

113TH CONGRESS
2D SESSION

S. RES. 368

Designating February 28, 2014, as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 27, 2014

Mr. BROWN (for himself, Mr. BARRASSO, Mr. WICKER, Mr. COONS, Mr. BENNET, Mr. WHITEHOUSE, Mrs. FEINSTEIN, Mr. PRYOR, and Ms. WARREN) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating February 28, 2014, as “Rare Disease Day”.

Whereas a rare disease or disorder is one that affects a small number of patients – in the United States, typically less than 200,000 individuals annually;

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 more than half of the population affected by rare diseases in the United States;

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

Whereas great strides have been made in research and treatment for rare diseases as a result of the Orphan Drug Act (Public Law 97-414);

Whereas the Food and Drug Administration has made great strides in involving the patient in the drug review process as part of its Patient-Focused Drug Development program, an initiative that originated in the Food and Drug Administration Safety and Innovation Act (Public Law 112-144);

Whereas a third of all treatments approved by the Food and Drug Administration in 2013 were orphan products intended to treat rare diseases;

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 the rare disease community and their families;

Whereas rare diseases and conditions include epidermolysis bullosa, progeria, sickle cell anemia, spinal muscular atrophy (SMA), Duchenne muscular dystrophy (DMD), Tay-Sachs, cystic fibrosis, pulmonary fibrosis, many childhood cancers, and fibrodysplasia ossificans progressiva;

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 their diseases;

Whereas the rare disease community made great strides in 2013, including the passage of the National Pediatric Research Network Act (Public Law 113-55), which calls special attention to rare diseases and directs the National

Institutes of Health to facilitate greater collaboration among researchers;

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, an 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 2013 marked the 30th anniversary of the Orphan Drug Act and the National Organization for Rare Disorders;

Whereas the National Organization for Rare Disorders sponsors Rare Disease Day in the United States 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 60 countries in 2013; 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, 2014, as “Rare

3 Disease Day”;

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

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

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