



# State of North Carolina

**ROY COOPER**  
GOVERNOR

## PITT HOPKINS SYNDROME AWARENESS DAY

2021

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

### A PROCLAMATION

**WHEREAS**, Pitt Hopkins Syndrome is a rare and severe neurological disorder 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**, approximately 1000 people worldwide have been diagnosed with Pitt Hopkins Syndrome, however, given the fact that the discovery of the gene occurred in 2007, there are likely many other cases that remain undiagnosed; and

**WHEREAS**, given 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 Pitt Hopkins research and this date was chosen to bring attention to the fact that it is a disorder caused by 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 the funding of research, education and advocacy; and

**WHEREAS**, The Foundation's goal is to educate and bring practical treatment into current medical practices to treat Pitt Hopkins Syndrome;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim September 18, 2021, as "PITT HOPKINS SYNDROME AWARENESS 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 fourteenth day of September in the year of our Lord two thousand and twenty-one and of the Independence of the United States of America the two hundred and forty-sixth.