

State of Aorth Carolina JOSH STEIN GOVERNOR

RARE DISEASE DAY

2025

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 in the United States, according to the Centers for Disease Control and Prevention, and approximately 7,000 rare diseases affect people worldwide; and

WHEREAS, each disease distinctly affects a small number of people; however, there are an estimated 30 million Americans living with some form of rare disease; and

WHEREAS, 95 percent of all rare diseases do not have an FDA approved drug treatment, leaving millions of Americans with diseases without options for an 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 access to treatments or ancillary services, leaving many people affected by less widely known rare diseases to bear a greater share of burden of funding research and raising public awareness to support the search for treatments; and

WHEREAS, the National Organization for Rare Disorders 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, JOSH STEIN, Governor of the State of North Carolina, do hereby proclaim February 28, 2025, as "RARE DISEASE DAY" in North Carolina, and commend its observance to all citizens.

JOSH STEIN Governor

IN WITH SS WHERE F, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this thirteenth day of February in the year of our Lord two thousand and twenty-fifth and of the Independence of the United States of America the two hundred and forty-ninth.