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**ACR-14 Rare Disease Day.** (2017-2018)

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**Assembly Concurrent Resolution No. 14**

CHAPTER 25

Relative to Rare Disease Day.

[ Filed with Secretary of State April 05, 2017. ]

LEGISLATIVE COUNSEL'S DIGEST

ACR 14, Nazarian. Rare Disease Day.

This measure would proclaim February 28, 2017, 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

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

WHEREAS, While each of these diseases may affect a small number of people, rare diseases as a group affect almost 30 million Americans; and

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

WHEREAS, While more than 450 drugs and biologics have been approved for the treatment of rare diseases, according to the 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 has a rare disease; 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 28, 2017; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature hereby proclaims February 28, 2017, 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 Chief Clerk of the Assembly transmit copies of this resolution to the author for appropriate distribution.