

# State of North Carolina

## **ROY COOPER**

**GOVERNOR** 

#### RETT SYNDROME AWARENESS MONTH

2022

#### BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

### A PROCLAMATION

**WHEREAS**, Rett syndrome is a rare postnatal genetic neurological disorder that occurs almost exclusively in females and rarely males; and

**WHEREAS**, every two hours, a child is born in the United States with Rett syndrome, but the child's symptoms usually do not appear until ages 6 months to 18 months; and

WHEREAS, a regression period follows where acquired motor skills are lost, leading to lifelong impairments, including loss of speech, seizures, scoliosis, and irregular breathing patterns; more than half of those affected lose their ability to walk; the hallmark sign of Rett syndrome is near-constant repetitive hand movements while awake; and

WHEREAS, those diagnosed with Rett syndrome require maximum assistance with daily living activities for their entire lives; and

**WHEREAS**, the disorder is not degenerative and biomedical research in mice suggests that neurological symptoms may be reversed, even after decades of severe symptoms; and

**WHEREAS**, with the discovery of the gene that causes Rett syndrome (1999), research that proves the theory of reversibility of the disease (2007), the discovery of breakthrough testing in vitro models (2010), and the launch of five disease-modifying human clinical trials – with more in the pipeline– we have reached an unprecedented and historic moment; we must continue to advance research that will result in life-changing solutions for all people with Rett syndrome; and

**WHEREAS**, the State of North Carolina believes in continuing our efforts in bringing awareness to the medical community, pharmaceutical industry, researchers, therapists, teachers, caregivers, and the general public;

**NOW, THEREFORE,** I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim October, 2022, as "**RETT SYNDROME AWARENESS MONTH**" in North Carolina, and commend its observance to all citizens.



Roy Cooper

**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 third day of October 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-seventh.