

HR 8039

2024

House Resolution

A resolution recognizing February 29, 2024, as "Rare Disease Day" in Florida.

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

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

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

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

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

WHEREAS, while the public is familiar with some rare diseases, such as muscular dystrophy and amyotrophic lateral sclerosis, better known as Lou Gehrig's disease, and is

26 sympathetic to those affected, many patients and families
 27 affected by lesser-known rare diseases bear a large share of the
 28 burden of funding research and raising public awareness to
 29 support the search for treatments, and

30 WHEREAS, thousands of Floridians are among those affected
 31 by rare diseases, since nearly 1 in 10 Americans has a rare
 32 disease, and were given a voice in 2021 with the establishment
 33 in this state of the Rare Disease Advisory Council, and

34 WHEREAS, the Orphan Drug Act, championed in Congress by
 35 Florida Representative Gus Bilirakis, has encouraged and
 36 promoted the discovery and development of biopharmaceuticals
 37 designed to treat and potentially cure rare diseases, and

38 WHEREAS, many of the world's leading academic institutions,
 39 academic medical centers, biotech companies, and pharmaceutical
 40 companies that are conducting research and seeking cures for
 41 rare diseases are doing so in this state, NOW, THEREFORE,

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 43 Be It Resolved by the House of Representatives of the State of
 44 Florida:

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 46 That February 29, 2024, is recognized as "Rare Disease Day"
 47 in Florida.