

Assembly Concurrent Resolution

No. 13

Introduced by Assembly Members Huffman and Hill

February 1, 2011

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

LEGISLATIVE COUNSEL’S DIGEST

ACR 13, as introduced, 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
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

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

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

11 WHEREAS, Because nearly one in 10 Americans have a rare
12 disease, Californians are among those affected by those diseases;
13 and

14 WHEREAS, The National Organization for Rare Disorders
15 (NORD) is organizing a nationwide observance of Rare Disease
16 Day on February 28, 2011, on which patients, medical
17 professionals, researchers, government officials, and companies
18 developing treatments for rare diseases will join together to focus
19 attention on rare diseases as a public health issue; now, therefore,
20 be it

21 *Resolved by the Assembly of the State of California, the Senate*
22 *thereof concurring*, That the Legislature proclaims February 28,
23 2011, as Rare Disease Day in California; and be it further

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