COMMONWEALTH OF PENNSYLVANIA

PROCLAMATION

BY THE

GOVERNOR

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, 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, and 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, Josh Shapiro, Governor of the Commonwealth of Pennsylvania, do hereby proclaim September 16, 2023, to be

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 eleventh day of July two thousand twenty-three, the year of the Commonwealth the two hundred forty-eighth.

Governor Josh Shapiro