

# STATE OF ILLINOIS

EXECUTIVE DEPARTMENT

## Proclamation

**WHEREAS**, Usher Syndrome is a relatively rare genetic disorder caused by a mutation in any 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**, 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**, Usher syndrome, which is incurable presently, impacts three major senses in the body:

- Vision: vision loss in Usher syndrome is caused by a progressive vision disorder known as retinitis pigmentosa (RP); RP causes the light-sensing cells in the retina to gradually deteriorate, initially resulting in night blindness, followed by a narrowing of the visual field, commonly known as tunnel vision.

- Hearing: children with Usher syndrome are born with or develop hearing loss; it is estimated that upward of 10 percent of people with congenital bilateral, sensorineural hearing loss have Usher syndrome.

- Balance: balance is achieved and maintained through input from your eyes, the vestibular organs in the inner ear and the sensory systems of the body, such as the skin, muscles and joints - thus, people with Usher syndrome suffer from severe balance issues due to vestibular dysfunction; 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**, there are at least eleven different genetic types of Usher syndrome, as determined by the genes that are involved; one cannot determine the genetic type by clinical testing, as DNA testing is the only reliable way of determining the true genetic type; and,

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

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

**THEREFORE**, I, JB Pritzker, Governor of the State of Illinois, do hereby designate September 18, 2021, as **Usher Syndrome Awareness Day** in the state of Illinois.

*In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of Illinois to be affixed.*

*Done at the Capitol in the City of Springfield,*  
*this* TWENTY-FIRST *day of* SEPTEMBER, *in*  
*the Year of Our Lord, two thousand and*  
TWENTY-ONE, *and of the State of Illinois,*  
*two hundred and* THIRD.



*Deese White*  
SECRETARY OF STATE

*JB Pritzker*  
GOVERNOR