

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)**

(Coauthor: Senator Wyland)

February 4, 2010

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

LEGISLATIVE COUNSEL'S DIGEST

ACR 117, as introduced, 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 340 orphan drugs and
- 11 biologics have been approved for the treatment of rare diseases

1 affecting between 11 and 14 million people according to the United
2 States Food and Drug Administration, that leaves well over 15
3 million Americans affected by rare diseases with no treatment
4 specific to their disease; and

5 WHEREAS, Individuals and families affected by rare diseases
6 often experience problems such as a sense of isolation, difficulty
7 in obtaining an accurate and timely diagnosis, few treatment
8 options, and problems related to accessing or being reimbursed
9 for treatment; and

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

15 WHEREAS, Because one in 10 Americans have a rare disease,
16 1,000 of residents of California are among those affected by those
17 diseases; and

18 WHEREAS, The National Organization for Rare Disorders
19 (NORD) is organizing a nationwide observance of Rare Disease
20 Day on February 28, 2010, on which patients, medical
21 professionals, researchers, government officials, and companies
22 developing treatments for rare diseases will join together to focus
23 attention on rare diseases as a public health issue; now, therefore,
24 be it

25 *Resolved by the Assembly of the State of California, the Senate*
26 *thereof concurring*, That the Legislature proclaims February 28,
27 2010, as Rare Disease Day in California; and be it further

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