ACR-61 Congenital Disorders of Glycosylation Awareness Day. (2017-2018)

Assembly Concurrent Resolution No. 61

CHAPTER 68

Relative to Congenital Disorders of Glycosylation Awareness Day.

[Filed with Secretary of State June 06, 2017.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 61, Nazarian. Congenital Disorders of Glycosylation Awareness Day.

This measure would recognize May 16, 2017, as Congenital Disorders of Glycosylation Awareness Day, and commend those medical professionals, researchers, advocates, parents, and families who have committed themselves to better understanding and promoting awareness of congenital disorders of glycosylation.

Fiscal Committee: no

WHEREAS, In communities throughout the State of California and the United States of America, many families must endure the suffering of loved ones affected by congenital disorders of glycosylation (CDG); and

WHEREAS, CDG is the umbrella term for a rapidly expanding group of rare genetic, metabolic disorders caused by defects in the body’s complex biochemical process of glycosylation; and

WHEREAS, Glycosylation is the process by which “sugar trees”—glycans—are created, altered, and chemically attached to specific proteins and lipids, thereby creating glycoproteins and glycolipids, respectively, which serve numerous important functions in various tissues and organs. Glycosylation involves many different genes in the encoding of numerous varying proteins, including enzymes, and a deficiency or lack of one of these enzymes may lead to various symptoms potentially affecting multiple organ systems; and

WHEREAS, CDG can be associated with a broad range of symptoms and may vary in severity from mild, disabling cases to severe, life-threatening forms. Most often inherited as autosomal recessive conditions, CDG is usually apparent from infancy, with individual disorders representing a mutation to a specific gene; and

WHEREAS, First reported in medical literature by Dr. Jaak Jaeken and his colleagues in 1980, CDG, as a wide-ranging family of disorders, has since expanded to include more than 125 individual disorders, the most commonly diagnosed of which is PMM2-CDG, whose symptoms typically include neurological problems, visual complications, cerebellar hypoplasia, liver disease, kidney cysts, heart abnormalities, diarrhea, and abnormal fat distribution under the skin, among others. Most other forms of CDG cause a similar range of symptoms, with the exception of MPI-CDG, which does not produce neurological problems; and

WHEREAS, CDG affects males and females in equal numbers, and while the exact incidence rate or prevalence of these disorders in the general population remains unknown, with researchers believing that many cases go unrecognized or misdiagnosed, PMM2-CDG alone has been reported in more than 900 individuals; and

WHEREAS, Although not as widespread nor widely understood as other disorders and illnesses, CDG has nonetheless affected many American individuals and their families, and until a cure is found, the responsibility of supporting efforts to provide treatment for those living with any one of these myriad, varying disorders remains of utmost importance; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature recognizes May 16, 2017, as Congenital Disorders of Glycosylation Awareness Day, and commends those medical professionals, researchers, advocates, parents, and families who have committed themselves to better understanding and promoting awareness of congenital disorders of glycosylation; and be it further

Resolved, That the Chief Clerk of the Assembly transmit copies of this resolution to the Governor and to the author for appropriate distribution.