116TH CONGRESS
2D SESSION

H. RES. 840

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 7, 2020

Mr. CARSON of Indiana (for himself, Mr. HUDSON, Mrs. AXNE, Mrs. BEATTY, Mr. BILIRAKIS, Mrs. BROOKS of Indiana, Mr. BUTTERFIELD, Mr. DEFAZIO, Mr. FITZPATRICK, Ms. LEE of California, Mr. MALINOWSKI, Ms. MATSUI, Ms. ROYBAL-ALLARD, Mr. RUSH, and Mr. VISCLOSKY) 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 more than 7,000 rare diseases affect approximately 30,000,000 people in the United States and their families;

Whereas children with rare diseases account for a significant proportion of the population affected by rare diseases;

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

Whereas rare diseases and conditions cross the medical spectrum;

Whereas individuals 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 although over 840 drugs and biologics have been approved for the treatment of rare diseases by the Food and Drug Administration, millions of people in the United States have rare diseases for which there is no approved treatment;

Whereas lack of effective treatments and difficulty in obtaining reimbursement for life-altering and often life-saving treatments remain significant challenges for individuals with rare diseases and their families;

Whereas, as a result of the Orphan Drug Act, there have been important advances in research of and treatment for rare diseases;

Whereas the Food and Drug Administration has taken great strides in gathering patient perspectives to inform the drug review process as part of its Patient-Focused Drug Development program, an initiative that was reaffirmed under the Food and Drug Administration Reauthorization Act of 2017;

Whereas the 115th Congress passed a 10-year extension of the Children's Health Insurance Program, ensuring coverage for many children with rare diseases;

Whereas both the Food and Drug Administration and the National Institutes of Health have established special offices to support and facilitate rare disease research and treatments;

Whereas the National Organization for Rare Disorders, a nonprofit 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 the National Organization for Rare Disorders sponsors ''Rare Disease Day'' in the United States and partners with many other major rare disease organizations 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'' was observed in the United States for the first time on February 28, 2009, and observed in more than 100 countries in 2019; 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

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 treat-

ments, diagnostics, and cures for, rare diseases and disorders.

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