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THE GENERAL ASSEMBLY OF PENNSYLVANIA

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**HOUSE BILL**

**No. 883**      Session of  
2007

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INTRODUCED BY KENNEY, CURRY, J. TAYLOR, BISHOP, SONNEY, MYERS,  
McILHATTAN, WATSON, REICHLEY, YOUNGBLOOD, SCAVELLO, O'NEILL,  
PETRONE, NAILOR, KOTIK, CAPPELLI, JOSEPHS, BAKER, CRUZ,  
FABRIZIO, COHEN, HENNESSEY, VULAKOVICH, WALKO, SOLOBAY,  
RUBLEY, GEIST, FREEMAN, CALTAGIRONE, JAMES, DENLINGER, HESS,  
GRUCELA, GOODMAN AND MELIO, MARCH 22, 2007

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SENATOR ERICKSON, PUBLIC HEALTH AND WELFARE, IN SENATE, AS  
AMENDED, MARCH 12, 2008

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AN ACT

1 Amending the act of September 9, 1965 (P.L.497, No.251),  
2 entitled "An act requiring physicians, hospitals and other  
3 institutions to administer or cause to be administered tests  
4 for phenylketonuria and other metabolic diseases upon infants  
5 in certain cases," further providing for newborn child  
6 screening and testing; and making editorial changes.

7 The General Assembly of the Commonwealth of Pennsylvania  
8 hereby enacts as follows:

9 Section 1. The title of the act of September 9, 1965  
10 (P.L.497, No.251), known as the Newborn Child Testing Act, is  
11 amended to read:

12 AN ACT

13 Requiring physicians, hospitals and other institutions to  
14 administer or cause to be administered tests for  
15 [phenylketonuria and other metabolic diseases] genetic <—  
16 ~~metabolic, hormonal and functional conditions~~ DISEASES upon <—  
17 infants in certain cases.

1 Section 2. Section 3 of the act, added July 9, 1992

2 (P.L.398, No.86), is amended to read:

3 Section 3. Newborn Child Screening and Follow-up Program.--

4 (a) In order to assist health care providers to determine  
5 whether treatment or other services are necessary to avert  
6 mental retardation, permanent disabilities or death, the  
7 department, with the approval of the board, shall establish a  
8 program providing for:

9 (1) The screening tests of newborn children for [diseases.]

10 ~~phenylketonuria (PKU), maple syrup urine disease (MSUD), sickle~~ <—  
11 ~~cell disease (hemoglobinopathies), galactosemia, congenital~~  
12 ~~adrenal hyperplasia (CAH) and primary congenital~~  
13 ~~hyperthyroidism.~~ THE FOLLOWING DISEASES: <—

14 (I) PHENYLKETONURIA (PKU).

15 (II) MAPLE SYRUP URINE DISEASE (MSUD).

16 (III) SICKLE-CELL DISEASE (HEMOGLOBINOPATHIES).

17 (IV) GALACTOSEMIA.

18 (V) CONGENITAL ADRENAL HYPERPLASIA (CAH).

19 (VI) PRIMARY CONGENITAL HYPERTHYROIDISM.

20 (2) Follow-up services relating to confirmatory screening,  
21 testing, assessment and diagnosis of newborn children with  
22 abnormal [or inconclusive], INCONCLUSIVE OR UNACCEPTABLE <—  
23 screening test results[.] for the following diseases:

24 [(b) The department, with the approval of the board, shall  
25 establish by regulation those diseases, in addition to  
26 phenylketonuria (PKU), maple syrup urine disease (MSUD) and  
27 sickle-cell disease (hemoglobinopathies, for which newborn  
28 children shall be tested and the methods for testing and  
29 disseminating test results.]

30 (i) Phenylketonuria (PKU).

- 1     (ii) Maple syrup urine disease (MSUD).
- 2     (iii) Sickle-cell disease (hemoglobinopathies).
- 3     (iv) Isovaleric acidemia/Isovalery-CoA dehydrogenase
- 4 deficiency (IVA).
- 5     (v) Glutaric acidemia Type I/Glutaryl-CoA dehydrogenase
- 6 deficiency Type I (GA I).
- 7     (vi) 3-Hydroxy 3-methylglutaryl-CoA lyase deficiency (HMG).
- 8     (vii) Multiple carboxylase deficiency (MCD).
- 9     (viii) Methylmalonic acidemia (mutase deficiency) (MUT).
- 10    (ix) Methylmalonic acidemia (Cbl A,B).
- 11    (x) 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC).
- 12    (xi) Propionic acidemia/Propionyl-CoA carboxylase deficiency
- 13 (PROP).
- 14    (xii) Beta-ketothiolase deficiency (BKT).
- 15    (xiii) Medium chain acyl-CoA dehydrogenase deficiency
- 16 (MCAD).
- 17    (xiv) Very long-chain acyl-CoA dehydrogenase deficiency
- 18 (VLCAD).
- 19    (xv) Long-chain L-3-OH acyl-CoA dehydrogenase deficiency
- 20 (LCHAD).
- 21    (xvi) Trifunctional protein deficiency (TFP).
- 22    (xvii) Carnitine uptake defect (CUD).
- 23    (xviii) Homocystinuria (HCY).
- 24    (xix) Tyrosinemia type I (TYR I).
- 25    (xx) Argininosuccinic acidemia (ASA).
- 26    (xxi) Citrullinemia (CIT).
- 27    (xxii) Hb S/Beta-thalassemia (Hb S/Th).
- 28    (xxiii) Hb S/C disease (Hb S/C).
- 29    ~~(xxix)~~ (XXIV) Congenital hypothyroidism (HYPOTH).
- 30    (xxv) Biotinidase deficiency (BIOT).

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1        (xxvi) Congenital adrenal hyperplasia (CAH).

2        (xxvii) Galactosemia (GALT).

3        (xxviii) Cystic fibrosis (CF).

4        (b.1) All laboratories performing the screening tests for  
5 newborn children shall report the results to the department for  
6 follow-up activities.

7        (c) No screening test shall be performed if a parent or  
8 guardian dissents on the ground that the test conflicts with a  
9 religious belief or practice.

10       (d) The department, with the approval of the board, shall  
11 establish, by periodic publication in the Pennsylvania Bulletin,  
12 changes to the lists under subsection (a)(1) and (2) of those  
13 diseases for which newborn children shall be tested and for  
14 which the department shall provide follow-up services.

15       ~~(e) The department, with the approval of the board, shall~~       <—  
16 ~~establish by regulation the methods for testing for those~~  
17 ~~diseases listed under subsection (a)(1).~~

18       ~~(f) (E) Notwithstanding any provisions of this act or the~~       <—  
19 ~~act of April 23, 1956 (1955 P.L.1510, No.500), known as the~~  
20 ~~"Disease Prevention and Control Law of 1955," to the contrary,~~  
21 ~~test results and diagnoses based upon screening tests for the~~  
22 ~~diseases listed in this section for newborn children shall be~~  
23 ~~reported to the department. The department shall establish, by~~  
24 ~~periodic publication in the Pennsylvania Bulletin, the method~~  
25 ~~for reporting test results to the department.~~

26       ~~(g) (F) Test results for genetic diseases listed in this~~       <—  
27 ~~section, and any diseases subsequently added by the department~~  
28 ~~under subsection (d), shall be subject to the confidentiality~~  
29 ~~provisions of the "Disease Prevention and Control Law of 1955."~~

30       Section 3. This act shall take effect July 1, 2008 2009.       <—