WEST VIRGINIA LEGISLATURE

2026 REGULAR SESSION

Introduced

House Bill 5581

FISCAL NOTE

By Delegate Crouse

[Introduced February 16, 2026; referred to the

Committee on Health and Human Resources]

A BILL amend and reenact §16-22-3 of the Code of West Virginia, 1931, as amended, relating to additions to newborn screening tests.

Be it enacted by the Legislature of West Virginia:

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.

(a) The hospital or birthing center in which an infant is born, the parents or legal guardians, the physician attending a newborn child, or any person attending a newborn child not under the care of a physician shall require and ensure that each such child be tested for phenylketonuria, galactosemia, hypothyroidism, sickle cell anemia and certain other diseases specified by the Bureau for Public Health. The Bureau for Public Health shall also require testing for congenital adrenal hyperplasia, cystic fibrosis and biotinidase deficiency. No later than July 1, 2008, the Bureau for Public Health shall also require testing for isovaleric acidemia, glutaric acidemia type I, 3-Hydroxy-3-methylglutaric aciduria, multiple carboxylase deficiency, methylmalonic acidemia-mutase deficiency form, 3-methylcrotonyl-CoA carboxylase deficiency, methylmalonic acidemia, Cbl A and Cbl B forms, propionic acidemia, beta-ketothiolase deficiency, medium-chain acyl-CoA dehydrogenase deficiency, very long-chain acyl-CoA dehydrogenase deficiency, long-chain hydroxyacyl-CoA dehydrogenase deficiency, trifunctional protein deficiency, carnitine uptake defeat, maple syrup urine disease, homocystinuria, citrullinemia type I, argininosuccinate acidemia, tyrosinemia type I, hemoglobin S/Beta-thalassemia, sickle C disease, <u>infantile GM1 gangliosidosis</u>, and hearing deficiency.

(b) A positive result on any test specified in subsection (a) of this section, or a positive result for any other diseases specified by the Bureau for Public Health, shall be promptly reported

to the Bureau for Public Health by the director of the laboratory performing such test.

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

(d) The Bureau for Public Health shall propose rules for legislative approval in accordance with ~~article three, chapter twenty-nine~~ §29A-3-1 *et seq.* of this code. These legislative rules shall include:

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

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

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

NOTE: The purpose of this bill is to add infantile GM1 gangliosidosis to the list of newborn screening tests.

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