



State of North Carolina

ROY COOPER
GOVERNOR

PITT HOPKINS SYNDROME AWARENESS DAY

2018

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 18th 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 750 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, because Pitt Hopkins Syndrome is so rare, online support groups play a pivotal role in helping individuals, families, and their loved ones build a community and increase awareness; and

WHEREAS, the Pitt Hopkins Research Foundation recognizes September 18 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 18th 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, 2018, 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 seventeenth day of September 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.