State of North Carolina

ROY COOPER
GOVERNOR

CONGENITAL DISORDERS OF GLYCOSYLATION AWARENESS DAY

2019

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, congenital disorders of glycosylation (CDG) are a group of rare metabolic disorders that affect normal organ development and the neurological system leaving children, adolescents, and adults impaired with significant physical and developmental disabilities; and

WHEREAS, CDG is severely underdiagnosed and misdiagnosed, with only approximately 1,000 cases diagnosed with CDG globally, and a mere 180 cases currently reported in the United States; and

WHEREAS, lack of public awareness and visibility of CDG contributes to underdiagnosis and difficulties in accessing specialized services and proper rehabilitation and support; and

WHEREAS, early diagnosis of CDG is important to ensure timely management of clinical complications, genetic counseling, and, when available, treatment and therapeutic remedies; and

WHEREAS, the goals of CDG Awareness Day are to educate the public and promote accurate and timely diagnosis of these rare genetic, metabolic disorders;

NOW, THEREFORE, I, ROY COOPER, Governor of the State of North Carolina, do hereby proclaim May 16, 2019, as "CONGENITAL DISORDERS OF GLYCOSYLATION AWARENESS DAY" in North Carolina, and commend its observance to all citizens.

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 eighth day of May in the year of our Lord two thousand and nineteen and of the Independence of the United States of America the two hundred and forty-second.