



## MGFA October 2017 E-Update

### MGFA News

#### Flu shot advice.

**Flu Season -- Alert about Vaccinations, Including Flu Vaccine:** It is generally believed that vaccinations, e.g. influenza, are safe in patients with MG (with a major caveat below). The evidence suggests that vaccine-related worsening of MG is rare and thus most MG specialists believe the benefits of immunization outweigh any small risk related to possible transient worsening of MG symptoms.

Flu is an illness that needs to be taken seriously according to U.S. health officials who are worried that this season could be a bad one. That's why the U.S. Centers for Disease Control and Prevention (CDC) is urging everyone 6 months and older to get a flu shot. The CDC is expressing extra concern because Australia, which experiences its flu season in summer due to its location in the southern hemisphere, has been hard hit this year. The major culprit has been the H3N2 flu strain, which is known for causing severe disease, especially among older people. Small clusters of H3N2 are already showing up in the United States, according to published reports. "We don't know what's going to happen but there's a chance we could have a season similar to Australia," said Dr. Daniel Jernigan, influenza chief at the CDC. For more information, go to the Centers for Disease Control and Prevention link [Frequently Asked Flu Questions 2017-2018 Influenza Season ...](#)

**Exception/caveat:** If you are taking immunosuppressive medication such as Prednisone, Azathioprine or Mycophenolate, it is usually recommended that you avoid live, attenuated vaccine. Examples of live, attenuated vaccines include the shingles vaccine and the nasal spray form of the influenza vaccine (The influenza injection is inactivated and thus not alive, so it is much safer in immunosuppressed patients.) Discuss this with your physician.  
**As always, please consult your physician regarding your individual case.**

#### **MGFA Advocates MG Community Action on Proposals to Repeal and Replace the Affordable Care Act (ACA)**

On September 20 the Myasthenia Gravis Foundation issued a **Call to Action: Protect Patients with Pre-conditions**. MGFA was concerned that the Graham-Cassidy bill, which was pulled

from Senate consideration before September 30 after it was determined it had insufficient votes to pass , would have taken away the current law’s provision guaranteeing that people with chronic conditions have access to affordable health insurance. Although the Senate vote was cancelled, the instructions that MGFA provided for your **patient advocacy efforts** are still relevant as Congress may not yet have given up its effort to repeal and replace the ACA. Therefore, MGFA will provide updates as needed and urges your vigilance. As news develops, follow information at [www.myasthenia.org](http://www.myasthenia.org), <http://www.nationalhealthcouncil.org/> and [www.rarediseases.org](http://www.rarediseases.org). Be familiar with how to contact your Senators and Representatives. Go to <https://www.senate.gov/senators/contact/> and <http://www.house.gov/representatives/find/>.

## **Annual MGFA Scientific Session Focuses on Latest Research, Treatment Costs for Patients**

The annual MGFA Scientific Session, in conjunction with the annual meeting of the American Academy of Neuromuscular and Electrodiagnostic Medicine (AANEM), was held September 13 in Phoenix, Arizona. MG neurologists from across the nation discussed the latest research findings, clinical trials, and some of the hot-topic issues concerning rising treatment costs for patients as new drugs potentially come on the market. Twenty-two abstracts were also reviewed and accepted for platform or poster presentations. The conference was led by MGFA MSAB members, Jeffrey Guptill, MD (Duke), Michael Hehir, MD (U. of Vermont) and Amanda Guidon, MD (Massachusetts General Hospital). Included in this E-Update are some of the stories presented at the Scientific Session.

## **MGFA Webinar Answers Patient Questions**

The MGFA hosted a patient webinar on Tuesday, Oct. 3, at 5 p.m. eastern, featuring MG doctors Jonathan Goldstein and Sami Khella. Dr. Goldstein and Dr. Khella responded to questions submitted in advance by MG patients. The webinar was open to all patients and caregivers. A recording will be available after October 31, 2017 on the MGFA web site [www.myasthenia.org](http://www.myasthenia.org). Dr. Goldstein, currently with the Hospital for Special Surgery, Director of Perioperative Neurology was on the faculty of Yale Medical School for the past 20 years was the Director of Neuromuscular Disorders and also the Program Director for the Neuromuscular Medicine Fellowship. During this time, he developed an outstanding program to evaluate and treat patients with disorders involving strength and sensation. He also developed an internationally known program in MG and other autoimmune neurological conditions. Dr. Khella, Chief, Department of Neurology, Penn Presbyterian Medical Center is also a Professor of Clinical Neurology at the University of Pennsylvania with more than 20 years’ experience in treating and caring for patients with neurologic diseases. Dr. Khella is a founding member of the International Thymic Malignancy Interest Group (ITMIG) an internationally renowned group of physicians dedicated to the treatment of thymoma and other thymic malignancies. He has also developed the largest MG program in Philadelphia that also sponsors a patient support group that meets regularly. Check out MGFA’s complete Webinar offerings by going to <http://www.myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx> .

## **Did you join the MG Patient Registry?**

If not, make a point of doing so this week. You'll be helping the entire MG Community --“The only way we can really understand MG is if we have more information about who gets MG, when they get it, their symptoms” ... Robert Ruff, MD, PhD, Immediate Past Chairman Medical/Scientific Advisory Board and MGFA Board Member. Through the registry the MG community will help identify how each of us was diagnosed, how we are being treated, our insurance challenges, and how we are feeling. By making a patient community more accessible and understandable, a patient registry and its bounty of information can encourage pharmaceutical developers to pursue drug discovery in a disease such as MG. To join go to [MG Patient Registry Link](#).

## **MG Walks Near \$700,000 in Fundraising Efforts**

With recent Fall walks in Indiana, Kentucky, Ohio, Chicagoland, Virginia, Maryland, Portland and Utah, the MG Walks have climbed their nationwide fundraising total to close to \$675,000. nearing the year-end goal of raising \$900,000. Since the inception of the MG Walks in 2011, more than \$5 million has been raised to support MGFA's efforts to fund research, provide patient services, raise awareness, advocate on behalf of people who have MG, and ultimately find a cure. Visit [www.mgwalk.org](http://www.mgwalk.org) for information or call 1-855-649-2557.

### **UPCOMING WALKS**

- Oct. 8 Colorado  
Cherry Creek State Park, Hobie Hill Shelter, Aurora, CO
  
- Oct. 14 Mississippi  
Sam Coopwood Park, Holly Springs, MS
  
- Oct. 14 Southern Illinois  
Washington Park, Metropolis, IL
  
- Nov. 18 Houston  
Stude Park, Houston, TX
  
- Nov. 18 Sacramento  
William Land Park, Sacramento, CA
  
- Nov. 18 Greater Los Angeles  
Location: TBA
  
- Nov. 19 Austin, Texas  
East Metro Park, Manor, TX

- Nov. 19 Inland Empire  
Spirit Park, Menifee, CA
- Nov. 19 Bay Area  
Lake Merced Park, San Francisco, CA
- Dec. 2 Arkansas  
Lake Dardanelle State Park, Russellville, AR
- Dec. 3 Arizona  
Chaparral Park, Scottsdale, AZ

## **Don't Forget! The Next MGFA National Conference**

Kansas City, Kansas City here we come! The next National Conference will take place April 15<sup>th</sup> to 17<sup>th</sup> in Kansas City, MO at the Intercontinental Kansas City at the Plaza. And, our national walk will take place on April 14<sup>th</sup> – details will be forthcoming – but plan to form teams and be a Walker in KC! Known as the “City of Fountains”, Kansas City is an exciting, hidden gem in our nation’s heartland and is famous for its barbecue, fountains, jazz, creative arts scene, sports and more. *Mark your calendars* for a fun and educational experience that rare occasion when you can meet so many others in the MG Community both patient and professional. More information will be forthcoming soon. Watch the MG website and Facebook site for more!

## **MG Research and Clinical Trials**

### **New Data Proves Long Term Use of Eculizumab**

Data from an open-label extension study involving the use of eculizumab was on full display at the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) Annual Meeting in Phoenix, Arizona. The new data shows the drug to be safe and effective to treat patients with myasthenia gravis. Eculizumab is an antibody directed toward the complement system that has already been approved for paroxysmal nocturnal hemoglobinuria (PNH) and atypical hemolytic uremic syndrome (aHUS). The open label study (ECU-MG-302) was for patients who completed the 26-week, double-blind, placebo-controlled REGAIN study which tested the use of eculizumab in patients with anti-acetylcholine receptor refractory generalized myasthenia gravis. In the open label extension, patients received eculizumab (maintenance dose: 1200 mg every 2 weeks). The study found that patients who took eculizumab for 26 weeks in the REGAIN study and then continued to take the drug in the extension study (n=56), had stable scores on their myasthenia gravis activities of daily living (MG-ADL) questionnaire. Further, those switching from placebo to eculizumab (n=60) showed a statistically significant improvement in their scores within 1 week of treatment. [Click here](#) to read full story.

## **Neurologists Discuss Cost of Care for Refractory Myasthenia Gravis**

At the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) Annual Meeting in Phoenix, Arizona, Gautam Wali and colleagues compared the costs of various treatments for myasthenia gravis to determine which is the most cost-effective – the orphan drug rituximab, plasmapheresis, or intravenous immunoglobulin therapy for patients with refractory muscle-specific receptor tyrosine kinase (MuSK) positive myasthenia gravis. The rising costs of pharmaceutical agents is a common complaint among many, especially those unfamiliar with rare diseases. In many cases, the cost effectiveness of drugs used to treat rare conditions is unclear. Each of the treatments for refractory myasthenia gravis is costly, but just how costly remains to be seen. Wali et al developed a Markov model to calculate lifetime costs associated with rituximab, plasmapheresis, and IVIg for a 25-year old female with refractory MuSK-positive myasthenia gravis. To read the complete story, [click here](#).

## **Award Winning Study Reports that Women’s Quality of Life is Impacted More Than Men With MG**

At the 2017 American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) Annual Meeting, Dr. Ikjae Lee, Assistant Professor of Neurology at the University of Alabama at Birmingham, was honored as the Best Abstract Award Winner for his research, *Gender and Quality of Life In Myasthenia Gravis Patients From The Myasthenia Gravis Foundation of America Registry*. “Dr. Lee’s research has revealed meaningful insights into the treatment and management of patients with MG,” said Dr. Francis O. Walker, AANEM 2017 co-chair of the Program Committee, who selected the winner. “This is why we selected this abstract for the 2017 AANEM Best Abstract Award. This research will help fellow MG doctors in determining the right treatment options for MG patients.”

The [MGFA Patient Registry](#) is a confidential database of people with Myasthenia Gravis (MG) built for research, treatment and patient information. In his review of the data, Dr. Lee said, “Sex differences were clearly present in the MG population and the effect of thymectomy appeared to be different as well.” The key findings of his research showed that quality of life is impaired more so in women than in men with MG. Specifically, it showed that daily function was more impaired, comorbid autoimmune disease was more common, fatigue and depression scores were worse in women as well. When looking at quality of life scores of those with and without thymectomy, his research showed that quality of life scores were significantly better in women who had thymectomy than those who did not. The improvement was not observed in men who had thymectomy.

The full list of 2017 AANEM Annual Meeting abstracts is printed in the September 2017 issue of [Muscle & Nerve](#) and is available here in [PDF](#).

## **Argenx Announces Orphan Drug Designation for ARGX-113 for the Treatment of Myasthenia Gravis**

Argenx a clinical-stage biotechnology company developing a deep pipeline of differentiated antibody-based therapies for the treatment of severe autoimmune diseases and cancer, announced that the Office of Orphan Products Development of the U.S. Food and Drug Administration (FDA) has granted orphan status for the use of ARGX-113 for the treatment of myasthenia gravis. ARGX-113 has the potential to eliminate patient symptoms while minimizing common side effects seen with current treatments by reducing the pathogenic IgG levels. Orphan drug status is granted by FDA to a drug or biological product to treat a rare disease or condition. Orphan drug designation qualifies for various development incentives, including tax credits for qualified clinical testing, a waiver from FDA's application User Fee for marketing application, and a 7-year period of marketing exclusivity in the US. The granting of an orphan designation request does not alter the standard regulatory requirements and process for obtaining marketing approval. Safety and effectiveness of a drug must be established through adequate and well-controlled studies. [Click here](#) to read the press release.

## **New Study to Establish Evidence for MG Treatments**

For the first time, patients and clinicians may soon have empirical evidence for the best treatments for myasthenia gravis, thanks to a newly funded research project led by MGFA Medical/Scientific Advisory Board member Donald Sanders, MD, Duke University School of Medicine, and Pushpa Narayanaswami, MD (Beth Israel Deaconess Medical Center/Harvard Medical School), and funded by a \$2.5 million grant from the Patient-Centered Outcomes Research Institute (PCORI). This grant application has been in the works for nearly a year---with MGFA providing use of the MG Patient Registry and funding a focus group to provide evidence of need. MGFA Board member, Jurgen Venitz, MD, PhD and support group leader Kathie Bibeau are advisors on the project. We at MGFA look forward to continuing to work closely with Drs. Sanders and Narayanaswami and their team as this landmark project is launched. [Click here](#) to read the press release. [Click here](#) to read more about the study.

## **MG and MG Patients in the Media**

### **MGFA Ambassador, Chef Sean Brock, honored in Charleston, SC**

MGFA's Ambassador, the highly acclaimed chef, Sean Brock, known for his Southern culinary creations and restaurants in Charleston, SC and Nashville, TN, has been named "Favorite Chef" in Charleston. Brock's honor was announced in the Charleston, SC *Post and Courier* annual "Charleston's Choice" awards, which contains the low country's top picks in more than 300 categories. To view the publication, click on [www.postandcourier.com/2017charlestonschoice](http://www.postandcourier.com/2017charlestonschoice).

Chef Brock has spoken out about the challenges he faced in getting diagnosed and managing MG. He has begun planning a series of exclusive dinners aimed at raising funds for the MGFA's mission.

## **Pittsburgh Deacon Continues to Serve Others Despite MG**

Deacon Al Poroda was featured in the *Pittsburgh Catholic* for his fight with Myasthenia Gravis, and his ability to serve others in the parish despite the debilitating disease. "He could sit in a chair and feel sorry for himself, but he doesn't," said Tish Cardis, a parishioner at St. Damien of Molokai Parish in Monongahela, where Deacon Al ministers. His fight against the disease has inspired the St. Damien of Molokai faithful and given true witness to what it means to serve others. "That's what I wanted to do," he said of his call to the diaconate. "I wanted to serve the people I was ordained to serve." Deacon Al, 53, first experienced MG symptoms in September 2015 and received a final diagnosis in March 2016. The deacon said that he has been strengthened by the help of the church and its pastor, Father Terza. He also noted the "overwhelming" support of parishioners, who have helped him and his wife learn how to go from being helpers to accepting help. [Click here](#) to read the full story.

## **Newark Community Warrior and MG Patient Featured in New Jersey Star-Ledger Newspaper**

Margaret Barnes-Williams, an MG patient diagnosed in 1989 and having MG for nearly 30 years, was featured in the New Jersey newspaper, the *Star-Ledger*, for her work in the community. She's been a school volunteer, a teacher's aide, parent liaison, youth counselor, summer camp coordinator, parent and teacher mediator, and attendance counselor. Diagnosed in 1989, Barnes-Williams said her condition was in remission until 2013, when she was laid off by the Newark school system. The stress of unemployment landed her in the intensive care unit, she said. She could barely breathe and felt like her life was slipping away. "I flatlined," she said. In that moment, she heard three voices from deceased family members telling her, "Everything would be alright." A pacemaker was implanted and she pulled through. Stress became an afterthought, even though you'd think community work would be a source of consternation. "When she works with the community, she doesn't get stressed out," her husband said. "She's cool with that." [Click here](#) to read the full story.

## **Myrtle Beach Support Group Featured in Local Newspaper**

The Myasthenia Gravis Foundation of America's Myrtle Beach support group in South Carolina was featured in *The Sun News*, Myrtle Beach's local newspaper. The local facilitator, Beverly Watrous, spoke from personal experience in her effort to help others encountering similar straits with MG. The Myrtle Beach group meets 1-3 p.m. on the second Saturday of each month in the Lakeside Crossing development's community room, 140 Lakeside Crossing Drive, Conway, off Myrtle Ridge Drive, just west of U.S. 501. The group is one of only two in South Carolina, the other convening in Mount Pleasant. For more information, contact Beverly at 843-504-8063, or email [beverly-w@live.com](mailto:beverly-w@live.com) (For other support group information in other locations, contact the

MGFA at 800-541-5454 or [www.myasthenia.org](http://www.myasthenia.org)). [Click here](#) to read the Myrtle Beach story and view the support group photo.

## **Benefit Fundraiser Held for Tampa Entertainer, MG Patient**

Tampa entertainer John Timpanelli has been singing professionally for more than 40 years. Recently as he continues to battle MG, which he was diagnosed with four years ago, a group of friends and entertainers has rallied to help with the financial strains Timpanelli and his family are enduring. “That’s What Friends Are For,” a benefit show for Timpanelli, took place Sept. 10. When Timpanelli was 17, he performed in Las Vegas with Buddy Hackett. He has performed with entertainers such as Shirley Jones, Carol Channing and Red Skelton, and spent more than 15 years headlining on cruise ships. Timpanelli most recently has been known for putting together musical revues and dinner shows. But after a medical procedure in April, the singing voice that has been both Timpanelli’s passion and career was silenced. While undergoing a thymectomy (surgical removal of the thymus gland), the singer’s vocal cord was inadvertently paralyzed. He continues to undergo blood transfusions to boost his strength and help alleviate symptoms. He still has his speaking voice, but Timpanelli admits it is severely limited. [Click here](#) to read the full story.

## **“Art Moves Me” Therapeutic Dance Program Helps MG Patient**

The Burchfield Penney Art Center in Buffalo, New York, was featured on National Public Radio for its therapeutic class, “Art Moves Me,” designed for people with neurological movement disorders. Participants first discuss a painting and then begin the Art Moves Me dance class. Held every Wednesday morning through December, the class mostly helps Parkinson’s patients, but one participant whom the program is helping has both Parkinson’s and Myasthenia Gravis. “Learning a new language or learning to play a new musical instrument – all of those things help build the neuro pathways in your brain, and so this is not just a joy for me, but I hope its building the neuro pathways,” said Marsha Guillaume of Amherst. [Click here](#) to read the full story.

## **New York Times features Story about MG**

Lisa Sanders, M.D., a contributing writer for the *New York Times* magazine and the author of “Every Patient Tells a Story: Medical Mysteries and the Art of Diagnosis,” chronicled the trail that doctors followed to reach a diagnosis of MG in a 94-year woman. In her article published on September 26, 2017, Dr. Sanders described MG symptoms, and showed that MG has no age limit. The woman was admitted to Yale New Haven Hospital in Connecticut with a droopy eyelid, trouble talking and swallowing and a history of double vision. Doctors thought initially that she had had a stroke, but when tests ruled out that diagnosis they planned to discharge her with instructions for follow up appointments with her eye doctor and an ear, nose and throat specialist. They considered and ruled out MG in part because of her age and the fact that her symptoms were constant, rather than intermittent. However, when she choked on her food, doctors called in neurologist Dr. Richard Nowak, director of Yale’s MG clinic and a member of MGFA’s Medical/Scientific Advisory Board. Even before seeing the patient, Dr. Nowak told the



resident that he thought she had myasthenia gravis adding that age was not a factor. Nowak said that he recently diagnosed the disease in a 98-year-old man. The blood tests for the 94-year-old patient were positive and she was diagnosed with MG. To read the full article, click on [All Signs Pointed to a Stroke. Then the Tests Come Back Negative.](#)

## **New York Teen with Congenital MG Plays Baseball**

Nico Santiago, of Irondequoit, New York was born with congenital myasthenia gravis. He was sick when he was young, dealing with frequent respiratory infections and multiple hospitalizations. He grew stronger and at age 5, he played Challenger Baseball, a Little League Baseball division that enables children and adults of all ages with physical and mental challenges to play baseball. On August 26, the fields in his community were enhanced by the official opening of Miracle Field of Greater Rochester (NY). The Miracle League was formed in 1999 to offer children with disabilities the opportunity to play, and the first Miracle Field opened in 2000 in Rockdale County, Georgia. The fields, made with a rubberized surface that it is fully wheelchair-accessible, are designed specifically for individuals with physical and/or cognitive challenges. Bases and pitching mounds are painted onto the surface to eliminate raised obstacles that are found on a typical baseball field. The dugouts are enlarged to accommodate wheelchairs and other apparatus.

Nico Santiago, 17, is now a high school senior. In addition to Challenger baseball, he plays for the Rochester Rookies, a Junior Wheelchair and Ambulatory Sports program. “I am really looking forward to seeing this field unify people together,” he said. “It is not just for people in wheelchairs, it’s for people who can also walk. I can tell my friends, ‘Hey let’s go out and play some baseball.’ I can do that with this field.” For information, visit [Miracle Field to open Aug. 26 in Webster](#)

## **What is Myasthenia Gravis?**

This is the question posed by Anna Medaris Miller, staff writer for the *U.S. News and World Report*. In her article, published on July 25, 2017 she described MG, its symptoms, treatments and the need for greater awareness about MG among the public and medical professionals. Miller wrote the article based on interviews with MGFA CEO Nancy Law and Sally O’Meara, a nursing lecturer at Oakland University in Rochester, Michigan, both MG patients, and Gil Wolfe, MD, chair of the department of neurology at the University at Buffalo School of Medicine and Biomedical Sciences. To read the full article, click on <http://health.usnews.com/health-care/patient-advice/articles/2017-07-25/what-is-myasthenia-gravis>

## **Dr. Ruff’s Editorial on Ohio Drug Price Relief Act Published in Akron Beacon Journal**

Bob Ruff, Immediate Past Chairman of the MGFA Medical/Scientific Advisory Board (MSAB) and current board member of the MGFA, had an editorial published in the *Akron Beacon Journal*, voicing his support for Issue 2, the Ohio Drug Price Relief Act. “I passionately believe that people need to be able to get the medications they need at reasonable prices. I doubt that all

those who speak for the opposition on this issue can say the same.” Ruff continued, “Costs of medications are skyrocketing, and consumers are left with no real options. If a consumer thinks one brand of car is too expensive, he or she can shop for another model. With medications, we’re forced to pay whatever the price is because our health and lives depend on it. The pricing of treatments for severe illnesses do not follow usual economic models where introducing a cheaper-to-produce product would lower prices.” [Click here](#) to read his complete editorial.

## **Other Health News and Studies**

### **The Effect of Happiness on People Living with a Chronic Condition**

Researchers at the University of Washington Healthy Aging Rehabilitation Research and Training Center sought to find out if happiness could potentially protect people living with a chronic condition from distress. They also wanted to find out if different approaches to happiness would be equally effective in promoting well-being. They defined happiness in three basic ways: we can engage in pleasurable activities; we can find meaning in life and the things we do; or we can be completely absorbed or engaged in an activity. Researchers found that people living with chronic conditions who are middle-aged report more distress than those who were younger or older, and people who had more than one condition were experiencing more distress. They also found that people who were less happy were more distressed. In particular, they reported that finding purpose or meaning in life was associated with being less distressed. The study, “Benefits of Happiness and Finding Your Sense of Purpose” was released in July. To learn more, click on <http://agerrtc.washington.edu/node/216>.

## **News from the Public Sector**

**U.S. House of Representatives** [www.congress.gov](http://www.congress.gov)

**U.S. Senate** [www.senate.gov](http://www.senate.gov)

### **Graham Cassidy bill to Repeal and Replace the ACA**

The latest effort to repeal and replace the Affordable Care Act (ACA), known as the Graham-Cassidy bill, was pulled from Senate consideration after the Republican leadership in the Senate determined that there were not enough votes to pass it. The withdrawal followed September 25 release of the Congressional Budget Office (CBO) preliminary report of the bill in conjunction with the Joint Committee on Taxation (JCT). The CBO and JCT estimated that passage of Graham-Cassidy would reduce by millions the number of people with comprehensive health

insurance that covers high-cost medical events compared with the baseline projections for each year during the decade. The CBO reported that the number could vary widely depending on how states implemented the legislation and further stated that the direction of the effect is clear – a reduction in the number of insured people relative to the number under current law. To read the report and history of CBO reports on related legislation, click on <https://www.cbo.gov/publication/53126> .

The MGFA, concerned that the Graham-Cassidy bill could have taken away the provision in the current law that guarantees that people with chronic conditions have access to affordable health insurance, issued a **Call to Action: Protect Patients with Pre-conditions** on September 20. Although the Senate vote on the proposal was cancelled, the instructions that MGFA provided for your **patient advocacy efforts** are still relevant as Congress may not have given up its effort to repeal and replace the ACA. Therefore, MGFA will provide updates as needed and urges your vigilance. As news develops follow information at [www.myasthenia.org](http://www.myasthenia.org), <http://www.nationalhealthcouncil.org/> and [www.rarediseases.org](http://www.rarediseases.org). Be familiar with how to contact your Senators and Representatives. Go to <https://www.senate.gov/senators/contact/> and <http://www.house.gov/representatives/find/>.

## **Health and Human Services (HHS) [HHS.gov](http://www.hhs.gov)**

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

On September 14, CMS announced details for providers about the transition to new Medicare numbers and cards. In a statement dated September 21, CMS wrote: CMS, through the Medicare Administrative Contractors (MACs), recently mailed letters to all Medicare Fee-For-Service providers about our work to assign new numbers (known as Medicare Beneficiary Identifiers or MBIs) and issue new Medicare cards to all people with Medicare beginning in April 2018. Our top priorities are to make sure:

- Your Medicare patients have continuous access to care.
- You have the tools and information you need for a smooth transition. Starting in June 2018, you can look up your patients’ new Medicare numbers through your MAC’s secure web portal.

CMS also unveiled the [new Medicare card design](#) and issued a [press release](#) with more information about the project.

### **Office of the Inspector General (OIG)**

#### **Medical Identify Theft**

On October 2, the OIG posted medical identity theft information on its web site. The OIG stated, “Medical identity theft is when someone steals or uses your personal information (like your

name, Social Security number, or Medicare number), to submit fraudulent claims to Medicare and other health insurers without your authorization. Medical identity theft can disrupt your medical care, and wastes taxpayer dollars. You should protect your personal information, check medical bills and statements, and report questionable charges or fraud.” For details about protecting yourself from medical identity theft, click on <https://go.usa.gov/xn3YX>.

## **Health Resources and Services Agency (HRSA)**

### **Nursing Workforce Report**

On July 21 the National Center for Health Workforce Analysis (NCHWA) released its report on the supply and demand projections for registered nurses (RNs), and licensed practical/vocational nurses (LPNs) in 2030. According to the study, which used 2014 as the base year, the U.S. is expected to have an inequitable distribution of RNs and LPNs across states. Specifically, seven states are projected to have a shortage of RNs and thirty-three states are expected to experience a shortage of LPNs. NCHWA also released a series of Program Highlights for academic year 2015-2016, which summarize the characteristics and accomplishments of the Bureau of Health Workforce programs and their trainees. The [Supply and Demand Projections of the Nursing Workforce: 2014-2030](#) report and the [Program Highlights](#) are both available on [NCHWA’s website](#).

## **U.S. Food and Drug Administration (FDA)**

### **Hurricane Season Advice**

Hurricane season spans June 1 through November 30. With nearly 2 months more of possible storm threats, people who live in hurricane prone areas need to be prepared. The FDA released “Hurricane Season: Be Prepared,” which appears on [the FDA’s Consumer Updates page](#). It provides suggestions including packing medicines when preparing to evacuate and safeguarding medicines during the storm. To view the FDA Update, click on <https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm403865.htm>. In addition, the University of Texas Health Sciences Center released “Hurricane and Flood Handbook: Preparing Before the Storm.” Click on <https://www.uthealthleader.org/story/hurricane-flood-2>

## **News from Other Organizations**

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

On September 14, NORD joined nearly 140 patient organizations, including MGFA, in sending a letter to Congress in support of the Orphan Drug Tax Credit (ODTC). NORD stated that the ODTC is vital to orphan diseases because, without it, one-third fewer orphan drugs would be

developed going forward. The ODTC allows drug manufacturers to claim a tax credit of 50 percent of the qualified costs of clinical research and drug testing of orphan drugs (drugs for diseases affecting 200,000 Americans or fewer) and therefore provides incentives to develop products for rare diseases. NORD stated that in the decade before the Orphan Drug Act, only 10 medicines were developed for rare diseases. Since 1983, more than 3,500 potential treatments have been designated as orphan drugs, and the FDA approved more than 500 orphan therapies, a direct result of the incentives provided by the ODA, including the tax credit. Go to [www.rarediseases.org](http://www.rarediseases.org) “ADVOCATE” Menu for more information.