



State of North Carolina

ROY COOPER
GOVERNOR

KLEEFSTRA SYNDROME AWARENESS DAY

2024

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, Kleefstra Syndrome is a rare genetic disorder characterized by intellectual disability, low muscle tone, severe expressive speech delay, and a distinctive facial appearance, with a spectrum of additional clinical features; it is estimated that about 1 in 120,000 individuals are born with this condition; and

WHEREAS, people living with this condition may also have seizures, sleep disorders, autism, developmental delays, regressive behavior, and more; and

WHEREAS, addressing the many medical and therapy needs early in life is imperative to helping families successfully care for their children at home; the need for more education, awareness, and support for families is desperately needed; and

WHEREAS, it is appropriate that each year, on September 17, we set aside time to recognize Kleefstra Syndrome Awareness Day and the individuals affected by it; and

WHEREAS, the State of North Carolina is proud to recognize charitable organizations like IDefine, founded by parents of affected individuals, for their continued efforts towards empowering families, fueling research, and educating communities;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim September 17, 2024, as “**KLEEFSTRA SYNDROME AWARENESS DAY**” in North Carolina, and commend its observance to all citizens.



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.