

1 SENATE MEMORIAL 108

2 **53RD LEGISLATURE - STATE OF NEW MEXICO - FIRST SESSION, 2017**

3 INTRODUCED BY

4 Nancy Rodriguez

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10 A MEMORIAL

11 DECLARING FEBRUARY 28, 2017 "WORLD RARE DISEASE DAY" IN THE
12 SENATE.

13
14 WHEREAS, there are approximately seven thousand different
15 types of rare diseases and disorders, with more being
16 discovered each day; and

17 WHEREAS, thirty million people in the United States are
18 living with rare diseases, which equates to one in ten
19 Americans; and

20 WHEREAS, it is estimated that three hundred fifty million
21 people worldwide suffer from rare diseases; and

22 WHEREAS, if all the people with rare diseases lived in one
23 country, it would be the world's third-most-populous country,
24 according to statistics compiled by Global genes; and

25 WHEREAS, in the United States, a condition is considered

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1 "rare" if it affects fewer than two hundred thousand people
2 combined in a particular rare disease group; and

3 WHEREAS, eighty percent of rare diseases are genetic in
4 origin and are present throughout a person's life, even if
5 symptoms do not immediately appear; and

6 WHEREAS, approximately fifty percent of the people
7 affected by rare diseases are children, and thirty percent of
8 children with rare diseases do not live to see their fifth
9 birthday; and

10 WHEREAS, rare diseases are responsible for thirty-five
11 percent of deaths in the first year of life; and

12 WHEREAS, according to the EveryLife foundation for rare
13 diseases, drug treatments have not been approved by the federal
14 food and drug administration for ninety-five percent of rare
15 diseases; and

16 WHEREAS, during the first twenty-five years of the Orphan
17 Drug Act, passed in 1983, only three hundred twenty-six new
18 drugs were approved by the federal food and drug administration
19 and brought to market for all rare diseases combined; and

20 WHEREAS, although rare and genetic diseases, and many of
21 their symptoms, are unfamiliar to many doctors, rare diseases
22 as a whole represent a large medical challenge;

23 NOW, THEREFORE, BE IT RESOLVED BY THE SENATE OF THE STATE
24 OF NEW MEXICO that February 28, 2017 be declared "World Rare
25 Disease Day" in the senate; and

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BE IT FURTHER RESOLVED that a copy of this memorial be transmitted to Global genes.

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