

Introduced by Senator Monning

(Principal coauthor: Assembly Member Achadjian)

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(Coauthors: Assembly Members Chang, Dodd, Gallagher, Kim, Lackey,
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February 12, 2016

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

LEGISLATIVE COUNSEL’S DIGEST

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

This measure would proclaim February 29, 2016, as Rare Disease Day in California and 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 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 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

Americans still have rare diseases for which there is no approved treatment; and

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

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

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

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

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

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

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

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