113TH CONGRESS
1ST SESSION

S. RES. 57

Designating February 28, 2013, as ''Rare Disease Day''.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 26, 2013

Mr. BROWN (for himself, Mr. BARRASSO, Mr. WHITEHOUSE, Mr. PRYOR, and Mrs. HAGAN) submitted the following resolution; which was considered and agreed to

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RESOLUTION

Designating February 28, 2013, as ''Rare Disease Day''.

Whereas rare diseases and disorders are those that affect a small number of patients, typically less than 200,000 people in the United States;

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 rare diseases and conditions include epidermolysis bullosa, progeria, sickle cell anemia, Tay-Sachs, cystic fi-

brosis, many childhood cancers, and fibrodysplasia ossificans progressiva;

Whereas people with rare diseases experience challenges that include difficulty in obtaining an accurate diagnosis, limited treatment options, and difficulty finding physicians or treatment centers with expertise in their diseases;

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; 96 Stat. 2049) and amendments made by that Act;

Whereas 2013 marks the 30th anniversary of the Orphan Drug Act and therefore a time to reflect upon the successes of that Act and the challenges to be addressed in the future;

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, was a primary force behind the enactment of the Orphan Drug Act and remains a critical public voice for people with rare diseases;

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 has become a global event occurring annually on the last day of February and was observed in more than 60 countries in 2012;

Whereas Rare Disease Day was observed in the United States for the first time on February 28, 2009; and

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

Resolved, That the Senate—

(1) designates February 28, 2013, as ''Rare Disease Day'';

(2) recognizes the importance of improving awareness and encouraging accurate and early diagnosis of rare diseases and disorders; and

(3) supports a national and global commitment to improving access to, and developing new treatments, diagnostics, and cures for, rare diseases and disorders.

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