

By Senator Baxley

12-01106-22

20221116__

Senate Resolution

A resolution recognizing February 28, 2022, 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 sympathetic to those affected, many patients and families affected by lesser-known rare diseases bear a large share of the burden of funding research and raising public awareness to support the search for treatments, and

12-01106-22

20221116__

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,

42

43 Be It Resolved by the Senate of the State of Florida:

44

45 That February 28, 2022, is recognized as "Rare Disease Day"
46 in Florida.