

House Resolution

No. 32

Introduced by Assembly Member Mullin

February 14, 2014

House Resolution No. 32—Relative to Rare Disease Day.

1 WHEREAS, There are nearly 7,000 diseases and conditions
2 considered rare, each affecting fewer than 200,000 Americans;
3 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

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

13 WHEREAS, While more than 400 orphan drugs and biologics
14 have been approved for the treatment of rare diseases affecting up
15 to 14 million people according to the United States Food and Drug
16 Administration, millions of Americans affected by rare diseases
17 have no treatment specific to their disease; and

18 WHEREAS, Besides dealing with their specific medical
19 problems, individuals and their families affected by rare diseases
20 struggle with obtaining an accurate and timely diagnosis, few
21 treatment options, and accessing or being reimbursed for treatment;
22 and

23 WHEREAS, While some rare diseases are relatively well known,
24 many others are not known at all by the public, making patients

1 and their families bear a large share of the burden for fundraising
2 and research; and

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

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

9 WHEREAS, A nationwide observance of Rare Disease Day will
10 take place on February 28, 2014, when patients, medical
11 professionals, researchers, government officials, and companies
12 developing treatments for rare diseases will join together to focus
13 attention on rare diseases as a public health issue; now, therefore,
14 be it

15 *Resolved by the Assembly of the State of California,* That the
16 Assembly proclaims February 28, 2014, as Rare Disease Day in
17 California; and be it further

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