Oklahoma Chapter Myasthenia Gravis
Patient Support Meetings for 2013

Winter time meeting note: if on the morning of the patient support meeting there are icy roads or dangerous driving conditions existing the patient support group meeting scheduled will be cancelled.

- **February 10, 2013 – 2:00 pm – Oklahoma City Support Group** – Tami Brown OTR/L and Anita Miller COTA, will be presenting their program “Home Sweet Home: Equipment Options to Promote Comfort and Quality of Life.” Anita currently works at Samaritan Home Care services and serves on the Board for the Occupational Therapy Assistant Program at Oklahoma City Community College. Tami is currently a member of the Spinal Cord Team at Integris Jim Thorpe Rehabilitation hospital.

- **March 10, 2013 – 2:00 pm – Tulsa – Annual Meeting of the Oklahoma Chapter.** Our guest speaker will be Jackie Abels, MA, RD, LD, who is a Renal Dietitian with Saint Francis Hospital. She will be discussing “MG & the foods you eat and chewing & swallowing difficulty concerns with MG.”

- **April 7, 2013 – 2:00 pm – Oklahoma City Support Group** – program to be announced later.

- **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** – program to be announced later.

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., 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.
Chapter Web Page Information

Have you checked out our chapter web page at http://www.myasthenia.org/chapters/Oklahoma/?
We have the last three years of newsletters available on it and we always have our patient support group meetings listed. Now if you lose your newsletter or cannot remember when the next patient support group meeting is you can fast find the information by checking our web pages. We have pictures of our Oklahoma City and Tulsa patient support picnics, as well as support group meeting pictures. The chapter’s web page has our yearly Chapter Annual Meeting Report as well as a listing of the chapter services we offer.

The chapter office can now take your donations, dues and memorials over the phone when you are using a major bank credit card such as Visa, Discover or a bank debit card. Just give us a call at the OKMGF office 918-494-4951 to make your donation.

Save this Date

The Myasthenia Gravis Foundation of America, Inc.’s National Conference will be on May 8-10, 2013 at the InterContinental at Miami Doral in Miami, Florida. More information will be available later on line at http://myasthenia.org/

MG Medication Discontinuation

The MGFA and the MSAB wish to inform MGFA members and others in the MG community that ambenonium chloride (Mytelase) will no longer be produced. This is an older acetylcholinesterase inhibitor and is rarely used in clinical practice. Pyridostigmine (Mestinon) has been the mainstay of anticholinesterase therapy for many years in myasthenia gravis. If you have been taking ambenonium, please contact your treating physician for available alternatives. Please visit www.myasthenia.org for further details.

Gil Wolfe, MD, FAAN
Chair, MGFA M/SAB MGFA

Tor Holtan, CEO

Are you planning on moving? If so please let the MG Chapter office know your new address. It costs the chapter over $1.00 to have a newsletter returned and then to send a new one to your new address. Help us continue to serve you efficiently and help us save money!
MG Triggers

Many things can affect one’s myasthenia gravis. Sometimes your MG may get worse for no apparent reason. Many MGer’s can tolerate some of the things on this list without any MG upsets, while others can not. Be aware that some of these items may intensify your MG symptoms.

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<thead>
<tr>
<th>Stress (good and bad)</th>
<th>Hot tubs</th>
<th>Illness</th>
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<tr>
<td>Anxiety (good and bad)</td>
<td>Colds</td>
<td>Thrills (roller coaster)</td>
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<td>Hot weather</td>
<td>Infections</td>
<td>Lack of sleep</td>
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<td>Cold weather</td>
<td>Diarrhea</td>
<td>Surgery</td>
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<td>Humidity</td>
<td>Depression</td>
<td>Sedatives</td>
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<td>Certain Medications</td>
<td>Low potassium level</td>
<td>Botulinum Toxin (Botox)</td>
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<td>Intense negative situations</td>
<td>Low thyroid level</td>
<td>Magnesium</td>
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<td>(news of a death, traumatic event, car accident)</td>
<td>Hunger</td>
<td>Calcium Channel Blockers</td>
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<td>Fever</td>
<td>Quinine</td>
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<td>Illness</td>
<td>Alcoholic beverages</td>
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<td>Smoking (second-hand smoke)</td>
<td>Fumes</td>
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<td>Saunas</td>
<td>Insecticides</td>
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<td>Sudden fear</td>
<td>Anger</td>
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<td>Pet flea sprays</td>
<td>Aerosols</td>
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<td>Household cleaners</td>
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Study of MG patients with autoantibodies to muscle-specific tyrosine kinase (MuSK)

In a recent paper, Jeffrey T. Guptill MD and Donald B. Sanders MD reviewed data on 110 MuSK-MG patients from two clinics, in Italy and the USA, that follow a large number of these patients.


Myasthenia gravis (MG) patients with autoantibodies to muscle-specific tyrosine kinase (MuSK) have a clinically distinct subset of the disease. In part because the disease is rare, information on the treatment and outcomes in MuSK-MG patients has been limited and conflicting. In a recent paper, Guptill et al. reviewed data on 110 MuSK-MG patients from two clinics, in Italy and the USA, that follow a large number of these patients. Interestingly, the clinical features, response to treatment, and patient outcomes were remarkably similar between the two study sites. Eighty-five percent of patients with MuSK-MG were female and the first symptoms typically occurred between ages 30 and 40. Ocular (drooping eyelids or double vision) and/or bulbar symptoms (such as difficulty swallowing, talking, chewing) were present in most patients early in the disease. Shortly after the onset of symptoms most patients had moderate or severe disease and they often rapidly deteriorated. MG crisis, resulting in the temporary use of a ventilator, occurred in 28% of the patients. More patients responded to plasma exchange than intravenous immunoglobulin (IVIg) during exacerbations. Long-term outcomes were comparable to those of patients with AChR-Ab–positive MG, although MuSK-MG patients often required chronic use of two or more immunosuppressive medications, such as prednisone and azathioprine, to control the disease. The few patients who received rituximab responded very well. The available data was insufficient to determine if thymectomy was beneficial for patients with MuSK-MG.

Myasthenia Gravis Foundation of America, Inc., www.myasthenia.org
NEVER GIVE UP

by Annaben Kazemi

Have you ever wondered why some people seem to remain calm in the face of disaster, while others seem to fall apart? People who are able to keep their cool have what psychologists call resilience, or an ability to cope with problems and setbacks.

At some point, everyone experiences varying degrees of setbacks. Some of life’s challenges might be relatively minor, while others are on a much larger scale. Resilience does not eliminate stress or erase life's trials. However, resilient people are able to utilize their skills and strengths to cope with difficulties and face the challenges that life brings. This quality of resilience is especially vital in patients who are coping with chronic illness.

When resiliency is missing, patients may instead become overwhelmed by their diagnosis. They may dwell on the negative and use unhealthy coping mechanisms to deal with the challenges of having a complex chronic illness. Dealing with change (going from an active lifestyle to one that has more limitations) or loss (grieving the existence one used to have before being diagnosed) is an inevitable part of having a chronic illness. But resiliency gives patients the strength to tackle problems associated with their illness, overcome setbacks and move on with their lives.

I am constantly amazed and awed by the stories patients share about thriving in spite of their illness. Their inspirational stories have caused me to notice some common characteristics. These particular patients tend to:

- Have a "where there's a will, there's a way" attitude
- See problems as opportunities
- "Hang tough" when things are difficult
- See small windows of opportunity and making the most of them
- Have deep-rooted faith in a system of meaning
- Have a healthy social support network
- Have a wide comfort zone and are open to trying new approaches

Patients who are resilient draw on strengths in themselves, their relationships and their communities to overcome difficulties brought on by their diagnosis. Resilient patients often find meaning even in times of trouble and gain confidence from overcoming adversity. In this way, resilience can contribute to a deeply satisfying life despite all the changes a chronic illness can bring.

So how can chronically ill patients become more resilient? Surprisingly, resilient behavior is not simply an inborn trait found in a few individuals. As a matter of fact, many experts believe resilience is actually quite common, and people are very capable of learning resilience skills. Resilience may take time to build, so patients should not become discouraged if they still struggle to cope with their disease. Instead, they can start with the five suggestions below.

1. **Find a sense of purpose in life:** After Vicky Modell’s son, Jeffrey, died at the age of 15 from complications of primary immunodeficiency, she founded the Jeffrey Modell Foundation, a global nonprofit organization dedicated to early diagnosis, research and ultimately finding a cure.
2. **Develop a strong social network:** Having caring, supportive people around acts as a protective factor. Connect online through IG Living’s Facebook page, teen group or join a blog dialog.
3. **Embrace change:** Flexibility is an essential part of resilience. By learning what alternatives are available, patients will be better equipped to adapt and respond to the challenges of illness.
4. **Be optimistic:** Staying optimistic during dark periods can be difficult, but maintaining a hopeful outlook is an important part of resiliency. What patients are dealing with may be difficult, but it is important to remain hopeful and positive about the future.
5. **Nurture Oneself:** Patients need to be good to themselves. Losing appetite, ignoring exercise and not getting enough sleep are all common reactions to a crisis situation. It’s important to make time for activities that are enjoyed. By taking care of their own needs, patients can boost their overall health and resilience.

Resilience doesn’t develop overnight, but life’s difficulties can be faced with courage and patience. Refuse to give up! At IG Living, we believe in you.

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2013 Students of Parents with Disabilities Scholarships Available

In January 2013, scholarships will be available for application for those whose mother or father has a disability. Each scholarship award is $1,000 to an outstanding high school senior or college student who has at least one parent with a disability. Selection criteria includes academic performance, community service, letters of recommendation and an essay describing the experience of growing up with a parent with a disability. For scholarship applications go to Through the Looking Glass’ website at www.lookingglass.org.

NEW GUIDELINES FOR SOCIAL SECURITY DISABILITY APPLY TO THOSE LIVING WITH MG

Those living with MG and considering filing for disability benefits should acquaint themselves with the Social Security Administration’s listing of disabling impairments, Disability Evaluation Under Social Security, also known as the “Blue Book” (http://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm). Here you will see two of the criteria that the SSA uses to consider disability: “A. Significant difficulty with speaking, swallowing or breathing while on prescribed therapy; or, B. Significant motor weakness of muscles of extremities on repetitive activity against resistance while on prescribed therapy”. The Blue Book also states that “In conditions which are episodic in character, such as multiple sclerosis or myasthenia gravis, consideration should be given to frequency and duration of exacerbations, length of remissions and permanent residuals”.

It is highly recommended that those filing for disability make sure that their medical file thoroughly describes how their disabling condition limits their ability to use their arms, legs or bodily functions. This will be the SSA’s primary source for information about the patient’s condition in making their determination. So it is essential that this information is conveyed to doctors during appointments and that it gets into the patient’s medical record. No one likes to focus on the activities of daily living that you can’t perform or that require assistance, but when you’re in the doctor’s office, you need to be specific and thorough. You never know when identifiable information will be valuable.

It is also recommended to have a Social Security disability lawyer assist in putting a disability claim together to eliminate errors and omissions, to wade through the technical nature of the requirements and to suggest strategies that can help attain benefits.
MG Chapter Dues for 2013 are now due.

Yes, we are a non-profit organization, but there are many reasons why you should pay your chapter dues. The Oklahoma Myasthenia Gravis Chapter has operating expenses just as most businesses do. We do not receive any government assistance. We have to pay for the chapter office’s telephone, internet service, printings, mailings and salaries. Please support our chapter and help us to continue to offer our services to other myasthenics, families and health care professionals.

Myasthenia Gravis and Vaccinations
Madeleine Batenjany, MSN, RN, ANP-C

Individuals with MG are at risk for the complications of infections or disease but MG itself is not a reason to avoid vaccination. It is important to protect against certain viruses or invading germs which can cause an exacerbation of MG. An individual may also be at risk for complications of infections due to other health problems in addition to their MG.

Vaccines help an individual reduce their chance of getting an infectious disease. Some examples include flu, pneumonia, tetanus, hepatitis A or B, etc…

Always discuss your vaccination needs with your physician. There can be some restrictions to having certain vaccines or the timing of administration due to an individual’s allergies, or use of immunosuppressive and immunomodulatory drugs such as Prednisone, Imuran (azothiaprine), Cellcept (mycophenolate mofetil), Cyclosporine, and IVIG.

The purpose of vaccination is to provide immunity against a specific organism(s) which can cause a particular disease or in the case of influenza reduce the risk for the suspected disease causing strains of flu for the season. We are born with an immune system to help fight infection and diseases by invading bacteria and viruses. The body considers these as foreign antigens and makes antibodies to fight them and help protect us from the disease they can cause. When an individual is immunosuppressed or compromised, they are at greater risk for infections and disease.

How Vaccines Work?

Vaccines contain antigens or parts of antigens which cause diseases. The antigens in vaccines are either killed or made very weak. They are usually given by injection and are strong enough for the body’s immune system to make antibodies against them. The cells involved in making antibodies become “memory cells” and can remain for a long time or may require a booster vaccine to help them produce more antibodies to prevent re-infection of a specific disease.

Vaccines can be described as:
1. Live attenuated vaccines: The disease causing organism is weakened so it will not cause a full blown disease. This is given to healthy individuals who can build antibodies against the organism in order to avoid getting the disease. MG patients should not receive this type of vaccine.
2. Inactivated vaccines: The disease causing organism is killed, and the body makes antibodies against it.
3. Extracts of or detoxified toxins: A toxin which can cause the disease is inactivated before it is given to the patient. An example is the tetanus vaccine. Individuals with MG may receive an inactivated vaccine, but not a live attenuated vaccine. It is recommended to receive a yearly flu vaccine. The pneumonia and tetanus vaccines are also recommended when appropriate. Always check with your physician before receiving any vaccinations and report any previous allergies to vaccines.

For more information about vaccinations refer to the following websites: http://www.cdc.gov/vaccines/vac-gen/howwpd.htm
http://www.myasthenia.org

References: cdc.gov/vaccines/vpd-vac/should-not-vacc.htm
DONATIONS – HONORARIIUMS – MEMORIALS

The following are the names of those who have paid their Chapter memberships or have made contributions to the Chapter from October 26—December 31, 2012.

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<th>In Memory of Melba Christine Weichbrodt</th>
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<td>Loree &amp; Sevier White</td>
<td>Gordon &amp; Sue Kay</td>
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<td>Nathan &amp; Jennifer Veal</td>
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<td>Julie Kay Hughes</td>
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<th>In Honor of Kay Northcutt &amp; Debby Clemons</th>
<th>Donations &amp; Dues</th>
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<td>Stephen &amp; Elsie Lake</td>
<td>Leon Seaton</td>
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<td>Robert &amp; Shelia Brown</td>
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<td>Hank &amp; Joan Bowen</td>
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<td>Joe Gibbon</td>
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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.

May no myasthenic ever feel alone in their disease.

Contact Information

_Hovak_ is published quarterly by the Oklahoma Chapter of the Myasthenia Gravis Foundation of America, Inc., 4606 E 67th St S, Suite 100, Tulsa, OK 74136, Editor: Peggy Foust

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webpage: http://www.myasthenia.org/chapters/Oklahoma/

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.

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OKMGF Board Members
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Vice President/Secretary- Margret Feller
DeAnna Cooper, Ed. D., Kay Northcutt, D. Min., Emerson Pollard, 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
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