

# State of North Carolina

**ROY COOPER**  
GOVERNOR

**PURA SYNDROME AWARENESS DAY**

**2020**

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

**A PROCLAMATION**

**WHEREAS**, PURA syndrome is a rare condition characterized by intellectual disability and delayed development of speech and motor skills; and

**WHEREAS**, this condition severely affects expressive communication, often rendering those affected unable to speak at all; additionally, as a result of PURA syndrome, people may learn to walk later than their peers, or may never walk at all, have difficulty swallowing food due to weak muscle tone, and may experience recurrent seizures, among many other symptoms; and

**WHEREAS**, this syndrome is caused by mutations in the PURA gene, which provides instructions for making the protein, Pur-alpha; it is not currently understood how a partial loss of Pur-alpha function leads to the signs and symptoms of PURA syndrome; and

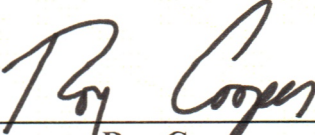
**WHEREAS**, cases of PURA syndrome can often occur in people with no family history of the disorder; and

**WHEREAS**, increased awareness of this rare condition can help ensure the health and well-being of those affected by PURA syndrome currently, and may help prevent or treat cases discovered in the future; and

**WHEREAS**, the State of North Carolina encourages organizations, health care practitioners, and all people to promote awareness about this condition, and commends the important work done every day by the families of those affected;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim June 1, 2020, as **"PURA SYNDROME AWARENESS 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-eighth day of May 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.