

1 AN ACT relating to newborn and infant screenings.

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, cystic fibrosis (CF), 3-
25 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), tyrosinemia type I (TYR I),
6 spinal muscular atrophy (SMA), ~~and~~krabbe disease; and cytomegalovirus
7 (CMV). The listing of tests for heritable disorders to be performed shall include all
8 conditions consistent with the recommendations of the American College of
9 Medical Genetics.

10 (3) The administrative officer or other person in charge of each institution caring for
11 infants twenty-eight (28) days or less of age and the person required in pursuance of
12 the provisions of KRS 213.046 shall register the birth of a child and cause to have
13 administered to every such infant or child in its or his care a screening for critical
14 congenital heart disease (CCHD) prior to discharge unless CCHD has been ruled
15 out or diagnosed with prior echocardiogram or prenatal diagnosis of CCHD.

16 (4) Each health care provider of newborn care shall provide an infant's parent or
17 guardian with information about the newborn screening tests required under
18 subsections (2) and (3) of this section. The institution or health care provider shall
19 arrange for appropriate and timely follow-ups to the newborn screening tests,
20 including but not limited to additional diagnoses, evaluation, and treatment when
21 indicated.

22 (5) Nothing in this section shall be construed to require the testing of any child whose
23 parents are members of a nationally recognized and established church or religious
24 denomination, the teachings of which are opposed to medical tests, and who object
25 in writing to the testing of his or her child on that ground.

26 (6) The cabinet shall make available the names and addresses of health care providers,
27 including but not limited to physicians, nurses, and nutritionists, who may provide

1 postpartum home visits to any family whose infant or child has tested positive for a
2 newborn screening test.

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

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

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

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

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

1 screening, counseling, testing, or specialty services for newborns or children at risk
2 for heritable disorders.

3 (10) This section shall be cited as the James William Lazzaro and Madison Leigh Heflin
4 Newborn Screening Act.

5 ➔SECTION 2. A NEW SECTION OF KRS CHAPTER 214 IS CREATED TO
6 READ AS FOLLOWS:

7 **(1) For the purposes of this section "department" means the Department for Public**
8 **Health in the Cabinet for Health and Family Services.**

9 **(2) The department shall provide public educational resources to inform pregnant**
10 **women and women who may become pregnant that include but are not limited to**
11 **information regarding the incidence of cytomegalovirus, the transmission of**
12 **cytomegalovirus before and during pregnancy, birth defects caused by congenital**
13 **cytomegalovirus, methods of diagnosing congenital cytomegalovirus, available**
14 **preventive measures, and resources for the family of an infant born with**
15 **congenital cytomegalovirus. The department may solicit and accept the assistance**
16 **of relevant medical associations or community resources to develop, promote, and**
17 **distribute the public educational resources.**

18 ➔Section 3. This Act may be cited as the "Bella Dawn Streeval Law."