

Assembly Concurrent Resolution No. 109

RESOLUTION CHAPTER 82

Assembly Concurrent Resolution No. 109—Relative to Rare Disease Day.

[Filed with Secretary of State August 21, 2012.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 109, Pan. Rare Disease Day.

This measure would proclaim February 29, 2012, as Rare Disease Day in California.

WHEREAS, There are nearly 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 Americans; and

WHEREAS, Of these 7,000 rare diseases, more than 80 percent of them are considered ultra rare, affecting less than a few thousand Americans; and

WHEREAS, While each of these diseases may affect small numbers 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 approximately 360 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between 11 and 14 million people according to the United States Food and Drug Administration, that leaves well over 15 million Americans affected by rare diseases with no treatment specific to their disease; and

WHEREAS, Besides dealing with their specific medical problems, individuals and their families affected by rare diseases struggle with obtaining an accurate and timely diagnosis, few, if any, treatment options, and problems related to accessing or being reimbursed for treatment; and

WHEREAS, While some rare diseases are relatively well known, many others are not known at all by the public, making patients and their families bear a large share of the burden for fundraising and research; and

WHEREAS, Because nearly one in 10 Americans have a rare disease, Californians are among those affected by those diseases; and

WHEREAS, Research into rare diseases builds greater understanding of the nature of disease and serves as a foundation for innovation in the United States; and

WHEREAS, The National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 29, 2012, on which patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases will join together to focus attention on rare diseases as a public health issue; and

WHEREAS, The theme for Rare Disease Day is solidarity, reaffirming the idea that people affected by rare diseases are “Rare But Strong Together”; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature proclaims February 29, 2012, 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.