

116TH CONGRESS
2D SESSION

S. RES. 529

Designating February 29, 2020, as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

MARCH 4, 2020

Mr. BROWN (for himself, Mr. BARRASSO, Mr. MARKEY, Ms. KLOBUCHAR, Mr. BOOKER, Mr. WHITEHOUSE, Mr. BLUMENTHAL, Mr. WICKER, and Mr. COONS) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating February 29, 2020, as “Rare Disease Day”.

Whereas a rare disease or disorder is a disease or disorder that affects a small number of patients;

Whereas, in the United States, a rare disease or disorder typically affects fewer than 200,000 individuals;

Whereas, as of the date of the adoption of this resolution, more than 7,000 rare diseases or disorders affect approximately 30,000,000 individuals in the United States and their families;

Whereas children with rare diseases or disorders account for a significant portion of the population affected by rare diseases or disorders in the United States;

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

Whereas, as a result of the enactment 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 and disorders;

Whereas the Food and Drug Administration has made strides in gathering patient perspectives to inform the drug review process as part of the Patient-Focused Drug Development program, an initiative that was reaffirmed under the FDA Reauthorization Act of 2017 (Public Law 115–52; 131 Stat. 1005);

Whereas, although the Food and Drug Administration has approved more than 840 orphan indications for drugs and biological products for the treatment of rare diseases and disorders, millions of individuals in the United States have a rare disease or disorder for which there is no approved treatment;

Whereas limited treatment options and difficulty obtaining reimbursement for life-altering and lifesaving treatments can be challenging for individuals with rare diseases or disorders and their families;

Whereas rare diseases and disorders include acrodermatitis enteropathica, medulloblastoma, Hartnup disease, mast cell activation syndrome, Usher syndrome, osteosarcoma, Kabuki syndrome, Fanconi anemia, Neurofibromatosis, NGLY1 deficiency, Chandler’s syndrome, tularemia, and Joubert syndrome;

Whereas individuals with rare diseases or disorders can experience difficulty in obtaining accurate diagnoses and find-

ing physicians or treatment centers with expertise in their rare disease or disorder;

Whereas the 115th Congress passed a 10-year extension of the Children’s Health Insurance Program under title XXI of the Social Security Act (42 U.S.C. 1397aa et seq.), ensuring health insurance coverage for many children with rare diseases or disorders;

Whereas the Food and Drug Administration and the National Institutes of Health support research on the treatment of rare diseases and disorders;

Whereas 2020 marks the 37th anniversary of the enactment of the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049);

Whereas Rare Disease Day is observed each year on the last day of February;

Whereas, in 2020, Rare Disease Day falls on the rarest of days, February 29;

Whereas Rare Disease Day is a global event that was first observed in the United States on February 28, 2009, and was observed in more than 100 countries in 2019; and

Whereas Rare Disease Day is expected to be observed globally for years to come, providing hope and information for rare disease and disorder patients around the world: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates February 29, 2020, as “Rare
3 Disease Day”; and

4 (2) recognizes the importance of, with respect
5 to rare diseases and disorders—

- 1 (A) improving awareness;
- 2 (B) encouraging accurate and early diag-
- 3 nosis; and
- 4 (C) supporting national and global efforts
- 5 to develop effective treatments, diagnostics, and
- 6 cures.

