



SPONSOR: Sen. Townsend on behalf of all Senators
Reps. Baumbach, Griffith on behalf of all Representatives

DELAWARE STATE SENATE
152nd GENERAL ASSEMBLY

SENATE CONCURRENT RESOLUTION NO. 116

DESIGNATING FEBRUARY 29, 2024, 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, and only about 500 have approved treatments in the United States, according to the National Institutes of
3 Health; and

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

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

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

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

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

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

20 WHEREAS, thousands of Delaware residents are among those affected by rare diseases since nearly 1 in 10
21 Americans have rare diseases; and

22 WHEREAS, as of July 2023, Delaware became the 27th state to establish a Rare Disease Advisory Council
23 through the passage of SB 55 to raise awareness and create a platform to educate the public, state agencies, and the General

Assembly about rare diseases and to make policy recommendations that improve patient access to critical health care services; and

WHEREAS, the National Organization for Rare Disorders organized a nationwide observance of “Rare Disease Day” on February 29, 2024, to provide an energy and focal point that enables rare diseases advocacy work to progress on the local, national, and international levels; and

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

NOW, THEREFORE:

BE IT RESOLVED by the Senate of the 152nd General Assembly of the State of Delaware, the House of Representatives concurring therein, that February 29, 2024, is recognized as “Rare Disease Day” in the State of Delaware.

SYNOPSIS

This Senate Concurrent Resolution recognizes February 29, 2024, as "Rare Disease Day" in Delaware.

Author: Senator Townsend