

WEST VIRGINIA LEGISLATURE

2021 REGULAR SESSION

Introduced

House Bill 2798

BY DELEGATES BOGGS, HANSHAW (MR. SPEAKER),
HORNBUCKLE, ROHRBACH, ROWAN, ZUKOFF, SYPOLT,
PAYNTER, WALKER, J. KELLY AND HAYNES

[Introduced March 01, 2021; Referred
to the Committee on Senior, Children, and Family
Issues then Health and Human Resources]

1 A BILL to amend and reenact §16-22-3 of the Code of West Virginia, 1931 as amended, relating
 2 to requiring the Health Department to mandate mucopolysaccharidosis type 1 (MPS1) test
 3 for newborn babies, to be known as Embie’s Law.

Be it enacted by the Legislature of West Virginia:

PREAMBLE: THIS ACT SHALL BE KNOWN AS EMBIE’S LAW

**ARTICLE 22. DETECTION AND CONTROL OF PHENYLKETONURIA,
 GALACTOSEMIA, HYPOTHYROIDISM, AND CERTAIN OTHER DISEASES IN
 NEWBORN CHILDREN.**

**§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 phenylketonuria,
 4 galactosemia, hypothyroidism, sickle cell anemia and certain other diseases specified by the
 5 Bureau for Public Health. ~~The Bureau for Public Health shall also require testing for congenital~~
 6 ~~adrenal hyperplasia, cystic fibrosis and biotinidase deficiency. No later than July 1, 2008~~ The
 7 Bureau for Public Health shall ~~also~~ require testing for isovaleric acidemia, glutaric acidemia type
 8 I, 3-Hydroxy-3-methylglutaric aciduria, multiple carboxylase deficiency, methylmalonic acidemia-
 9 mutase deficiency form, 3-methylcrotonyl-CoA carboxylase deficiency, methylmalonic acidemia,
 10 Cbl A and Cbl B forms, propionic acidemia, beta-ketothiolase deficiency, medium-chain acyl-CoA
 11 dehydrogenase deficiency, very long-chain acyl-CoA dehydrogenase deficiency, long-chain
 12 hydroxyacyl-CoA dehydrogenase deficiency, trifunctional protein deficiency, carnitine uptake
 13 defeat, maple syrup urine disease, homocystinuria, citrullinemia type I, argininosuccinate
 14 acidemia, tyrosinemia type I, hemoglobin S/Beta-thalassemia, sickle C disease, congenital
 15 adrenal hyperplasia, cystic fibrosis, biotinidase deficiency, mucopolysaccharidosis type I, and

16 hearing deficiency.

17 (b) A positive result on any test specified in subsection (a) of this section, or a positive
18 result for any other diseases specified by the Bureau for Public Health, shall be promptly reported
19 to the Bureau for Public Health by the director of the laboratory performing such test.

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

24 (d) The Bureau for Public Health shall propose rules for legislative approval in accordance
25 with article three, chapter twenty-nine of this code. These legislative rules shall include:

26 (1) A means for the Bureau for Public Health, in cooperation with other state agencies,
27 and with attending physicians, to provide medical, dietary and related assistance to children
28 determined to be afflicted with any disease specified in subsection (a) of this section and certain
29 other diseases specified by the Bureau for Public Health; ~~and~~

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

31 (3) Anything further considered necessary by the Bureau for Public Health to implement
32 the provisions of this section.

NOTE: The purpose of this bill is to enact Embie's Law, mandating newborn testing for mucopolysaccharidosis type 1 (MP1), a metabolic disorder, which although not curable, can be treated if diagnosed in young infants.

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