



State of North Carolina

Roy Cooper
Governor

RARE DISEASE DAY

2017

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, there are nearly 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 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”, other diseases lack awareness and funding for research; and

WHEREAS, thousands of North Carolina residents 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, 2017; and

WHEREAS, the State of North Carolina joins patients and caregivers, medical professionals, researchers, companies developing orphan products to treat people with rare diseases, and others in this worthwhile observance;

NOW, THEREFORE, I, ROY COOPER, do hereby proclaim February 28, 2017 as “**RARE DISEASE DAY**” in North Carolina, and commend its observance to all citizens.



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Governor

IN WITNESS WHEREOF, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this twenty-sixth day of January in the year of our Lord two-thousand and seventeen and of the Independence of the United States of America the two hundred and forty-first.