



A Proclamation by the Governor

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

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

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

WHEREAS, while more than 450 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), millions of Americans still 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 "Lou Gehrig's disease" and sympathetic to those affected, many patients and families affected by less widely known rare diseases bear a large share of the burden of funding research and raising public awareness to support the search for treatments; and

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

WHEREAS, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2014; and

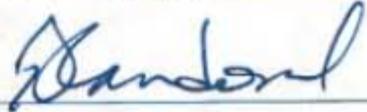
WHEREAS, thousands of patients and caregivers, medical professionals, researchers, companies developing orphan products to treat people with rare diseases, and others in the state of Nevada will participate in that observance.

NOW, THEREFOR, I, BRIAN SANDOVAL, GOVERNOR OF THE STATE OF NEVADA, do hereby proclaim February 28, 2014, as a day in honor of

RARE DISEASE DAY



In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of Nevada to be affixed at the State Capitol in Carson City, this 20th day of February, 2014.



Governor

By the Governor:


Secretary of State

By _____
Deputy