

116TH CONGRESS
1ST SESSION

S. RES. 90

Designating February 28, 2019, as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 28, 2019

Mr. BROWN (for himself, Mr. BARRASSO, Mr. WHITEHOUSE, Mr. MARKEY, Mr. BLUMENTHAL, Mr. COONS, Ms. STABENOW, Mr. BOOKER, and Ms. WARREN) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating February 28, 2019, as “Rare Disease Day”.

Whereas a rare disease or disorder is one that affects a small number of patients, which, in the United States, is considered to be a population of fewer than 200,000 individuals;

Whereas, as of the date of the adoption of this resolution, more than 7,000 rare diseases affect as many as 30,000,000 people in the United States and their families;

Whereas children with rare diseases account for a significant portion 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 the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049), there have been important advances made in the research of, 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 was reaffirmed under the FDA Reauthorization Act of 2017 (Public Law 115–52; 131 Stat. 1005);

Whereas, although more than 750 orphan indications for drugs and biological products have been approved by the Food and Drug Administration for the treatment of rare diseases, 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 McArdle disease, Ehlers-Danlos syndrome, acoustic neuroma, Paget disease, Landau-Kleffner syndrome, necrotizing fasciitis, mucopolysaccharidosis type I, Rasmussen encephalitis, Sanfilippo syndrome, Prader-Willi syndrome, Wagner syndrome, Barth syndrome, and many rare cancers;

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 disease affecting the individual;

Whereas the 115th Congress passed a 10-year extension of the Children’s Health Insurance Program under title XXI of the Social Security Act (42 U.S.C. 1397aa et seq.), ensuring health insurance coverage for many children with rare diseases;

Whereas both the Food and Drug Administration and the National Institutes of Health have established special offices to support and facilitate 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 2019 marks the 36th 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 that—

- (1) was first observed in the United States on February 28, 2009; and
 - (2) was observed in more than 90 countries in 2018;
- 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, 2019, 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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