

PROCLAMATION

Usher Syndrome Awareness Day

September 20, 2025

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, more than 400,000 people are affected by this genetic disorder worldwide, with at least 2,400 of those in Canada; and

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

Vision: 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.

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. 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. There are at least eleven 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, loss of independence; and

WHEREAS, the Usher syndrome community is uniting around the world to spread public awareness but especially to be recognized annually the 3rd Saturday of September:

NOW, THEREFORE, I, as the Honourable Donna Reardon, Mayor of Saint John, NB do hereby designate September 20 , 2025 as Usher Syndrome Awareness Day in the city of Saint John, New Brunswick.