

AMENDED IN ASSEMBLY FEBRUARY 25, 2010

AMENDED IN ASSEMBLY FEBRUARY 22, 2010

AMENDED IN ASSEMBLY FEBRUARY 16, 2010

CALIFORNIA LEGISLATURE—2009–10 REGULAR SESSION

Assembly Concurrent Resolution

No. 117

Introduced by Assembly Members Hill and Huffman

(Principal coauthors: Senators Corbett and Leno)

(Coauthors: Assembly Members Ammiano, Anderson, Block, Caballero, Coto, Fletcher, Fong, Galgiani, Harkey, Hayashi, Audra Strickland, Swanson, Torlakson, ~~and Villines~~, Villines, Arambula, Beall, Tom Berryhill, Blakeslee, Blumenfield, Bradford, Brownley, Buchanan, Charles Calderon, Cook, De La Torre, Emmerson, Eng, Evans, Feuer, Fuentes, Furutani, Gaines, Gilmore, Hagman, Hernandez, Jeffries, Jones, Knight, Lieu, Bonnie Lowenthal, Ma, Mendoza, Miller, Monning, Nava, Nestande, Niello, Nielsen, John A. Perez, V. Manuel Perez, Ruskin, Salas, Skinner, Torres, and Torrico)

(Coauthor: Senator Wyland)

February 4, 2010

Assembly Concurrent Resolution No. 117—Relative to Rare Disease Day.

LEGISLATIVE COUNSEL’S DIGEST

ACR 117, as amended, Hill. Rare Disease Day.

This measure would proclaim February 28, 2010, 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

4 WHEREAS, While each of these diseases may affect small
5 numbers of people, rare diseases as a group affect almost 30 million
6 Americans; and

7 WHEREAS, Many rare diseases are serious and debilitating
8 conditions that have a significant impact on the lives of those
9 affected; and

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

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

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

26 WHEREAS, Because nearly one in 10 Americans have a rare
27 disease, Californians are among those affected by those diseases;
28 and

29 WHEREAS, The National Organization for Rare Disorders
30 (NORD) is organizing a nationwide observance of Rare Disease
31 Day on February 28, 2010, on which patients, medical
32 professionals, researchers, government officials, and companies
33 developing treatments for rare diseases will join together to focus
34 attention on rare diseases as a public health issue; now, therefore,
35 be it

36 *Resolved by the Assembly of the State of California, the Senate*
37 *thereof concurring*, That the Legislature proclaims February 28,
38 2010, as Rare Disease Day in California; and be it further

- 1 *Resolved*, That the Chief Clerk of the Assembly transmit copies
- 2 of this resolution to the author for appropriate distribution.

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