

STATE OF TENNESSEE

PROCLAMATION

BY THE GOVERNOR

WHEREAS, Usher syndrome is a relatively rare genetic disorder caused by a mutation in one of at least 11 genes resulting in a combination of hearing loss and visual impairment and is a leading cause of combined deafness and blindness; and

WHEREAS, it is estimated that more than 400,000 people are affected by this genetic disorder worldwide, with as many as 25,000 of those in the United States; and

WHEREAS, vision loss in Usher syndrome is caused by a progressive vision disorder known as retinitis pigmentosa (RP), where light-sensing cells in the retina gradually deteriorate, initially resulting in night blindness, followed by a narrowing of the visual field; and

WHEREAS, children with Usher syndrome are born with or develop hearing loss and it is estimated that as many as 10% of people with congenital bilateral sensorineural hearing loss have Usher syndrome; and

WHEREAS, there are three clinical types: Type 1, Type 2 and Type 3, which are distinguished by the severity and age when the signs and symptoms appear; and

WHEREAS, because of limited public awareness, those affected with Usher syndrome may suffer from depression, anxiety, isolation, and loss of independence; and

WHEREAS, the Usher syndrome community is uniting around the world to spread public awareness but especially to be recognized annually on the 3rd Saturday of September;

NOW, THEREFORE, I, Bill Lee, Governor of the State of Tennessee, do hereby proclaim September 21, 2024, as

Usher Syndrome Hwareness 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 first day of July, 2024.

Governor

Secretary of State