

## THE GENERAL ASSEMBLY OF PENNSYLVANIA

## SENATE BILL

No. 9

Session of  
1991

INTRODUCED BY HOLL, BRIGHTBILL, SALVATORE, ROBBINS AND DAWIDA,  
JANUARY 15, 1991

AS RE-REPORTED FROM COMMITTEE ON APPROPRIATIONS, HOUSE OF  
REPRESENTATIVES, AS AMENDED, MARCH 31, 1992

## 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," providing for tests for maple syrup urine~~  
6 ~~disease.~~

7 AMENDING THE ACT OF SEPTEMBER 9, 1965 (P.L.497, NO.251), <—  
8 ENTITLED "AN ACT REQUIRING PHYSICIANS, HOSPITALS AND OTHER  
9 INSTITUTIONS TO ADMINISTER OR CAUSE TO BE ADMINISTERED TESTS  
10 FOR PHENYLKETONURIA AND OTHER METABOLIC DISEASES UPON INFANTS  
11 IN CERTAIN CASES," FURTHER PROVIDING FOR A NEWBORN CHILD  
12 SCREENING PROGRAM.

13 The General Assembly of the Commonwealth of Pennsylvania  
14 hereby enacts as follows:

15 ~~Section 1. Section 1 of the act of September 9, 1965~~ <—  
16 ~~(P.L.497, No.251), entitled "An act requiring physicians,~~  
17 ~~hospitals and other institutions to administer or cause to be~~  
18 ~~administered tests for phenylketonuria and other metabolic~~  
19 ~~diseases upon infants in certain cases," is amended to read:~~

20 ~~Section 1. Every hospital or other institution caring for~~  
21 ~~newborn infants, or any physician having in his care newborn~~

~~1 infants shall administer or cause to be administered to every  
2 such infant in its or his care a test for phenylketonuria and  
3 maple syrup urine disease approved by the Advisory Health Board  
4 of the State Department of Health and tests for such other  
5 metabolic diseases of the newborn which may lead to mental  
6 retardation or physical defects and which may be approved by  
7 such Advisory Health Board. No such test shall be made if the  
8 parent or guardian of the newborn child dissents on the ground  
9 that the test conflicts with his religious beliefs or practices.~~

10 ~~Section 2. This act shall take effect immediately.~~

11 SECTION 1. THE ACT OF SEPTEMBER 9, 1965 (P.L.497, NO.251), <—  
12 ENTITLED "AN ACT REQUIRING PHYSICIANS, HOSPITALS AND OTHER  
13 INSTITUTIONS TO ADMINISTER OR CAUSE TO BE ADMINISTERED TESTS FOR  
14 PHENYLKETONURIA AND OTHER METABOLIC DISEASES UPON INFANTS IN  
15 CERTAIN CASES," IS AMENDED BY ADDING SECTIONS TO READ:

16 SECTION 1. SHORT TITLE.--THIS ACT SHALL BE KNOWN AND MAY BE  
17 CITED AS THE "NEWBORN CHILD TESTING ACT."

18 SECTION 2. DEFINITIONS.--THE FOLLOWING WORDS AND PHRASES  
19 WHEN USED IN THIS ACT SHALL HAVE THE MEANINGS GIVEN TO THEM IN  
20 THIS SECTION UNLESS THE CONTEXT CLEARLY INDICATES OTHERWISE:

21 "BOARD." THE STATE ADVISORY HEALTH BOARD IN THE DEPARTMENT  
22 OF HEALTH.

23 "DEPARTMENT." THE DEPARTMENT OF HEALTH OF THE COMMONWEALTH.

24 "DISEASE." DISEASES LISTED BY THE DEPARTMENT OF HEALTH BY  
25 REGULATION WHICH LEAD TO MENTAL RETARDATION OR PHYSICAL DEFECTS,  
26 INCLUDING WITHOUT LIMITATION PHENYLKETONURIA (PKU), MAPLE SYRUP  
27 URINE DISEASE (MSUD) AND SICKLE-CELL DISEASE  
28 (HEMOGLOBINOPATHIES).

29 "HEALTH CARE PROVIDER." A HEALTH CARE FACILITY OR HEALTH  
30 CARE PRACTITIONER AS DEFINED BY REGULATIONS OF THE DEPARTMENT OF

1 HEALTH.

2 "NEWBORN CHILD." A CHILD LESS THAN 28 DAYS OF AGE.

3 "PROGRAM." THE NEWBORN CHILD SCREENING AND FOLLOW-UP PROGRAM  
4 ADMINISTERED BY THE DEPARTMENT OF HEALTH.

5 "REPEAT SPECIMEN." A SECOND OR SUBSEQUENT BLOOD SPECIMEN  
6 COLLECTED FROM A NEWBORN CHILD FOR THE SAME PURPOSE.

7 "UNACCEPTABLE SPECIMEN." A NEWBORN CHILD'S BLOOD SPECIMEN  
8 WHICH IS NOT SUITABLE IN QUALITY OR QUANTITY TO PERFORM NEWBORN  
9 SCREENING OR CONFIRMATORY TESTING FOR ONE OR MORE OF THE  
10 DISEASES COVERED BY THIS ACT OR THE REGULATIONS PROMULGATED  
11 THEREUNDER.

12 SECTION 2. SECTION 1 OF THE ACT IS AMENDED TO READ:

13 [SECTION 1. EVERY HOSPITAL OR OTHER INSTITUTION CARING FOR  
14 NEWBORN INFANTS, OR ANY PHYSICIAN HAVING IN HIS CARE NEWBORN  
15 INFANTS SHALL ADMINISTER OR CAUSE TO BE ADMINISTERED TO EVERY  
16 SUCH INFANT IN ITS OR HIS CARE A TEST FOR PHENYLKETONURIA  
17 APPROVED BY THE ADVISORY HEALTH BOARD OF THE STATE DEPARTMENT OF  
18 HEALTH AND TESTS FOR SUCH OTHER METABOLIC DISEASES OF THE  
19 NEWBORN WHICH MAY LEAD TO MENTAL RETARDATION OR PHYSICAL DEFECTS  
20 AND WHICH MAY BE APPROVED BY SUCH ADVISORY HEALTH BOARD. NO SUCH  
21 TEST SHALL BE MADE IF THE PARENT OR GUARDIAN OF THE NEWBORN  
22 CHILD DISSENTS ON THE GROUND THAT THE TEST CONFLICTS WITH HIS  
23 RELIGIOUS BELIEFS OR PRACTICES.]

24 SECTION 3. NEWBORN CHILD SCREENING AND FOLLOW-UP PROGRAM.--

25 (A) IN ORDER TO ASSIST HEALTH CARE PROVIDERS TO DETERMINE  
26 WHETHER TREATMENT OR OTHER SERVICES ARE NECESSARY TO AVERT  
27 MENTAL RETARDATION, PERMANENT DISABILITIES OR DEATH, THE  
28 DEPARTMENT SHALL ESTABLISH A PROGRAM PROVIDING FOR:

29 (1) THE SCREENING TESTS OF NEWBORN CHILDREN FOR DISEASES.

30 (2) FOLLOW-UP SERVICES RELATING TO CONFIRMATORY TESTING,

1 ASSESSMENT AND DIAGNOSIS OF NEWBORN CHILDREN WITH ABNORMAL OR  
2 INCONCLUSIVE SCREENING REST RESULTS.

3 (B) THE DEPARTMENT, WITH THE ADVICE OF THE BOARD, SHALL  
4 ESTABLISH BY REGULATION THOSE DISEASES FOR WHICH NEWBORN  
5 CHILDREN SHALL BE TESTED AND THE METHODS FOR TESTING AND  
6 DISSEMINATING TEST RESULTS.

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 SECTION 3. THE ACT IS AMENDED BY ADDING SECTIONS TO READ:

11 SECTION 4. PROCUREMENT OF SPECIMENS BY HEALTH CARE  
12 PROVIDERS.--(A) HEALTH CARE PROVIDERS SHALL CAUSE TO BE  
13 PROCURED BLOOD SPECIMENS OF NEWBORN CHILDREN FOR REQUIRED  
14 SCREENING AND CONFIRMATORY TESTS, AND SEND SUCH SPECIMENS TO A  
15 TESTING LABORATORY DESIGNATED BY THE DEPARTMENT.

16 (B) IF THE INITIAL SPECIMEN IS AN UNACCEPTABLE SPECIMEN, OR  
17 AS OTHERWISE REQUIRED BY THE DEPARTMENT BY REGULATION, THE  
18 HEALTH CARE PROVIDER SHALL COLLECT A REPEAT SPECIMEN FOR  
19 SCREENING AND CONFIRMATORY TESTS.

20 SECTION 5. FEES.--THE DEPARTMENT, WITH THE ADVICE OF THE  
21 BOARD, IS AUTHORIZED TO PROMULGATE REGULATIONS PROVIDING FOR THE  
22 COLLECTION OF FEES BY EACH HEALTH CARE PROVIDER WHO PROCURES  
23 BLOOD SPECIMENS UNDER THIS ACT.

24 SECTION 6. REGULATIONS.--THE DEPARTMENT SHALL HAVE THE  
25 AUTHORITY TO PROMULGATE REGULATIONS FOR THE IMPLEMENTATION AND  
26 ADMINISTRATION OF THIS ACT.

27 SECTION 4. ANY REGULATIONS PROMULGATED UNDER THE ACT PRIOR  
28 TO THE EFFECTIVE DATE OF THIS AMENDATORY ACT SHALL CONTINUE AND  
29 REMAIN IN FULL FORCE AND EFFECT UNTIL REPEALED, SUPERSEDED OR  
30 SUPPLEMENTED BY REGULATIONS PROMULGATED UNDER THE AUTHORITY OF

1 THIS AMENDATORY ACT.

2 SECTION 5. THIS ACT SHALL TAKE EFFECT JULY 1, 1992.