

114TH CONGRESS
2D SESSION

S. RES. 380

Designating February 29, 2016 as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 29, 2016

Mr. BROWN (for himself, Mr. BARRASSO, Mr. WICKER, Mr. WHITEHOUSE, Ms. WARREN, Mr. COONS, and Mr. HATCH) submitted the following resolution; which was referred to the Committee on the Judiciary

MARCH 1, 2016

Committee discharged; considered and agreed to

RESOLUTION

Designating February 29, 2016 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 the date of approval of this resolution, 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 about $\frac{1}{2}$ of the population affected by rare diseases in the United States;

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

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 (in this preamble referred to as the “FDA”) has made great strides in involving the patient in the drug review process as part of the Patient-Focused Drug Development program, an initiative that originated in the Food and Drug Administration Safety and Innovation Act (Public Law 112–144; 126 Stat. 993);

Whereas, although approximately 500 drugs and biological products for the treatment of rare diseases have been approved by the FDA, millions of people in the United States have a rare disease for which there is no such approved treatment;

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

Whereas rare diseases and conditions include epidermolysis bullosa, progeria, sickle cell anemia, spinal muscular atrophy, Duchenne muscular dystrophy, Tay-Sachs disease, cystic fibrosis, pulmonary fibrosis, many childhood cancers, fibrodysplasia ossificans progressiva, Smith-Magenis syndrome, Batten disease, and hemophilia;

Whereas people with rare diseases experience challenges that include difficulty in obtaining accurate diagnoses, limited

treatment options, and difficulty finding physicians or treatment centers with expertise in the rare diseases;

Whereas the rare disease community made significant progress during the 113th Congress, including the passage of the National Pediatric Research Network Act of 2013 (Public Law 113–55; 127 Stat. 644), which calls special attention to rare diseases and directs the National Institutes of Health (in this preamble referred to as the “NIH”) to facilitate greater collaboration among researchers;

Whereas the rare disease community continued this progress through the first session of the 114th Congress, including the passage of the Ensuring Access to Clinical Trials Act of 2015 (Public Law 114–63; 129 Stat. 549) and through increased funding for orphan products and rare disease research;

Whereas both the FDA and the NIH have established special offices to advocate for rare disease research and treatments;

Whereas the National Organization for Rare Disorders (in this preamble referred to 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 2016 marks the 33rd anniversary of the enactment of the Orphan Drug Act 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 observed in more than 80 countries in 2015; 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 29, 2016, 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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