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1 HOUSE RESOLUTION

WHEREAS, There are nearly 7,000 diseases and conditions 2 3 considered rare (each affecting fewer than 200,000 Americans) 4 in the United States, according to the National Institutes of 5 Health (NIH); and WHEREAS, While each of these diseases may affect small 6 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 Food and Drug Administration (FDA), millions of Americans still 14 15 have rare diseases for which there is no approved treatment; 16 and 17 WHEREAS, Individuals and families affected by 18 diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to 19 20 treatments or ancillary services; and

- 1 WHEREAS, While the public is familiar with some rare
- diseases, many patients and families affected by less widely
- 3 known rare diseases bear a large share of the burden of funding
- 4 research and raising public awareness to support the search for
- 5 treatments; and
- 6 WHEREAS, Residents of Illinois are among those affected by
- 7 rare diseases because nearly one in 10 Americans have rare
- 8 diseases; and
- 9 WHEREAS, The National Organization for Rare Disorders
- 10 (NORD) is organizing a nationwide observance of Rare Disease
- Day on February 28, 2018; therefore, be it
- 12 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE
- 13 HUNDREDTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that we
- declare February 28, 2018 as Rare Disease Day in the State of
- 15 Illinois; and be it further
- 16 RESOLVED, That a suitable copy of this resolution be
- 17 presented to the National Organization for Rare Disorders.