This year's Rare Disease Week on Capitol Hill will be held February 25th – February 28th and is a great way to be a voice for all those with MG and be heard by your National Representatives (they really do listen). We would love to have you join us to ensure the needs of everyone with MG and others with rare diseases are met.

**What is Rare Disease Week?** RDLA, a program of EveryLife Foundation, hosts a free event on Capitol Hill to bring the rare disease community and their caregivers together to advocate on federal legislative healthcare issues, meet other advocates, share their unique stories with legislators, and express why it's important to pass key reform bills.

[Click Here to Register]

Below (continued on pg, 2), you may review the 2020 schedule and a brief description of the day. All events are catered to participants with special needs and staff is there to assist at every turn.

For more information on the event, please contact event organizer:
Shannon von Felden
svonfelden@everylifefoundation.org

For more information on joining MGFA at the event, please contact:
Lisa Douthit
MGFA’s Legislative Representative
lisa@lisadouthit.com
562-458-9548

Nakeshia Betsill
Director of Volunteer Advocacy Programs
nbetsill@myasthenia.org
202-591-2493
**Rare Disease Week on Capitol Hill 2020 Schedule of Events**

**Please note that you may sign-up for as much or little as you like however, in order to meet with your representatives on Thursday you are required to attend the Legislative Conference on Wednesday to learn how to advocate.**

**Monday, February 24th**
Time TBD: FDA’s Rare Disease Day Public Meeting, FDA, 10903 New Hampshire Ave, Silver Spring, MD

**Tuesday, February 25th**
1:00 to 2:00 pm: Rare Disease Congressional Caucus briefing and Group Photo on Capitol Hill  
5:30 to 9:00 pm: Cocktail Reception and Rare Disease Documentary Screening, Ronald Reagan Building, 1300 Pennsylvania Ave. NW

Advocates will have the opportunity to attend the Rare Disease Congressional Caucus briefing, which will convene policy experts and rare disease stakeholders to educate Congressional staff and the public on issues of importance to the rare disease community.

**Wednesday, February 26th**
8:00 to 4:45 pm: Legislative Conference, Ronald Reagan Building, 1300 Pennsylvania Ave. NW  
6:00 to 8:00 pm: YARR (Young Adults) Meetup, 1012 14th Street NW, Washington, DC

Advocates attend RDLA’s Legislative Conference to learn about the legislative process, legislation currently under consideration by Congress, and effective advocacy techniques to build a relationship with Members of Congress and staff. The conference is crafted to educate advocates with little to no political experience and provide useful updates to those with a history of political action. RDLA’s aim is to have every advocate leave the Legislative Conference with confidence in their ability to make a difference on Capitol Hill.

**Thursday, February 27th**
7:00 to 8:30 am: Hill Day Breakfast, Ronald Reagan Building, 1300 Pennsylvania Ave. NW  
9:00 to 5:00 pm: Scheduled Meetings w. Members of the House and Senate on Capitol Hill  
5:00 to 7:00 pm: Rare Artist Reception, Capitol Hill

Keynote speakers at breakfast will prepare attendees for their meetings with Members of Congress and staff. Advocates will put what they learned at the Legislative Conference to work as they advocate for the legislation most relevant to them in Lobby Day meetings. That evening, the EveryLife Foundation will host the Rare Artist Reception with artists from around the country displaying their work and sharing their experience with rare disease with Members of Congress and staff.

**Friday, February 28th**
8:30 to 4:00 pm: Rare Disease Day at NIH in Bethesda, MD, 9000 Rockville Pike, Bethesda, MD

Various panels discuss the current state of healthcare and what’s on the horizon. For more information click here to register for this event separately.

For more information on the event, please contact program organizer Shannon von Felden at svonfelden@everylifefoundation.org