



# 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*, adults with PKU who discontinue treatment are at risk for serious medical issues such as depression, impulse control disorder, phobias and tremors; 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*, 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*, funding for PKU research is limited and federal funds are needed to continue research for new treatments for PKU. However, scientists and researchers are hopeful that breakthrough in PKU research will be forthcoming; and

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

*NOW, THEREFORE*, I, Kay Ivey, Governor of Alabama, do hereby proclaim April 18, 2019, as

## 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 28th day of March 2019.

*Kay Ivey*

Kay Ivey, Governor