

HR 8079

2025

1 House Resolution

2 A resolution recognizing February 28, 2025, as "Rare
3 Disease Day" in Florida.

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

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

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

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

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

23 WHEREAS, thousands of Floridians are among those affected
24 by rare diseases, since nearly 1 in 10 Americans has a rare

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25 | disease, and were given a voice in 2021 with the establishment
26 | in this state of the Rare Disease Advisory Council, and

27 | WHEREAS, the Orphan Drug Act, championed in Congress by
28 | Florida Representative Gus Bilirakis, has encouraged and
29 | promoted the discovery and development of biopharmaceuticals
30 | designed to treat and potentially cure rare diseases, NOW,
31 | THEREFORE,

32 |

33 | Be It Resolved by the House of Representatives of the State of
34 | Florida:

35 |

36 | That February 28, 2025, is recognized as "Rare Disease Day"
37 | in Florida.