



**Senate Request: Please Advance the Cures Legislation to the Senate Floor  
Immediately**

**Background:** In 2016, Chairman Lamar Alexander (R-TN) held three hearings in the HELP Committee to pass individual companion bills to HR 6 although as of June 2016, no package has been sent to the Senate floor for consideration. In the House, Energy & Commerce (E&C) Chairman Fred Upton (R-MI) and Representative Diana DeGette (D-CO) lead a bipartisan effort to improve our nation's biomedical research and innovation system. In July 2015, the resulting bill, HR 6 or the 21<sup>st</sup> Century Cures Act, passed the House by a wide bipartisan margin.

**The Process:** The E&C Committee convened dozens of roundtables, hearings, and opportunities for public input and comment as they set out to uncover biomedical policy challenges. The Senate HELP committee took a similar approach involving a wide range of stakeholders, including federal agency leaders from the National Institutes of Health (NIH), Food and Drug Administration (FDA), patient advocates, and representatives from industry among others.

**The Provisions:** The 21<sup>st</sup> Century Cure Act (HR 6) contains a wide variety of provisions critical to the rare disease community. Both the NIH and FDA were provided billions and hundreds of millions in new funding respectively, along with special mandatory funding streams. In addition, bills to encourage the development of new therapies for rare and pediatric patients were included, such as the OPEN ACT (S 1421/HR 971) and the Advancing Hope Act (S 1878/HR 1537). The Senate, however, has been unable to reach a compromise on funding for NIH and FDA and some of the bills, including the OPEN ACT, were not included.

**The Ask:** With the conclusions of summer recess, legislators will have a very limited time window to pass legislation prior to the end of the session. The Senate must take action to advance a package to the floor for consideration and final vote. This legislation could be a game changer for the 30 million Americans with a rare disease, many of whom simply cannot afford to wait any longer. Further delays in legislation will result in delays in treatment. Please advance the 21<sup>st</sup> Century Cures legislation to the Senate floor right away. Time is running out.

*For more information, contact: Max Bronstein at the EveryLife Foundation for Rare Diseases: [mbronstein@everylifefoundation.org](mailto:mbronstein@everylifefoundation.org) and Vignesh Ganapathy, [vganapathy@everylifefoundation.org](mailto:vganapathy@everylifefoundation.org).*