



# E-Update

## E-Update Spring 2016 Edition June 2016

### MGFA News

#### **June Awareness Month is Here!**

June 2016 marks the sixteenth annual “**MG Awareness Month**,” the nationwide movement created by the Myasthenia Gravis Foundation of America, Inc. (MGFA) to raise awareness of the often misunderstood and under-diagnosed disease, Myasthenia Gravis (MG). Every June, MGFA and the MG Community throughout the country focus attention on spreading awareness about MG. Volunteers pour extra energy into the effort. You can too! With social media, we have an excellent tool to inform the public. By the end of June, we hope to have thousands saying “I have heard of MG!”

This year, MGFA is introducing a Twibbon! A Twibbon is a filter to add to your profile picture on Facebook and Twitter. [Click here to use the Twibbon](#). Close to 4,000 people have used the Twibbon so far, so please keep pushing up that number! Let’s see this on thousands of profile pictures. Also available for download is our 2016 June Awareness poster, which can be [found here](#). Support the work of others in the MG community by visiting and promoting their efforts. For instance, visit the video created by the Georgia MGFA Support Group and let others know about it too <https://youtu.be/-ekkmTGp0TQ>. - See more on the [MGFA web site](#).

#### **MGFA Kicks Off National Annual Conference with Community Walk; Raleigh Mayor Nancy McFarlane Gives Welcome Address; and MGFA Community Welcomes New CEO Nancy Law**

The Myasthenia Gravis Foundation of America (MGFA) kicked off its 2016 Annual National Conference (Raleigh, North Carolina on May 1-3), with the North Carolina MG Walk on Saturday, April 30 and a welcoming address by Raleigh Mayor, Nancy McFarlane, on May 2. Speaking at the North Carolina MG Walk was Walk Hero, Cathy Liner of Winston-Salem. She and hundreds of others walked at Lake Lynn Park at on April 30, to raise awareness. On May 1 a special inaugural workshop was held for Support Group Leaders, followed by 2 days of educational sessions for patients, families, medical professionals, and advocates to learn more about the disease, treatment options and current research.

MGFA’s newly appointed CEO Nancy Law gave an inspiring speech to conference attendees. She described her vision for MGFA as well as the foundation’s operational goals of research, patient services, awareness, and advocacy. She reiterated the theme for the conference,

“Together, we are stronger” and told the group that “if we embrace this—there is nothing we can’t accomplish. We may have weak muscles, but we do not have weak will, and we are not weak or ineffectual people. Every one of us has a talent or skill to contribute to our cause. Each of us has a voice, and a story to tell. We may be, by definition, living with a rare disease, but that does not mean that it has to be one that no one knows or understands. If we, who know what MG can do, don’t step up and work together—who will? Like snowflakes, as individuals we may at times feel fragile; but together, we can create a blizzard.”

[Click here to read the full transcript of Nancy’s speech](#)

[Click here to read Nancy’s bio](#)

## Research News

### Howard Publishes Article: “Rare Insight: A Physician’s Perspective on Myasthenia Gravis”

Dr. James F. Howard Jr., M.D., a Distinguished Professor of Neuromuscular Disease and Professor of Neurology & Medicine at the University of North Carolina at Chapel Hill School of Medicine, published an article, “*Rare Insight: A Physician’s Perspective on Myasthenia Gravis*,” on the *Rare Daily Global Genes* web site. Howard wrote, “As a physician specializing in the treatment of myasthenia gravis (MG), a rare, debilitating neurological disorder, I witness on a daily basis the adversities my patients face. Imagine being a hard-working, active adult—a mom who drove her kids to school every day, who liked to garden and exercise—suddenly faced with a disease that makes it difficult to see, walk or even talk. This is the reality of MG. It steals muscle strength to the point where those living with the disorder can no longer do the things they love. But many fight back, and I am consistently inspired by the strength and perseverance my patients exhibit to overcome these challenges and to not let their disease define them.”

[Click here to read the article](#)

### Study Explores Two New Antibodies Believed to Cause MG

A study of patients from across the nation with myasthenia gravis (MG) is helping determine the incidence of two new antibodies believed to cause the disease, and whether these patients need different treatment strategies. Researchers are examining the blood of patients from 22 centers specializing in the treatment of MG to determine what percentage of patients have one or both of the new antibodies and to characterize their clinical symptoms. “We want to know whether these patients have any unique symptoms so we can diagnose them early then confirm their diagnosis with a blood test,” said principle investigator Dr. Lin Mei, chairman of the Department of Neuroscience and Regenerative Medicine at the Medical College of Georgia at Augusta University.

[Click here to read the article](#)

### Stem Cell Transplant Successful in Seven MG Patients

Seven patients with severe myasthenia gravis who received autologous hematopoietic stem cell transplants have experienced long-term remission that has been symptom and treatment free for many years. “We are always reluctant to talk about this type of disease being cured, but these patients have all been disease free without any maintenance therapy since the procedure, which is very encouraging,” one of the treating physicians, Harold Atkins MD, University of Ottawa, Ontario, Canada, told *Medscape Medical News*. Dr. Atkins and colleagues describe their findings in a paper [published online](#) in *JAMA Neurology*.

## **3-D Technology Enriches Human Nerve Cells for Transplant to Brain; Improves Potential to Help Other Degenerative Diseases**

National Institutes of Health-funded scientists have developed a 3D micro-scaffold technology that promotes reprogramming of stem cells into neurons, and supports growth of neuronal connections capable of transmitting electrical signals. The injection of these networks of functioning human neural cells – compared to injecting individual cells -- dramatically improved their survival following transplantation into mouse brains. This is a promising new platform that could make transplantation of neurons a viable treatment for a broad range of human neurodegenerative disorders. [Click here to read article](#)

## **Researchers Pinpoint Part of the Brain That Recognizes Facial Expressions**

Researchers at The Ohio State University have pinpointed the area of the brain responsible for recognizing human facial expressions. It's on the right side of the brain behind the ear, in a region called the posterior superior temporal sulcus (pSTS). In a paper published in the *Journal of Neuroscience*, the researchers report that they used functional magnetic resonance imaging (fMRI) to identify a region of pSTS as the part of the brain activated when test subjects looked at images of people making different facial expressions. [Click here to read the article](#)

## **Men Miss Out on Bone Loss Screening**

Unlike women, men at risk for osteoporosis don't get routinely screened for bone loss, a new study shows. As a result, researchers found that men may not receive treatment or take the steps necessary to protect their bone health. In a Houston Methodist Hospital news release on May 5, endocrinologist Mary Ruppe stated, "Women have a screening safety net. Between their primary care physician and ob-gyn, women will begin bone density screenings at the appropriate age. Men are less likely to have routine primary care checkups and don't receive preventative care similar to what is provided for women." In the United States, roughly 1.5 million men older than 65 have osteoporosis, researchers noted and another 3.5 million men are at risk for this form of bone loss. Risk factors that could increase men's chances of developing bone loss include prescription steroid use. [Click here to read the article](#)

## **MG Patients in the News**

### **Georgia Support Group Receives Close to 1,000 YouTube Views with Video**

[Click here to watch video](#)

### **Georgetown Resident Finds Support from Lowcountry South Carolina MG Support Group**

Georgetown resident Deborah Cooper went to Charleston for what she thought would be a regular eye exam. When she left, however, her life, as she knew it, had changed forever. In the last several months, however, Cooper has managed to mitigate some of the troubles associated with MG after she learned about a support group at East Cooper Medical Center in Mount Pleasant. The Lowcountry SC Myasthenia Gravis Support Group works to help MG patients across South Carolina acquire information that can be, at times, difficult to find.

[Click here to read the article](#)

## **2016 National Conference Highlighted on Raleigh CBS News**

[Click here to watch video](#)

## **6th Annual Walk in Florida Featured on Boca Raton CBS Channel**

[Click here to watch video](#)

## **South Florida Walk Highlighted on CBS; Anchor Serves as Event Emcee**

[Click here to watch video](#)

## **Patient Niki Grossheim Promotes Wisconsin Walk on WeAreGreenBay TV**

Niki Grossheim - Wisconsin MG patient, support group leader, member of the MGFA Community Volunteer Committee, new mother, and newly-awarded MG Walk "Volunteer of the Year" – was interviewed on a Green Bay TV station to promote the MG Walk in Wisconsin.

[Click here to watch video](#)

## **Buford Man Raises Awareness About Rare Disorder**

Alexis Rodriguez was recently recognized nationally as an MVP by the Myasthenia Gravis Foundation of America for his work as an ambassador for the organization and advocate for the annual MG Walk, which raises money for patient services and research for those affected by the disorder. [Click here to read article](#)

## **Mount Pleasant Resident Honored by National Foundation**

Janet Myder of Mount Pleasant, co-founder of the Lowcountry Myasthenia Gravis (MG) Support Group, was honored as "Volunteer of the Year" by the Myasthenia Gravis Foundation of America (MGFA) during its annual conference in Raleigh, N.C. held May 1-3.

[Click here to read article](#)

## **Charleston Patient Receives Get Well Wishes on FOX News**

Charleston MG patient Lauren Jarman received "get well wishes" from one of the newscasters at the end of FOX Morning News.

[Click here to watch video](#)

*For additional news about MG patients in the media, [click here](#)*

## **MG Walks**

### **MG Walks Nearing \$400,000 Raised in First Four Months**

Through the first four months of 2016, the MG Walks have raised \$338,000 of their \$900,000 goal to generate awareness, renew hope, and create a community of support while raising important funds for the Myasthenia Gravis Foundation of America. The MG Walk allows people with MG to talk about their diagnosis, many for the first time, while experiencing an overwhelming amount of support from their loved ones. The Southern and Northern Wisconsin Walks, held on May 7, raised a combined \$30,000, while the North Carolina and South Carolina Walks, held on April 30, raised a combined \$35,000. Please support a Walk near you at [www.mgwalk.org](http://www.mgwalk.org)

### **MG Walks Raise More Than \$3.5 Million in First Five Years**

Since they were created five years ago on the national level, the [MG Walk:For a World Without Myasthenia Gravis](#) campaign has raised \$3.57 million, including close to \$500K in corporate sponsors. The Walks had 22,000 walkers on 2,300 teams, 43,500 donors, and close to 5,000 people following the Walk's efforts on social media through Facebook, Twitter and Instagram. Support any of the upcoming walks at [www.mgwalk.org](http://www.mgwalk.org)

## **MG Walks Hand Out Awards at National Conference**

The MG Walks group handed out several awards at the annual National Conference in Raleigh, including Silver Soles (\$500-\$999) fundraisers, Gold Toes (\$1,000+) fundraisers, and Top Teams (\$3,000+). Individual honorees included: Rockstar Award: #1 Fundraiser, Paul Goldstein at \$35,347 (TriState MG Walk); Big Easy Award: Most Cash sponsorships, Tommy Santora (New Orleans MG Walk); Rookie of the Year: Theresa Collins (Utah MG Walk); and MVP: Alexis Rodriguez (Georgia MG Walk).

## **News from the Public Sector**

### **Health and Human Services (HHS)**

#### Health Resources and Services Administration (HRSA)

On May 4, HHS Secretary Sylvia M. Burwell announced over \$260 million in funding to 290 health centers in 45 states, the District of Columbia, and Puerto Rico for facility renovation, expansion, or construction. Health centers will use this funding to increase their patient capacity and to provide additional comprehensive primary and preventive health services to medically underserved populations. "Today's awards will empower health centers to build more capacity and provide needed health care to hundreds of thousands of additional individuals and their families" said Secretary Burwell. To read more, click on [Read the news release](#)

#### Disability.Gov

Disability.gov has issued three sets of information through its "Disability Connection" weekly newsletter. One is related to the [Campaign for Disability Employment](#) (CDE), an initiative funded by the U.S. Department of Labor's Office of Disability Employment Policy. It provides information and resources for employers to understand their obligations under the Americans with Disabilities Act (ADA) of 1990 to provide reasonable accommodations for employees. For the list of 10 things employers should know, click on <https://www.disability.gov/disability-connection-newsletter-may-2016/>

The second set of information is a warning from the Federal Trade Commission (FTC) and the Social Security Administration (SSA) that scammers are trying to get personal information from people by calling and pretending to help with applications for disability benefits and claims. This information then is used for identify and benefit theft. If you receive such a call, contact the [SSA Fraud Hotline](#) at 1-800-269-0271 (TTY: 1-866-501-2101). For more information, click on <https://www.consumer.ftc.gov/blog/scammers-offering-help-disability-applications>

The third set of information addresses questions about housing including equal access, rental assistance and tips for first-time buyers. For the full list, click on

<https://content.govdelivery.com/accounts/USODEP/bulletins/1466288>

## **National Institute on Aging**

Caregiving can be both rewarding and challenging. From day-to-day tasks, like doctor's appointments and mealtime, to difficult situations like hospitalization and long-term care, caregivers have to make lots of decisions. It can be very fulfilling to care for a loved one, but it is important for caregivers to take care of themselves, too. Publications, websites, and other resources offer information and advice for family caregivers. For more information, click on <https://www.nia.nih.gov/health/featured/caregiving?utm>

Managing medications when you travel. Now that the summer travel season has begun, whether you're going on vacation or just getting away for the weekend, there are things to keep in mind when traveling with medications.

See how to manage your medications when you travel. Going abroad? [This FDA video has important tips. \(WATCH\).](#)

The information on [Taking Medicines](#) was developed for [NIHSeniorHealth](#) by the [National Institute of General Medical Sciences \(NIGMS\)](#) at NIH.

By the way, you may also find the ***MGFA's Travel Tips Part 1 & 2*** helpful during this summer season. Visit this [link](#) and scroll down toward the end of the General Information pamphlets to find these useful guides.

## **Centers for Medicare & Medicaid Services (CMS)**

In early April the CMS announced its largest-ever initiative to transform and improve how primary care is delivered and paid for in America. CMS reports that the effort, the Comprehensive Primary Care Plus (CPC+) model, will be implemented in up to 20 regions and can accommodate up to 5,000 practices, which would encompass more than 20,000 doctors and clinicians and the 25 million people they serve. The initiative is designed to provide doctors the freedom to care for their patients the way they think will deliver the best outcomes and to pay them for achieving results and improving care. For more information about the CPC+ model, including a fact sheet, please visit: <http://innovation.cms.gov/initiatives/Comprehensive-Primary-Care-Plus>.

## **U.S. Congress**

### **Accessible Air Travel**

The Muscular Dystrophy Association (MDA) has been working closely with a diverse set of stakeholders to advocate for enactment of increased accessibility to air travel. The Senate version of the Federal Aviation Authority (FAA) reauthorization bill contains provisions targeted for disabled passengers. These provisions would call for 1) studying the use of in-cabin wheelchair restraint systems, 2) identifying best practices in airport accessibility, 3) examining training policies regarding assistance for disabled air travelers and 4) creating an advisory committee with diverse stakeholders to investigate and report to Congress on the needs of passengers with disabilities. The bill recently passed the Senate 95 to 3 and is awaiting House of Representatives action. The MDA is also monitoring other activities related to travel policy

including the Department of Transportation (DOT) Accessible Air Transportation Advisory Committee (ACCESS), which held its first meeting recently to address three issues impacting accessibility: 1) lavatories, 2) service animals and 3) in-flight entertainment. The committee will consider all three issues in the coming months. For specific information on individual airlines' resources and accommodations for disabled passengers, click on [MDA's Accessible Travel Resource Center](#).

## **National Organization for Rare Diseases (NORD)**

NORD's RareAction Network<sup>SM</sup> released its May/June State Policy Legislative Tracker, a tool that tracks key legislative developments in the states. The purpose of the tracker according to NORD is "to improve the lives of people and families in the rare disease community." NORD further states, "In this version of the [State Policy Legislative Tracker](#), there is an increase in the bills being supported in both Massachusetts and Tennessee.

## **National Fire Protection Association (NFPA)**

The NFPA has addressed the issue of safety for disabled persons during an emergency. A free guide, "Emergency Evacuation Planning Guide for People with Disabilities" is available for downloading at [www.nfpa.org/disabilities](http://www.nfpa.org/disabilities). The guide provides information on the five general categories of disabilities (mobility, visual, hearing, speech, and cognitive) and the four elements of evacuation information that occupants need: notification, way finding, use of the way, and assistance. It also includes a checklist that building services managers and people with disabilities can use to design a personalized evacuation plan, as well as government resources and text based on the relevant code requirements and ADA criteria.