



# EMPOWERING THE RARE DISEASE COMMUNITY

A PROGRAM OF THE EVERYLIFE FOUNDATION FOR RARE DISEASES

## **RDLA October 2018 Newsletter**

### **Capitol Hill Updates**

**Increased NIH Funding Passed for FY2019:** The Senate passed the FY 2019 Labor, Health and Human Services Appropriations bill on August 23, 2018, which increased the NIH budget by \$2 billion, up 5% from last year, to \$39.1 billion with \$711 million for the 21<sup>st</sup> Century Cures Act. The Senate and House passed the conference report in September and the President signed it into law on September 28, 2018.

**Opioid Legislation Passed:** On September 17<sup>th</sup>, the Senate passed the Opioid Crisis Response Act of 2018 (OCRA), a package of bills that directs funding to federal agencies to establish or expand programs dealing with prevention, treatment and recovery. The House passed their version of an opioid legislative package, SUPPORT for Patient and Communities Act, in June 2018. The House and Senate worked to reconcile differences between the two bills, and the House passed the conference report on September 28, 2018. The Senate needs to vote on the conference report before it can be sent to the President to sign into law.

**Senate Hearing on October 3<sup>rd</sup>:** EveryLife Foundation's Board Chair, Mark Dant, will testify at the Senate HELP Subcommittee on Children and Families hearing titled "Rare Diseases: Expediting Treatment for Patients". The hearing will be held on October 3, 2018 at 2:30 pm in 430 Dirksen Senate Office Building. The hearing will have patient advocates, clinicians, and industry professionals testify on what Congress can do to improve the process and help ensure patients with rare genetic diseases have treatment options to alleviate their conditions.

**Rare Disease In-District Lobby Days:** Rare Disease advocates across the country met with their Senators and Representatives in their home states during the July and August recesses. Advocates educated Members and their staff about rare diseases and policies and legislation that affect the community. In all, 270 advocates met with 245 Members and/or staff in 46 states and the District of Columbia. Thanks to all the Rare Disease Advocates who participated!

**The Deferment for Active Cancer Treatment Act Signed into Law:** The Deferment for Active Cancer Treatment Act, HR 2976/S 1509, was passed by the House and Senate as part of the LHHS minibus and signed into law by the President on September 28, 2018. This new law will allow young adult cancer patients to pause interest from being added to student loans while they are fighting a life-threatening illness.

**The Ensuring Lasting Smiles Act, HR 6689/S 3369:** The Ensuring Lasting Smiles Act was introduced in August by Senators Tammy Baldwin and Joni Ernst and in the House by Representatives Collin Peterson and David Young. HR 6689/S 3369 will ensure health insurance coverage for medically necessary treatment and procedures for individuals both with congenital anomalies or birth defects, including any serious dental and oral-related procedures that are necessary to maintaining health and overall function.

### **Community Action Alerts & Policy Resources**

**The OPEN Act:** The EveryLife Foundation for Rare Diseases asks you to take action to support the Orphan Product Extensions Now, Accelerating Cures and Treatments (OPEN ACT, HR 1223/S 1509) before the end of this Congress. The OPEN ACT could bring hundreds of safe, effective, and affordable medicines to rare disease patients within the next several years by incentivizing drug makers to repurpose therapies for the treatment of life-threatening rare diseases. Take action [here](#).

**Election Day:** Americans will head to the polls to elect their local, state, and federal representatives on November 6, 2018. This process and free elections are essential to our democracy. Make sure you are registered to vote so that you can vote in this election. You can find out how to register in your state by visiting [www.vote.gov](http://www.vote.gov).

Research America provides information on their website to encourage advocates to urge candidates in the 2018 election to make scientific, medical, and health research a national priority. You can learn more [here](#).

### **Community Events**

**National Advocates Briefing on the States: 2019 and Beyond, October 11, 2018:** This event will take place on October 11, 2018 at the Willard InterContinental Hotel in Washington, DC.

**RDLA Monthly Webinar and In-Person Meeting, October 17, 2018:** After a hiatus, the RDLA Monthly Webinar and In-Person Meetings will return on Wednesday, October 17<sup>th</sup>. The RDLA Monthly Meetings are an opportunity to educate patient advocates about pressing health policy topics so that they can be successful legislative advocates. The meetings are attended either through a Webinar or in person in Washington, DC. Advocates, staffers, and industry are welcome to join. Register to join at on the [RDLA website](#). If you would like to present at the meeting about a current policy issue, please email Shannon von Felden at [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org).

**BIO Patient and Health Advocacy Summit, October 25-26, 2018:** The Summit will take place on October 25 and 26, 2018 at the Park Hyatt hotel in Washington, DC. This event brings together patient advocacy organizations, academia, regulators, biotechnology industry, and others to discuss important policy and issues and best practices. Register [here](#) to attend.

**Save the Date: Rare Disease Week on Capitol Hill, February 24-27, 2019:** RDLA will bring over 500 patient advocates to Washington, DC for a week of events dedicated to empowering

patients, families, and friends to become legislative advocates. Advocates will have an opportunity to meet with Members of Congress and learn best practices for successful advocacy.

RDLA offers travel stipends to participants to offset the cost of attending Rare Disease Week on Capitol Hill. The 2019 travel stipend application will open on October 8th and close on December 14th, 2018. Registration for the event begins on January 3, 2019 at [rareadvocates.org/rdw](http://rareadvocates.org/rdw).

On February 27th, as part of Rare Disease Week on Capitol Hill, the NIH will host Rare Disease Day at NIH. This event aims to raise awareness about rare diseases, the people they affect and NIH research collaborations to advance new treatments.

### **Join Our Mailing List and On Social Media**

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\*\*\*This E-Blast shares action alerts, legislative, and policy news and events from the patient advocacy community. RDLA does not take positions on the issues herein, but serves as a supportive clearinghouse for the rare disease community. Send us an email if you'd like your alerts and/or events included! Email [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org).