

# State of North Carolina

**ROY COOPER**  
GOVERNOR

## **KLEEFSTRA SYNDROME AWARENESS DAY**

**2022**

**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

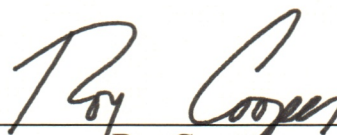
**WHEREAS**, addressing the many medical and therapy needs early in life is imperative to helping families successfully care for their children at home; the need for more education, awareness, and support for families is desperately needed; and

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

**WHEREAS**, charitable organizations like IDefine, founded by parents of affected individuals, work to help support these individuals through their continued efforts of empowering families, fueling research, and educating communities;

**NOW, THEREFORE**, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim September 17, 2022, as “**KLEEFSTRA 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 sixteenth day of September in the year of our Lord two thousand and twenty-two and of the Independence of the United States of America the two hundred and forty-eighth.