



STATE OF TENNESSEE
PROCLAMATION
BY THE GOVERNOR

WHEREAS, Pitt Hopkins Syndrome is a rare and potentially 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 500 people worldwide have been diagnosed with Pitt Hopkins Syndrome, however, given the fact that the discovery of the gene only occurred recently, 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 18th 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 18th chromosome; and

WHEREAS, The Pitt Hopkins Research Foundation is a volunteer organization comprised 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 bring practical treatment into current medical practice;

NOW, THEREFORE, I, Bill Haslam, Governor of the State of Tennessee, do hereby proclaim September 18, 2018 as

Pitt Hopkins Syndrome Awareness Day

in Tennessee and encourage all citizens to join me in this worthy observance.



IN WITNESS WHEREOF, I have hereunto set my hand and caused the official seal of the State of Tennessee to be affixed at Nashville on this thirteenth day of August, 2018.

Handwritten signature of Bill Haslam in blue ink.

Governor

Handwritten signature of the Secretary of State in blue ink.

Secretary of State