



HR0651

LRB102 26110 LAW 35602 r

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HOUSE RESOLUTION

2           WHEREAS, The National Institutes of Health reports that  
3 there are nearly 7,000 diseases and conditions that affect  
4 fewer than 200,000 Americans, which means that they are  
5 considered rare; and

6           WHEREAS, While each of these diseases may affect small  
7 numbers of people, rare diseases as a group affect nearly 30  
8 million Americans, 50 percent of whom are children; and

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

12           WHEREAS, While the Food and Drug Administration has  
13 approved drugs and biologics for more than 1,000 rare disease  
14 indications, millions of Americans have rare diseases for  
15 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, such as muscular dystrophy and amyotrophic lateral  
2 sclerosis, better known as Lou Gehrig's disease, and is  
3 sympathetic to those affected, many patients and families  
4 affected by lesser-known rare diseases bear a large share of  
5 the burden of funding research and raising public awareness to  
6 support the search for treatments; and

7 WHEREAS, With nearly one in ten Americans diagnosed with a  
8 rare disease, thousands of Illinois residents are among those  
9 affected by rare diseases; those affected were given a voice  
10 in 2017 with the establishment in this state of the Rare  
11 Disease Advisory Commission; and

12 WHEREAS, The Orphan Drug Act has encouraged and promoted  
13 the discovery and development of biopharmaceuticals designed  
14 to treat and potentially cure rare diseases; and

15 WHEREAS, Many of the world's leading academic  
16 institutions, academic medical centers, biotech companies, and  
17 pharmaceutical companies that are conducting research and  
18 seeking cures for rare diseases are doing so in this State;  
19 therefore, be it

20 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE  
21 HUNDRED SECOND GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
22 we declare February 28, 2022 as Rare Disease Day in the State

1 of Illinois in order to raise awareness of rare diseases,  
2 support individuals and families who struggle with rare  
3 diseases, bring attention to the need for research and funding  
4 to support the discovery and development of therapies designed  
5 to treat and potentially cure rare diseases, and support the  
6 continued work of the Illinois Rare Disease Commission; and be  
7 it further

8       RESOLVED, That suitable copies of this resolution be  
9 presented to iBIO, the Illinois Biotechnology Industry  
10 Organization, Chairperson Maria Bellefeuille of the Illinois  
11 Rare Disease Commission, and the Department of Public Health.