



MYASTHENIA GRAVIS  
FOUNDATION OF AMERICA, INC.

# E-Update

## E-Update Winter 2016 Edition

February 2016

### MGFA News

**National Conference** “*Together We are Stronger*” is the theme for the MGFA 2016 national conference set for May 1-3 in Raleigh, NC. The tentative agenda contains information about exciting educational sessions that address MG issues for all ages and interests. Attendees will hear reports from health professionals and researchers; stories and advice from patients and caregivers; tips for managing MG and coping; information to help understand MG crisis and information and support for parents of young children with MG.

Go to [www.myasthenia.org](http://www.myasthenia.org) to view the tentative agenda, register for the conference, and make hotel reservations.

### **Rare Disease Day 2016—the Patient Voice**

This year's Rare Disease Day was February 29, 2016 and the theme was the *Patient Voice*. Although one day is devoted to enabling people to participate in the "conversation" about rare disease such as MG with people from all over the world, the activities and strategies to enhance awareness can be used throughout the year. To learn more about rare disease advocacy and related activities, click on [www.myasthenia.org](http://www.myasthenia.org). MGFA suggests using social media, planning activities for support groups, and holding in-person meetings and educational sessions with local community residents, leaders and elected officials. Remember, it is not necessary to limit your advocacy efforts to February 29<sup>th</sup>. They can be used effectively all year round.

### **June is MG Awareness Month**

It's time to start planning for ***June is MG Awareness Month***. This is our observance and a wonderful chance to make your community aware of MG. Observance activities can be small or large. Wear your MG T-shirt, join an MG

Walk, tell your story and talk about MG at your house of worship, club or other gathering. Make it a point to start up conversations about MG, in a very low-key way, when opportunities strike. Work with your support group to develop ideas for what you can do locally. As you gear up for June, be on the lookout for MGFA's June Awareness Poster to be distributed via mail to Support Group and other volunteers in April. Share the poster by asking to put it up in places such as your local library, doctor's office or house of worship bulletin board. If you need some posters, please contact the National Office after April 16th at 1-800-541-5454. Look for the next Foundation Focus in late March/early April with its article on the month for more ideas. Or, check out the 2015 Spring Issue of Foundation Focus on line with its article **Top 10 Things to Do During June Awareness Month** by going to [www.myasthenia.org](http://www.myasthenia.org) – <http://myasthenia.org/AboutMGFA/FoundationFocusNewsletter.aspx>, choose Spring 2015 for that year's cover article.

### **MGFA Walks**

As of this writing the Spring Walk Season is starting up again in New Orleans - 3/5/16, Tampa Bay - 3/12/16; South Florida - 3/13/16; Tallahassee - 3/13/16; Orlando - 3/19/16 Georgia - 4/2/16; North Carolina & South Carolina – take place 4/30 in conjunction with the MGFA National Conference. As Spring and Summer heat up many other MG Walks are taking place around the country North, South, East and West. Walks are a wonderful community builder, awareness creator and opportunity to support research and patient services through the MGFA our national organization. Walks are becoming even better with the MG Snowflake program where walkers maximize the value of their efforts by holding snowflake parties; encouraging local businesses to support the Walks by selling snowflakes and encouraging team members to make their personalized snowflakes to display at the team finish line. Here's a great quote illustrating our theme: *Snowflakes are one of nature's most fragile things, but just look at what they can do when they stick together.* – Vesta M. Kelly. For more on the Walks and the Snowflake campaign go to [www.mgwalk.org](http://www.mgwalk.org) and to <http://www.mgwalk.org/snowflake/> Remember to enjoy the snowflakes!

## **Research News**

**CuraVac Inc Developing Immunotherapies** CuraVac, Inc. is developing a new class of immunotherapies against autoimmune diseases. On February 9, 2016 the company announced that it has launched a phase 1b study of its lead program, CV-MG01. This program was developed for the treatment and potential cure of myasthenia gravis and received orphan drug designation from the FDA in 2011 and the European Medicines Agency (EMA) in 2009. A European phase 2b study is planned for 2017, subject to further funding. The

company also plans to launch a parallel phase 2b study in the United States. To view the CuraVac press release, go to: <http://www.curavac.com/wp-content/uploads/2016/02/160209-Curavac-Plans-Ph2-Studies-final1.pdf>

**Catalyst Pharmaceuticals** On February 8 Catalyst announced the initiation of a clinical trial to evaluate safety, tolerability and efficacy of Firdapse® (amifampridine phosphate) as a symptomatic treatment for patients with MuSK-antibody positive myasthenia gravis (MuSK-MG). The study will be conducted by a team of researchers in Milan, Italy. For information, click on <http://ir.catalystpharma.com/releasedetail.cfm?ReleaseID=953737>

On February 17 Catalyst announced that the company received a "Refusal to File" letter from the U.S. Food and Drug Administration (FDA) regarding its New Drug Application (NDA) for Firdapse®, the company's investigational drug for the treatment of Lambert Eaton Myasthenic Syndrome (LEMS) and congenital myasthenic syndromes. The letter stated that after a preliminary review, the FDA has found that the application was not sufficiently complete, and FDA requested additional supporting information. For further information, click on: <http://ir.catalystpharma.com/releasedetail.cfm?releaseid=955223>

## **News from the Public Sector**

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

#### **Disability.Gov**

The January 2016 Newsletter *Disability Connection* features tips for job hunting at <https://www.disability.gov/disability-connection-newsletter-january-2016/> Tips include job seekers' employment rights under the Americans with Disabilities Act (ADA), job placement programs, interviewing, and help for veterans .

### **White House Conference on Aging (WHCOA)**

#### **WHCOA Final Report**

The WHCOA has completed its work and issued its final report that can be found at <http://www.whitehouseconferenceonaging.gov/2015-WHCOA-Final-Report.pdf>

### **U.S. Congress**

#### **Recognize, Assist, Include, Support, and Engage Family Caregivers**

**Act (S1719/HR3099)** Known as the RAISE Family Caregivers Act, this bipartisan legislation has passed in the Senate but still needs to be passed in the House. Passage efforts are led by Senators Collins (ME) with original

cosponsors Senators Baldwin (WI), Ayotte (NH), Bennet (CO) and Mikulski (MD). The legislation calls for the HHS Secretary to develop, maintain and update an integrated strategy to recognize and support family caregivers. MGFA has joined with 50 other organizations to advocate for its enactment and urges individuals to contact their respective members of Congress to support this legislation. For information about the act, go to: <http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2015/raise-family-caregivers-act.html> To locate congressional members and their contact information, go to: <http://www.house.gov/representatives/>

**Advancing Research for Neurological Diseases (HR292/S849)** This act, created to set up a nationwide system to track the incidence and prevalence of neurological diseases, has been included in the 21<sup>st</sup> Century Cures Act (HR6). To track the bill, click on: <https://www.congress.gov/bill/114th-congress/house-bill/6>

## State Government

### **State Caregiver Legislation**

A total of eighteen states have passed laws in the past 2 years that recognize caregivers' roles when a patient is hospitalized. For example, a new California law requires hospitals to give patients the opportunity to name a caregiver who will be notified when the patient is to be discharged and provide information to the caregiver about follow up care. Arkansas, New Hampshire, Oregon and Virginia have enacted similar laws. The AARP has launched a campaign advocating caregiver legislation in all states and has crafted a model bill, the Caregiver Advise, Record, Enable Act. (CARE Act) as a result of findings in its survey of caregivers. To view AARP's report from the survey, click on: <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html> To view the California bill, go to <http://leginfo.legislature.ca.gov/> and enter "SB675."

## American Autoimmune Related Diseases Association (AARDA)

### **The State of Autoimmune Disease Summit**

On December 28, 2015 the AARDA released "Highlights from The State of Autoimmune Disease: A National Summit" held in early 2015 in Washington, D.C. The AARDA describes the highlights as providing "important information and updates to patients, physicians, researchers and those who oversee and set U.S. health and health care policy." The report may be downloaded at <http://www.aarda.org/>. AARDA invites individuals interested in autoimmune

diseases to utilize the report, including reproducing it either in whole or in part with proper credit given to the AARDA.

**National Rehabilitation Information Center (NARIC)**

The core mission of NARIC is to collect and disseminate the results of research funded by the National Institute on Disability and Rehabilitation Research (NIDILRR). The February 10 issue of NARIC's weekly digest of new research featured an article on key factors for successfully integrating service dogs in the workplace. Service dogs or assistance dogs are used by many people with disabilities to maintain independence at home, at work, and in the community. For details, click on: [What are Key Factors in Successfully Integrating Service Dogs in the Workplace?](#)

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