



# State of North Carolina

**ROY COOPER**  
GOVERNOR

**RARE DISEASE DAY**

**2018**

**BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA**

**A PROCLAMATION**

**WHEREAS**, a rare disease is defined as a condition that affects fewer than 200,000 people; according to the National Institute of Health (NIH), there are as many as 7,000 rare diseases; and

**WHEREAS**, each of these diseases individually affects a small number of people; however, the total number of Americans living with some form of rare disease is estimated at between 25 – 30 million; and

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

**WHEREAS**, more than 450 drugs and biologic products 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 lack of access to treatments or ancillary services; and

**WHEREAS**, the public is familiar with some rare diseases, such as cystic fibrosis and Lou Gehrig's disease, and sympathetic to those affected; however, many patients and families affected by lesser known rare diseases bear a large share of the burden of funding research and raising public awareness for support; and

**WHEREAS**, more than one million residents of North Carolina, and approximately 1 in 10 Americans, suffer from a rare disease; and

**WHEREAS**, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2018; and

**WHEREAS**, thousands of patients and caregivers, medical professionals, researchers, companies developing orphan products to treat people with rare diseases, and others in the state of North Carolina will participate in this observance;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim February 28, 2018, as "RARE DISEASE DAY" in North Carolina, and commend its observance to all citizens.



  
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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-sixth day of February in the year of our Lord two thousand and eighteen and of the Independence of the United States of America the two hundred and forty-second.