

AMENDED IN ASSEMBLY APRIL 25, 2016

AMENDED IN ASSEMBLY APRIL 12, 2016

Senate Concurrent Resolution

No. 108

Introduced by Senator Monning

(Principal coauthor: Assembly Member Achadjian)

**(Coauthors: Senators Anderson, Bates, Fuller, Glazer, Hall,
Hertzberg, Leno, Runner, Vidak, and Wieckowski)**

(Coauthors: Assembly Members Baker, Chang, Dodd, Gallagher, Cristina Garcia, Kim, Lackey, Levine, Wagner, ~~and Waldron~~ Waldron, Achadjian, Alejo, Travis Allen, Arambula, Atkins, Bigelow, Bloom, Bonilla, Bonta, Brough, Brown, Burke, Calderon, Campos, Chau, Chávez, Chiu, Chu, Cooley, Cooper, Dababneh, Dahle, Daly, Eggman, Frazier, Beth Gaines, Eduardo Garcia, Gatto, Gipson, Gomez, Gonzalez, Gordon, Gray, Grove, Hadley, Harper, Roger Hernández, Holden, Irwin, Jones, Jones-Sawyer, Linder, Lopez, Low, Maienschein, Mathis, Mayes, McCarty, Medina, Melendez, Mullin, Nazarian, Obernolte, O'Donnell, Patterson, Quirk, Rendon, Ridley-Thomas, Rodriguez, Salas, Santiago, Steinorth, Mark Stone, Thurmond, Ting, Weber, Wilk, and Wood)

February 12, 2016

Senate Concurrent Resolution No. 108—Relative to Rare Disease Day.

LEGISLATIVE COUNSEL'S DIGEST

SCR 108, as amended, Monning. Rare Disease Day.

This measure would proclaim February 29, 2016, as Rare Disease Day in California and would provide for the recognition of Rare Disease Day in California in subsequent years, as specified.

Fiscal committee: no.

1 WHEREAS, There are nearly 7,000 diseases and conditions
2 that are considered rare, each affecting fewer than 200,000
3 Americans, according to the National Institutes of Health; and

4 WHEREAS, While each of these diseases may affect a small
5 number 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 more than 450 drugs and biologics have
11 been approved for the treatment of rare diseases, according to the
12 United States Food and Drug Administration, millions of
13 Americans still have rare diseases for which there is no approved
14 treatment; and

15 WHEREAS, Individuals and families affected by rare diseases
16 often experience problems such as diagnosis delay, difficulty
17 finding a medical expert, and lack of access to treatments or
18 ancillary services; and

19 WHEREAS, While the public is familiar with some rare
20 diseases, many patients and families affected by less widely known
21 rare diseases bear a large share of the burden of funding research
22 and raising public awareness to support the search for treatments;
23 and

24 WHEREAS, Residents of California are among those affected
25 by rare diseases because nearly one in 10 Americans have rare
26 diseases; and

27 WHEREAS, Every year on the last day of February a nationwide
28 observance of rare diseases is organized with patients, medical
29 professionals, researchers, government officials, and companies
30 developing treatments for rare diseases; and

31 WHEREAS, This year's national Rare Disease Day observance
32 will take place on February 29, 2016; now, therefore, be it

33 *Resolved by the Senate of the State of California, the Assembly*
34 *thereof concurring*, That the Legislature hereby proclaims February
35 29, 2016, as Rare Disease Day in California; and be it further

36 *Resolved*, That every year thereafter the Legislature shall
37 recognize Rare Disease Day in California on the last day of
38 February; and be it further

- 1 *Resolved*, That the Secretary of the Senate transmit copies of
- 2 this resolution to the author for appropriate distribution.

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