

# State of North Carolina

**ROY COOPER**  
GOVERNOR

## PITT HOPKINS SYNDROME AWARENESS DAY

2022

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

### A PROCLAMATION

**WHEREAS**, Pitt Hopkins Syndrome is a rare and severe genetic condition that affects brain and nervous system development caused by a spontaneous mutation or deletion on the 18<sup>th</sup> chromosome; and

**WHEREAS**, Pitt Hopkins Syndrome is characterized by developmental delays, moderate to severe intellectual disability, breathing problems, epilepsy or recurrent seizures, gastrointestinal issues, and distinctive facial features; and

**WHEREAS**, fewer than 5,000 people in the United States have been diagnosed with Pitt Hopkins Syndrome; given that the discovery of the gene occurred in 2007, there are likely many more individuals with the disorder whose cases remain undiagnosed; and

**WHEREAS**, due to its rarity, online support groups play a pivotal role for individuals, families, and their loved ones in order to connect and increase awareness; and

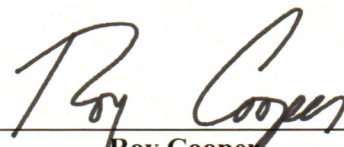
**WHEREAS**, the Pitt Hopkins Research Foundation annually celebrates September 18<sup>th</sup> as International Pitt Hopkins Syndrome Awareness Day to raise awareness and funding for research; this date was chosen to bring attention to the disorder's cause, which is a spontaneous mutation or deletion on the 18<sup>th</sup> chromosome; and

**WHEREAS**, the Pitt Hopkins Research Foundation is a volunteer organization of families and professionals dedicated to finding a cure for Pitt Hopkins Syndrome through research funding, education, and advocacy; the Foundation's goal is to bring practical treatment into current medical use; and

**WHEREAS**, the State of North Carolina encourages people to raise awareness, increase education, and garner support for individuals with Pitt Hopkins Syndrome and their families in our communities;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim September 18, 2022, as "**PITT HOPKINS 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 sixteenth day of September in the year of our Lord two thousand and twenty-two and of the Independence of the United States of America the two hundred and forty-eighth.