RDLA November 2018 Newsletter

Capitol Hill Updates

Opioid Legislation Becomes Law: On September 17th, 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 had passed their version of an opioid legislative package, SUPPORT for Patient and Communities Act, in June 2018. The House and Senate worked via conference to reconcile differences between the two bills. The House passed the conference agreement on September 28th and the Senate passed it on October 3rd. The bill was signed into law by the President on October 24, 2018.

Access to Genetic Counselor Services Act Introduced: The Access to Genetic Counselor Services Act, HR 7083, was introduced in October by Representatives Paulsen (R-MN) and Loebsack (D-IA). HR 7083 proposes to expand coverage of services provided by genetic counselors under the Medicare Part B program.

Community Action Alerts & Policy Resources

The Ensuring Lasting Smiles Act (ELSA): The National Foundation for Ectodermal Dysplasias (NFED) asks you to write your member of Congress and ask them to cosponsor the Ensuring Lasting Smiles Act (S.3369/H.R.6689). ELSA will assure that individuals born with congenital anomalies receive health benefits for the medically necessary treatments they need. ELSA would require all groups and individual health care plans to covers procedures to restore or repair normal body function for any missing or abnormal body part, including teeth. It closes a loophole that allows health care plans to deny such procedures as "cosmetic". Take action here.

The Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act, S. 2465: Sick Cells and the Sickle Cell Disease Association of America asks you to write your Representatives and ask them to support S. 2465 and bring it to the House floor for a vote before the end of the year. On February 26, 2018, the U.S. House of Representatives passed the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act, HR 2410 (Rep. Danny Davis, D-IL). On February 28, 2018, Senator Cory Booker (D-NJ) and Senator Tim Scott (R-SC) introduced S. 2465, the companion bill in the Senate. The Senate bill incorporated changes to include "other heritable blood disorders" in addition to sickle cell disease and passed the Senate on October 11, 2018. Since the passed

Senate bill includes changes, the House must bring the Senate passed bill to the House floor for a vote before it can be sent to the President to be signed into law. 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 to vote during early voting or on election day to ensure your voice is heard.

Community Events

RDLA Monthly Webinar and In-Person Meeting, November 14, 2018: The last RDLA Monthly Webinar and In-Person Meeting of 2018, will take place on Wednesday, November 14th. 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 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.

Leveraging Real-World Treatment Experience from Expanded Access Protocols, November 19, 2018: The Reagan-Udall Foundation for the Food and Drug Administration invites representatives from government, industry, physicians, patients, and advocacy groups to a public meeting at the FDA White Oak campus in Maryland. Speakers include Scott Gottlieb, MD, FDA Commissioner and Janet Woodcock, MD, Director, FDA Center for Drug Evaluation and Research. Register to attend here.

Expand Access 2.0 Summit: The Expand Access 2.0 Summit will take place on January 22-23, 2019 at the National Press Club in Washington, DC. The summit will establish best practices for pre-approval access to new medicines and is free for patients. Register to attend here.

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 is open until December 14th, 2018. Registration for the event begins on January 3, 2019 at rareadvocates.org/rdw.

On February 28th, 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.

EveryLife Foundation's Rare Giving Program: The EveryLife Foundation's Rare Giving program is now accepting applications for sponsorship of upcoming rare disease events that encourage collaboration among rare diseases and/or promote audience engagement in advocacy

for public policy. Examples of events that we have financially supported include the Conference for Adrenal Insufficiency, Utah Rare Symposium, Family Education Summit at Camp Sunshine, PFDD meeting for Charcot-Marie-Tooth & related inherited Neuropathies.
To request sponsorship of your 2019 event, please submit a letter of request that includes the projected number of attendees, participating organizations, diseases covered, agenda and website links along with sponsorship levels and benefits to Lindsey Cundiff at lcundiff@everylifefoundation.org by November 30, 2018. Lindsey will notify all applicants in December whether they are able to sponsor their events.

Join Our Mailing List and On Social Media
Stay up to date on breaking rare disease legislative news by following @RareAdvocates on Twitter and Facebook and rare_advocates on Instagram.

Receive this from a friend? Sign-up for our email list to make sure you don't miss monthly newsletters and action alerts!

***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.