No. 2008-36

AN ACT

HB 883

Amending 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," further providing for newborn child screening and testing; and making editorial changes.

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

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

AN ACT

Requiring physicians, hospitals and other institutions to administer or cause to be administered tests for **[phenylketonuria and other metabolic diseases]** ***genetic diseases*** upon infants in certain cases.

Section 2. Section 3 of the act, added July 9, 1992 (P.L.398, No.86), is amended to read:

Section 3. Newborn Child Screening and Follow-up Program.—(a) In order to assist health care providers to determine whether treatment or other services are necessary to avert mental retardation, permanent disabilities or death, the department, with the approval of the **[board]** ***Newborn Screening and Follow-up Technical Advisory Committee,***[1] shall establish a program providing for:

(1) The screening tests of newborn children for **[diseases.]** ***the following diseases:***

(i) Phenylketonuria (PKU).

(ii) Maple syrup urine disease (MSUD).

(iii) Sickle-cell disease (hemoglobinopathies).

(iv) Galactosemia.

(v) Congenital adrenal hyperplasia (CAH).

(vi) Primary congenital hypothyroidism.

(2) Follow-up services relating to ***case management, referrals,*** confirmatory testing, assessment and diagnosis of newborn children with abnormal **[or inconclusive]**, ***inconclusive or unacceptable*** screening test results**[.]** ***for the following diseases:***

[(b) The department, with the approval of the board, shall establish by regulation those diseases, in addition to phenylketonuria (PKU), maple syrup urine disease (MSUD) and sickle-cell disease

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[1] "Advisory Board," in enrolled bill.

(hemoglobinopathies, for which newborn children shall be tested and the methods for testing and disseminating test results.]

(i) Phenylketonuria (PKU).

(ii) Maple syrup urine disease (MSUD).

(iii) Sickle-cell disease (hemoglobinopathies).

(iv) Isovaleric acidemia/Isovalery-CoA dehydrogenase deficiency (IVA).

(v) Glutaric acidemia Type I/Glutaryl-CoA dehydrogenase deficiency Type I (GA I).

(vi) 3-Hydroxy 3-methylglutaryl-CoA lyase deficiency (HMG).

(vii) Multiple carboxylase deficiency (MCD).

(viii) Methylmalonic acidemia (mutase deficiency) (MUT).

(ix) Methylmalonic acidemia (Cbl A,B).

(x) 3-Methylcrontonyl-CoA carboxylase deficiency (3MCC).

(xi) Propionic acidemia/Propionyl-CoA carboxylase deficiency (PROP).

(xii) Beta-ketothiolase deficiency (BKT).

(xiii) Medium chain acyl-CoA dehydrogenase deficiency (MCAD).

(xiv) Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD).

(xv) Long-chain L-3-OH acyl-CoA dehydrogenase deficiency (LCHAD).

(xvi) Trifunctional protein deficiency (TFP).

(xvii) Carnitine uptake defect (CUD).

(xviii) Homocystinuria (HCY).

(xix) Tyrosinemia type I (TYR I).

(xx) Argininosuccinic acidemia (ASA).

(xxi) Citrullinemia (CIT).

(xxii) Hb S/Beta-thalassemia (Hb S/Th).

(xxiii) Hb S/C disease (Hb S/C).

(xxiv) Congenital hypothyroidism (HYPOTH).

(xxv) Biotinidase deficiency (BIOT).

(xxvi) Congenital adrenal hyperplasia (CAH).

(xxvii) Galactosemia (GALT).

(xxviii) Cystic fibrosis (CF).

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

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

(d) The department, with the approval of the Newborn Screening and Follow-up Technical Advisory Committee,[1] shall establish, by periodic publication in the Pennsylvania Bulletin, changes to the lists under subsection (a)(1) and (2) of those diseases for which newborn children shall be screened and laboratory screening results reported.

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[1] "Advisory Board," in enrolled bill.

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

(f) Test results for genetic diseases listed in this section and any diseases subsequently added by the department under subsection (d) shall be subject to the confidentiality provisions of the "Disease Prevention and Control Law of 1955."

Section 3. This act shall take effect July 1, 2009.

APPROVED—The 4th day of July, A.D. 2008.

EDWARD G. RENDELL