



SR0080

LRB103 30899 MST 57438 r

1

SENATE 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, which is better known as Lou Gehrig's disease, and
3 is 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 10 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 SENATE OF THE ONE HUNDRED THIRD GENERAL
21 ASSEMBLY OF THE STATE OF ILLINOIS, that we declare March 9,
22 2023 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 Bellefeuille of the Illinois
10 Rare Disease Commission, and the Department of Public Health.