
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 232 Session of
2019

INTRODUCED BY BARRAR, BIZZARRO, BOBACK, BURNS, CALTAGIRONE,
DeLUCA, DiGIROLAMO, HEFFLEY, HILL-EVANS, KORTZ, LONGIETTI,
MEHAFFIE, MILLARD, MURT, NEILSON, RYAN AND SONNEY,
APRIL 15, 2019

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
APRIL 15, 2019

A RESOLUTION

1 Designating May 16, 2019, as "Congenital Disorders of
2 Glycosylation (CDG) Awareness Day" in Pennsylvania.

3 WHEREAS, Congenital disorders of glycosylation (CDG) is a
4 group of rare metabolic disorders that affect normal organ
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
10 160 cases of CDG currently reported in the United States; and

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

1 WHEREAS, The goal is to raise awareness and increase the
2 accurate and timely diagnosis of this rare group of inherited
3 metabolic disorders known as CDG; therefore be it

4 RESOLVED, That the House of Representatives designate May 16,
5 2019, as "Congenital Disorders of Glycosylation (CDG) Awareness
6 Day" in Pennsylvania.