

112TH CONGRESS
2D SESSION

S. RES. 563

Designating December 3, 2012, as “National Phenylketonuria Awareness Day”.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 19, 2012

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

RESOLUTION

Designating December 3, 2012, as “National Phenylketonuria Awareness Day”.

Whereas phenylketonuria 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 mental retardation and other neurological problems, such as memory loss and mood disorders, when treatment is not started within the first few weeks of life;

Whereas newborn screening for phenylketonuria was initiated in the United States in 1963 and was mandated by the Newborn Screening Saves Life Act of 2008 (42 U.S.C. 201 note);

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

Whereas the 2012 Phenylketonuria Scientific Review Conference affirmed the recommendation of lifelong dietary treatment for phenylketonuria made by the National Institutes of Health Consensus Development Conference Statement 2000;

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

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

Whereas children born from untreated mothers with phenylketonuria may have a condition known as maternal PKU syndrome, which can cause small brains, mental retardation, birth defects of the heart, and low birth weight;

Whereas phenylketonuria is treated with medical food;

Whereas, although there is no cure for phenylketonuria, a treatment involving medical food and restricting phenylalanine intake can prevent progressive, irreversible brain damage;

Whereas maintaining a strict medical diet for phenylketonuria can be difficult to achieve, and poor metabolic control can result in a significant decline in mental and behavioral performance;

Whereas access to health coverage for medical food varies across the United States, and the long-term costs associated with caring for untreated children and adults far exceed the cost of providing medical food treatment;

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

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

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

1 *Resolved*, That the Senate—

2 (1) designates December 3, 2012, as “National
3 Phenylketonuria Awareness Day”;

4 (2) encourages all people in the United States
5 to become more informed about phenylketonuria;
6 and

7 (3) respectfully requests that the Secretary of
8 the Senate transmit a copy of this resolution to the
9 National PKU Alliance, a non-profit organization
10 dedicated to improving the lives of individuals with
11 phenylketonuria.

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