

115TH CONGRESS
2D SESSION

H. RES. 1154

Affirming the importance of the Orphan Drug Act, applauding its lifesaving contributions over its 35-year history, and recognizing the need to continue supporting research and development for rare diseases.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 16, 2018

Mr. LANCE (for himself, Mr. BUTTERFIELD, and Ms. ESHOO) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Affirming the importance of the Orphan Drug Act, applauding its lifesaving contributions over its 35-year history, and recognizing the need to continue supporting research and development for rare diseases.

Whereas 30,000,000 people in the United States, or nearly 1 out of every 10 Americans, lives with at least 1 of more than 7,000 known rare diseases;

Whereas the Orphan Drug Act of 1983 (Orphan Drug Act) was enacted to provide research and development incentives to encourage the development of new therapies for diseases affecting fewer than 200,000 people in the United States;

Whereas in the 10 years prior to enactment of the Orphan Drug Act, only 10 therapies for rare diseases were developed by private industry and approved for patients;

Whereas since enactment of the Orphan Drug Act, research and development of therapies addressing rare diseases has resulted in more than 650 new therapies for rare diseases;

Whereas experts estimate that without the Orphan Drug Tax Credit, one of the Orphan Drug Act's incentives, at least a third of the new treatments would likely not have been developed;

Whereas the Orphan Drug Act continues to result in increased research and successful therapeutic development along the full range of rare diseases, including the rarest diseases;

Whereas people with rare diseases benefit from new orphan drugs through longer and higher quality of life;

Whereas society benefits from new orphan drugs through increased productivity from those affected as well as a potential decline in the resources devoted to health care, disability, caregiving, and related spending;

Whereas despite the success of the Orphan Drug Act, only approximately 5 percent of the more than 7,000 identified rare diseases have at least one FDA-approved treatment option; and

Whereas the significant, lifesaving accomplishments of the Orphan Drug Act over the course of its 35 years should be recognized: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

1 (1) applauds the tremendous growth in research
2 and development into new therapies for rare diseases
3 and the resulting number of FDA-approved thera-
4 pies for people living with rare diseases;

5 (2) recognizes that significant research and de-
6 velopment efforts and related investments are need-
7 ed to develop therapies to treat and cure the thou-
8 sands of rare diseases for which no treatment op-
9 tions are currently available; and

10 (3) affirms the need to continue supporting
11 public and encouraging private investment in re-
12 search and development of new treatments for rare
13 diseases.

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