

PROCLAMATION

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, it is estimated that one in 10 have rare diseases; and

WHEREAS, Rare Disease Day will be observed annually on February 28, and is sponsored by the National Organization for Rare Disorders (NORD); and

WHEREAS, patients, medical professionals, researchers, government officials, and companies developing orphan products to treat people with rare diseases, and others in the [City/State] of [City/State Name] will participate in that observance; and

NOW, THEREFORE I, (Name/title), [GOVERNMENT OFFICE TITLE] OF THE [CITY/STATE] OF [CITY/STATE NAME], do hereby proclaim February 28 to be

RARE DISEASE DAY

and urge all the citizens of the [City/State] of [City/State Name] to take cognizance of this event and participate fittingly in its observance.