



STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, Usher Syndrome is a relatively rare genetic disorder caused by a mutation in any one of 10 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 approximately 20,000 to 50,000 of those in the United States; and

WHEREAS, Usher Syndrome, which is presently incurable, impacts three major senses in the body:

- *Vision: Vision loss in Usher syndrome is caused by a progressive vision disorder known as retinitis pigmentosa, which 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 and it is estimated that upward of ten percent of people with congenital bilateral, sensorineural hearing loss have Usher syndrome;*
- *Balance: Balance is achieved and maintained through input from one's eyes, the vestibular organs in the inner ear and the sensory systems of the body, such as the skin, muscles and joints. As a result, 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 there are at least 10 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 the limited public awareness, those affected with Usher syndrome may suffer with depression, anxiety, isolation and loss of independence; and

WHEREAS, the third Saturday of September is designated as Usher Syndrome Awareness Day to promote worldwide awareness and education, and provide resources for affected families, medical professionals and the community at-large;

NOW, THEREFORE, I, Philip D. Murphy, Governor of the State of New Jersey, do hereby proclaim:

SEPTEMBER 16, 2023
AS
USHER SYNDROME AWARENESS DAY

in New Jersey.



GIVEN, under my hand and the Great Seal of the State of New Jersey, this fifteenth day of September in the year two thousand twenty-three, the two hundred forty-eighth year of the Independence of the United States.

Philip D. Murphy

GOVERNOR