

118TH CONGRESS
2D SESSION

H. RES. 1036

Expressing support for the designation of February 29, 2024, as “Rare Disease Day”.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 29, 2024

Mr. CARSON (for himself, Mr. BACON, Ms. BARRAGÁN, Mrs. BEATTY, Ms. CARAVEO, Mr. DAVIS of North Carolina, Mr. FITZPATRICK, Mr. GALLEGO, Mrs. GONZÁLEZ-COLÓN, Mr. HUDSON, Ms. JACKSON LEE, Ms. KAMLAGER-DOVE, Mr. KEAN of New Jersey, Ms. LEE of California, Mr. MCGOVERN, Mr. MULLIN, Ms. NORTON, Ms. PORTER, Ms. SEWELL, Ms. STANSBURY, Mr. SWALWELL, Ms. TLAIB, Ms. TOKUDA, and Mr. TRONE) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing support for the designation of 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 the 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 this year 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, in 2022, the Center for Drug Evaluation and Research, in the Food and Drug Administration (referred to in this preamble as “FDA”), established the Accelerating Rare disease Cures Program with a vision of speeding and increasing the development of effective and safe treatment options to address the unmet needs of patients with rare diseases;

Whereas the 117th Congress passed into law as part of the Consolidated Appropriations Act, 2023 (Public Law 117–328; 136 Stat. 4459), provisions creating the rare disease endpoint advancement pilot program in the FDA to support the development of novel efficacy endpoints to help facilitate the development and timely approval of rare disease treatments;

Whereas, although the FDA has approved more than 1,100 orphan indications for drugs and biological products for the treatment of rare diseases and disorders, more than 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, 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 the Medicaid Services Investment and Accountability Act of 2019 (Public Law 116–16; 133 Stat. 852), which included provisions for improving access to coordinated, patient-centered health care for children with complex and rare medical conditions in Medicaid, and became effective October 1, 2022;

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 100 countries in 2022; 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 House of Representatives—

1 (1) expresses support for the designation of
2 “Rare Disease Day”; and

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

5 (A) improving awareness;

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

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

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