115TH CONGRESS
1ST SESSION

H. RES. 157

Expressing support for the designation of the last day of February each year, as ''Rare Disease Day''.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 28, 2017

Mr. CARSON of Indiana (for himself, Mr. MCCAUL, Ms. BORDALLO, Mr. CROWLEY, Mr. DEUTCH, Mr. LANCE, Mr. MACARTHUR, Mr. MARINO, Ms. MOORE, Ms. NORTON, and Mr. PETERS) submitted the following resolution; which was referred to the Committee on Energy and Commerce

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RESOLUTION

Expressing support for the designation of the last day of February each year, as ''Rare Disease Day''.

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

Whereas nearly 7,000 rare diseases affect nearly 30,000,000 people in the United States and their families;

Whereas over half of all rare diseases affect children;

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

Whereas rare diseases and conditions cross the medical spectrum and include a broad range of diseases such as epidermolysis bullosa, progeria, sickle cell anemia, Tay-

Sachs, Leigh's disease, WAGR syndrome, cystic fibrosis, most childhood cancers, fibrodysplasia ossificans progressiva, Friedreich's ataxia, and tuberous sclerosis;

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 more than 450 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration, millions of people in the United States have rare diseases for which there is no approved treatment;

Whereas challenges to reimbursement for life-altering and often life-saving treatments still exist, such as in reimbursement for medical foods that treat rare metabolic disorders;

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

Whereas the Food and Drug Administration has taken 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;

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'' is a global event occurring 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 anticipated to continue to be observed globally in years to come, providing hope and information for rare disease patients around the world: Now, therefore, be it

Resolved, That the House of Representatives—

(1) supports the designation of ''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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