

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)

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 ~~numbers~~ *number* of people, rare diseases as a group affect almost
- 6 30 million 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

1 WHEREAS, While more than 450 drugs and biologics have
2 been approved for the treatment of rare diseases, according to the
3 United States Food and Drug Administration, millions of
4 Americans still have rare diseases for which there is no approved
5 treatment; and

6 WHEREAS, Individuals and families affected by rare diseases
7 often experience problems such as diagnosis delay, difficulty
8 finding a medical expert, and lack of access to treatments or
9 ancillary services; and

10 WHEREAS, While the public is familiar with some rare
11 diseases, many patients and families affected by less widely known
12 rare diseases bear a large share of the burden of funding research
13 and raising public awareness to support the search for treatments;
14 and

15 WHEREAS, Residents of California are among those affected
16 by rare diseases because nearly one in 10 Americans have rare
17 diseases; and

18 WHEREAS, Every year on the last day of February a nationwide
19 observance of rare diseases is organized with patients, medical
20 professionals, researchers, government officials, and companies
21 developing treatments for rare diseases; and

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

24 *Resolved by the Senate of the State of California, the Assembly*
25 *thereof concurring*, That the Legislature hereby proclaims February
26 29, 2016, as Rare Disease Day in California; and be it further

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

30 *Resolved*, That the Secretary of the Senate transmit copies of
31 this resolution to the author for appropriate distribution.

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