118TH CONGRESS
2D SESSION

S. RES. 636

Designating February 29, 2024, as ''Rare Disease Day''.

IN THE SENATE OF THE UNITED STATES

APRIL 10, 2024

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

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RESOLUTION

Designating February 29, 2024, 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 adoption of this resolution, more than 30,000,000 individuals in the United States are living with at least 1 of the more than 7,000 known rare diseases or disorders;

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;

Whereas 2024 marks the 41st anniversary of the enactment of the Orphan Drug Act (Public Law 97–414; 96 Stat. 2049), a landmark law enabling tremendous advances in the research and treatment of rare diseases and disorders;

Whereas programs such as the Accelerating Rare disease Cures Program of the Food and Drug Administration (referred to in this preamble as the ''FDA'') aim to drive scientific and regulatory innovation and engagement to accelerate the availability of treatments for patients with rare diseases;

Whereas 28 of the 55 novel drugs approved by the Center for Drug Evaluation and Research of the FDA in 2023—

(1) were approved to prevent, diagnose, or treat a rare disease or condition; and

(2) received an orphan-drug designation;

Whereas, although the FDA has approved more than 1,100 drugs and biological products for an orphan indication for the treatment of a rare disease or disorder, approximately 90 percent of rare diseases do not have a treatment approved by the FDA for their condition;

Whereas financing life-altering and lifesaving treatments can be challenging for individuals with a rare disease or disorder and their families;

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 National Institutes of Health support innovative research on the treatment of rare diseases and disorders;

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

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 106 countries in 2023: Now, therefore, be it

Resolved, That the Senate—

(1) designates February 29, 2024, 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 research efforts to develop effective treatments, diagnostics, and cures.

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