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HR-6 (2015-2016)

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AMENDED IN ASSEMBLY MARCH 02, 2015

CALIFORNIA LEGISLATURE— 2015–2016 REGULAR SESSION

HOUSE RESOLUTION

NO. 6

Introduced by Assembly Member Achadjian

~~(Coauthor: Assembly Member Mullin)~~ (Coauthors: Assembly Members Mullin, Alejo, Travis Allen, Atkins, Baker, Bigelow, Bloom, Bonilla, Bonta, Brown, Burke, Calderon, Campos, Chau, Chávez, Chiu, Chu, Cooper, Dababneh, Dahle, Daly, Dodd, Eggman, Frazier, Beth Gaines, Gallagher, Cristina Garcia, Gatto, Gipson, Gomez, Gonzalez, Gordon, Gray, Grove, Harper, Roger Hernández, Holden, Irwin, Jones, Jones-Sawyer, Kim, Lackey, Levine, Linder, Lopez, Low, Maienschein, Mathis, Mayes, McCarty, Medina, Melendez, Nazarian, Obernolte, O'Donnell, Patterson, Perea, Quirk, Rendon, Ridley-Thomas, Rodriguez, Salas, Santiago, Steinorth, Mark Stone, Ting, Wagner, Waldron, Weber, Williams, and Wood)

February 02, 2015

Relative to Rare Disease Day.

LEGISLATIVE COUNSEL'S DIGEST

HR 6, as amended, Achadjian.

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

WHEREAS, Of these 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 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 more than 400 orphan drugs and biologicals have been approved for the treatment of rare diseases affecting up to 14 million people, according to the United States Food and Drug Administration, millions of Americans affected by rare

diseases have no treatment specific to their disease; and

WHEREAS, Besides dealing with their specific medical problems, individuals and their families affected by these rare diseases struggle with obtaining accurate and timely diagnosis, few treatment options, and 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 of fundraising and research; and

WHEREAS, Nearly one in 10 Americans has a rare disease, and a large number of Californians are among those affected by those diseases; and

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

WHEREAS, A nationwide observance of Rare Disease Day will take place on February 28, 2015, when 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; now, therefore, be it

Resolved by the Assembly of the State of California, That the Assembly proclaims February 28, 2015, 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.