

118TH CONGRESS  
2D SESSION

# S. RES. \_\_\_\_\_

Designating February 29, 2024, as “Rare Disease Day”.

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## IN THE SENATE OF THE UNITED STATES

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Mr. BROWN (for himself and Mr. BARRASSO) submitted the following resolution; which was referred to the Committee on \_\_\_\_\_

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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 25,000,000 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, since 2022, governmental agencies have increased their commitment to speeding up and increasing the development of effective and safe treatment options to address the unmet needs of patients with rare diseases;

Whereas programs such as the Accelerating Rare disease Cures Program have taken the lead in driving scientific and regulatory innovation and engagement to accelerate the availability of treatments for patients with rare diseases, in addition to pilot programs such as the rare disease endpoint advancement pilot program in the Food & Drug Administration (referred to in this preamble as the “FDA”) to help facilitate the development and timely approval of rare disease treatments;

Whereas 28 of the 55 novel drugs approved by 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 limited treatment options and financing 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, Sanfilippo syndrome, microtia, cystinosis, 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 FDA and 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;

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; 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, 2024, 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

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