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From the President

Change. No one likes it, but we all have to deal with it. It affects our personal lives, our professional lives, our health, our community, and our world. People move in and out of our lives, whether they physically move and we lose touch, or they (or we) change and we grow apart. It's also something patients with MG and their friends and loved ones have to deal with. For me, being diagnosed with MG at 29 years old has certainly changed the course of my life, my goals, and my hopes. I'm certainly not happy about that – but, it has also expanded my world and introduced me to some amazing people, and for that I am incredibly grateful. What about you – how has your life been changed and expanded?

~Jennifer

HAVE YOU SEEN OUR NEW WEBSITE??

Special thanks to Michael Schwarz for all of his hard work revising our Chapter website! He has done a fantastic job adding new content and keeping it updated (and ever-so-patiently answering all of my questions and special requests!)

Check it out!

www.mggeorgia.org

Officers
Jennifer Faucett, President
Alexis Rodriguez, Vice President
Reba Herzfeld, Treasurer
Kathryn Rodriguez, Secretary
In the Spotlight!

Reba Herzfeld
Treasurer of the Georgia Chapter

Just a little about me... I’m old enough to be Jennifer, Alexis, and Kathryn’s mother, but who cares about age! I was diagnosed with Ocular Myasthenia Gravis, or “OMG,” about 7 or 8 years ago after having “heavy eyelids” for a few years. After 6 doctors and 4 ½ years of trying, I finally was referred to a specialist who confirmed OMG. I had lid lift surgery but still have many problems with my right lid being heavy and droopy when I am tired. Further surgery is not an option – if I had it, then I wouldn’t be able to close my eyes!

I’m married to Bennett and have two daughters, a step-daughter, and a step-son. Between us, we have five grandchildren and several grand dogs (though Bennett doesn’t claim the dogs). We love to travel, especially cruising. I’ve done volunteer work most of my adult life, being President, secretary, and treasurer of a Hadassah chapter over the years (thought not all at once!). I was also treasurer of our Synagogue Sisterhood for three years and the Atlanta Orchid Society for six years. In my earlier adulthood, I was president of the Bankhead Shrine Auxiliary.

When called upon, I work at Dressler’s Jewish Funeral Home, and drive the Hearse occasionally.

My hobbies are reading, knitting, sewing, collecting cookbooks, cooking, and traveling with my husband.

If you would like to be “In the Spotlight!” send your story in your own words to info@mggeorgia.org

Support Groups

Support group meetings are open to everyone – patients, friends, caregivers – and provide opportunities for support, information, and sharing.

Atlanta-Area Support Group

When: 1st Monday of each month (except for July and September)
6:30 p.m. – 8:00 p.m.

Where: Chamblee First United Methodist Church
4147 Chamblee-Dunwoody Road
Atlanta, GA 30341

We meet in the Fellowship Hall, which is located at the back of the church. Park in the back parking lot, enter through the back door, and follow the signs to the Fellowship Hall.

Additional Support Groups

Are you interested in leading or co-leading a monthly or quarterly support group meeting?

We are looking for individuals to lead support groups in other parts of the state. If you are interested, please call (770-427-3441) or email (info@mggeorgia.org) for more information. Training and leadership support is available!

Also, please let us know if you are interested in attending a support group in your area.
Chapter Meeting – November 3, 2012

Join us for a special Chapter meeting on Saturday, November 3, with Dr. Henry Kaminski, Dr. Gary Cutter, and Dr. Charlene Hafer-Macko

Where: Chamblee First United Methodist Church
        4147 Chamblee-Dunwoody Road
        Atlanta, GA 30341

When:
        11:15 a.m.  Registration
        11:45 a.m.  Lunch
        12:30 p.m.  Speakers
        3:00 pm  Meeting concludes

Registration is $15 for the first registrant, $10 for each additional registrant over age 12. Children age 12 and under are free. The registration fee includes lunch and childcare. To register, go to www.mggeorgia.org/meetings-and-events/ or mail in the registration form below.

About Our Speakers

Dr. Henry Kaminski is the Chair of the Neurology Department at George Washington University and the past Chair of the Medical / Scientific Advisory Board of the Myasthenia Gravis Foundation of America. Dr. Kaminski is involved with research into biomarkers in MG, the effectiveness of thymectomies, and the role of complement in Myasthenia Gravis.

Dr. Gary Cutter is a Professor of Biostatistics at the University of Alabama – Birmingham, and is involved in the design of clinical trials for cancer, MS, and MG. He is involved in the thymectomy trial and the development of a Myasthenia Gravis patient registry.

Dr. Charlene Hafer-Macko is an Assistant Professor of Neurology at the University of Maryland and a member of both the Medical / Scientific Advisory Board of the Myasthenia Gravis Foundation of America and the National Board of Directors of the MGFA. Dr. Hafer-Macko is currently researching the effect of exercise in MG.

November Meeting Registration

Name: ________________________________  Total # Registrants: ____________
Address: ________________________________  Registration fee Enclosed: $__________
                      ________________________________  Phone: ______________
Name(s) of Additional Registrants: ________________________________
Email Address: ________________________________

Do you need hotel information? ____________  Do you need childcare? ____________

For those interested, we will help coordinate a group dinner on Friday and/or Saturday night (note that these dinners are not part of the conference, though).

Are you interested in dinner Friday night? ____________  Saturday night? ____________

Please make checks payable to Georgia Chapter – MGFA and mail it and this form to Georgia Chapter – MGFA, P.O. Box 889085, Atlanta, GA 30356
Tips & Tricks for Energy Management

Conserving our energy during the day can be very important. Here are some tips and tricks from other patients to help conserve energy on daily routines:

- Use an electric toothbrush
- Put clean dishes that you use frequently on the table instead of an overhead cupboard
- Keep things you use often at arm’s level so you don’t have to reach up for them
- Use a Crock Pot for cooking dinner. You can make it in the morning and have a great dinner in the evening.
- If you live in a two-story house, put the things you may need through the day into a backpack that you can bring downstairs. This cuts down on the number of times you have to go upstairs for something.
- Use an eye patch to help reduce double vision. Alternate which eye you cover.
- Consider using a clothes steamer instead of an iron and ironing board.

**Recommendations obtained from members of the DailyStrength Myasthenia Gravis web forum. http://www.dailystrength.org/c/Myasthenia-Gravis/support-group

Things That Can Worsen MG

A variety of factors can affect one’s myasthenia gravis. Unfortunately, many of these factors are beyond our control. However, being aware that these can make MG worse can help you in managing your MG. Keep in mind, too, that not all people will be affected by the following factors.

<table>
<thead>
<tr>
<th>Stress &amp; Anxiety</th>
<th>Lack of Sleep</th>
<th>Alcohol</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quinine / Tonic Water</td>
<td>Illness</td>
<td>Depression</td>
</tr>
<tr>
<td>Low potassium levels</td>
<td>Heat</td>
<td>Surgery</td>
</tr>
<tr>
<td>Humidity</td>
<td>Overexertion</td>
<td>Repetitive Use of a Muscle</td>
</tr>
</tbody>
</table>

In addition, some medications can make MG worse:

- Certain Antibiotics (neomycin, Levaquin, ciprofloxacin, Telithromycin, azithromycin, etc.)
- Beta Blockers (atenolol, timolol, propranolol, etc.)
- Calcium Channel Blockers
- Magnesium
- Botulinum Toxin (Botox)
- Sedatives

NOTE: This is a small, limited list of potentially dangerous drugs for patients with MG. Also, not everyone will be affected by these medications. Always consult your doctor before adding any new medications (including vitamins and alternative treatments).
Research Round Up

• $240,000, 3-year Fellowship Awarded: In April, Qin Li Jiang, MD, a researcher at the University of Illinois-Chicago, received a $240,000 grant for her research into the causes of Myasthenia Gravis. The grant will be paid over three years and will support Dr. Jiang’s research on the role of regulatory T-lymphocyte cells in autoimmune diseases, including Myasthenia Gravis. The grant is a joint award from the Myasthenia Gravis Foundation of America, Inc. and the American Brain Foundation (formerly the American Academy of Neurology Foundation) to support and encourage clinicians in their research into Myasthenia Gravis.

• Thymectomy Trial: A “thymectomy” is surgery to remove one’s thymus gland. Thymectomies have been used world-wide to treat patients with MG who do not have a thymoma. (A thymoma is a tumor on the thymus.) However, conclusive scientific evidence of the effectiveness of thymectomies is lacking. Because of this question’s importance, a clinical trial to assess the effectiveness of thymectomy is currently underway and still recruiting patients to be involved. If you are interested in the trial, you can find more information at: https://mgtx.soph.uab.edu/MGTX/about.htm

• Can we “see” the damaged acetylcholine receptors? At its 2012 Annual Meeting, the MGFA awarded a research grant to Hans Katzberg for his proposal to study PET radiolabeling in patients with Myasthenia Gravis. PET radiolabeling is used in cancer patients to “see” the cancer cells or tumors. Katzberg proposes to use this technology to attempt to “see” the damaged acetylcholine receptors that cause Myasthenia Gravis. This is one study where we hope to “see” some exciting results!! (yeah, I know – that’s a really bad pun. But I couldn’t help it). 😊

• CK-2017357: Cytokinetics, Inc. is studying the effect of CK-2017357 (also known as “Tirasemtiv”) in patients with Myasthenia Gravis. According to Cytokinetics’s website, Tirasemtiv is a “fast skeletal muscle troponin activator” that increases the muscle’s sensitivity to calcium (which is needed for muscle contractions) (http://www.cytokinetics.com/ck2017357). This results in stronger muscle contractions and slower fatigability. This trial is currently recruiting patients. For additional information, visit: http://clinicaltrials.gov/ct2/show/NCT01268280?term=myasthenia+gravis&rank=19.

• Granulocyte-macrophage colony stimulating factor (“GMC-SF”): Last March, Dr. Matthew Meriggioli at the University of Illinois–Chicago received a grant of $530,480 from the MDA for a three-year study to see if GMC-SF can rebalance the immune system. Based on research in the lab, it appears that GMC-SF triggers regulatory immune cells that moderate the immune system attack that causes Myasthenia Gravis.

DISCLAIMER: Please note that any medical or personal views expressed in this newsletter are those of the individual author(s) and do not reflect any official position of the Myasthenia Gravis Foundation of America, Inc. or the Georgia Chapter of the MGFA. The information presented in this newsletter is intended to provide the reader with general information to be used solely for educational purposes and is not intended as medical advice. Each patient’s situation is unique, and treatment, diagnosis and other decisions should be determined in consultation with the patient’s doctor(s). If you have any medical questions, please discuss them with your doctor, as he or she best knows your situation.
# HONORARİUMS AND MEMORIALS

The Georgia Chapter would like to recognize donations made in honor of or in memory of the following individuals:

<table>
<thead>
<tr>
<th>In Honor of:</th>
<th>By:</th>
</tr>
</thead>
<tbody>
<tr>
<td>My daughters, Beth and Leigh</td>
<td>Regina Burrell</td>
</tr>
<tr>
<td>Dianne George</td>
<td>Betty Hoffman</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>In Memory of:</th>
<th>By:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara Shaw, wife of Jamison Shaw</td>
<td>Dianne Altobelli</td>
</tr>
<tr>
<td>and mother of Candy Shaw Codner</td>
<td></td>
</tr>
<tr>
<td>Essie Anthony</td>
<td>Ginger Hines and</td>
</tr>
<tr>
<td></td>
<td>Juanita Buren</td>
</tr>
<tr>
<td>Jason Hoffman</td>
<td>Betty Hoffman</td>
</tr>
<tr>
<td>Alphonso Jackson</td>
<td>Anthony Jackson</td>
</tr>
<tr>
<td>Mr. Newsome, father of Mollie</td>
<td>Bonnie Preston</td>
</tr>
<tr>
<td>Sudhoff</td>
<td>Claudia Roberson</td>
</tr>
<tr>
<td>Jerry Roberson</td>
<td>Ernette Schultz</td>
</tr>
<tr>
<td>Mr. Elbert M. Newsome</td>
<td></td>
</tr>
<tr>
<td>Sara Shaw, wife of Jamison Shaw</td>
<td>Cheryl Stanley</td>
</tr>
<tr>
<td>and mother of Candy Shaw Codner</td>
<td></td>
</tr>
<tr>
<td>Mr. Elbert M. Newsome</td>
<td>Charles Sudhoff</td>
</tr>
<tr>
<td>Mr. Elbert M. Newsome</td>
<td>Mollie Sudhoff</td>
</tr>
<tr>
<td>Jean Eberhardt, mother of Cai</td>
<td>William Truncali</td>
</tr>
<tr>
<td>Eberhardt</td>
<td></td>
</tr>
<tr>
<td>Mr. Charles Briggs, Jr.</td>
<td>Shugart Enterprises, Inc.</td>
</tr>
</tbody>
</table>

You can make a donation in honor of or in memory of someone by sending your check payable to “Georgia Chapter – MGFA” and a note stating whom the donation is in honor of or in memory of to the Georgia Chapter – MGFA, P.O. Box 889085, Atlanta, GA 30356
MEMBERSHIP FORM

Please Print and Return to Georgia Chapter – MGFA, P.O. Box 889085, Atlanta, GA 30356

Name: ____________________________ I have MG _____ Yes _____ No
Name: ____________________________ I have MG _____ Yes _____ No
Address: __________________________ Phone (H): __________________________
______________________________ Phone (W): __________________________

Email Address: __________________________

Please send me information via email _____ Yes _____ No

I want to support MGFA by joining (or renewing) my membership or making a contribution:
☐ $10 Individual Membership ☐ $20 Family Membership ☐ $________ Additional Donation
☐ My additional donation is (__) in honor or (__) in memory of __________________________

Please send an acknowledgement to: __________________________

*If you would like to pay by credit card or PayPal Account, just go online to www.mggeorgia.org and click on the yellow “Donate” button**

CHAPTER DIRECTORY

Some individual have expressed interest in a membership directory so our members can connect with each other. Participation in the directory is voluntary and the directory will not be shared outside of the MGFA.

☐ Yes! Please include my (__) name, (__) address, (__) email address, and (__) phone in the Georgia Chapter Membership directory.

☐ No, please do not include my contact information in the Georgia Chapter Membership directory.

MEMBERSHIP SURVEY

The Georgia Chapter of the MGFA exists to serve you. To do this effectively, we need to know what you want! Please complete this short survey to give us a better idea of how we can serve you.

I am interested in participating in the following:

☐ In-person Support Groups ☐ Online Support Groups ☐ Pen Pal program

☐ Hearing presentations by Medical Professionals about Myasthenia Gravis

☐ Other(s): __________________________________________________________

I am interested in volunteering to help the Georgia Chapter by:

☐ Answering emails or phone calls ☐ Representing the Chapter at Community Health Fairs

☐ Writing articles for the Chapter Newsletter ☐ Participating in Other Awareness Programs

☐ Other(s): __________________________________________________________

Other Suggestions: __________________________________________________________
The Mission of the Myasthenia Gravis Foundation of America, Inc.

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.