

112TH CONGRESS
2D SESSION

S. RES. 383

Designating February 29, 2012, as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 29, 2012

Mr. BROWN of Ohio (for himself and Mr. BARRASSO) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating February 29, 2012, as “Rare Disease Day”.

Whereas rare diseases and disorders are those diseases and disorders that affect a small patient population, which in the United States is typically a population of fewer than 200,000 people;

Whereas, as of the date of approval of this resolution, nearly 7,000 rare diseases affect 30,000,000 people and their families in the United States;

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 life-threatening and lack an effective treatment;

Whereas rare diseases and disorders include epidermolysis bullosa, progeria, sickle cell anemia, Tay-Sachs disease,

cystic fibrosis, many childhood cancers, and fibrodysplasia ossificans progressiva;

Whereas people with a rare disease experience challenges that include difficulty in obtaining an accurate diagnosis, limited treatment options, and difficulty finding a physician or treatment center with expertise in the disease;

Whereas great strides have been made in research and treatment for rare diseases as a result of the Orphan Drug Act (21 U.S.C. 360aa et seq.);

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 that occurs annually on the last day of February;

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

Whereas Rare Disease Day is expected to be observed globally in 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, 2012, 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 the commitment of the United
8 States and all countries to improving access to, and
9 developing, new treatments, diagnostics, and cures
10 for rare diseases and disorders.

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