THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE BILL

No. 9

Session of 1991

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

SENATE AMENDMENTS TO HOUSE AMENDMENTS, JUNE 22, 1992

AN ACT

Amending the act of September 9, 1965 (P.L.497, No.251), entitled "An act requiring physicians, hospitals and other 2 institutions to administer or cause to be administered tests 4 for phenylketonuria and other metabolic diseases upon infants in certain cases, "further providing for a newborn child 6 screening program. 7 The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows: 9 Section 1. The act of September 9, 1965 (P.L.497, No.251), entitled "An act requiring physicians, hospitals and other 10 11 institutions to administer or cause to be administered tests for 12 phenylketonuria and other metabolic diseases upon infants in 13 certain cases," is amended by adding sections to read: 14 Section 1. Short Title .-- This act shall be known and may be 15 cited as the "Newborn Child Testing Act." 16 Section 2. Definitions. -- The following words and phrases when used in this act shall have the meanings given to them in 17

this section unless the context clearly indicates otherwise:

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- 1 "Board." The State Advisory Health Board in the Department
- 2 of Health.
- 3 <u>"Department." The Department of Health of the Commonwealth.</u>
- 4 "Disease." Diseases listed by the Department of Health by
- 5 regulation which lead to mental retardation or physical defects,
- 6 including without limitation Phenylketonuria (PKU), maple syrup
- 7 urine disease (MSUD) and sickle-cell disease
- 8 (hemoglobinopathies).
- 9 <u>"Health care provider." A health care facility or health</u>
- 10 care practitioner as defined by regulations of the Department of
- 11 Health.
- 12 "Newborn child." A child less than 28 days of age.
- 13 "Program." The Newborn Child Screening and Follow-up Program
- 14 administered by the Department of Health.
- 15 <u>"Repeat specimen." A second or subsequent blood specimen</u>
- 16 <u>collected from a newborn child for the same purpose.</u>
- 17 "Unacceptable specimen." A newborn child's blood specimen
- 18 which is not suitable in quality or quantity to perform newborn
- 19 screening or confirmatory testing for one or more of the
- 20 diseases covered by this act or the regulations promulgated
- 21 thereunder.
- 22 Section 2. Section 1 of the act is amended to read:
- 23 [Section 1. Every hospital or other institution caring for
- 24 newborn infants, or any physician having in his care newborn
- 25 infants shall administer or cause to be administered to every
- 26 such infant in its or his care a test for phenylketonuria
- 27 approved by the Advisory Health Board of the State Department of
- 28 Health and tests for such other metabolic diseases of the
- 29 newborn which may lead to mental retardation or physical defects
- 30 and which may be approved by such Advisory Health Board. No such

- 1 test shall be made if the parent or quardian of the newborn
- 2 child dissents on the ground that the test conflicts with his
- 3 religious beliefs or practices.]
- 4 <u>Section 3. Newborn Child Screening and Follow-up Program.--</u>
- 5 (a) In order to assist health care providers to determine
- 6 whether treatment or other services are necessary to avert
- 7 mental retardation, permanent disabilities or death, the
- 8 department, WITH THE APPROVAL OF THE BOARD, shall establish a
- 9 program providing for:
- 10 (1) The screening tests of newborn children for diseases.
- 11 (2) Follow-up services relating to confirmatory testing,
- 12 assessment and diagnosis of newborn children with abnormal or
- 13 <u>inconclusive screening rest TEST results.</u>
- (b) The department, with the advice APPROVAL of the board, <-

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- 15 <u>shall establish by regulation those diseases, IN ADDITION TO</u>
- 16 PHENYLKETONURIA (PKU), MAPLE SYRUP URINE DISEASE (MSUD) AND
- 17 SICKLE-CELL DISEASE (HEMOGLOBINOPATHIES), for which newborn
- 18 children shall be tested and the methods for testing and
- 19 disseminating test results.
- 20 (c) No screening test shall be performed if a parent or
- 21 guardian dissents on the ground that the test conflicts with a
- 22 religious belief or practice.
- 23 Section 3. The act is amended by adding sections to read:
- 24 <u>Section 4. Procurement of Specimens by Health Care</u>
- 25 <u>Providers.--(a) Health care providers shall cause to be</u>
- 26 procured blood specimens of newborn children for required
- 27 screening and confirmatory tests, and send such specimens to a
- 28 <u>testing laboratory designated by the department.</u>
- (b) If the initial specimen is an unacceptable specimen, or
- 30 as otherwise required by the department by regulation, the

- 1 health care provider shall collect a repeat specimen for
- 2 <u>screening and confirmatory tests</u>.
- 3 <u>Section 5. Regulations.--The department, WITH THE APPROVAL</u>
- 4 OF THE BOARD, shall have the authority to promulgate regulations
- 5 for the implementation and administration of this act.
- 6 Section 4. Any regulations promulgated under the act prior
- 7 to the effective date of this amendatory act shall continue and
- 8 remain in full force and effect until repealed, superseded or
- 9 supplemented by regulations promulgated under the authority of

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- 10 this amendatory act.
- 11 Section 5. This act shall take effect July 1, 1992, OR
- 12 IMMEDIATELY, WHICHEVER IS LATER.