

119TH CONGRESS
1ST SESSION

S. RES. _____

Designating February 27, 2025, as “Rare Disease Day”.

IN THE SENATE OF THE UNITED STATES

Mr. BARRASSO (for himself and Mr. BLUMENTHAL) submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Designating February 27, 2025, 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 is defined as affecting 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 10,000 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 2025 marks the 42nd 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 26 of the 50 novel drugs approved by the Center for Drug Evaluation and Research of the FDA in 2024—

(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 882 drugs and biological products with 1,300 orphan indications as of the date of adoption of this resolution, approximately 95 percent of rare diseases still 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: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates February 27, 2025, as “Rare
3 Disease Day”; and

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

6 (A) improving awareness;

7 (B) encouraging accurate and early diag-
8 nosis; and

9 (C) supporting national and global re-
10 search efforts to develop effective treatments,
11 diagnostics, and cures.