GENERAL ASSEMBLY
COMMONWEALTH OF KENTUCKY

2015 REGULAR SESSION

SENATE BILL NO. 75

AS ENACTED

WEDNESDAY, MARCH 11, 2015

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ALISON LUNDERGAN GRIMES
SECRETARY OF STATE
COMMONWEALTH OF KENTUCKY
BY K. Adler

1 AN ACT related to newborn screening for krabbe disease.

2 ***Be it enacted by the General Assembly of the Commonwealth of Kentucky:***

3 ➔Section 1. KRS 214.155 is amended to read as follows:

4 (1) The Cabinet for Health and Family Services shall operate a newborn screening
5 program for heritable and congenital disorders that includes but is not limited to
6 procedures for conducting initial newborn screening tests on infants twenty-eight
7 (28) days or less of age and definitive diagnostic evaluations provided by a state
8 university-based specialty clinic for infants whose initial screening tests resulted in
9 a positive test. The secretary of the cabinet shall, by administrative regulation
10 promulgated pursuant to KRS Chapter 13A:

11 (a) Prescribe the times and manner of obtaining a specimen and transferring a
12 specimen for testing;

13 (b) Prescribe the manner of procedures, testing specimens, and recording and
14 reporting the results of newborn screening tests; and

15 (c) Establish and collect fees to support the newborn screening program.

16 (2) The administrative officer or other person in charge of each institution caring for
17 infants twenty-eight (28) days or less of age and the person required in pursuance of
18 the provisions of KRS 213.046 shall register the birth of a child and cause to have
19 administered to every such infant or child in its or his care tests for heritable
20 disorders, including but not limited to phenylketonuria (PKU), sickle cell disease,
21 congenital hypothyroidism, galactosemia, medium-chain acyl-CoA dehydrogenase
22 deficiency (MCAD), very long-chain acyl-CoA deficiency (VLCAD), short-chain
23 acyl-CoA dehydrogenase deficiency (SCAD), maple syrup urine disease (MSUD),
24 congenital adrenal hyperplasia (CAH), biotinidase disorder, and cystic fibrosis (CF),
25 3-methylcrotonyl-CoA carboxylase deficiency (3MCC), 3-OH 3-CH3 glutaric
26 aciduria (HMG), argininosuccinic acidemia (ASA), beta-ketothiolase deficiency
27 (BKT), carnitine uptake defect (CUD), citrullinemia (CIT), glutaric acidemia type I

1 (GA I), Hb S/beta-thalassemia (Hb S/Th), Hb S/C disease (Hb S/C), homocystinuria
2 (HCY), isovaleric acidemia (IVA), long-chain L-3-OH acyl-CoA dehydrogenase
3 deficiency (LCAD), methylmalonic acidemia (Cbl A,B), methylmalonic acidemia
4 mutase deficiency (MUT), multiple carboxylase deficiency (MCD), propionic
5 acidemia (PA), trifunctional protein deficiency (TFP), ~~[and]~~tyrosinemia type I
6 (TYR I)***, and krabbe disease***. The listing of tests for heritable disorders to be
7 performed shall include all conditions consistent with the recommendations of the
8 American College of Medical Genetics.
9 (3) The administrative officer or other person in charge of each institution caring for
10 infants twenty-eight (28) days or less of age and the person required in pursuance of
11 the provisions of KRS 213.046 shall register the birth of a child and cause to have
12 administered to every such infant or child in its or his care a screening for critical
13 congenital heart disease (CCHD) prior to discharge unless CCHD has been ruled
14 out or diagnosed with prior echocardiogram or prenatal diagnosis of CCHD.
15 (4) Each health care provider of newborn care shall provide an infant's parent or
16 guardian with information about the newborn screening tests required under
17 subsections (2) and (3) of this section. The institution or health care provider shall
18 arrange for appropriate and timely follow-ups to the newborn screening tests,
19 including but not limited to additional diagnoses, evaluation, and treatment when
20 indicated.
21 (5) Nothing in this section shall be construed to require the testing of any child whose
22 parents are members of a nationally recognized and established church or religious
23 denomination, the teachings of which are opposed to medical tests, and who object
24 in writing to the testing of his or her child on that ground.
25 (6) The cabinet shall make available the names and addresses of health care providers,
26 including but not limited to physicians, nurses, and nutritionists, who may provide
27 postpartum home visits to any family whose infant or child has tested positive for a

1 newborn screening test.

2 (7) A parent or guardian shall be provided information by the institution or health care
3 provider of newborn care about the availability and costs of screening tests not
4 specified in subsections (2) and (3) of this section. The parent or guardian shall be
5 responsible for costs relating to additional screening tests performed under this
6 subsection, and these costs shall not be included in the fees established for the
7 cabinet's newborn screening program under subsection (1) of this section. All
8 positive results of additional screening of these tests shall be reported to the cabinet
9 by the institution or health care provider.

10 (8) (a) For the purposes of this subsection, a qualified laboratory means a clinical
11 laboratory not operated by the cabinet that is accredited pursuant to 42 U.S.C.
12 sec. 263a, licensed to perform newborn screening testing in any state, and
13 reports its screening results using normal pediatric reference ranges.

14 (b) The cabinet shall enter into agreements with public or private qualified
15 laboratories to perform newborn screening tests if the laboratory operated by
16 the cabinet is unable to screen for a condition specified in subsection (2) of
17 this section.

18 (c) The cabinet may enter into agreements with public or private qualified
19 laboratories to perform testing for conditions not specified in subsection (2) of
20 this section. Any agreement entered into under this paragraph shall not
21 preclude an institution or health care provider from conducting newborn
22 screening tests for conditions not specified in subsections (2) and (3) of this
23 section by utilizing other public or private qualified laboratories.

24 (9) The secretary for health and family services or his or her designee shall apply for
25 any federal funds or grants available through the Public Health Service Act and may
26 solicit and accept private funds to expand, improve, or evaluate programs to provide
27 screening, counseling, testing, or specialty services for newborns or children at risk

1 for heritable disorders.

2 (10) This section shall be cited as the James William Lazzaro and Madison Leigh Heflin

3 Newborn Screening Act.

4 ➔Section 2. Section 1 of this Act may be cited as the Anna Claire Taylor Law.

President of Senate

Speaker-House of Representatives

Attest: Chief Clerk of Senate

Approved Governor

Date 3/19/15