

AMENDED IN ASSEMBLY FEBRUARY 28, 2011

CALIFORNIA LEGISLATURE—2011–12 REGULAR SESSION

Assembly Concurrent Resolution

No. 13

Introduced by Assembly Members Huffman and Hill

(Coauthors: Assembly Members Achadjian, Alejo, Allen, Ammiano, Atkins, Beall, Bill Berryhill, Block, Blumenfeld, Bonilla, Brownley, Buchanan, Butler, Charles Calderon, Carter, Chesbro, Cook, Davis, Dickinson, Donnelly, Eng, Feuer, Fletcher, Fong, Fuentes, Furutani, Galgiani, Garrick, Gatto, Gordon, Grove, Hagman, Hall, Harkey, Hayashi, Roger Hernández, Huber, Hueso, Jeffries, Jones, Lara, Logue, Bonnie Lowenthal, Ma, Mansoor, Mendoza, Mitchell, Monning, Morrell, Nestande, Nielsen, Olsen, Pan, Perea, John A. Pérez, V. Manuel Pérez, Portantino, Silva, Skinner, Smyth, Solorio, Swanson, Torres, Valadao, Wagner, Wieckowski, Williams, and Yamada)

February 1, 2011

Assembly Concurrent Resolution No. 13—Relative to Rare Disease Day.

LEGISLATIVE COUNSEL'S DIGEST

ACR 13, as amended, Huffman. Rare Disease Day.

This measure would proclaim February 28, 2011, as Rare Disease Day.

Fiscal committee: no.

- 1 WHEREAS, There are nearly 7,000 diseases and conditions
- 2 considered rare (each affecting fewer than 200,000 Americans);
- 3 and

1 WHEREAS, While each of these diseases may affect small
2 numbers of people, rare diseases as a group affect almost 30 million
3 Americans; and

4 WHEREAS, Many rare diseases are serious and debilitating
5 conditions that have a significant impact on the lives of those
6 affected; and

7 WHEREAS, While approximately 360 orphan drugs and
8 biologics have been approved for the treatment of rare diseases
9 affecting between 11 and 14 million people according to the United
10 States Food and Drug Administration, that leaves well over 15
11 million Americans affected by rare diseases with no treatment
12 specific to their disease; and

13 WHEREAS, Individuals and families affected by rare diseases
14 often experience problems such as a sense of isolation, difficulty
15 in obtaining an accurate and timely diagnosis, few treatment
16 options, and problems related to accessing or being reimbursed
17 for treatment; and

18 WHEREAS, Some rare diseases, such as Lou Gehrig's disease
19 and Huntington's disease, are relatively well known, many others
20 are not known at all by the public, making patients and their
21 families bear a large share of the burden for fundraising and
22 research; and

23 WHEREAS, Because nearly one in 10 Americans have a rare
24 disease, Californians are among those affected by those diseases;
25 and

26 WHEREAS, The National Organization for Rare Disorders
27 (NORD) is organizing a nationwide observance of Rare Disease
28 Day on February 28, 2011, on which patients, medical
29 professionals, researchers, government officials, and companies
30 developing treatments for rare diseases will join together to focus
31 attention on rare diseases as a public health issue; now, therefore,
32 be it

33 *Resolved by the Assembly of the State of California, the Senate*
34 *thereof concurring*, That the Legislature proclaims February 28,
35 2011, as Rare Disease Day in California; and be it further

36 *Resolved*, That the Chief Clerk of the Assembly transmit copies
37 of this resolution to the author for appropriate distribution.

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