



Proclamation

By the Governor of Alabama

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 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 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; and

WHEREAS, the Foundations goal is to bring practical treatment into current medical practice;

NOW, THEREFORE, I, Kay Ivey, Governor of Alabama, do hereby proclaim September 18, 2019, as

Pitt Hopkins Syndrome Awareness Day

in the state of Alabama.



*Given Under My Hand and the Great Seal of the
Office of the Governor at the State Capitol in the City
of Montgomery on the 7th day of August 2019.*

Kay Ivey

Kay Ivey, Governor