



ACR-43 Rare Disease Day. (2019-2020)

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Assembly Concurrent Resolution No. 43

CHAPTER 34

Relative to Rare Disease Day.

[Filed with Secretary of State April 09, 2019.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 43, Bonta. Rare Disease Day.

This measure would proclaim February 28, 2019, as Rare Disease Day in California.

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, Of these nearly 7,000 rare diseases, more than 80 percent are considered ultra rare, affecting less than a few thousand Americans; 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 600 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, such as "Lou Gehrig's disease," and are sympathetic to those affected, 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, Thousands of residents of California are among those affected by rare diseases because nearly one in 10 Americans has a rare disease; and

WHEREAS, The National Organization for Rare Disorders is organizing a nationwide observance of Rare Disease Day on February 28, 2019; and

WHEREAS, Thousands of patients, caregivers, medical professionals, researchers, companies developing orphan products to treat people with rare diseases, and others in the State of California will participate in that observance; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature hereby proclaims February 28, 2019, as Rare Disease Day in California; and be it further

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