

115TH CONGRESS
1ST SESSION

S. RES. 73

Designating February 28, 2017, as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 28, 2017

Mr. BROWN (for himself, Mr. BARRASSO, Mr. WHITEHOUSE, Ms. WARREN, Mr. MARKEY, Mr. COONS, Mr. WICKER, Mr. VAN HOLLEN, Ms. STABENOW, Mrs. FEINSTEIN, Ms. KLOBUCHAR, Mr. HATCH, and Mr. BOOKER) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating February 28, 2017, as “Rare Disease Day”.

Whereas a rare disease or disorder is one that affects a small number of patients and, in the United States, typically fewer than 200,000 individuals annually are affected by a rare disease or disorder;

Whereas, as of February 2017, nearly 7,000 rare diseases affect approximately 30,000,000 people in the United States and their families;

Whereas children with rare genetic diseases account for approximately $\frac{1}{2}$ of the population affected by rare diseases in the United States;

Whereas many rare diseases are serious and life-threatening and lack effective treatments;

Whereas, as a result of Federal laws like the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049), there have been important advances made in research on, and treatment for, rare diseases;

Whereas the Food and Drug Administration has made great strides in gathering patient perspectives to inform the drug review process as part of the Patient-Focused Drug Development program, an initiative that originated under the Food and Drug Administration Safety and Innovation Act (Public Law 112–144; 126 Stat. 993);

Whereas, although nearly 600 drugs and biological products for the treatment of rare diseases have been approved by the Food and Drug Administration, millions of people in the United States have a rare disease for which there is no approved treatment;

Whereas lack of access to effective treatments and difficulty in obtaining reimbursement for life-altering, and even life-saving, treatments remain significant challenges for people with rare diseases and their families;

Whereas rare diseases and conditions include Von Hippel-Lindau syndrome, fibrous dysplasia, sickle cell anemia, spinal muscular atrophy, Duchenne muscular dystrophy, dermatomyositis, cystic fibrosis, Friedreich’s ataxia, many childhood cancers, amyotrophic lateral sclerosis, epidermolysis bullosa, frontotemporal dementia, and metachromatic leukodystrophy;

Whereas people with rare diseases experience challenges that include—

- (1) difficulty in obtaining accurate diagnoses;
- (2) limited treatment options; and

(3) difficulty finding physicians or treatment centers with expertise in the rare diseases;

Whereas the rare disease community gained important new tools during the 114th Congress with the passage of the 21st Century Cures Act (Public Law 114–255), which—

(1) streamlines the review by the Commissioner of Food and Drugs of genetically targeted therapies;

(2) incentivizes the development of rare pediatric disease therapies;

(3) strengthens pediatric medical research; and

(4) adds billions of dollars of funding for the National Institutes of Health;

Whereas both the Food and Drug Administration and the National Institutes of Health have established special offices to advocate for rare disease research and treatments;

Whereas the National Organization for Rare Disorders (referred to in this preamble as “NORD”), a nonprofit organization established in 1983 to provide services to, and advocate on behalf of, patients with rare diseases, remains a critical public voice for people with rare diseases;

Whereas 2017 marks the 34th anniversary of the enactment of the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049) and the establishment of NORD;

Whereas NORD sponsors Rare Disease Day in the United States and partners with many other major rare disease organizations to increase public awareness of rare diseases;

Whereas Rare Disease Day is observed each year on the last day of February;

Whereas Rare Disease Day is a global event, first observed in the United States on February 28, 2009, and was observed in more than 85 countries in 2016; and

Whereas Rare Disease Day is expected to be observed globally for years to come, providing hope and information for rare disease patients around the world: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates February 28, 2017, as “Rare
3 Disease Day”;

4 (2) recognizes the importance of improving
5 awareness and encouraging accurate and early diag-
6 nosis of rare diseases and disorders; and

7 (3) supports a national and global commitment
8 to improving access to and developing new treat-
9 ments, diagnostics, and cures for rare diseases and
10 disorders.

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