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DELAWARE STATE SENATE
144th GENERAL ASSEMBLY

SENATE BILL NO. 78

AN ACT TO AMEND TITLE 18 OF THE DELAWARE CODE RELATING TO HEALTH INSURANCE AND
NEWBORN SCREENING.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

1 Section 1. Amend Chapter 33, Subchapter III, Title 18, by inserting therein a new section, designated as §3355,
2 which shall read as follows:

3 §3355. Phenylketonuria (PKU) and other inherited metabolic diseases.

4 (a) Definitions: In this section the following words shall have the meanings indicated:

5 (1) "Inherited metabolic diseases" shall mean diseases caused by an inherited abnormality of
6 biochemistry. The words "inherited metabolic diseases" shall also include any diseases for which the
7 State screens newborn babies.

8 (2) a. "Low protein modified formula or food product" means a formula or food
9 product that is:

10 (i) specially formulated to have less than one (1) gram of protein per serving; and is

11 (ii) intended to be used under the direction of a physician for the dietary treatment of
12 an inherited metabolic disease.

13 b. "Low protein modified food product" does not include a natural food that is naturally low in
14 protein.

15 (3) "Medical formula or food" means a formula or food that is:

16 a. intended for the dietary treatment of an inherited metabolic disease for which
17 nutritional requirements and restrictions have been established by medical research; and

18 b. formulated to be consumed or administered enterally under the direction of a
19 physician.

20 (b) Application of this section. The provisions of this section shall apply to any health insurance contract
21 that:

22 (1) provides coverage for a family member of the insured; and

23 (2) is delivered or issued for delivery in the State.

24 (c) A health insurance contract shall, under the family member coverage, include

25 coverage for medical formulas and foods and low protein modified formulas and

26 modified food products for the treatment of inherited metabolic diseases, if such medical formulas

27 and foods or low protein modified formulas and food products are:

28 (1) prescribed as medically necessary for the therapeutic treatment of inherited metabolic
29 diseases, and are:

30 (2) administered under the direction of a physician.

31 Section 2. Amend Chapter 35, Subchapter III, Title 18, by inserting therein a new section, designated as §3571,
32 which shall read as follows:

33 “§3571. Phenylketonuria (PKU) and other inherited metabolic diseases.

34 (a) Definitions: In this section the following words shall have the meanings indicated:

35 (1) “Inherited metabolic diseases” shall mean diseases caused by an inherited abnormality of
36 biochemistry. The words “inherited metabolic diseases” shall also include any diseases for which the
37 State screens newborn babies.

38 (2) a. “Low protein modified formula or food product” means a formula or food product that is:

39 (i) specially formulated to have less than one (1) gram of protein per serving; and
40 is

41 (ii) intended to be used under the direction of a physician for the dietary treatment
42 of an inherited metabolic disease.

43 b. “Low protein modified food product” does not include a natural food that is naturally low in
44 protein.

45 (3) “Medical formula or food” means a formula or food that is:

46 a. intended for the dietary treatment of an inherited metabolic disease for which
47 nutritional requirements and restrictions have been established by medical research; and

48 b. formulated to be consumed or administered enterally under the direction of a
49 physician.

50 (b) Application of this section. The provisions of this section shall apply to any
51 health insurance contract that:

- 52 (1) provides coverage for a family member of the insured; and
53 (2) is delivered or issued for delivery in the State.
- 54 (c) A health insurance contract shall, under the family member coverage, include
55 coverage for medical formulas and foods and low protein modified formulas and
56 modified food products for the treatment of inherited metabolic diseases, if such
57 medical formulas and foods or low protein modified formulas and food products are:
- 58 (1) prescribed as medically necessary for the therapeutic treatment of inherited
59 metabolic diseases, and are:
60 (2) administered under the direction of a physician.

61 Section 3. Amend Chapter 35, Subchapter IV, Title 18, by renumbering §§3571 – 3577 as §§3572 - 3578.

SYNOPSIS

This Bill provides that certain medical formulas and food expenses in the on-going treatment of Phenylketonuria (PKU) and other inherited metabolic diseases shall be covered in health insurance contracts and also in group and blanket health insurance policies.

PKU is one of a number of inherited metabolic diseases for which Delaware newborns are screened. PKU occurs in 1 in every 10,000 to 1 in every 25,000 live births. Other inherited metabolic diseases occur at similar or lower frequencies.

Undetected and untreated, PKU and other inherited metabolic diseases, can result in severe mental retardation, complicated medical conditions, extensive health care costs, or death. Such outcomes can be prevented by following a very strict, medically prescribed diet, which includes specially prescribed medical formulas or foods (such as low phenylalanine formula, and modified low protein foods). The preparation of these medical formulas and foods is complex and expensive.

Author: Senator Henry