



State of North Carolina

ROY COOPER
GOVERNOR

RARE DISEASE DAY

2020

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 people worldwide; and

WHEREAS, each of these diseases distinctly affects a relatively small number of people; however, there are an estimated 30 million Americans living with some form of rare disease; 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 are no approved treatments; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and limited access to treatments or ancillary services; many people affected by less widely known rare diseases bear a greater share of burden of funding research, and raising public awareness to support the search for treatments; and

WHEREAS, the North Carolina Rare Disease Advisory Council was created in 2015 to provide increased understanding of research, diagnosis, treatment and education relating to rare diseases; and

WHEREAS, many North Carolinians are among the approximately 1 in 11 Americans who suffer from a rare disease; and

WHEREAS, the National Organization for Rare Disorders (NORD) organizes an annual, global observance of Rare Disease Day on the last day of February each year; 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 29, 2020, 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 twenty-fifth day of February in the year of our Lord two thousand and twenty and of the Independence of the United States of America the two hundred and forty-fourth.