

# The Commonwealth of Massachusetts



## A Proclamation

Whereas, Usher Syndrome is a relatively rare genetic disorder caused by a mutation in any one of at least 11 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 currently incurable, affects more than 400,000 people worldwide, with at least 25,000 of those in the United States; and

Whereas, Vision loss in Usher Syndrome is caused by a progressive vision disorder known as retinitis pigmentosa (RP) 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; and

Whereas, Children with Usher Syndrome are born with or later develop hearing loss. It is estimated that upward of 10 percent of people with congenital 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 four clinical types: Type 1, Type 2, Type 3 and Type 4, which are distinguished by the severity and age when the signs and symptoms appear. There are at least 11 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 limited public awareness, those affected with Usher Syndrome may suffer from depression, anxiety, isolation and loss of independence; and

Whereas, The Usher Syndrome community is uniting around the world to spread public awareness but especially to be recognized annually on the 3rd Saturday of September,

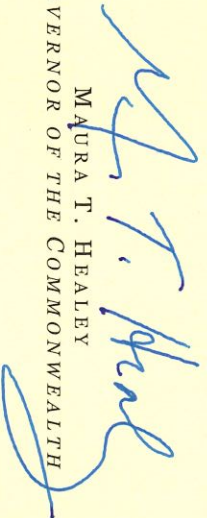
Now, Therefore, I, Maura T. Healey, Governor of the Commonwealth of Massachusetts, do hereby proclaim September 16<sup>th</sup>, 2023, to be,


## USHER SYNDROME AWARENESS DAY

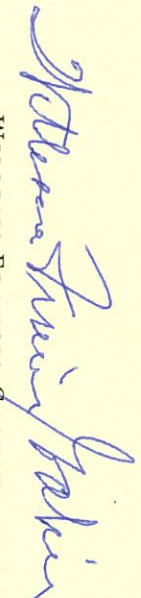
And urge all the residents of the Commonwealth to take cognizance of this event and participate fittingly in its observance.

Given at the Executive Chamber in Boston, this first day of September, in the year two thousand and twenty-three, and of the Independence of the United States of America, the two hundred and forty-seventh.

BY HER EXCELLENCY

  
MAURA T. HEALEY  
GOVERNOR OF THE COMMONWEALTH

  
KIMBERLEY DRISCOLL  
LT. GOVERNOR OF THE COMMONWEALTH

  
WILLIAM FRANCIS GALVIN  
SECRETARY OF THE COMMONWEALTH

God Save the Commonwealth of Massachusetts