

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~~

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

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

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

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

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

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

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

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

"HEALTH CARE PROVIDER." A HEALTH CARE FACILITY OR HEALTH
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 TEST 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.