

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

ENGROSSED

LLS NO. R24-1054.01 Rebecca Hausmann x2172

HJR24-1019

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HOUSE JOINT RESOLUTION 24-1019

101 **CONCERNING THE DECLARATION OF FEBRUARY 29, 2024, 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 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
February 29, 2024

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 birthday;
3 and

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

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

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

11 WHEREAS, Direct medical costs for people with rare diseases are
12 three to five times higher than those for nonrare diseases; yearly the costs
13 amount to an estimated \$400 billion; and

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

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

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

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

29 WHEREAS, This Rare Disease Day, special events and activities
30 are planned for February 29th; individuals and families affected by rare
31 diseases will be sharing their stories on social media, radio, and TV; in
32 newspaper interviews; and at community events; and

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

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

8 *Be It Resolved by the House of Representatives of the*
9 *Seventy-fourth General Assembly of the State of Colorado, the Senate*
10 *concurring herein:*

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

12 (1) Declare February 29, 2024, Rare Disease Day in Colorado, to
13 help raise awareness of rare diseases within Colorado;

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

16 (3) Recognize and support all of these individuals on this Rare
17 Disease Day, in 2024, and every day;

18 (4) Salute you for all that it means to live with a rare disease and
19 the humanity that you show in so doing; and

20 (5) On Leap Day 2024, the rarest of days, and the day on which
21 around the country we recognize Rare Disease Day, take a moment to
22 appreciate the more than 500,000 Coloradans, and the more than 30
23 million Americans, who live with a rare disease today.