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THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 98 Session of 2015

INTRODUCED BY GREENLEAF, HAYWOOD, WOZNIAK, FONTANA, FARNESE, DINNIMAN, PILEGGI, RAFFERTY, BREWSTER, SCAVELLO, SCHWANK, AUMENT, SMITH, VULAKOVICH, MENSCH, TARTAGLIONE AND ALLOWAY, MAY 4, 2015

INTRODUCED AND ADOPTED, MAY 4, 2015

A RESOLUTION

Designating the month of May 2015 as "Phenylketonuria Awareness Month" in Pennsylvania.

WHEREAS, Phenylketonuria (PKU), is a rare, inherited metabolic disorder that is characterized by the inability of the body to process the essential amino acid phenylalanine, or Phe, which is found in all foods containing proteins; and

WHEREAS, PKU is caused by a deficiency of the liver-produced enzyme phenylalanine hydroxylase (PAH); and

WHEREAS, When this enzyme is absent or deficient, Phe accumulates in the blood and is toxic to brain tissue; and

WHEREAS, Symptoms of PKU can be mild or severe and, in a child, may include delayed development, behavioral, emotional and social problems, poor bone strength, skin rashes (eczema), a musty odor in the child's breath, skin or urine and an abnormally small head; and

WHEREAS, If treatment of the disease is not started within the first few weeks of life, PKU can result in intellectual

disability and other neurological problems, such as memory loss and mood disorders; and

WHEREAS, In 1934, PKU was discovered in Norway by Dr. Asbjörn Fölling, one of Norway's first physicians to apply chemistry to medicine; and

WHEREAS, In 1961, Dr. Robert Guthrie developed a laboratory test to detect PKU in newborns; and

WHEREAS, In 1963, newborn screening for PKU was initiated in the United States; and

WHEREAS, In 1965, the General Assembly enacted the Newborn Child Testing Act, requiring newborn children to be screened for six genetic or metabolic disorders, including PKU; and

WHEREAS, About 1 in every 15,000 infants is born with PKU in the United States; and

WHEREAS, According to Department of Health figures for 2013, of the 139,022 newborns screened, 21 were diagnosed with PKU, or approximately 1 in 6,500 births; and

WHEREAS, Early detection of PKU through newborn blood screening is crucial in helping to prevent major health problems; and

WHEREAS, When treatment is begun within the first few weeks of life and adhered to, affected children can expect normal development and a normal life span; and

WHEREAS, Although there is no cure for PKU, treatment involving medical foods and medications and restriction of Phe intake can prevent progressive, irreversible brain damage; and

WHEREAS, Access to health insurance coverage for medical food varies across the United States, and the long-term costs associated with caring for untreated children and adults with PKU far exceeds the cost of providing medical food treatment;

and

WHEREAS, In 1996, the General Assembly enacted The Medical Foods Insurance Coverage Act, requiring health insurance carriers in Pennsylvania to cover the cost of formulas that are medically necessary to treat PKU and certain other disorders that prevent children from consuming normal foods; and

WHEREAS, The 2012 Phenylketonuria Scientific Review Conference affirmed the recommendation of lifelong dietary treatment for PKU made by the National Institutes of Health Consensus Development Conference Statement 2000; and

WHEREAS, The American College of Medical Genetics and Genomics and Genetic Metabolic Dieticians International published medical and dietary guidelines on the optimal treatment of PKU in 2014; and

WHEREAS, Adults with PKU who discontinue treatment are at risk for serious medical issues, such as depression, impulse control disorder, phobias, tremors and pareses; and

WHEREAS, Women with PKU must maintain strict metabolic control before and during pregnancy to prevent fetal damage; and

WHEREAS, Children born from untreated mothers with PKU may have a condition known as maternal phenylketonuria syndrome, which can cause small brains, intellectual disabilities, birth defects of the heart and low birth weights; and

WHEREAS, Researchers across the United States are conducting important research projects involving PKU; and

WHEREAS, The National PKU Alliance, a nonprofit organization, is dedicated to improving the lives of individuals with phenylketonuria and pursuing a cure; and

WHEREAS, "Phenylketonuria Awareness Month" increases public awareness of the disease and patients' circumstances,

acknowledges the impact of the disease on patients and families and recognizes research for treatment and a cure for PKU; therefore be it

RESOLVED, That the Senate designate the month of May 2015 as "Phenylketonuria Awareness Month" in Pennsylvania and urge all Pennsylvanians to learn about this disease.