

STATE OF NORTH DAKOTA

PROCLAMATION

USHER SYNDROME AWARENESS DAY

SEPTEMBER 21, 2019

WHEREAS, Usher Syndrome is a relatively rare genetic disorder caused by a mutation in any one of at least 10 genes resulting in a combination of hearing loss and visual impairment, is a leading cause of combined deafness and blindness and may impact an individual's balance; and

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

WHEREAS, vision loss in Usher Syndrome is caused by a progressive vision disorder known as retinitis pigmentosa, 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 develop hearing loss, and it is estimated that 10 percent of people with congenital bilateral, sensorineural hearing loss have Usher Syndrome; and

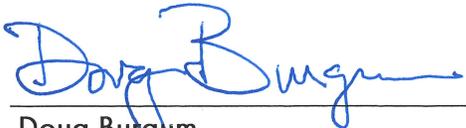
WHEREAS, balance is achieved and maintained through input from your eyes, the vestibular organs in the inner ear and the sensory systems of the body, such as the skin, muscles and joints, and people with Usher Syndrome suffer from severe balance issues due to vestibular dysfunction; and

WHEREAS, there are three clinical types of Usher Syndrome, distinguished by the severity and age when the signs and symptoms appear, and there are at least 11 different genetic types of Usher Syndrome, as determined by the genes that are involved, and 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 on the third Saturday of September annually the Usher Syndrome community unites to spread public awareness of this rare genetic disorder.

NOW, THEREFORE, as Governor of the State of North Dakota, I do hereby proclaim September 21, 2019, **USHER SYNDROME AWARENESS DAY** in the State of North Dakota.





Doug Burgum

GOVERNOR

ATTEST: 

Alvin A. Jaeger

SECRETARY OF STATE