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Assembly
California Legislature
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Monday, February 24, 2014
11:50 AM
State Capitol, Room 3162

CONSENT AGENDA

Resolutions

1. HR 32 (Mullin) Relative to Rare Disease Day.

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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.

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Date of Hearing: February 24, 2014

ASSEMBLY COMMITTEE ON RULES

Richard S. Gordon, Chair

HR 32 (Mullin) – As Introduced: February 14, 2014

SUBJECT: Rare Disease Day.

SUMMARY: Proclaims February 28, 2014, as Rare Disease Day in California. Specifically, this resolution makes the following legislative findings:

- 1) There are nearly 7,000 diseases and conditions considered rare; and, rare diseases as a group affecting almost 30 million Americans.
- 2) Many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and, 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.
- 3) Research into rare diseases builds greater understanding of the nature of disease and serves as a foundation for innovation in the United States.
- 4) Because nearly one in 10 Americans has a rare disease, Californians are among those affected by those diseases.

FISCAL EFFECT: None

REGISTERED SUPPORT / OPPOSITION:

Support

California Healthcare Institute

Opposition

None on file

Analysis Prepared by: Nicole Willis / RLS. / (916) 319-2800



February 21, 2014

The Honorable Richard Gordon
Chair, Assembly Committee on Rules
State Capitol, Room 3016
Sacramento, CA 95814

RE: HR 32 (Mullin) – SUPPORT

Dear Chairman Gordon:

On behalf of the California Healthcare Institute (CHI), the statewide public policy association representing the innovative life sciences sector – biotechnology, pharmaceutical, medical device and diagnostics companies, venture capital firms, research universities and institutes and its 267,000 workers – I am writing in support of HR 32, a resolution that recognizes Rare Disease Day in California on February 28, 2014.

Rare diseases are those which affect less than 200,000 Americans. While the total number of patients affected by any one rare disease may be small, collectively 30 million Americans suffer from a rare disease, or about 10 percent of the population. In California alone, that equals nearly four million patients who suffer from a rare disease.

There are nearly 7,000 known rare diseases and conditions. Over 400 orphan drugs have been approved to treat rare diseases, however, for 15 million patients in the United States suffering from a rare disease or condition, there are no treatment options.

CHI is supporting HR 32 to shine a light on the research and innovation taking place in California to develop treatments and cures for rare diseases. Our member companies work tirelessly to expand the understanding of rare diseases and give hope to patients suffering from rare diseases that currently have no treatment options.

We encourage the legislature to proclaim February 28, 2014 as "Rare Disease Day" in California, in conjunction with other Rare Disease Day observations in the United States and around the world.

Sincerely,

A handwritten signature in black ink, appearing to read 'Eve Bukowski', written in a cursive style.

Eve Bukowski
Vice President, State Government Affairs

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