

Date of Hearing: February 17, 2026

ASSEMBLY COMMITTEE ON RULES
Blanca Pacheco, Chair
ACR 132 (Dixon) – As Introduced February 10, 2026

SUBJECT: Rare Disease Day.

SUMMARY: Designates February 28, 2026, as Rare Disease Day, and recognizes the importance of improving awareness, encouraging accurate and early diagnosis, and supporting national and global efforts to develop effective treatments, diagnostics, and cures. Specifically, **this resolution** makes the following legislative findings:

- 1) A rare disease or disorder, many of which are serious and life-threatening, affect a small number of patients. In the United States, a rare disease or disorder affects fewer than 200,000 individuals.
- 2) This year marks the 43rd anniversary of the enactment of the federal Orphan Drug Act, a landmark law enabling tremendous advances in the research and treatment of rare diseases and disorders.
- 3) In 2022, the Center for Drug Evaluation and Research, in the United States Food and Drug Administration (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.
- 4) 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.
- 5) 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.
- 6) Supported by California's world-renowned research and education institutions, the California life sciences sector has led the way by developing innovative technologies and treatments. Nearly 200 rare disease drugs and treatments originated in California through a patient-first approach.
- 7) Limited treatment options and financing life-altering and lifesaving treatments can be challenging for individuals with rare diseases or disorders and their families.
- 8) Rare Disease Day is observed each year on the last day of February. Rare Disease Day is a global event that was first observed in the United States on February 28, 2009, and has grown to be observed by over 100 countries in 2026. 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.

FISCAL EFFECT: This resolution is keyed non-fiscal by Legislative Counsel.

REGISTERED SUPPORT / OPPOSITION:

Support

None on file

Opposition

None on file

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