

Assembly Concurrent Resolution

No. 109

Introduced by Assembly Member Pan

(Coauthors: Assembly Members Ammiano, Atkins, Eng, Garrick, Gordon, Hayashi, Roger Hernández, Logue, Bonnie Lowenthal, Mitchell, V. Manuel Pérez, Silva, Smyth, and Williams)

February 14, 2012

Assembly Concurrent Resolution No. 109—Relative to Rare Disease Day.

LEGISLATIVE COUNSEL’S DIGEST

ACR 109, as introduced, Pan. Rare Disease Day.

This measure would proclaim February 29, 2012, as Rare Disease Day in California.

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, Of these 7,000 rare diseases, more than 80 percent
- 5 of them 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
- 10 WHEREAS, Many rare diseases are serious and debilitating
- 11 conditions that have a significant impact on the lives of those
- 12 affected; and

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

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

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

16 WHEREAS, Because nearly one in 10 Americans have a rare
17 disease, Californians are among those affected by those diseases;
18 and

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

22 WHEREAS, The National Organization for Rare Disorders
23 (NORD) is organizing a nationwide observance of Rare Disease
24 Day on February 29, 2012, on which patients, medical
25 professionals, researchers, government officials, and companies
26 developing treatments for rare diseases will join together to focus
27 attention on rare diseases as a public health issue; and

28 WHEREAS, The theme for Rare Disease Day is solidarity,
29 reaffirming the idea that people affected by rare diseases are “Rare
30 But Strong Together”; now, therefore, be it

31 *Resolved by the Assembly of the State of California, the Senate*
32 *thereof concurring*, That the Legislature proclaims February 29,
33 2012, as Rare Disease Day in California; and be it further

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