

State of North Carolina

ROY COOPER
GOVERNOR

RARE DISEASE DAY

2019

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, a rare disease is a condition that affects fewer than 200,000 people; according to the National Institute of Health (NIH), approximately 7,000 rare diseases affect humans, of which only a few hundred have any treatment; and

WHEREAS, each of these diseases individually affects a relatively small number of people; however, the total combined number of Americans living with some form of rare disease is estimated at 30 million; and

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

WHEREAS, more than 450 drugs and biologics have been approved by the Food and Drug Administration (FDA) for the treatment of rare diseases, but 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 limited or no access to treatments or ancillary services; and

WHEREAS, while the public is familiar with some rare diseases, many patients and families affected by less widely known conditions bear a large share of the burden of funding research and raising public awareness to support the search for treatments; and

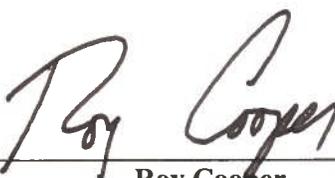
WHEREAS, many North Carolinians are among the approximately 1 in 10 Americans who suffer from a rare disease; and

WHEREAS, the National Organization for Rare Disorders (NORD) organizes an annual, nationwide observance of Rare Disease Day on February 28, 2019; and

WHEREAS, the State of North Carolina recognizes the many patients, caregivers, medical professionals, researchers, and individuals working to combat rare diseases in our state, and encourages people to raise awareness and support for those affected by rare diseases and their families in our communities;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim February 28, 2019, as "RARE DISEASE DAY" in North Carolina, and commend its observance to all citizens.





Roy Cooper
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 eighth day of February in the year of our Lord two thousand and nineteen and of the Independence of the United States of America the two hundred and forty-second.