THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION No. 970 Session of 2020

INTRODUCED	BY BARRAR,	BOBACK,	BURNS,	GREEN,	HENNESSI	EY, JONES,
KINSEY,	LONGIETTI,	MILLARD,	MURT,	NEILSON	N, RYAN,	SCHLOSSBERG,
SONNEY,	READSHAW A	ND KORTZ,	AUGUST	r 25, 20	020	

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, AUGUST 25, 2020

A RESOLUTION

Designating May 16, 2020, as "Congenital Disorders of 1 Glycosylation (CDG) Awareness Day" in Pennsylvania. 2 WHEREAS, Congenital disorders of glycosylation (CDG) is a 3 group of rare metabolic disorders that affect normal organ 4 5 development and the neurological system, leaving children, 6 adolescents and adults impaired with significant physical and 7 developmental disabilities; and 8 WHEREAS, CDG is severely underdiagnosed and misdiagnosed with 9 approximately 1,200 cases diagnosed with CDG globally and only 160 cases of CDG currently reported in the United States; and 10 11 WHEREAS, Lack of public awareness and visibility of CDG 12 contributes to underdiagnosis and difficulties in accessing 13 specialized services and proper rehabilitation and support; and 14 WHEREAS, Early diagnosis of CDG is important to ensure timely 15 management of clinical complications, genetic counseling and 16 when available, treatment and therapeutic remedies; and 17 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; therefore be it
RESOLVED, That the House of Representatives designate May 16,
2020, as "Congenital Disorders of Glycosylation (CDG) Awareness
Day" in Pennsylvania.