

2016 First Extraordinary Session

HOUSE RESOLUTION NO. 13

BY REPRESENTATIVE ZERINGUE

SPECIAL DAY/WEEK/MONTH: Recognizes Monday, February 29, 2016, as Rare Disease Day in the state of Louisiana

1 A RESOLUTION

2 To recognize Monday, February 29, 2016, as Rare Disease Day in the state of Louisiana.

3 WHEREAS, according to the National Institutes of Health, there are nearly 7,000
4 diseases and conditions that are considered rare in the United States; and

5 WHEREAS, while each of these diseases may affect small numbers of people, rare
6 diseases as a group affect nearly thirty million Americans; and

7 WHEREAS, many rare diseases are serious and debilitating and significantly impact
8 the lives of those affected; and

9 WHEREAS, while more than four hundred fifty drugs and biologics have been
10 approved for the treatment of rare diseases according to the Food and Drug Administration,
11 millions of Americans still have rare diseases for which there is no approved treatment; and

12 WHEREAS, individuals and families affected by rare diseases often experience
13 problems such as diagnosis delay, difficulty in finding a medical expert, and lack of access
14 to treatments or ancillary services; and

15 WHEREAS, many patients and families affected by rare diseases bear the burden of
16 funding research and raising public awareness to support the search for treatments; and

17 WHEREAS, thousands of residents in the state of Louisiana are among those affected
18 by rare diseases since nearly one in ten Americans have a rare disease; and

19 WHEREAS, Monday, February 29, 2016, has been designated by the National
20 Organization for Rare Disorders (NORD) for a nationwide observance of Rare Disease Day;
21 and

1 WHEREAS, thousands of patients, caregivers, medical professionals, researchers,
2 companies that develop orphan products to treat people with rare diseases, and others in the
3 state of Louisiana will participate in the nationwide observance.

4 THEREFORE, BE IT RESOLVED that the House of Representatives of the
5 Legislature of Louisiana does hereby recognize Monday, February 29, 2016, as Rare Disease
6 Day in the state of Louisiana and does hereby encourage all Louisiana citizens to learn more
7 about rare diseases and what can be done to support individuals with rare diseases and their
8 families.

9 BE IT FURTHER RESOLVED that a suitable copy of this Resolution be transmitted
10 to Melody Ferrufino.

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

HR 13 Original

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