

Commonwealth of Pennsylvania



Governor's Office

PROCLAMATION

USHER SYNDROME AWARENESS DAY
September 17, 2022

WHEREAS, Usher syndrome is a relatively rare genetic disorder that affects more than 400,000 people worldwide and is caused by a mutation in any one of ten genes resulting in a combination of hearing loss and visual impairment, and is a leading cause of combined deafness and blindness; and

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

WHEREAS, 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; 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 and bilateral sensorineural hearing loss have Usher syndrome; and

WHEREAS, 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. 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, it is vital that we educate the citizens of our state, the medical community, and the public regarding the devastating effects of this disorder and promote awareness of this condition for the good of the public health and to unite those affected.

THEREFORE, I, Tom Wolf, Governor of the Commonwealth of Pennsylvania, do hereby proclaim September 17, 2022, as USHER SYNDROME AWARENESS DAY in recognition of individuals with Usher syndrome, as well as their families, friends, medical professionals, and advocates. I encourage all Pennsylvanians to provide their support in furthering Usher syndrome awareness and acceptance.



GIVEN under my hand and the Seal of the Governor, at the City of Harrisburg, on this fifteenth day of August two thousand and twenty-two, and of the commonwealth the two hundred and forty-seventh.

Tom Wolf
TOM WOLF
Governor