Proclamation

CITY OF NORTHAMPTON
COMMONWEALTH OF MASSACHUSETTS

Usher Syndrome Awareness Day
September 15, 2018

WHEREAS, Usher Syndrome is a relatively rare genetic disorder caused by a mutation in any one of 10 genes resulting in a combination of hearing loss and visual impairment, and is a leading cause of combined deafness and blindness; and,

WHEREAS, more than 400,000 people are affected by this genetic disorder worldwide, with approximately 50,000 of those living in the United States; and,

WHEREAS, Usher Syndrome, which is incurable presently, impacts three major senses in the body:

   Vision: vision loss 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.

   Hearing: children with Usher Syndrome are born with or develop hearing loss. It is estimated that upward of 10 percent of people with congenital bilateral, sensorineural hearing loss have Usher Syndrome.

   Balance: 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. Those 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. 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 with depression, anxiety, isolation, and loss of independence; and,

WHEREAS, on this day we join with the Usher Syndrome community to spread public awareness about this condition.

NOW, THEREFORE, I, David J. Narkewicz, Mayor of Northampton, do hereby proclaim September 15, 2018 as Usher Syndrome Awareness Day in Northampton.

IN WITNESS WHEREOF, I have set my hand and imprinted the City seal, this 6th day of September in the year 2018.

David J. Narkewicz, Mayor