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GOVERNOR

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September 13, 2022

Dear Friends,

On behalf of the citizens of Maine, I write this letter to help raise awareness about Usher Syndrome Awareness Day which is recognized annually on the third Saturday in September.

Usher syndrome is a rare genetic disease that causes hearing loss, vision loss, and sometimes balance problems. It is the most common cause of combined deafness and blindness. More than 400,000 people are affected by the disorder worldwide, including as many as 25,000 people in the United States. There are three clinical types of Usher syndrome that are distinguished by the severity and age when the signs and symptoms appear, and at least eleven different genetic types as determined by the genes that are involved. DNA testing is the only reliable way of determining the true genetic type.

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. Those with Usher syndrome are born with or develop hearing loss. People with certain types of Usher syndrome also experience severe balance issues due to vestibular dysfunction. Because of limited public awareness, those with the disease may suffer from depression, anxiety, isolation, and loss of independence.

I truly am grateful for the patients, caregivers, medical providers, and organizations throughout the country who are raising awareness about Usher syndrome. It is through greater awareness that we can ensure early diagnosis for children and further medical research to find better treatments and, hopefully, a cure for this rare disease.

Thank you,

Janet T. Mills  
Governor



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