
THIRD READING

Bill No: ACR 33
Author: Zbur (D), et al.
Introduced: 2/14/25
Vote: 21

SUBJECT: Rare Disease Day

SOURCE: Author

DIGEST: This resolution designates February 28, 2025, as Rare Disease Day and, with respect to rare diseases and disorders, would recognize the importance of improving awareness, encouraging accurate and early diagnosis, and supporting national and global efforts to develop effective treatments, diagnostics, and cures.

ANALYSIS: This resolution makes the following legislative findings:

- 1) In the United States, a rare disease or disorder affects fewer than 200,000 individuals. Children with rare diseases or disorders account for a significant portion of the population affected by rare diseases or disorders in the United States.
- 2) 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. Many rare diseases and disorders are serious and life-threatening.
- 3) Rare diseases and disorders include sickle cell anemia, spinal muscular atrophy, amyotrophic lateral sclerosis (ALS), thyroid eye disease, myotonic dystrophy, t-cell prolymphocytic leukemia, Sanfilippo syndrome, microtia, cystinosis, meatal atresia, and conductive deafness.
- 4) In 2024, California established the Jacqueline Marie Zbur Rare Disease Advisory Council to raise awareness of rare diseases and to provide recommendations to the Legislature to improve access to care.

This resolution designates February 28, 2025, as Rare Disease Day and, with respect to rare diseases and disorders, would recognize the importance of

improving awareness, encouraging accurate and early diagnosis, and supporting national and global efforts to develop effective treatments, diagnostics, and cures.

Related/Prior Legislation

HR 70 (Maienschein, 2024) – Adopted in the Assembly.

HR 16 (Maienschein, 2023) – Adopted in the Assembly.

HR 91 (Maienschein, 2022) – Adopted in the Assembly.

HR 25 (Bonta, Maienschein, and Waldron, 2021) – Adopted in the Assembly.

FISCAL EFFECT: Appropriation: No Fiscal Com.: No Local: No

SUPPORT: (Verified 3/4/25)

None received

OPPOSITION: (Verified 3/4/25)

None received

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