



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 500-1000 people worldwide have been diagnosed with Pitt-Hopkins Syndrome, there are likely many other cases that remain undiagnosed since the discovery of the gene in 2007; and

WHEREAS, given its rarity, online support groups play a pivotal role in connecting individuals, families and their loved ones and increasing 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 of families and professionals dedicated to finding a cure for Pitt-Hopkins Syndrome through the funding of research, education and advocacy;

NOW, THEREFORE, I, Bill Lee, Governor of the State of Tennessee, do hereby proclaim September 18, 2021 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 fourth day of August, 2021.

Bill Lee

Governor

Julie Parrott

Secretary of State