

PROCLAMATION CONGENITAL DISORDERS OF GLYCOSYLATION AWARENESS DAY MAY 11, 2018

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 disability; and

WHEREAS, CDG is severely under-diagnosed and misdiagnosed with only approximately 1,000 cases diagnosed with CDG globally, and only 160 cases currently reported in the United States; and

WHEREAS, lack of public awareness and visibility of CDG contributes to under-diagnosis 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 goal is to raise awareness and increase the accurate and timely diagnosis of this rare group of inherited metabolic disorders known as CDG.

NOW, THEREFORE, as Governor of the State of North Dakota, I do hereby proclaim May 11, 2018, CONGENITAL DISORDERS OF GLYCOSYLATION AWARENESS DAY in the State of North Dakota.

Doug Burgum

ATTEST:

Alvin A. Jaeger Secretary of State