



Proclamation

By the Governor of Alabama

WHEREAS, Phenylketonuria, PKU or Phenylalanine Hydroxylase Deficiency, is a rare, inherited metabolic disorder that is characterized by the inability of the body to process the essential amino acid phenylalanine and which causes intellectual disability and other neurological problems, such as memory loss and mood disorders, when treatment is not started within the first few weeks of life; and

WHEREAS, newborn screening for PKU was initiated in the United States in 1963, and was recommended for inclusion in state newborn screening programs under the Newborn Screening Saves Lives, Act of 2007 (Public Law 110-204); and

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

WHEREAS, medical foods are medically necessary for children and adults living with PKU, and adults with PKU who discontinue treatment are at risk for serious medical issues such as depression, impulse control disorder, phobias, tremors and pareses. 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, although there is no cure for PKU, lifelong treatment involving medical foods, medications, and restriction of phenylalanine 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 exceed the cost of providing medical food treatment; and

WHEREAS, gaps in medical foods coverage have a detrimental impact on individuals with PKU, their families, and society. Funding for PKU research is limited and federal funds are needed to continue research for new treatments for PKU; and

WHEREAS, scientists and researchers are hopeful that breakthroughs in PKU research will be forthcoming, and researchers across the United States are conducting important research projects involving PKU; and

WHEREAS, the establishment of the PKU Awareness Day will provide the opportunity to share experience and information with the public and media, and to raise public awareness;

NOW, THEREFORE, I, Kay Ivey, Governor of Alabama, do hereby proclaim March 30, 2018, as

Phenylketonuria (PKU) Awareness Day

in the State of Alabama.



Given Under My Hand and the Great Seal of the Office of the Governor at the State Capitol in the City of Montgomery on the 21st day of March 2018.

Kay Ivey
Kay Ivey, Governor