

113TH CONGRESS
1ST SESSION

H. RES. 91

Expressing support for designation of February 28, 2013, as Rare Disease Day.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 28, 2013

Mr. CARSON of Indiana (for himself, Mr. BURGESS, Mr. CARTWRIGHT, Mr. CASSIDY, Mrs. CHRISTENSEN, Mr. CONYERS, Mr. CROWLEY, Mr. HOLT, Mr. LANCE, Ms. LEE of California, Mr. LEVIN, Ms. NORTON, Ms. SPEIER, and Ms. WASSERMAN SCHULTZ) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for designation of February 28, 2013,
as Rare Disease Day.

Whereas rare diseases and disorders are those which affect small patient populations, typically populations smaller than 200,000 people in the United States;

Whereas nearly 7,000 rare diseases affect 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 fibrosis, 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 disease;

Whereas great strides have been made in research and treatment for rare diseases as a result of the Orphan Drug Act;

Whereas 2013 marks the 30th anniversary of the Orphan Drug Act and therefore a time to reflect upon its successes to date and 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 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;

Whereas February 28, 2013, would be an appropriate date to designate as Rare Disease Day; and

Whereas Rare Disease Day is anticipated 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 House of Representatives—

2 (1) supports the designation of Rare Disease
3 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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