

AMENDMENTS TO SENATE BILL NO. 983

Sponsor: SENATOR DiSANTO

Printer's No. 1448

1 Amend Bill, page 1, lines 6 and 7, by striking out "Newborn
2 Child Screening" in line 6 and all of line 7

3 Amend Bill, page 2, lines 7 through 14, by striking out all
4 of said lines

5 Amend Bill, page 2, by inserting between lines 24 and 25

6 "Secretary." The Secretary of Health of the Commonwealth.
7 * * *

8 "Unlicensed midwife." The term includes nationally certified
9 midwives, traditional midwives, Amish, Mennonite or Plain
10 midwives and other specific cultural or spiritual community-
11 based midwives not licensed to practice midwifery in this
12 Commonwealth.

13 Amend Bill, page 2, line 26, by inserting after "amended"
14 and the section is amended by adding a subsection

15 Amend Bill, page 3, line 1, by striking out the bracket
16 before "with"

17 Amend Bill, page 3, line 3, by striking out "Committee] in
18 consultation with the board" and inserting

19 [Committee] Board

20 Amend Bill, page 4, lines 29 and 30, by striking out "Globoid
21 Cell Leukodystrophy (Krabbe).

22 (viii)"

23 Amend Bill, page 5, line 1, by striking out "(ix)" and
24 inserting

1 (viii)

2 Amend Bill, page 5, line 2, by striking out "(x)" and
3 inserting

4 (ix)

5 Amend Bill, page 5, lines 3 through 30; page 6, lines 1
6 through 3; by striking out all of lines 3 through 30 on page 5,
7 all of lines 1 and 2 and "(xxxv)" in line 3 on page 6 and
8 inserting

9 (x)

10 Amend Bill, page 6, line 4, by striking out "(Reserved)." and
11 inserting

12 A birthing facility, certified-nurse midwife, unlicensed
13 midwife or health care practitioner shall order the screening
14 tests of new children for the following diseases:

15 (i) Isovaleric acidemia/Isovalery-CoA dehydrogenase
16 deficiency (IVA).

17 (ii) Glutaric acidemia Type I/Glutaryl-CoA dehydrogenase
18 deficiency Type I (GA I).

19 (iii) 3-Hydroxy 3-methylglutaryl-CoA lyase deficiency (HMG).

20 (iv) Multiple carboxylase deficiency (MCD).

21 (v) Methylmalonic acidemia (mutase deficiency) (MUT).

22 (vi) Methylmalonic acidemia (Cbl A, B).

23 (vii) 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC).

24 (viii) Propionic acidemia/Propionyl-CoA carboxylase
25 deficiency (PROP).

26 (ix) Beta-ketothiolase deficiency (BKT).

27 (x) Medium chain acyl-CoA dehydrogenase deficiency (MCAD).

28 (xi) Very long-chain acyl-CoA dehydrogenase deficiency
29 (VLCAD).

30 (xii) Long-chain L-3-OH acyl-CoA dehydrogenase deficiency
31 (LCHAD).

32 (xiii) Trifunctional protein deficiency (TFP).

33 (xiv) Carnitine uptake defect (CUD).

34 (xv) Homocystinuria (HCY).

35 (xvi) Tyrosinemia type I (TYR I).

36 (xvii) Argininosuccinic acidemia (ASA).

37 (xviii) Citrullinemia (CIT).

38 (xix) Hb S/Beta-thalassemia (Hb S/Th).

39 (xx) Hb S/C disease (Hb S/C).

40 (xxi) Biotinidase deficiency (BIOT).

41 (xxii) Cystic fibrosis (CF).

42 (xxiii) Severe combined immunodeficiency disease (SCID).

43 (xxiv) Globoid Cell Leukodystrophy (Krabbe).

1 Amend Bill, page 6, line 7, by striking out "Follow-up
2 services provided" and inserting

3 The department shall provide follow-up services

4 Amend Bill, page 6, line 8, by striking out "shall include"
5 and inserting

6 relating to

7 Amend Bill, page 6, line 13, by striking out the bracket
8 before "with"

9 Amend Bill, page 6, lines 14 and 15, by striking out
10 "Committee] in consultation with the board" and inserting
11 [Committee] Board

12 Amend Bill, page 6, line 17, by striking out the bracket
13 before "changes"

14 Amend Bill, page 6, line 17, by striking out "] additions"

15 Amend Bill, page 6, line 18, by striking out the bracket
16 before "lists"

17 Amend Bill, page 6, line 18, by striking out "] list"

18 Amend Bill, page 6, line 18, by striking out the bracket
19 before "and"

20 Amend Bill, page 6, line 18, by striking out the bracket
21 after "(2)"

22 Amend Bill, page 6, line 20, by inserting after "reported."

23 Prior to making any change, the department and board shall
24 jointly transmit a notice to the Legislative Reference Bureau
25 for publication in the Pennsylvania Bulletin that establishes a
26 public comment period of at least 30 days.

27 (d.1) The board shall consist of multidisciplinary members
28 appointed by the secretary. The board shall include at least the
29 following:

30 (1) An ethicist.

31 (2) Three pediatric physicians.

32 (3) A neonatologist.

- 1 (4) A genetic counselor.
- 2 (5) A hematologist.
- 3 (6) Two clinical geneticists.
- 4 (7) A nurse midwife.
- 5 (8) A parent advocate.
- 6 (9) A representative recommended by a hospital association.

7 Amend Bill, page 7, line 1, by striking out "sections" and
8 inserting

9 a section

10 Amend Bill, page 7, lines 2 through 30; page 8, lines 1
11 through 9; by striking out "Newborn Child Screening Program
12 Account.--(a)" in line 2, all of lines 3 through 30 on page 7,
13 all of lines 1 through 8 and "Section 3.3." in line 9 on page 8

14 Amend Bill, page 8, line 12, by striking out "3(a)(1)" and
15 inserting

16 3(a)

17 Amend Bill, page 8, line 14, by striking out "3(a)(1)" and
18 inserting

19 3(a)