

# State of North Carolina

**ROY COOPER**  
GOVERNOR

**USHER SYNDROME AWARENESS DAY**

**2024**

**BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA**

## **A PROCLAMATION**

**WHEREAS**, Usher syndrome is a relatively rare genetic disorder caused by a mutation in any of at least 11 genes resulting in a combination of hearing loss and visual loss, 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 25,000 of those in the United States, and 635 to 1,800 people with Usher syndrome in North Carolina; and

**WHEREAS**, Usher syndrome is incurable, and it impacts three major senses in the body – vision, caused by the progressive disorder, retinitis pigmentosa, which causes light-sensing cells in the retina to deteriorate resulting in night blindness followed by tunnel vision; hearing, a loss at birth, or developed over time; and balance, in which the vestibular organs of the inner ear dysfunction; and

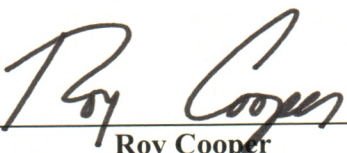
**WHEREAS**, there are three clinical types of Usher syndrome - Types 1, 2 and 3 – which are determined by DNA testing and distinguished by the severity and age when the signs and symptoms appear, and 11 different genetic types of Usher syndrome can manifest, as determined by the genes that are involved; and

**WHEREAS**, because of limited public awareness, those affected with Usher syndrome may struggle with depression, anxiety, isolation, and loss of independence; and

**WHEREAS**, the Usher syndrome Coalition's Ambassador of North Carolina, the North Carolina Department of Health and Human Services, Division of Services for the Deaf and Hard of Hearing, Division of Services for the Blind, Department of Public Instruction's North Carolina Deaf-Blind Project, North Carolina Deaf-Blind Associates, RHA Deaf Mental Health Services, and the Helen Keller National Center Southeast are uniting to spread public awareness, and support the Usher syndrome community to be recognized annually, on the 3<sup>rd</sup> Saturday of September;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim September 21, 2024, as "**USHER SYNDROME AWARENESS DAY**" in North Carolina, and commend its observance to all citizens.



  
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**Roy Cooper**  
Governor

**IN WITNESS WHEREOF**, I have hereunto set my hand and affixed the Great Seal of the State of North Carolina at the Capitol in Raleigh this tenth day of September in the year of our Lord two thousand and twenty-four and of the Independence of the United States of America the two hundred and forty-ninth.