

**Second Regular Session
Seventy-fifth General Assembly
STATE OF COLORADO**

REVISED

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SJR26-014

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Senate Committees

House Committees

SENATE JOINT RESOLUTION 26-014

101 **CONCERNING THE DECLARATION OF FEBRUARY 28, 2026, AS RARE**
102 **DISEASE DAY.**

1 WHEREAS, Coloradans with rare diseases, and their families,
2 friends, and caretakers, know the challenges they face every day, such as
3 finding knowledgeable providers, obtaining appropriate treatments, and
4 paying and traveling for care, and the many other ways in which life can
5 be extra challenging because of a rare disease; and

6 WHEREAS, One in ten people and more than 500,000 Coloradans
7 live with a rare disease; and

8 WHEREAS, According to the National Institutes of Health, there
9 are more than 30 million Americans, nearly 10% of the country's
10 population, living with a rare disease today; and

Shading denotes HOUSE amendment. Double underlining denotes SENATE amendment.
Capital letters or bold & italic numbers indicate new material to be added to existing law.
Dashes through the words or numbers indicate deletions from existing law.

HOUSE
Final Reading
March 2, 2026

SENATE
Final Reading
February 27, 2026

1 WHEREAS, An estimated 15 million children in the United States
2 have a rare disease, and, sadly, 30% will not live to see their fifth
3 birthday; and

4 WHEREAS, There are more than 10,000 rare diseases, which are
5 defined as medical conditions affecting fewer than 200,000 Americans,
6 and most of these conditions may affect only a few hundred individuals;
7 and

8 WHEREAS, These rare diseases are often lifelong, and many are
9 terminal; and

10 WHEREAS, Most rare diseases are genetic or have a genetic
11 component; no individual or family is immune from a rare disease; and

12 WHEREAS, Direct medical costs for people with rare diseases are
13 three to five times higher than those for people with nonrare diseases;
14 each year the costs amount to an estimated \$400 billion nationwide and
15 \$12 billion in Colorado; and

16 WHEREAS, Fewer than 5% of the known 10,000 rare diseases
17 have an FDA-approved treatment; and

18 WHEREAS, In 1983, the National Organization for Rare
19 Disorders pioneered the passage of the federal "Orphan Drug Act", the
20 world's first law incentivizing drug development for rare diseases by
21 offering market exclusivity and tax credits; and

22 WHEREAS, The zebra is the official mascot for rare disease
23 patients because, historically, medical professionals were taught that
24 when they "hear hoofbeats", they should not expect to see a zebra and
25 should instead look for the more common answer, a horse; and

26 WHEREAS, Today, we know that one in ten Americans is like a
27 "zebra", living with a rare condition; it is not always obvious to recognize
28 or diagnose a person with a rare disease, and, as a result, this can cause
29 a delay in care and can often negatively impact a person's quality of life
30 or life expectancy; and

31 WHEREAS, This Rare Disease Day, special events and activities
32 are planned for February 27th and 28th, including lighting up Denver's

1 City and County Building; additionally, individuals and families affected
2 by rare diseases will be sharing their stories on social media, radio, and
3 TV; in newspaper interviews; and at community events; and

4 WHEREAS, We see our constituents with these conditions and
5 acknowledge the need for better understanding, the need for access to
6 care, and the financial impact on families; and

7 WHEREAS, We also see that these families, despite the
8 challenges, live their lives with optimism, hope for the future, courage,
9 kindness for others, and, most of all, acceptance that this is, through no
10 fault of their own, the life that they have been granted; now, therefore,

11 *Be It Resolved by the Senate of the Seventy-fifth General Assembly*
12 *of the State of Colorado, the House of Representatives concurring herein:*

13 That we, the members of the Colorado General Assembly:

14 (1) Declare February 28, 2026, to be Rare Disease Day in
15 Colorado to help raise awareness of rare diseases within Colorado;

16 (2) "Show our stripes" in solidarity with our community of
17 individual "zebras" living with a rare disease;

18 (3) Recognize and support all of these individuals on this Rare
19 Disease Day, in 2026 and every day;

20 (4) Salute these individuals for all that it means to live with a rare
21 disease and the humanity that they show in so doing; and

22 (5) On this day, as we recognize Rare Disease Day around the
23 country, take a moment to appreciate the more than 500,000 Coloradans,
24 and the more than 30 million Americans, who live with a rare disease
25 today.

26 *Be it Further Resolved*, That copies of this Joint Resolution be sent
27 to the members of the Colorado Rare Disease Advisory Council.