

House Resolution

No. 7

Introduced by Assembly Member Levine

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February 14, 2013

House Resolution No. 7—Relative to Rare Disease Day.

- 1 WHEREAS, There are nearly 7,000 diseases and conditions
2 considered rare, each affecting fewer than 200,000 Americans;
3 and
4 WHEREAS, Of these 7,000 rare diseases, more than 80 percent
5 are considered ultra rare, affecting less than a few thousand
6 Americans; and
7 WHEREAS, While each of these diseases may affect small
8 numbers of people, rare diseases as a group affect almost 30 million
9 Americans; and

1 WHEREAS, Many rare diseases are serious and debilitating
2 conditions that have a significant impact on the lives of those
3 affected; and

4 WHEREAS, While more than 350 orphan drugs and biologics
5 have been approved for the treatment of rare diseases affecting up
6 to 14 million people according to the United States Food and Drug
7 Administration, millions of Americans affected by rare diseases
8 have no treatment specific to their disease; and

9 WHEREAS, Besides dealing with their specific medical
10 problems, individuals and their families affected by rare diseases
11 struggle with obtaining an accurate and timely diagnosis, few
12 treatment options, and accessing or being reimbursed for treatment;
13 and

14 WHEREAS, While some rare diseases are relatively well known,
15 many others are not known at all by the public, making patients
16 and their families bear a large share of the burden for fundraising
17 and research; and

18 WHEREAS, Because nearly one in 10 Americans has a rare
19 disease, Californians are among those affected by those diseases;
20 and

21 WHEREAS, Research into rare diseases and development of
22 therapies builds greater understanding of the nature of disease and
23 serves as a foundation for innovation in the United States; and

24 WHEREAS, A nationwide observance of Rare Disease Day will
25 take place on February 28, 2013, when patients, medical
26 professionals, researchers, government officials, and companies
27 developing treatments for rare diseases will join together to focus
28 attention on rare diseases as a public health issue; now, therefore,
29 be it

30 *Resolved by the Assembly of the State of California*, That the
31 Assembly proclaims February 28, 2013, as Rare Disease Day in
32 California; and be it further

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

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