115TH CONGRESS
2D SESSION

S. RES. _____

Designating February 28, 2018, as ''Rare Disease Day''.

IN THE SENATE OF THE UNITED STATES

Mr. BROWN (for himself, Mr. BARRASSO, Mr. MARKEY, Mr. WHITEHOUSE, Ms. WARREN, Ms. STABENOW, Mr. WICKER, Mr. BOOKER, Ms. KLOBUCHAR, and Mr. HATCH) submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Designating February 28, 2018, as ''Rare Disease Day''.

Whereas a rare disease or disorder is one that affects a small number of patients, which in the United States is considered to be a population of less than 200,000 individuals;

Whereas, as of February 2018, nearly 7,000 rare diseases affect approximately 30,000,000 people in the United States and their families;

Whereas children with rare diseases account for about half of the population affected by rare diseases in the United States;

Whereas many rare diseases are serious and life-threatening and lack effective treatments;

Whereas, as a result of the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049), important advances have been made in the research and treatment of rare diseases;

Whereas the Food and Drug Administration has made great strides in gathering patient perspectives to inform the drug review process as part of the Patient-Focused Drug Development program, an initiative that originated under the Food and Drug Administration Safety and Innovation Act (Public Law 112–144; 126 Stat. 993);

Whereas, although more than 600 drugs and biological products have been approved by the Food and Drug Administration for the treatment of rare diseases, millions of people in the United States have a rare disease for which there is no approved treatment;

Whereas lack of access to effective treatments and difficulty in obtaining reimbursement for life-altering, and even life-saving, treatments still remain significant challenges for people with rare diseases and their families;

Whereas rare diseases and conditions include aplastic anemia, porphyria, spina bifida, stiff person syndrome, Gaucher disease, diffuse pulmonary lymphangiomatosis, adrenoleukodystrophy, Noonan syndrome, Rett syndrome, Moebius syndrome, Castleman Disease, epidermolytic ichthyosis, and short bowel syndrome;

Whereas people with rare diseases experience challenges that include—

(1) difficulty in obtaining an accurate diagnosis;

(2) limited treatment options; and

(3) difficulty finding physicians or treatment centers with expertise in rare diseases;

Whereas the rare disease community gained important new tools during the 115th Congress with the enactment of the FDA Reauthorization Act of 2017 (Public Law 115–52; 131 Stat. 1005), which—

(1) advanced and facilitated the development and timely approval of drugs and biologics for rare diseases, including diseases affecting children;

(2) reauthorized user fees to help deliver safe and effective treatments to individuals with rare diseases;

(3) supported the utilization of real-world evidence;

(4) supported patient-focused drug development; and

(5) supported the National Evaluation System for Health Technology;

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 (referred to as ''NORD'' in this preamble), 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 2018 marks the 35th anniversary of the enactment of the Orphan Drug Act and the establishment of NORD;

Whereas NORD 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 is a global event that was first observed in the United States on February 28, 2009, and observed in more than 94 countries in 2017; and

Whereas Rare Disease Day is expected 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, 2018, 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.