

STATE OF NORTH CAROLINA OFFICE OF THE GOVERNOR

Josh Stein Governor

September 20, 2025

Usher Syndrome Coalition c/o Ms. Clara Obermeier 3918 Massey Run Raleigh, NC 27616

Dear Usher Syndrome Coalition,

I am writing to acknowledge September 20, 2025, as Usher Syndrome Awareness Day. This day is dedicated to spreading awareness and knowledge about Usher syndrome, a rare genetic disorder that affects balance, hearing, and vision.

Usher syndrome is the most common condition that affects both hearing and vision, accounting for about 50 percent of all hereditary deafblindness cases. There are three clinical types of Usher syndrome. Symptoms for each type appear at different times and with differing levels of severity, but all types lead to deafblindness. There is currently no treatment for the hearing, vision, and balance issues associated with Usher syndrome; however, early invention services are critical to helping children manage progressive hearing and vision loss.

I commend the Usher Syndrome Coalition for its dedication to improving the care and quality of life of people affected by Usher syndrome through patient services, education, and research. I want to also recognize the medical researchers who are identifying the new modes of intervention to halt the progression of the disorder. Above all, my heart goes out to those who suffer from Usher syndrome and their families.

This September 20, I ask all North Carolinians to join me in recognizing Usher Syndrome Awareness Day. May we take this opportunity to educate ourselves and offer support to the families in our community who will benefit from greater awareness of this rare genetic disorder.

Sincerely,

Josh Stein Governor