Headline News

21st Century Cures Draft Legislation Released
The powerful Energy & Commerce Committee has released a draft of the much-anticipated 21st Century Cures legislation. The draft addresses a wide-variety of issues of interest to the rare disease community, including expanded access policies, drug repurposing and exclusivity extensions (OPEN ACT), patient focused drug development, and a host of other medical issues. Already, some dissent has emerged from the Democrats who claim their issues were not included in the bill. We will continue to closely track and monitor changes to the legislation and alert advocates for action opportunities. You may view the full bill and summary here. FaegreBD consulting has also released an analysis of what the path forward might look like.

Cystic Fibrosis in the State of the Union
As many of you no doubt heard, the President's address highlighted the work of one outstanding advocate, Bill Elder Jr., on behalf of the cystic fibrosis community. During the speech, Bill was invited to sit next to First Lady Michelle Obama in recognition of his efforts. In collaboration with Vertex Pharmaceuticals Inc., the Cystic Fibrosis Foundation was able to play a major role in financing the research that enabled a new treatment for the deadly disease.

Community Action Alerts

Deadline Approaching, Sign-On to Support the OPEN ACT
The EveryLife Foundation for Rare Diseases is calling for organizations to sign-on support the OPEN ACT, legislation to incentivize repurposing of existing drugs for rare disease indications. To date, over 100 organizations have signed-on! Support in Congress is growing as well - the Energy & Commerce Committee has included this
legislation as part of the broader, 21st Century Cures package. Read the letter to Congress and view the action alert here. To sign-on, send an email to Max Bronstein mbronstein@everylifefoundation.org. Signing deadline is Friday, January 30th.

Sign-on to support the Advancing Research for Neurological Diseases Act HR 292
Reps. Burgess (R-TX) and Van Hollen (D-MD) have introduced HR 292, the Advancing Research for Neurological Diseases Act of 2015. The bill would create a national data collection system at the Centers for Disease Control (CDC) focused on neurological diseases, including Parkinson's disease. It is estimated that between 500,000 to 1.5 million Americans are living with Parkinson's, but this lack of understanding inhibits Parkinson's research, programs, and services. The Parkinson's Action Network (PAN) strongly supports this legislation. Similar legislation passed unanimously in the House of Representatives in 2010 but stalled in the Senate – PAN need's your help! Learn more here and click here to take action.

Congress Needs to Hear from You: Submit Your Patient Stories
Rare Disease Week is just a few weeks away! For those who are unable to attend this year, please send us your stories so we can hand deliver them to your Members of Congress on your behalf. Click here to complete the form, and feel free to email Andy Russell arussell@everylifefoundation.org should you have any questions.

Sign-on to Protect Incentives for Medical Innovation
The Global Colon Cancer Association and the Information Technology and Innovation Foundation are leading an effort on a national medical innovation declaration to be delivered to U.S. government leaders, highlighting the importance of robust incentives to encourage investment in R&D for life-saving biopharmaceuticals. Click here to sign-on.

Upcoming Events

February 23-27: Rare Disease Week is right around the corner!
We are less than one month away from this year’s Rare Disease Week on Capitol Hill. Have you registered yet? Rare Disease Week (Feb 23-27) is a five day event aimed at empowering the rare disease community. If you would like more information, or have any questions about all the events, we have scheduled an
informational webinar for Jan. 28th.

Additionally, there are still travel scholarships available to advocates from the following states: Alaska, Arizona, Arkansas, Hawaii, Idaho, Iowa, Kentucky, Maine, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Mexico, North Dakota, South Carolina, South Dakota, Utah, Vermont, West Virginia, and Wyoming. Please click here to apply.

February 26: Rare Disease Congressional Caucus Briefing
Mark your calendars for the next Rare Disease Congressional Caucus briefing, being held on Capitol Hill from noon-1:30pm on Thursday, February 26 (room TBA). The briefing will address the urgent health care policy needs of the rare disease community - click here to register.

February 18: Rare Disease Week Webinar
The next Rare Disease Week Webinar will be held on Wednesday, February 18 at 2pm (Eastern time). The webinar will provide an overview of Rare Disease Week and provide participants the opportunity to ask any questions they may have. Click here to register.

March 3rd: Blue Skies & Brickwork Health Policy Summit
Novartis is holding its 10th annual Blue Skies & Brickword Health Policy Summit on Tuesday, March 3rd, in Washington D.C. from 8:30am-2:00pm. The event will take place at the Newseum, located at 555 Pennsylvania Ave. NW, DC. You may RSVP and view the event summary here.

January 29: Scoring Progress Against Cancer
A new tool called PACE Continuous Innovation Indicators will help inform policymakers about the impact of cancer innovation. Keynote will feature John C. Lechleiter, CEO of Eli Lilly and Company. The event will take place at the Knight Conference Center at the Newseum, 555 Pennsylvania Ave, NW DC, on Thursday, January 29 from noon-2:45pm. RSVP to rsvptocll@togorun.com.