



HR0153

LRB104 12372 LAW 22608 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% 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 U.S. 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 a 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 (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 of the Rare Disease Advisory Commission in this
11 State; 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 FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that
22 we declare March 5, 2025 as Rare Disease Day in the State of

1 Illinois in order to raise awareness of rare diseases, support
2 individuals and families who struggle with rare diseases,
3 bring attention to the need for research and funding to
4 support the discovery and development of therapies designed to
5 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 the Illinois Biotechnology Innovation
10 Organization, Chairperson Maria Pollock of the Illinois Rare
11 Disease Commission, and the Department of Public Health.