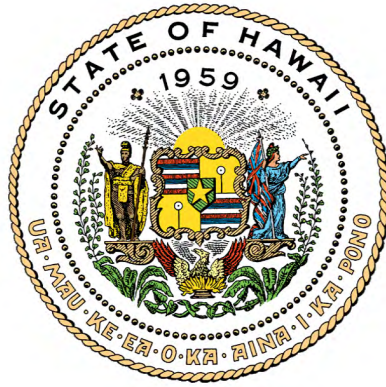




Proclamation

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

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

WHEREAS, Usher syndrome, which is currently incurable, impacts three major senses in the body: vision, hearing and balance; and

WHEREAS, vision loss tied to 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 (a.k.a. tunnel vision) and can lead to blindness; and

WHEREAS, children with Usher syndrome are born with or develop hearing loss. It is estimated that upward of ten percent of people with congenital bilateral, sensorineural hearing loss have Usher syndrome; and

WHEREAS, balance is achieved and maintained through input from the eyes, inner ear and sensory systems of the body, such as 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 of Usher syndrome: Type 1, Type 2 and Type 3, which are distinguished by severity and age at which symptoms begin to appear.

WHEREAS, there are at least ten different genetic types of Usher syndrome, as determined by the genes involved. DNA testing is the only reliable way of determining the true genetic type; and

WHEREAS, due to limited public awareness, those living with Usher syndrome may suffer from depression, anxiety, isolation and a loss of independence; and

NOW, THEREFORE, I, Josh Green, M.D., Governor of the State of Hawai'i, do hereby proclaim September 20, 2025, as

“USHER SYNDROME AWARENESS DAY”

in Hawai'i and urge all citizens to unite alongside the Usher syndrome community to raise public awareness in order to increase equal access, inclusivity and research as they pertain to those impacted by this highly nuanced and debilitating syndrome.

Done at the State Capitol in the Executive Chambers, Honolulu, State of Hawai'i, this nineteenth day of September 2025.



Josh Green, M.D.
Governor, State of Hawai'i