



SR0726

LRB103 36811 MST 66922 r

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SENATE RESOLUTION

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

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

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

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WHEREAS, While the Food and Drug Administration has approved drugs and biologics for more than 1,000 rare disease indications, millions of Americans have rare diseases for which there is no approved treatment; and

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

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WHEREAS, While the public is familiar with some rare

1 diseases, such as muscular dystrophy and amyotrophic lateral  
2 sclerosis (Lou Gehrig's disease), and is sympathetic to those  
3 affected, many patients and families affected by lesser-known  
4 rare diseases bear a large share of the burden of funding  
5 research and raising public awareness to support the search  
6 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; these people were given a voice in 2017 with the  
10 establishment in this State of the Rare Disease Advisory  
11 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 SENATE OF THE ONE HUNDRED THIRD GENERAL  
21 ASSEMBLY OF THE STATE OF ILLINOIS, that we declare March 6,  
22 2024 as Rare Disease Day in the State of Illinois in order to

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

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