapter’s red arrow signs pointing the way to our meetings.

If there is not a support group in your area consider starting one. The Chapter office can help. Contact us at 918-494-4951 or at oklahoma@myasthenia.org.
Overall, the pregnancy risks are higher in women who have MG, but with careful monitoring, women with MG can successfully birth healthy children. It is imperative that women with MG who are considering getting pregnant discuss pregnancy with the care giver treating their MG. Below are some questions that women often ask in this situation.

**Will My Baby Inherit My MG?**

Most patients with MG have acquired autoimmune MG; the type of disease associated with antibodies to acetylcholine receptors (AChR-Abs) or to a protein called muscle specific kinase (MuSK). Women who have acquired autoimmune MG will not pass on MG to their children. Only women with congenital (manifesting at or soon after birth) forms of MG, which are rare and which manifest in infancy or childhood, risk passing MG to their children. Please talk to the physician who treats your MG about what type of MG you have.

**What Kind of Complications Can Occur during Delivery?**

Having stated that women who have acquired MG will not pass on their MG to their children, we need to discuss transient neonatal MG (TNMG). TNMG describes a condition in which the baby has transient weakness due to being exposed to AChR-Abs from the mother. A large study showed that TNMG occurred in about 4% of deliveries to women with MG (Jackson, 2003). Provided that TNMG is anticipated, it can be treated and the baby will not have any lasting problems. Due to the possibility of TNMG, pregnancies of women with MG should be considered as high risk pregnancies. They should be carefully monitored. Deliveries should be done in a hospital setting. The hospital should have staff who have experience with MG. Again, discuss the issues of following the pregnancy and the site of delivery with the physician who treats your MG. Other findings of the above mentioned study were that mothers with MG were more likely to deliver in a university hospital and more likely to have a cesarean delivery. Cesarean sections are likely more common in women with MG, due to concern that women with MG are more likely to fatigue during labor. It is important to note that in the findings of the study, there were no differences in the average birth weight, age at birth, frequency of birth defects or stillborn rate of the newborns of MG mothers compared to other births.

**What Effects Does MG Have On Delivery?**

The discussion of the study on pregnancy and MG (Jackson, 2003) indicated that the only complication of pregnancy that was higher in women with MG was premature rupture of the membranes holding the amniotic fluid. Women with MG were more likely to deliver via cesarean section, perhaps as a precautionary measure. While women with MG can successfully deliver babies vaginally, they are more likely to tire during a long labor, which may explain why cesarean sections are more common for women with MG.

**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, azathiaprine, 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]
When a medical emergency happens, it can be a scary and chaotic time. It is important to be prepared ahead of time so medical personnel can have the information they need to help you.

The medical emergency may be because your myasthenia gravis (MG) is not in control or because of another health reason. Either way, the paramedics and Emergency Department personnel need to know you have MG.

**What do the paramedics and Emergency Department doctors and nurses need to know?**

- Current symptoms – what is wrong right now
- Health history
- All of your pertinent health history
- List all of your medical conditions and how this medical condition affects you
- Make sure they know you have MG even if you are calling 911 for a reason not related to your MG.
- They may be unfamiliar with MG, so have some resource information ready for them.
- A current list of your medications (typed). Keep a copy at home, in your car and in your purse or wallet. If there is time, take your pill bottles with you in the ambulance.
- A list of your allergies and your response to that allergy
- Your family doctor’s name, phone number and clinic location
- Emergency contact names and phone numbers
- Your preferred hospital
- Your pharmacy

**Your Advanced Directive /Health Care Directive (Living Will)**

It is helpful to have this prepared and available at home BEFORE there is a medical emergency. It is hard to find things quickly when you or your family are sick, stressed or scared. Keep this information in a place where you can get it quickly. I have created a form for you to use so you have all this information in one place.

**MG Resources for Paramedics & EMS**

Let your local Emergency Medical Service (EMS) provider know about MG. If you call 911 for an ambulance from your home, which ambulance service responds? Find out and take them information on MG and let them know about your special needs. There are resources for the EMS/ED personnel on the MGFA website www.myasthenia.org. They can order the brochure Medications and Myasthenia Gravis: A Reference for Health Care Professionals. This brochure includes the full list of medications to avoid and the “MG: A Manual for the Health Care Provider” Chapter 5 is on Emergency Management of MG.
How to Describe MG

It is helpful to have a description of MG for the paramedics as they may not be familiar with this rare disease.

- Myasthenia Gravis (MG) is a chronic autoimmune neuromuscular disorder that is characterized by fluctuating weakness of the voluntary muscle groups.
- Refer them to more information available at www.myasthenia.org. They can look for the list of medications to avoid and the PDF of “MG: A Manual for the HealthCare Provider. Chapter 5 is on Emergency Management”.

Information about Crisis

Tell them what medications you take for your MG. Let them know:

- If I am in a crisis situation I may not be able to talk, swallow or breath well. I will be very weak.
- I may have excess saliva.

**There are 2 types of MG crisis**, but they look the same in an emergency situation. Support my airway and the Emergency Department doctor will determine which type of crisis I am.

1. **Myasthenic Crisis** - I may not have enough of my anticholinesterase medication and may need more. I may be very weak and have trouble breathing, coughing and swallowing.

2. **Cholinergic Crisis** – I have too much anticholinesterase medication in my system. I may be weak, have trouble breathing, be sweaty, have excess saliva, loose stools, a slow heartbeat, vomiting, and tiny pupils. Cholinergic crisis can be treated with antimuscarinic drugs like atropine.

Drugs to be Avoided in MG

Tell them to be careful what medications they give you. Increased weakness in a significant number of MG patients has been reported with the following drugs; use only with caution and monitor for exacerbation of MG symptoms:

- Neuromuscular blocking agents such as succinylcholine and vecuronium should only be used by an anesthesiologist familiar with MG
- Quinine, quinidine or procainamide
- Selected antibiotics, particularly aminoglycosides, telithromycin (Ketek) and ciprofloxacin (Note: Many other antibiotics have been reported to increase MG weakness in occasional patients.)
- Beta-blockers (propranolol, timolol maleate eye drops)
- Calcium channel blockers
- Iodinated contrast agents (a form of X-ray dye)
- Drugs to be Avoided in MG — This list is not all inclusive; they should consult with your primary physician or pharmacist.

Numerous additional medications are reported to increase weakness in occasional patients with MG.

- The MG patient and physician should be alert to this possibility whenever a new medication is prescribed.

Being Prepared for a Medical Emergency” was presented at the Minnesota State Chapter MGFA 40th Annual Meeting on September 30, 2012.
Information to Give Emergency Providers

Emergency Information for ______________________________
DOB __________

Medications: list all prescription and over the counter medications

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Dose</th>
<th>Reason for Taking</th>
<th>Comments</th>
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Allergies:

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<th>Allergy</th>
<th>What Happens?</th>
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Primary Physician
Name: ________________
Clinic Location: ____________________________
Phone Number: ________________
Preferred Hospital: ____________________________
Pharmacy: ____________________________
Insurance: ____________________________

Advanced Directive: I have an Advanced Directive on file at ____________________________

Emergency Contact Numbers:
Name: ________________
Relationship: ________________
Home) (____ ______
Cell) (____ ______
Work) (____ ______

Name: ________________
Relationship: ________________
Home) (____ ______
Cell) (____ ______
Work) (____ ______

I have the following medical conditions:

Myasthenia Gravis (MG)
MG is a chronic autoimmune neuromuscular disorder that is characterized by fluctuating weakness of the voluntary muscle groups.


Increased weakness in a significant number of MG patients has been reported with the following drugs; use only with caution and monitor for exacerbation of MG symptoms:
- Neuromuscular blocking agents such as succinylcholine and vecuronium
- Selected antibiotics, particularly aminoglycosides, telithromycin (Ketek) and ciprofloxacin
- Beta-blockers
- Calcium channel blockers
- Iodinated contrast agents (X-ray dye)

I take ___ medications for my MG
If I am in a crisis situation I may not be able to talk, swallow or breathe well. I will be very weak. I may have excess saliva.

There are 2 types of MG crisis, but they look the same in an emergency situation. Support my airway and the Emergency Department doctor will determine which type of crisis I am. They may give me an Edrophonium Chloride (Tension®) Test.

Myasthenic Crisis - I may not have enough of my anticholinesterase medication and may need more. I may be very weak and have trouble breathing, coughing and swallowing.

Cholinergic Crisis – I have too much anticholinesterase medication in my system. I may be weak, have trouble breathing, be sweaty, have excess saliva, loose stools, a slow heartbeat, vomiting, and tiny pupils. Cholinergic crisis can be treated with antimuscarinic drugs like atropine.
The following are the names of those who have paid their Chapter memberships or have made contributions to the Chapter from January 11 — March 12, 2013.

**In Memory of Robert Brown**  
John & Janis Higgins

**In Honor of Dr. Kay Northcutt**  
Frances E. Oney

**Donations & Dues**  
Harold & Norma Spradlin  
Richard Hill  
Ray & Doris Vanscoy  
Charles Welch  
Barbara Chastain  
Eugene Griswold  
Roger Driggers  
Liana Deason  
Katye & Micheal Carr  
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Dana Johnson  
Michael V. Parks  
Jaimie Kaczmarek  
Janice Corrigan  
Norma Thomas  
Gary Bryan  
Jim & Deborah Rainey  
Gary Beck

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**

*Hovak* is published quarterly by the [Myasthenia Gravis Foundation of America, Inc.](http://myasthenia.org/LivingwithMG/MGFAChapters/Oklahoma.aspx), 4606 E 67th St S, Suite 100, Tulsa, OK 74136, Editor: Peggy Foust

Tele #: 918-494-4951, fax: 918-494-4951  
email: oklahoma@myasthenia.org  
webpage: [http://myasthenia.org/LivingwithMG/MGFAChapters/Oklahoma.aspx](http://myasthenia.org/LivingwithMG/MGFAChapters/Oklahoma.aspx)

The OKMGF Chapter office is open: Monday & Friday - 11:00 a.m. - 4:00 p.m., Wednesday 9:00 a.m. - 4:00 p.m.  
Office Staff: Peggy Foust, Executive Director & Margret Feller

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355 Lexington Ave, 15th Floor, NY, NY 10017-6603  
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Monday – Friday 8:00 a.m. – 5:00 p.m.  
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you do not wish to receive HOVAK, fill out the following and mark to be removed from our list.

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Uniting for a Cure —Together we are Stronger