



HR0073

LRB098 10710 MST 41034 r

1 HOUSE RESOLUTION

2 WHEREAS, Rare diseases and disorders are those which affect  
3 small patient populations, typically populations smaller than  
4 200,000 individuals in the United States; and

5 WHEREAS, Nearly 7,000 rare diseases affect millions of  
6 Americans and their families; and

7 WHEREAS, Children with rare genetic diseases account for  
8 more than half of the population affected by rare diseases in  
9 the United States; and

10 WHEREAS, Many rare diseases are serious, life-threatening,  
11 and lack an effective treatment; and

12 WHEREAS, Rare diseases and conditions include  
13 epidermolysis bullosa, progeria, sickle cell anemia,  
14 Tay-Sachs, cystic fibrosis, many childhood cancers,  
15 fibrodysplasia ossificans progressiva, and Williams Syndrome;  
16 and

17 WHEREAS, People with rare diseases experience challenges  
18 that include difficulty in obtaining an accurate diagnosis,  
19 limited treatment options, and difficulty finding physicians  
20 or treatment centers with expertise in their disease; and

1           WHEREAS, Great strides have been made in research and  
2 treatment for rare diseases as a result of the Orphan Drug Act  
3 and other acts of Congress; and

4           WHEREAS, The United States Food and Drug Administration and  
5 National Institutes of Health have established special offices  
6 to advocate for rare disease research and treatments; and

7           WHEREAS, The National Organization for Rare Disorders, an  
8 organization established in 1983 to provide services to, and  
9 advocate on behalf of, patients with rare diseases, was a  
10 primary force behind the enactment of the Orphan Drug Act and  
11 remains a critical public voice for people with rare diseases;  
12 and

13           WHEREAS, The National Organization for Rare Disorders  
14 sponsors Rare Disease Day nationwide to increase public  
15 awareness of rare diseases; and

16           WHEREAS, Rare Disease Day has become a global event  
17 occurring annually on the last day of February; and

18           WHEREAS, Rare Disease Day was observed in the United States  
19 for the first time on February 28, 2009; and

1           WHEREAS, Rare Disease Day is anticipated to be observed  
2 globally in years to come, providing hope and information for  
3 rare disease patients around the world; and

4           WHEREAS, It is fitting that the Illinois House joins in  
5 this global observance and takes part in the fight against rare  
6 diseases; therefore, be it

7           RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE  
8 NINETY-EIGHTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
9 we designate the last day of February in 2013 and 2014 as Rare  
10 Disease Day in the State of Illinois; and be it further

11           RESOLVED, That we recognize the importance of improving  
12 awareness and encouraging accurate and early diagnosis of rare  
13 diseases and disorders; and be it further

14           RESOLVED, That we wholeheartedly support a State,  
15 national, and global commitment to improving access to and  
16 developing new treatments, diagnostics, and cures for rare  
17 diseases and disorders.