III

117TH CONGRESS
2D SESSION

S. RES. 523

Designating February 28, 2022, as ''Rare Disease Day''.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 17, 2022

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

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RESOLUTION

Designating February 28, 2022, 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 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 1 in 10 individuals in the United States;

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 (FDA) 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 1,000 orphan indications for drugs and biological products for the treatment of rare diseases and disorders, 95 percent of rare diseases do not have an FDA-approved treatment for their condition;

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 sickle cell anemia, spinal muscular atrophy, amyotrophic lateral sclerosis, thyroid eye disease, myotonic dystrophy, t-cell prolymphocytic leukemia, microtia, meatal atresia, and conductive deafness;

Whereas individuals with rare diseases or disorders can experience difficulty in obtaining accurate diagnoses and finding physicians or treatment centers with expertise in their rare disease or disorder;

Whereas the 116th Congress passed a 4-year extension of the Rare Pediatric Disease Priority Review Voucher program under section 529(b) of the Federal Food, Drug, and

Cosmetic Act (21 U.S.C. 360ff(b)) as part of the Consolidated Appropriations Act, 2021 (Public Law 116–260; 134 Stat. 1182), providing an incentive for the development of therapies for children with rare diseases;

Whereas the 116th Congress passed the Advancing Care for Exceptional Kids Act (Public Law 116–16; 133 Stat. 852), improving access to coordinated, patient-centered health care for children with complex and rare medical conditions in Medicaid;

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

Whereas 2022 marks the 39th 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 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 2021; 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

Resolved, That the Senate—

(1) designates February 28, 2022, as ''Rare Disease Day''; and

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

(A) improving awareness;

(B) encouraging accurate and early diagnosis; and

(C) supporting national and global efforts to develop effective treatments, diagnostics, and cures.

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