



HR0851

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HOUSE RESOLUTION

2 WHEREAS, There are nearly 7,000 diseases and conditions
3 considered rare (each affecting fewer than 200,000 Americans)
4 in the United States, according to the National Institutes of
5 Health; and

6 WHEREAS, While each of these diseases may affect small
7 numbers of people, rare diseases as a group affect almost 30
8 million Americans; and

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

12 WHEREAS, While more than 450 drugs and biologics have been
13 approved for the treatment of rare diseases according to the
14 Food and Drug Administration, millions of Americans still have
15 rare diseases for which there is no approved treatment; and

16 WHEREAS, Individuals and families affected by rare
17 diseases often experience problems such as diagnosis delay,
18 difficulty finding a medical expert, and lack of access to
19 treatments or ancillary services; and

20 WHEREAS, While the public is familiar with some rare

1 diseases, many patients and families affected by less widely
2 known rare diseases bear a large share of the burden of funding
3 research and raising public awareness to support the search for
4 treatments; and

5 WHEREAS, Residents of Illinois are among those affected by
6 rare diseases as nearly one in 10 Americans have rare diseases;
7 and

8 WHEREAS, The National Organization for Rare Disorders is
9 organizing a nationwide observance of Rare Disease Day on
10 February 29, 2016; therefore, be it

11 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE
12 NINETY-NINTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, we
13 declare February 29, 2016 as "Rare Disease Day" in the State of
14 Illinois.