

**House Resolution**

**No. 6**

**Introduced by Assembly Member Achadjian**

**(~~Coauthor: Assembly Member Mullin~~)**

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February 2, 2015

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House Resolution No. 6—Relative to Rare Disease Day.

- 1     WHEREAS, There are nearly 7,000 diseases and conditions  
2 that are considered rare, each affecting fewer than 200,000  
3 Americans; and  
4     WHEREAS, Of these 7,000 rare diseases, more than 80 percent  
5 are considered ultra rare, affecting less than a few thousand  
6 Americans; and  
7     WHEREAS, While each of these diseases may affect small  
8 numbers of people, rare diseases as a group affect almost 30 million  
9 Americans; and

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

4 WHEREAS, While more than 400 orphan drugs and biologicals  
5 have been approved for the treatment of rare diseases affecting up  
6 to 14 million people, according to the United States Food and Drug  
7 Administration, millions of Americans affected by rare diseases  
8 have no treatment specific to their disease; and

9 WHEREAS, Besides dealing with their specific medical  
10 problems, individuals and their families affected by these rare  
11 diseases struggle with obtaining accurate and timely diagnosis,  
12 few treatment options, and accessing or being reimbursed for  
13 treatment; and

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

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

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

24 WHEREAS, A nationwide observance of Rare Disease Day  
25 will take place on February 28, 2015, when patients, medical  
26 professionals, researchers, government officials, and companies  
27 developing treatments for rare diseases will join together to focus  
28 attention on rare diseases as a public health issue; now, therefore,  
29 be it

30 *Resolved by the Assembly of the State of California, That the*  
31 *Assembly proclaims February 28, 2015, as Rare Disease Day in*  
32 *California; and be it further*

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

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