



SPONSOR: Rep. Baumbach & Rep. Griffith & Rep. Spiegelman on behalf of all Representatives & Sen. Townsend & Sen. Poore on behalf of all Senators

HOUSE OF REPRESENTATIVES
151st GENERAL ASSEMBLY

HOUSE CONCURRENT RESOLUTION NO. 47

DESIGNATING FEBRUARY 28, 2022, AS "RARE DISEASE DAY" IN THE STATE OF DELAWARE.

1 WHEREAS, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000
2 Americans) in the United States, according to the National Institutes of Health (NIH); and

3 WHEREAS, while each of these diseases may affect small numbers of people, rare diseases as a group affect
4 almost 30 million Americans; and

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

7 WHEREAS, while more than 450 drugs and biologics have been approved for the treatment of rare diseases
8 according to the Food and Drug Administration (FDA), millions of Americans still have rare diseases for which there is no
9 approved treatment; and

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

12 WHEREAS, while the public is familiar with some rare diseases such as "Lou Gehrig's disease" and sympathetic
13 to those affected, many patients and families affected by less widely known rare diseases bear a large share of the burden of
14 funding research and raising public awareness to support the search for treatments; and

15 WHEREAS, one example of a much less know rare disease is Lissencephaly, a condition that is characterized by
16 agyria or pachygyria, which means absence or incomplete development, respectively, of the brain gyri or convolution,
17 causing the brain's surface to appear unusually smooth with an estimated less than 1,000 individuals diagnosed worldwide
18 and many others undiagnosed; and

19 WHEREAS, thousands of Delaware residents are among those affected by rare diseases since nearly one in 10
20 Americans have rare diseases; and

21 WHEREAS, the National Organization for Rare Disorders (NORD) organized a nationwide observance of "Rare
22 Disease Day" on February 28, 2022; and

23 WHEREAS, thousands of patients and caregivers, medical professionals, researchers, companies developing
24 orphan products to treat people with rare diseases, and others in the State of Delaware will participate in that observance.

25 NOW, THEREFORE:

26 BE IT RESOLVED by the House of Representatives of the 151st General Assembly of the State of Delaware, the
27 Senate concurring therein, that February 28, 2022, is recognized as “Rare Disease Day” in the State of Delaware.

SYNOPSIS

This House Concurrent Resolution recognizes February 28, 2022, as "Rare Disease Day" in Delaware.