MYASTHENIA GRAVIS FOUNDATION OF AMERICA, INC.

Foundation Focus

News about myasthenia gravis for patients, family and friends

Spring 2013

Join a 2013 MG Walk!

Anywhere, USA	Virtual MG Walk
Tallahassee, FL	2013 Tallahassee MG Walk 3/2/2013
Atlanta ,GA	2013 Georgia MG Walk 3/2/2013
Orlando, FL	2013 Orlando MG Walk 3/2/2013
Tampa Bay, FL	2013 Tampa Bay Area MG Walk 3/3/2013
Jacksonville, FL	2013 Jacksonville MG Walk 3/3/2013
Palm Beach ,FL	2013 Palm Beach MG Walk 3/3/2013
Las Vegas, NV	2013 Las Vegas MG Walk 3/9/2013
New Orleans, LA	2013 New Orleans MG Walk 4/6/2013
Boston, MA	2013 New England MG Walk 5/4/2013
Miami, FL	2013 Miami MG Walk 5/10/2013
Milwaukee, WI	2013 Wisconsin MG Walk 5/18/2013
New York, NY	2013 TriState MG Walk 6/1/2013
Naperville, IL	2013 Illinois MG Walk 9/29/2013

MG walk

For a World Without Myasthenia Gravis

MGFA, 355 Lexington Avenue, 15th Floor, New York, NY 10017-6603 | (800) 541-5454 | (212) 370-9047 fax | mgfa@myasthenia.org | www.myasthenia.org

Message from Chairman Sam Schulhof

Dear Friends,

2013 promises to be another year of growth for MGFA, as it continues to explore opportunities and implement new programs in research, education and awareness. We will continue to look at organizational and structural optimization to ensure that MGFA is sustainable and able to deliver on its mission, and ultimately, its vision of "A World Without MG".

Looking back at 2012, MGFA established a presence on Facebook and began to look at how we might use other social media to communicate more effectively and provide useful and timely information and tools to enable greater awareness, peer to peer sharing and enhanced communication between patients and the medical professional. In late December we unveiled "myMG," an application for smart phones that provides the patient the capability to track their "MG Quality of Life" measures and "MG Activities of Daily Life," and to share it with their health care provider. Additional applications and enhancements are already being planned for 2013.

We are working closely with Dr. James "Chip" Howard, the editor of *"Myasthenia Gravis A Manual for the Health Care Provider"* and his team of authors to update the manual and add new content. We have partnered with TrueNorth Technology Solutions, Inc. to transform the manual into an interactive iBook . We believe that this program will help increase awareness within the medical community and will be a useful tool for educating first responders, patients and their caregivers as well as others in the community.

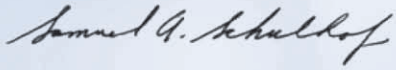
The development of the MG Patient Registry that we announced at last year's National Conference also is well under way. We will be introducing it at this year's National Conference in Miami, May 9-10. Henry Kaminski, MD and Gary Cutter, PhD, who are leading the development of the Registry, will be speaking at the conference. For those attending the conference there will be an opportunity to learn more about the Registry and get assistance in filling out the questionnaire to become a member of the Registry.

As you read this edition of *Foundation Focus* you will notice that we have directed attention toward young people who have MG. The lead article focuses on young adults, and the newsletter also includes personal stories about the experiences of a young professional and the mother of a teenager diagnosed with MG. These articles reflect MGFA's increased attention to children, adolescents and young adults, and they will be an added focus of our work in 2013.

Last, but by no means least, the "MG Walks" are continuing to grow in number (30) this year and in participants, and Walgreens will continue its sponsorship of the Walks. In the two years we have been doing these walks, MGFA has raised over $1 million dollars for research and related programs.

On behalf of the MGFA Board of Directors and the National Office Staff, I wish you a healthy and happy New Year and look forward to seeing you at the National Conference in Miami in May.

Thank you for your support towards making the MGFA vision a reality.



Conference Honors Robert Ruff, MD, PhD

A conference, "Frontiers in Neuromuscular Disease and Neurorehabilitation," was held at the Louis Stokes Cleveland Department of Veterans Affairs Medical Center on October 18-19 to honor the scientific, clinical and mentoring contributions of Dr. Robert L. Ruff. Also sponsored by Case Medical Center, the conference featured 32 basic and clinical scientists, many who had worked with Dr. Ruff or been trained by him. The conference attracted an audience of over a hundred, from across the US and from Europe. The keynote speaker was Dr. Story Landis, Director of the National Institute of Neurology Disorders and Stroke, who described how the NIH was committed to supporting clinician scientists, especially young investigators starting out on their careers, noting the substantial number of such individuals contributing to this conference – a tribute to Dr. Ruff. Neuromuscular components of the conference included contributions by MGFA Medical Scientific Board members Drs. Vanda Lennon and Henry Kaminski Linda Kusner, who discussed basic mechanisms and new treatment approaches to MG. Other aspects of the conference dealt with current concepts of neurorehabilitation, stroke and general neurology, all of which Dr. Ruff has made scientific contributions to during his illustrious career.

Myasthenia Gravis in a Young Adult*

By Nancy L. Kuntz, MD

What Is myasthenia gravis?

Myasthenia gravis (MG) is a disorder which produces fatigue in voluntary muscles, and is caused by an auto-immune antibody-mediated attack directed against portions of the neuromuscular junction in skeletal muscles. This disorder occurs in people of all ages, but onset during adolescence and young adult years is relatively common. Why it occurs in certain people and not others is unclear. Individuals with MG frequently have personal and family histories of other autoimmune diseases such as diabetes mellitus, thyroid disease and certain arthritic conditions. Dr. Daniel Drachman at Johns Hopkins University is currently working on a Genome-Wide Association Study involving more than a thousand individuals with MG, and it is likely that the issue of "genetic susceptibility" to MG will be better understood in the future. MG, like all autoimmune disorders, tends to be chronic or long-standing, but sometimes patients can have long clinical remissions during which the symptoms are absent or much less noticeable. Individuals with MG need to prepare to manage their disease for an undetermined period of time—sometimes lifelong. Treatments are "symptomatic," or directed toward specific symptoms, and "immune-modulating," or directed toward decreasing the antibody mediated disease process.

What life style issues will affect my health if I have myasthenia gravis?

Many individuals with MG respond to their medical treatments and may not require major adjustments to their lifestyles. However, the issues relating to promoting general good health discussed here are helpful to everyone and will be particularly helpful to individuals with MG who are having current problems with fatigue, despite medical therapy.

Sleep: Sleep experts recommend that all adults try to get 9 hours of continuous sleep per 24 hours in order to promote optimum health. A small fraction of the young adult population gets that amount

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**This article addresses youthful onset of autoimmune Myasthenia Gravis, not Congenital Myasthenia, which is in a grouping of inherited neuromuscular transmission disorders. See "Congenital Myasthenia" described by Robert L. Ruff M.D. on page 7 of this newsletter.*

MG in a Young Adult continued from p. 3

of sleep each night. Solid sleep is very restoring for individuals with myasthenia gravis. If insomnia, snoring or restless startles that cause wakening interrupt sleep for an individual with MG, a sleep medicine evaluation and possible overnight sleep recording may uncover treatable issues. Having a regular bedtime and bedtime routine, and sleeping without ongoing sources of light and noise, contributes to restorative sleep. This means no TV, radio or frequent tweets/texts/phone calls during sleeping hours. Having routinely good sleep habits allows one to indulge in occasional late nights with fewer consequences to your health and energy levels.

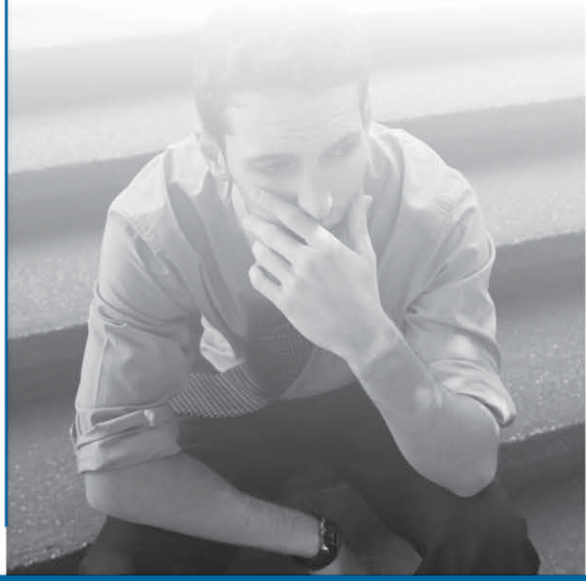
Nutrition: Good nutrition is important for individuals with MG. Decreased levels of physical activity and corticosteroid medications are some of the factors that can contribute to increased weight. Being overweight increases the work of walking and being physically active, and while it should be avoided in all people, it is even more important for individuals with MG. Adequate vitamin D levels promote immune health. Adequate calcium and vitamin D intake is important to bone health and is an important preventive measure for anyone with a health problem that may interfere with normal amounts of walking or weight-bearing, and is prescribed corticosteroid medications. Adequate fiber content in the diet is important for maintaining good bowel habits and long-term heart health. Anyone with childhood habits avoiding salads, roughage and vegetables should reconsider these old habits—possibly taking a cooking class or adult education class on vegetarian meals. These could be great social events as well as promoting a healthier diet.

Exercise: Regular aerobic exercise is very important for everyone with myasthenia gravis. This might seem to be an unusual recommendation for people with fatigable muscles. However, the absence of exercise or the "couch potato" lifestyle leads to clearly worse outcomes for people with MG. Scientists and health practitioners are working to develop sound guidelines for type, intensity and duration of exercise that will benefit individuals with MG. In the meantime, scheduling regular aerobic exercise is smart—continuous exercise associated with small increases in heart rate and a bit of sweating but not so hard and fast that you cannot continue to talk. Perhaps begin with 5-10 minutes of exercise several times per week and gradually increase to 30 minutes 3-6 days per week. During flares of disease activity or in individuals whose disease is not well-controlled with treatment, it is reasonable to both back off the intensity of scheduled exercise as well as scheduling breaks or rest periods between other activities. Be sure to discuss any exercise program with your neurologist and primary care doctor.

Medication: Be familiar with your medications and work with your physician to optimize the timing of your medication to your particular daily schedule. Be honest about your sleep and meal schedule and discuss how much variability in the timing of doses is acceptable. Be proactive about all new medication (prescription and over-the-counter) and make certain that interactions between medications and their impact on MG is known before your start new medications. Each person with MG has a responsibility to be involved with this as well as their physician and pharmacist.

Sudden Changes: Be aware that there can be sudden changes in your strength with MG. Sudden changes in swallowing, speaking, shortness of breath or arm/leg strength are possible. Changes in the ability to speak clearly (either due to changes in strength of facial/throat muscles or changes in breathing capacity) are most challenging to deal with because it makes it hard to tell people about it. It is important to have family/friends who are aware of this as a possibility and/or to have a plan to communicate without speaking (carrying a notebook that you can write notes to explain the change along with a Medic Alert bracelet or medallion).

Live SMART! There is always a finite amount of energy one has to expend during a 24-hour period. Using technologies such as computers, word processors, electric toothbrushes, electric blenders/mixers, electric dishwashers and no-iron clothing all decrease the amount of manual effort required to produce similar results. Personal choices such as hairstyles that do not require hours of blow-drying can save energy on a daily basis. Actively evaluating your personal and work commitments is time well spent. It can allow you to excuse yourself from those activities that are less important so that you have adequate time for important things. Consider using the "myMG" smartphone app featured on the MGFA website to track your symptoms and medication for MG as an efficient way to manage your MG with your physician.



What about dating, sexual activity, pregnancy and having children?

Individuals with MG should have the same approach toward developing relationships, participating in sexual activity and family planning that all young adults should use. This begins with a solid education regarding the emotional, psychological and biological aspects of relationships and sex, including safe sexual practices. In addition, individuals with MG need to be aware of their own physical status —how many hours of sleep they need each night, do they have any particular weakness they need to cope with (fatigue of their smile which can create miscommunication), how much exercise can be done without experiencing fatigue and what time of day that can be done.

Individuals with MG are able to have healthy children. It is important for each person with MG to discuss their own personal medication regimen with their physician in order to know whether there is any consequence of their medications on their fertility or whether there is any increased risk of birth defects.

Women with autoimmune MG need to be aware that there is about a 30% chance of having a flare of disease activity during the first trimester of the pregnancy. It is important, therefore, that women with MG plan their pregnancies, and set up communication between their treating neurologist and an obstetrician who is familiar with MG and/or high-risk pregnancies. An observational study of a large group of women with MG who became pregnant noted that there was an increased frequency of delivery by caesarian section, probably due to the issue of muscle fatigue occurring during labor (Jackson C, 2003). Also, about 4-10% of infants born to mothers with autoimmune myasthenia gravis have transient symptoms of weakness during the newborn period lasting a few days to a few weeks. This transient newborn weakness can be trivial or significant enough to require temporary support of feeding and/or breathing. Strength always returns to normal in these newborns.

Will my children inherit myasthenia from me?

Children inherit many things from their parents—coloring, stature and tendencies toward certain types of diseases. Some families have high rates of allergies, cancers or autoimmune disorders and others do not. MG is not a disease that is directly inherited from parents. It is an autoimmune disorder and there are families whose broad genetic traits increase the chance of autoimmune disorders, including MG, occurring. You and your children will have been born into a family with increased tendency for autoimmune diseases. The risk of MG or other autoimmune diseases occurring in your children may be minimally greater than in the general population but that is a low overall risk.

What can I do to make the future better for myself and others with myasthenia gravis?

One of the most important investments in the future is taking good care of your health in the ways suggested above and with the specific recommendations of your personal physician and health care team. Considering your personal, daily needs for managing your MG while you make decisions about your career and your home is important. Choosing a career or position that provides flexibility in scheduling to allow breaks if needed, minimizes physically stressful commutes, allows time for exercise and provides a work environment that minimizes need for constant physical or manual activity

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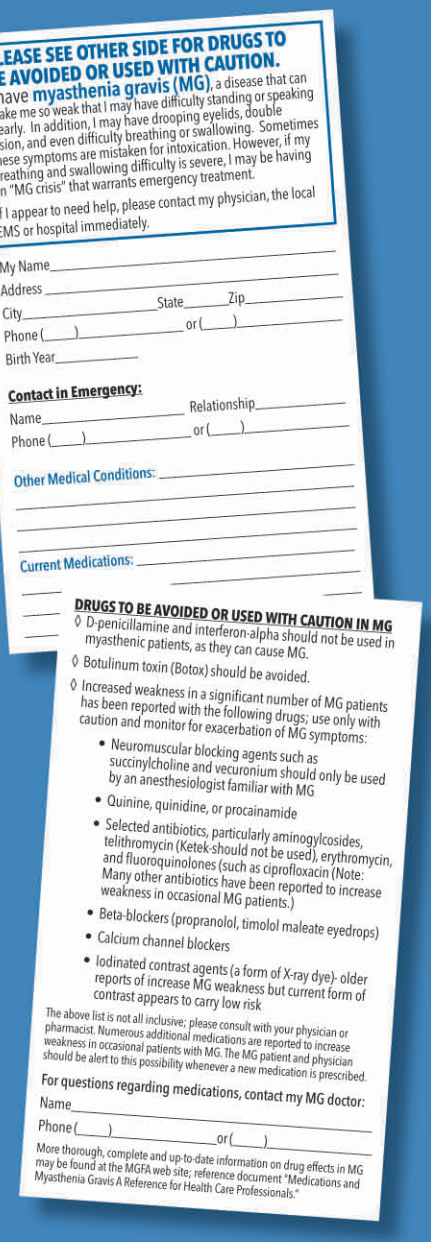
Introducing the newest edition of the Emergency Alert Card:



PLEASE SEE OTHER SIDE FOR DRUGS TO BE AVOIDED OR USED WITH CAUTION.

I have **myasthenia gravis (MG)**, a disease that can make me so weak that I may have difficulty standing or speaking clearly. In addition, I may have drooping eyelids, double vision, and even difficulty breathing or swallowing. Sometimes these symptoms are mistaken for intoxication. However, if my breathing and swallowing difficulty is severe, I may be having an "MG crisis" that warrants emergency treatment.

If I appear to need help, please contact my physician, the local EMS or hospital immediately.

My Name_____

Address _____

City_____ State_____ Zip_____

Phone (____) _____ or (____) _____

Birth Year_____

Contact in Emergency:

Name_____ Relationship_____

Phone (____) _____ or (____) _____

Other Medical Conditions: _____

Current Medications: _____

DRUGS TO BE AVOIDED OR USED WITH CAUTION IN MG

◊ D-penicillamine and interferon-alpha should not be used in myasthenic patients, as they can cause MG.

◊ Botulinum toxin (Botox) should be avoided.

◊ 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-should not be used), erythromycin, and fluoroquinolones (such as ciprofloxacin (Note: Many other antibiotics have been reported to increase weakness in occasional MG patients.)
- Beta-blockers (propranolol, timolol maleate eyedrops)
- Calcium channel blockers
- Iodinated contrast agents (a form of X-ray dye)- older reports of increase MG weakness but current form of contrast appears to carry low risk

The above list is not all inclusive; please consult with your 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.

For questions regarding medications, contact my MG doctor:

Name_____

Phone (____) _____ or (____) _____

More thorough, complete and up-to-date information on drug effects in MG may be found at the MGFA web site; reference document "Medications and Myasthenia Gravis A Reference for Health Care Professionals."

To receive a copy of the card, please visit our website at www.myasthenia.org or contact MGFA's National Office at (800) 541-5454.

Personal Stories

Jasmine Snow

When I was first diagnosed with MG I was completely overwhelmed, which made me even more scared than I already was. My first concern was that I did not want to be a "sick" person. I wanted to figure out a way to live my life and deal with my MG in a way that would not change my lifestyle at all.

I am happy to say that my lifestyle has only endured a few small changes since I became an MG patient; but the changes were minor ones that have had huge effects and ultimately bettered my life aside from my MG. I made sure to reevaluate the way that I eat, how much rest I get and how much exercise I get. I was never a gym person before, and it seemed daunting to me to have to work out throughout the week. But once I starting living a healthy lifestyle and making exercise a part of my routine I started to feel stronger, more confident and less worried about my health as a whole because I knew that I was doing all that I could do to take care of myself.

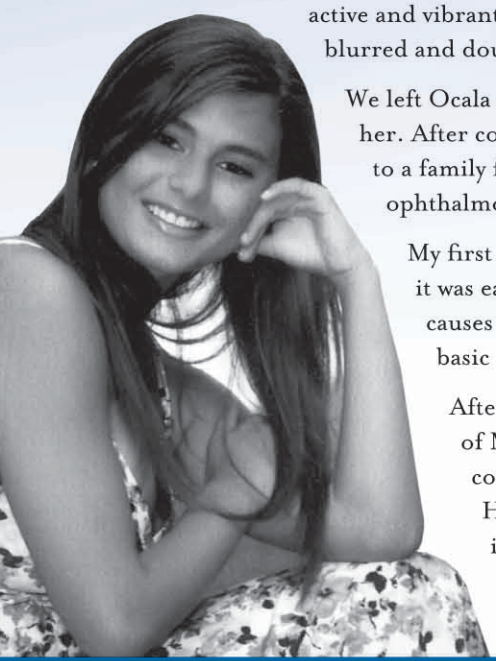
As far as my career goes, my biggest challenge is rest. Because I work in the fashion industry there is not much down time at all. So the days that I do get out of work early, or on my weekends, I really take that time to sleep in, go to bed early and get the rest that I need so I can recharge my body. It is also important to be honest with my co-workers and the people around me. I am not ashamed to tell people that I have MG, and that I sometimes get tired or need a break. I make light of it and do exactly what I need at that time to get myself together.

The most important thing is thinking positively. If you think you are sick, you are going to feel sick. The mind is a very powerful thing, and although you cannot control your symptoms, you can control how you deal with them and work through them. Being dramatic and feeling sorry for yourself will not get you anywhere, or at least I know it does not get ME anywhere. I definitely have my bad days; but instead of getting annoyed about it I take it lightly, as if it is any other part of my day, and keep a positive attitude then I find that it is easier to deal with!

My Daughter Nicolette

By: Carlana Hoffman

Finding out that your child has an incurable disease is something that no parent is ever prepared for. In early 2010, my beautiful, active and vibrant daughter Nicolette who was only 15 at the time began experiencing unusual symptoms of blurred and double vision while competing at a horse show in Ocala, Florida.



We left Ocala and came back home to Tallahassee to begin our search to find out what was the matter with her. After consulting an ophthalmologist who could not find anything wrong with our daughter, we turned to a family friend who was a pediatric neurologist. After he examined our daughter, he suggested we see an ophthalmological neurologist to confirm his suspicions of Myasthenia Gravis, or "MG."

My first thought was what in the world is myasthenia gravis? With today's technology and the internet it was easy and also frightening as a parent to learn that MG is a chronic autoimmune disease, which causes antibodies to attack and destroy neuromuscular connections, weakening muscles that control basic movements that enable walking, swallowing, blinking, breathing, and yes, even smiling.

After meeting with the ophthalmological neurologist who confirmed our doctor friend's diagnosis of MG, we began months of testing to try to get to the bottom of this diagnosis to positively confirm that our daughter Nicolette did indeed have MG. In April 2010 after a visit to Emory Hospital of Medicine and another test called an Electromyograph, it was revealed that Nicolette indeed had MG. We were devastated, but determined to make sure Nicolette had the best treatment or options available to her.

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Congenital Myasthenia

By Robert L. Ruff, MD, PhD, Chief, Neurology Service, Louis Stokes Cleveland Department of Veterans Affairs Medical Center | Member MSAB of the MGFA

Congenital myasthenia, also called inherited disorders of neuromuscular transmission, encompass a diverse group of inherited disorders of neuromuscular transmission. The major differences between congenital myasthenias and the more common autoimmune myasthenia gravis (MG) include the following points. 1) Congenital myasthenias, as the name implies, usually manifest early in life, often in infancy. 2) Congenital myasthenia gravis is not associated with antibodies against any components of the neuromuscular junction. 3) All of the congenital myasthenic disorders result from mutations that alter one of the components of the neuromuscular junction. The congenital myasthenic disorders are rare, and while all are associated with weakness, the patterns of weakness vary according to the nature of the defect in neuromuscular transmission that occurs with a specific disorder. Weakness associated with fatigue, that is weakness that worsens with activity, is a common feature of many congenital disorders of neuromuscular transmission.

Each of the congenital myasthenias results from a loss or alteration in the function of a component of the neuromuscular junction. There are congenital disorders of neuromuscular transmission that are associated with 1) impaired synthesis, packaging or release of the chemical transmitter at the neuromuscular junction, acetylcholine; 2) altered function acetylcholine esterase, the enzyme in the synaptic cleft that breaks down acetylcholine; 3) impaired function of the acetylcholine receptor; 4) altered expression of acetylcholine receptors with a deficiency of acetylcholine receptors or abnormal distribution of acetylcholine receptors; and 5) altered presence or operation of proteins in the neuromuscular junction that play critical roles in maintaining the proper structure of the neuromuscular junction.

I have studied the neuromuscular junction for over 40 years and I still find it beautiful. The structure is adapted to work best for each different muscle and for all vertebrate animals (animals with spinal cord and spinal columns). Consequently, each of the mutations that have been recognized impairs function. I know of no mutation that improves upon the function of the neuromuscular junction.

Treatment aims at supporting the individual and attempting to compensate for the genetic alteration in the neuromuscular junction. There are a few places in the United States that have seen enough cases of congenital myasthenia to be able to treat these rare conditions effectively. Unfortunately, even with the best of treatment, the prognosis for many of the congenital disorders of neuromuscular transmission can be extremely poor, with people dying during infancy or childhood. Hence, it is important to determine the precise nature of a particular congenital myasthenia disorder in order to know what to expect and what can be done. Dr. Andrew Engel at the Mayo Clinic in Minnesota has done the most research on the diagnosis and treatment of this group of disorders. There are other excellent centers across the United States and the MGFA can provide the names of physicians who have expertise in diagnosing and treating these rare disorders. The MGFA has supported research in the recognition and treatment of congenital disorders of neuromuscular transmission.

MGFA Patient Registry

The MGFA Patient Registry will be introduced at the 2013 National Conference May 8-10 in Miami. Make sure to attend the conference so that you can learn first-hand from Dr. Henry Kaminski what the registry is all about. We will also have staff available to answer questions and help you join the registry. If you are unable to attend the 2013 National Conference, please look for information in May on www.myasthenia.org regarding how to join the registry.

Increasing Awareness through Advocacy: June Awareness Month

Advocacy at the Myasthenia Gravis Foundation of America, Inc. (MGFA) is defined as a coordinated program of actions and strategies at the national, chapter and individual levels designed to educate the public, researchers, medical personnel, elected officials and individuals about MG to achieve positive change for people with MG, enhance awareness and influence public and private policy making.

This aspect of advocacy – disseminating public information about MG — has always been an integral part of MGFA's mission to improve the lives of people who have MG. In fact, it is the reason that the MGFA was founded in 1952.

Advocacy exists in many forms. Throughout the year, MGFA reaches out to the national media and provides tools for chapters to connect with their local media outlets. The Foundation also places news and updates on the MGFA web site and makes informational and educational materials available to patients who in turn help to educate their local communities about MG.

During the month of June each year, the MGFA National office, chapters and individuals enhance their outreach efforts and concentrate their activities on "June Awareness Month" advocacy. They are encouraged to use the many advocacy tools at their disposal to spread the word about MG and the need for further research to define the disease more clearly, expand treatments and find a cure. These tools are included in the major categories of print, electronic and social media.

In advance of this special month, MGFA assists chapters by providing communication resources such as sample press releases, MG fact sheets, posters and links to local radio stations and newspapers. In addition, MGFA encourages chapters and individuals to use the many other available options that are targeted toward diverse audiences. These include electronic media such as YouTube, blogs, websites, message boards, e-mails and chat rooms as well as innovative social networking such as Facebook and Twitter.

This issue of Foundation Focus contains a flyer version of the 2013 June Awareness poster. The poster will be available in hard copy and for downloading on MGFA's web site www.myasthenia.org. A roundtable discussion, "How to Energize Your Campaign and Get Media Attention," has been scheduled for May 9th,during the MGFA National Conference in Miami. Additional information about June Awareness advocacy and suggested tools and activities will be posted as June approaches.

In the meantime, MGFA and its community continue their efforts to advance public knowledge about MG, support people who have MG and those who love and care for them, facilitate research, raise awareness of MG and funds to cure it and build momentum toward achieving a World without MG.

Author: Janet A. Myder, MPA, MGFA Board of Directors/ Secretary, Communications Committee Chair, Low Country SC Myasthenia Gravis Support Group Co-Chair

MGFA's Facebook Page:

In order to serve our community better, the Myasthenia Gravis Foundation of America has created an MGFA Facebook page. For information about myasthenia gravis, research, support groups, etc., visit www.facebook.com and search Myasthenia Gravis Foundation of America. Please "like" the MGFA's new business page. MGFA does not monitor or participate in discussions between members of this group.

MYASTHENIA GRAVIS
FOUNDATION OF AMERICA, INC.

THE FACES OF MG

June is Myasthenia Gravis Awareness Month

Together We Are Stronger

MG is an autoimmune neuromuscular disease that affects all ages, races and genders. MG symptoms include weakness in muscles that control eye movements and eyelids, chewing, swallowing, coughing, facial expressions, arm and leg movements, and breathing. To learn more about MG and how you can help, visit online or call:
www.myasthenia.org or 1.800.541.5454

MG Walk: $1 million raised in first 2 years!!

MG walk
For a World Without Myasthenia Gravis

Now in its third year, the MG Walk's success is unprecedented for the MGFA as it has now raised $1 million dollars to fund critical research and programs of patient support. The Campaign has raised awareness, renewed hope and worked to build a connected and caring community of those affected by myasthenia gravis.

Through the MG Walk, patients and their families have connected as never before. Those whose lives have been touched by MG have a way to reach out to their circle of influence and invite them to join in creating a better future for all with MG. The MG Walk is giving myasthenia gravis a voice — a way for all walkers to say, "MG must be stopped. We need your help to find a cure."

The MG Walk has quickly become a central part of our mission delivery: to find a cure for myasthenia gravis and closely related disorders, improve treatment options and provide information and support to people with myasthenia gravis through research, education, community programs and advocacy. The Campaign has accomplished much, but there is still more to be done!

Raising Funds

The goal is a world without MG and that takes funding. The MG Walk is the MGFA's single greatest opportunity to raise significant dollars. By working together with walkers, volunteers, donors, sponsors, national and local leaders, we build on each others strengths. In 2013, the MG Walk hopes to raise more than $750,000, largely through $10, $25 and $50 donations secured by MG Walk participants. That is a powerful partnership that we would like YOU to be a part of.

Raising Awareness

Despite our best efforts and great progress, awareness of myasthenia gravis remains low. The MG Walk is an important vehicle to raise significant awareness. From media attention, to walkers in their T-shirts, to Walk materials in public locations, like in Walgreens pharmacies and doctor offices, to literally thousands of participants raising funds by talking to everyone about MG and its effects on a person's life, the MG Walk Campaign is a nation-wide awareness-raising machine.

How Can You Be A Part?

It takes more than people with MG to cure MG. We must look to our communities and enlist friends, family members, colleagues and even mere acquaintances to join us in the MG Walk. There will be 30 MG Walks in 2013, including the Virtual MG Walk where anyone, anywhere can participate! Please visit www.MGWalk.org for an updated list of markets and dates for the 2013 Campaign.

You can participate in a number of ways:

1. WALK. Register on-line at www.MGWalk.org and get started on your fundraising right away. Form a team and rally friends, family members and co-workers to join you.

2. VOLUNTEER. We can always use more help on the ground. There are activities and needs to suit all skill sets and work into most any time frame. Take an active role in your nearest walk and help make this year's MG Walk an even greater success!

3. DONATE. Do you work for a company that might like to be a sponsor? Or have access to a product donation that can minimize expenses? You can make a monetary donation on-line to or send in a check. Every donation makes an impact.

For more information on how to participate, volunteer or sponsor the MG Walk, please call 1-855-MG-WALKS (855-649-2557), email the MG Walk Office at Info@MGWalk.org or log on to www.MGWalk.org today!

Follow the MG Walk:

www.Facebook.com/MGWalks

https://Twitter.com/MG_Walk

https://Pinterest.com/MGWalk

"myMG" Smartphone Application

By: Denise Rossi

In December 2012, the Myasthenia Gravis Foundation of America, Inc (MGFA) launched "my MG," an innovative mobile application (or "app") for people with Myasthenia Gravis (MG) to track their MG. To date, more than 400 patients have signed on.

"my MG" is a software application designed to run on smartphones, tablet computers and other mobile devices. With "my MG", the MG community records symptoms and their impact on daily activities. The app allows you to record notes with each survey. The notes can collect information about medicines and life events that can impact your MG symptoms. You can then print your notes and survey results from your PC to share with your doctor.

The new app is available free by downloading from the Google app store or iTunes. For patients without access to a smartphone, tablet computers or other mobile device, "my MG" is available online at the MGFA website http://www.myasthenia.org.

Go to your app store today and see what is new in the conversation between MG patients and their doctors: "my MG".

Hurricane Sandy Impacts MGFA Foundation Focus Newsletters

When super-storm Sandy terrorized the East Coast region of the United States this past October, causing extensive damage to the New York City region, it also left its impact on Foundation Focus. Excessive flooding at the print shop where the MGFA's Fall 2012 Foundation Focus was produced ruined all the printed copies. The National Office worked closely with the printer to re-issue the editions as quickly as possible and the mailing was completed a few weeks later. We apologize for the delayed distribution of the newsletters. Thank you for your patience during that challenging time!

MGFA 2013 NATIONAL CONFERENCE

Wednesday May 8, 2013 – Friday May 10, 2013

Intercontinental at Doral Miami
2505 Northwest 87th Avenue, Miami, Florida, 33172

UNITING FOR A CURE

Together We Are Stronger

For registration information and hotel details, please visit http://www.myasthenia.org

MG in a Young Adult continued from p.5

(elevators rather than stairs, technology and automation rather than manual work) will be helpful. Choosing your home to minimize maintenance needs is important: living in an apartment or condominium or with friends/family rather than in a house that requires you perform your own yard work, snow removal and so forth. Considering the year-round weather when deciding on where to live is helpful—locating in an area of the country that will allow you to avoid extreme heat stress as well as severe, bitter cold. Finally, remaining well-informed about the advances in treating MG is an excellent investment of time as it will improve your spirits. Participation in fund-raising to move that research forward can be extremely fun as well as furthering research—consider MGFA sponsored golf tournaments, walk-a-thons, Shoe Dazzle or even creating your own fund-raising project.

So I can live with MG without letting it control me?

Myasthenia gravis is a health problem than can be managed with attention to general health and lifestyle, and treated in partnership with a health care team of doctors, nurses, nutritionists, therapists and trainers. It will be a part of your life but it should not define you. Individuals with MG are important members of our community—students, parents, professionals, business people, educators, workers, volunteers. Most people with MG do better when they have the support of family, friends and coworkers. Every person with MG has their own story. I look forward to hearing yours.

Nancy L. Kuntz, MD | Attending Pediatric Neurologist and Medical Director, Mazza Foundation Neuromuscular Program, Children's Memorial Hospital, Chicago | Associate Professor of Pediatrics, Northwestern University | MGFA Board and Medical/Scientific Advisory Board member

Reference:

Jackson C. 2003. The effect of MG on pregnancy and the newborn. Neurol 61: 1459-1460.

Myasthenia Gravis Foundation of America website — www.myasthenia.org

MYASTHENIA GRAVIS FOUNDATION OF AMERICA, INC.

2013 National Conference

No refunds will be made.

Registration Form

Please use one registration form per person

May 8-10, 2013

Intercontinental at
Doral Miami Hotel
2505 North West 87th Avenue
Doral, FL 33172-1610

Attendee Details:

First Name: Last Name:

Address:

City, State ZIP: Country:

Phone: E-mail:

Guest Details:

First Name: Last Name:

Additional Information:

EMERGENCY CONTACT:

First Name: Last Name:

Phone:

Are you a Chapter member? ☐ Yes ☐ No Chapter name:

Are you a first-time attendee? ☐ Yes ☐ No

Special needs:

Comments or questions?

Complete back of page.

Attendee Name: (first & last)

_____

Registration Options:

☐ **Full Registration** **$195**

(Full Registration includes complete conference handbook, breakfast and breaks each day, lunch on Friday and the Awards Dinner)

☐ **Students in Health Professions**..... **$125**

☐ **Awards Dinner Only**..... **$50**

☐ **One Day** **$110**

UNITING FOR A CURE

Together We Are Stronger

May 8-10, 2013

Payment Options:

Total Cost.....$_____

Please note: Your statement will read MGFA for this transaction.

☐ **Check (payable to MGFA)**

☐ **VISA**

☐ **MasterCard**

☐ **AMEX**

Card Number _____ Exp. Date _____

Name of Cardholder _____

Authorized Signature _____

Please send your registration form and payment to:

Myasthenia Gravis Foundation of America, Inc.
355 Lexington Avenue, 15th Floor
New York, NY 10017 fax: (212) 370-9047

If you have any questions, please call the MGFA national office at 1-800-541-5454

Intercontinental at Doral Miami Hotel
2505 North West 87th Avenue, Doral, FL 33172-1610

For registration information, preliminary program, and hotel details, please visit
http://www.myasthenia.org

To make your room reservations at the Intercontinental at Doral Miami please call 305-468-1400 and reference MGFA Annual Meeting

Personal Stories continued from p. 6

We came home and Nicolette's ophthalmological neurologist recommended having a thymectomy. Of course we wanted to know what a thymectomy was. A thymectomy is surgical removal of the thymus gland. The thymus gland lies behind the breastbone and is an important part of the immune system. A thymectomy frequently lessens the severity of the MG weakness after some months. In some people, the weakness may completely disappear. This is called a remission. The degree to which the thymectomy helps varies with each patient.

Again we returned to the Emory Hospital of Medicine in the summer of 2010 and Nicolette had a thymectomy. We were hopeful that she would go into remission, since there is no known cure for this disease. It has been over two years now and my daughter has not gone into remission.

However, my husband and I support her in her efforts to live a full life in spite of the disease. While she has given up her love of riding, she is staying positive and focused. She is a freshman at the University of Florida and is loving college life.

As a parent, I cherish my child and will make certain that she has every opportunity to experience everything she can. At the same time, Nicolette has learned how to make adjustments and cope with her disease to carry on a very normal life. My husband and I encourage her to maintain a positive outlook while being pragmatic about her disease and mindful of changes.

MGFA Welcomes New Board Member Carl Hansson

Carl is Chairman and CEO of TSS Photography, a youth sports, school, portrait and special event photography company; in addition, he serves as Chairman and CEO of Young Masters, a co-branded franchise system, that services franchises across the United States. Carl serves as a Director for Shamrock Sports Group, a company focused on creative, strategic solutions to execute successful and valuable partnership and sponsorship campaigns. Carl currently serves as the Chairman of the Make-A-Wish® of America National Advisory Council.

MGFA Chapter Updates:

Carolinas Chapter

The Carolinas Chapter is pleased to announce the election of Herb Johnson as Chairperson to serve the remaining year of George Naderman's term. Mr. Naderman will now be Vice-Chairperson. Herb has served on the board the past 2 years as Chair of a Special Committee for Assistance to our support groups. His goal as Chairperson is to continue the chapter's focus on Patient Advocacy. The chapter is seeking the support of group meeting leaders in the Carolinas. Please contact our local office if you have an interest.

The January 2013 monthly meeting of the chapter's Low Country SC Myasthenia Gravis Support Group featured speakers from the Evelyn Trammell Institute for Voice and Swallowing at the Medical University of South Carolina (MUSC) in Charleston, SC. A speech pathologist and otolaryngologist presented an outstanding in-depth presentation about the effects of Myasthenia Gravis (MG) on swallowing, speech, and voice. The program included descriptions of anatomy, physiology, common treatments, prognosis and recovery, as well as a Power Point presentation with videos showing the functions of the vocal cords, larynx and related structures. Speakers were not only very knowledgeable of MG, they also were very interested in learning from each attendee about the specific effects of MG on each one of them.

Great Lakes Chapter

Detroit Area Support meetings — First Thursday of the Month through May 2013 at University of Detroit-Mercy, Detroit, 6:30pm

Grand Rapids Support Meetings — First and Third Thursday of each month through May 2013 at Greenridge Realty, Inc., Grand Rapids. 7:00pm

Run/Walk — June 15, 2013 = Millennium Park, Grand Rapids

Walk — June 22, 2013 = Kensington Metropark, Milford

Golf Outing - August 10 = North Kent Golf Course, Rockford

Contact the Chapter for details:
(616) 956-0622
email myasthenia.info@gmail.com
www.mg-mi.org

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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.

Thank you

...to all of our wonderful donors!

Your generosity brings us closer to a world without MG.

MG walk
For a World Without Myasthenia Gravis

The goal of the MG Walk Campaign is to expand into new markets where we can bring together patients, create a community of active/engaged MG families and raise vital awareness & funding for myasthenia gravis! It is crucial that we go where we know we can garner the support needed to ensure success. If you are interested in seeing the MG Walk come to your area and you are excited to play an active part in its planning, promotion and production, we want to hear from you! Please contact the MG Walk Office at 1-855-MG-WALKS or Info@MGWalk.org or fill out our interest form found online at www.MGWalk.org. Thanks so much!