

WEST VIRGINIA LEGISLATURE

2019 REGULAR SESSION

Introduced

House Bill 2436

BY DELEGATE CAPITO

[Introduced January 15, 2019; Referred
to the Committee on Health and Human Resources]

1 A BILL to repeal §16-22-5 and §16-22-6, of the Code of West Virginia, 1931, as amended; to
 2 repeal §16-22A-1, §16-22A-2, §16-2D-3, and §16-2D-4 of said code; to repeal §16-44-1
 3 and §16-44-2, of said code; to amend and reenact §16-22-1, §16-22-2, and §16-22-3, of
 4 said code; all relating to diseases in newborn children; adding diseases to be tested;
 5 removing redundant code sections; providing rule-making authority, and making technical
 6 changes.

Be it enacted by the Legislature of West Virginia:

ARTICLE 22. DETECTION AND CONTROL DISEASES IN NEWBORN CHILDREN.

§16-22-1. Findings.

1 The Legislature finds that ~~phenylketonuria, galactosemia, hypothyroidism, and certain~~
 2 ~~other~~ diseases are usually associated with intellectual disability or other severe health hazards.
 3 Laboratory tests are readily available to aid in the detection of these diseases and hazards to the
 4 health of those suffering from these diseases may be lessened or prevented by early detection
 5 and treatment. Damage from these diseases, if untreated in the early months of life, is usually
 6 rapid and not appreciably affected by treatment.

§16-22-2. Program to combat intellectual disability or other severe health hazards; rules; facilities for making tests.

1 The ~~State~~ Bureau of Public Health is ~~authorized to establish and~~ shall carry out a program
 2 designed to combat intellectual disability or other severe health hazards in our state's population.
 3 ~~due to phenylketonuria, galactosemia, hypothyroidism, and certain other diseases specified by~~
 4 ~~the State Public Health Commissioner, and may adopt reasonable rules and regulations~~
 5 ~~necessary to carry out such a program~~ The Bureau of Public Health shall establish and maintain
 6 facilities at its state hygienic laboratory for testing specimens for the detection of phenylketonuria,
 7 galactosemia, hypothyroidism, and certain other diseases specified by the State Public Health
 8 Commissioner Tests shall be made by such laboratory of specimens upon request by physicians,
 9 hospital medical personnel and other individuals attending newborn infants. The State Bureau of

10 Public Health is authorized to establish additional laboratories throughout the state to perform
 11 these tests. for the detection of phenylketonuria, galactosemia, hypothyroidism, and certain other
 12 diseases specified by the State Public Health Commissioner

**§16-22-3. Tests for diseases specified by the state Public Health Commissioner; reports;
 assistance to afflicted children; Public Health Commissioner to propose rules.**

1 (a) The hospital or birthing center in which an infant is born, the parents or legal guardians,
 2 the physician attending a newborn child, or any person attending a newborn child not under the
 3 care of a physician shall require and ensure that each such child be tested for:

- 4 (1) Phenylketonuria,
- 5 (2) Galactosemia,
- 6 (3) Hypothyroidism,
- 7 (4) Sickle cell anemia; ~~and certain other diseases specified by the Bureau for Public~~
 8 ~~Health. The Bureau for Public Health shall also require testing for~~

- 9 (5) Congenital adrenal hyperplasia,
- 10 (6) Cystic fibrosis
- 11 (7) and Biotinidase deficiency ~~No later than July 1, 2008, the Bureau for Public Health~~
 12 ~~shall also require testing for~~

- 13 (7) Isovaleric acidemia,
- 14 (8) Glutaric acidemia type I,
- 15 (9) 3-Hydroxy-3-methylglutaric aciduria,
- 16 (10) Multiple carboxylase deficiency,
- 17 (11) Methylmalonic acidemia-mutase deficiency form,
- 18 (12) 3-methylcrotonyl-CoA carboxylase deficiency,
- 19 (13) Methylmalonic acidemia,
- 20 (14) Cbl A and Cbl B forms,
- 21 (15) Propionic acidemia,

- 22 (16) Beta-ketothiolase deficiency,
23 (17) Medium-chain acyl-CoA dehydrogenase deficiency,
24 (18) Very long-chain acyl-CoA dehydrogenase deficiency,
25 (19) Long-chain hydroxyacyl-CoA dehydrogenase deficiency,
26 (20) Trifunctional protein deficiency,
27 (21) Carnitine uptake defeat,
28 (22) Maple syrup urine disease,
29 (23) Homocystinuria, citrullinemia type I,
30 (24) Argininosuccinate acidemia,
31 (25) Tyrosinemia type I,
32 (26) Hemoglobin S/Beta-thalassemia,
33 (27) Sickle C disease; ~~and~~
34 (28) Hearing deficiency;
35 (29) Pulse oximetry screening; and
36 (30) Spinal muscular atrophy.

37 (b) A positive result on any test specified in §16-22-3(a) of this code, or a positive result
38 for any other diseases specified by the Bureau for Public Health, shall be promptly reported to the
39 Bureau for Public Health by the director of the laboratory performing such test.

40 (c) Newborn screenings shall be considered a covered benefit reimbursed to the birthing
41 facilities by Public Employees Insurance Agency, the state Children's Health Insurance Program,
42 the Medicaid program and all health insurers whose benefit package includes pregnancy
43 coverage and who are licensed under chapter 33 of this code.

44 (d) The Bureau for Public Health shall propose rules for legislative approval in accordance
45 with §29-3-1 *et. seq.* of this code. These legislative rules shall include:

46 (1) A means for the Bureau for Public Health, in cooperation with other state agencies,
 47 and with attending physicians, to provide medical, dietary and related assistance to children
 48 determined to be afflicted with any disease specified in §16-22-3(a) of this code and certain other
 49 diseases specified by the Bureau for Public Health; ~~and~~

50 (2) A means for payment for the screening provided for in this section; ~~and~~

51 (3) Add newborn screenings; and

52 (4) Anything further considered necessary by the Bureau for Public Health to implement
 53 the provisions of this section.

§16-22-5. Severability.

1 [Repealed.]

§16-22-6. Effective date.

1 [Repealed.]

ARTICLE 22A. TESTING OF NEWBORN INFANTS FOR HEARING IMPAIRMENTS.

§16-22A-1. Testing required.

[Repealed]

§16-22A-2. Rule making authorized.

[Repealed]

§16-22A-3. Fees for testing; payment of same.

[Repealed.]

§16-22A-4. Hearing impairment testing advisory committee established.

[Repealed]

ARTICLE 44. THE PULSE OXIMETRY NEWBORN TESTING ACT.

§16-44-1. Legislative findings.

[Repealed]

§16-44-2. Pulse oximetry screening required; definition; rules.

[Repealed]

NOTE: The purpose of this bill is to add pulse oximetry screening and spinal muscular atrophy to the list of required newborn screenings.

Strike-throughs indicate language that would be stricken from a heading or the present law and underscoring indicates new language that would be added.