

114TH CONGRESS
2D SESSION

S. RES. 627

Designating December 3, 2016, as “National Phenylketonuria Awareness Day”.

IN THE SENATE OF THE UNITED STATES

DECEMBER 1, 2016

Mr. ISAKSON (for himself and Ms. BALDWIN) submitted the following resolution; which was considered and agreed to

RESOLUTION

Designating December 3, 2016, as “National Phenylketonuria Awareness Day”.

Whereas phenylketonuria (in this preamble referred to as “PKU”) 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;

Whereas PKU is also referred to as Phenylalanine Hydroxylase Deficiency;

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);

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

Whereas PKU is treated with medical food;

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;

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

Whereas medical foods are medically necessary for children and adults living with PKU;

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

Whereas women with PKU must maintain strict metabolic control before and during pregnancy to prevent fetal damage;

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;

Whereas, although there is no cure for PKU, treatment involving medical foods, medications, and restriction of

phenylalanine intake can prevent progressive, irreversible brain damage;

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;

Whereas gaps in medical foods coverage has a detrimental impact on individuals with PKU, their families, and society;

Whereas scientists and researchers are hopeful that breakthroughs in PKU research will be forthcoming;

Whereas researchers across the United States are conducting important research projects involving PKU; and

Whereas the Senate is an institution that can raise awareness of PKU among the general public and the medical community: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates December 3, 2016, as “National
3 Phenylketonuria Awareness Day”;

4 (2) encourages all people in the United States
5 to become more informed about phenylketonuria and
6 the role of medical foods in treating phenyl-
7 ketonuria; and

8 (3) respectfully requests that the Secretary of
9 the Senate transmit an enrolled copy of this resolu-
10 tion to the National PKU Alliance, a nonprofit orga-

- 1 nization dedicated to improving the lives of individ-
- 2 uals with phenylketonuria.

