

# State of New York

## Executive Chamber

### Proclamation

**Whereas**, Usher syndrome is a rare genetic disorder caused by a mutation in any one of at least 10 different genes and is recognized as one of the leading causes of combined deafness and blindness; and

**Whereas**, more than 400,000 people worldwide are affected by this genetic disorder, with at least 25,000 of those being in the United States; and

**Whereas**, Usher syndrome is classified into three clinical types, which are distinguished by the severity of the individual's condition and the age at which their symptoms manifest; clinical testing cannot determine these type variants and DNA testing remains the only reliable method for precise genetic diagnosis; and

**Whereas**, vision loss associated with Usher syndrome results from a progressive condition known as retinitis pigmentosa, which causes the gradual deterioration of the retina's light-sensing cells, leading to tunnel vision followed by blindness; and

**Whereas**, most individuals with Usher syndrome are born with or develop hearing loss, accounting for approximately 10% of congenital sensorineural hearing loss cases; and

**Whereas**, additionally, balance impairment in individuals with Usher syndrome occurs due to vestibular dysfunction, disrupting the body's ability to maintain stability through sensory input from the inner ears, eyes, or musculoskeletal system; and

**Whereas**, due to limited public knowledge of the condition, those affected by Usher syndrome may experience depression, anxiety, social isolation, and loss of personal independence; and

**Whereas**, the New York State Early Intervention Program provides a comprehensive range of therapeutic and support services for children under the age of three with disabilities, including those living with Usher syndrome; and

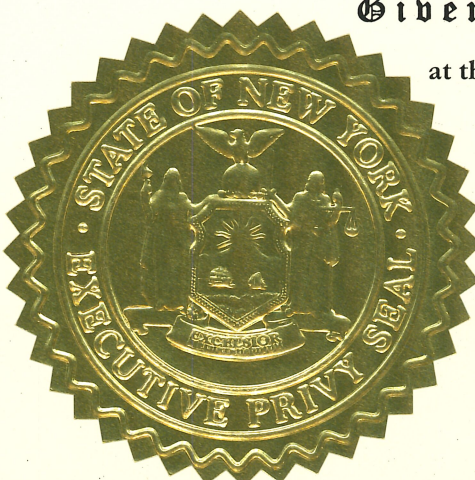
**Whereas**, individuals, families, and communities now come together to spread awareness of Usher syndrome and designate the third Saturday of September as Usher Syndrome Awareness Day for the benefit of all those affected by the disorder;

**Now, Therefore**, I, Kathy Hochul, Governor of the State of New York, do hereby proclaim September 20, 2025 as

## USHER SYNDROME AWARENESS DAY

in the Empire State.

**Given** under my hand and the Privy Seal of the State  
at the Capitol in the City of Albany this nineteenth day  
of September in the year two thousand twenty-five.



Secretary to the Governor  
Karen Persichilli Keogh

Governor