

WEST VIRGINIA LEGISLATURE

2026 REGULAR SESSION

Introduced

House Bill 5547

By Delegates Kimble, Ridenour, Butler, Mazzocchi,
and Anders

Introduced February 16, 2026; referred to the
Committee on Health and Human Resources then the
Judiciary]

1 A BILL to amend and reenact §16-22-3, the Code of West Virginia, 1931, as amended, and to
2 amend the code by adding a new article, designated §16-4G-1, §16-4G-2, §16-4G-3, §16-
3 4G-4, and §16-4G-5, relating to protecting the genetic privacy of newborn infants; defining
4 terms; requiring consent of parent or guardian for genetic screening, retention of blood
5 samples, and retention of test results; mandating the proposal of legislative rules to limit
6 the amount of blood that may be sampled or taken from newborn infants; limiting the
7 purposes for which blood samples and test results may be used; and declaring that the
8 requirement for informed, voluntary consent may not be abrogated.

Be it enacted by the Legislature of West Virginia:

ARTICLE 4G. NEWBORN GENETIC PRIVACY.

§16-4G-1. Definitions.

1 As used in this article:

2 "Newborn screening" or "newborn genetic screening" means a public health program of
3 procedure for screening infants shortly after birth for conditions that are treatable, but not
4 otherwise clinically evident in the newborn period.

5 "Blood spots" mean samples of blood that is collected onto a special filter paper by a health
6 care worker from a newborn child and submitted for newborn genetic screening.

§16-4G-2. Parental consent required for newborn genetic screening.

1 (a) Parental consent requirements. — Parents are permitted to refuse newborn genetic
2 screening or to choose private newborn genetic screening. Notwithstanding any other state or
3 federal law or regulation, prior to conducting newborn genetic screening, a health care facility or
4 health care provider must receive the express, separate, written, voluntary, informed consent of
5 the parents or guardian of a newborn child. A general consent permitting treatment signed by the
6 parents or guardian at admission to a facility does not fulfill this requirement. This consent
7 requirement cannot be waived for any reason.

8 (b) Limitation on Blood Spot Collection. — The Secretary of Health shall propose rules for

9 legislative approval, pursuant to §29A-3-1 et seq. of this code, to limit the number of blood spots
10 and the quantity of blood drawn from a newborn for newborn genetic screening to only the amount
11 needed to conduct newborn screening on the child. Additional blood for prospective purposes
12 shall not be collected without the express, separate, written, voluntary, informed consent of the
13 parent or guardian of the newborn child.

14 (c) Parental notification requirements – During each trimester of pregnancy that a patient is
15 seeking care, a health care facility or health care provider must provide the patient with written
16 information about the newborn genetic screening program including the right to opt out of testing
17 and the right to seek private testing.

§16-4G-3. Consent for retention, sharing and use of newborn blood spots required.

1 Notwithstanding any other state or federal law or regulation, the blood spots taken for
2 newborn genetic screening may not be retained by any health care facility or any state or county
3 agency, office, or archive longer than three weeks after the test results have been received and
4 must be destroyed unless express, separate, written, voluntary, informed consent is received no
5 sooner than 14 days from the date when both the mother and child have been discharged from a
6 health care facility or the birth of the child, whichever is later. The consent form must use easy to
7 understand language that does not threaten to penalize the parents or claim that the child may be
8 harmed in any way for refusing to consent to the retention of the newborn bloodspots. If a parent or
9 legal guardian consents to the retention of newborn blood spots or samples, the blood spots may
10 not be disseminated, shared, analyzed, or used for test development, public health studies,
11 newborn studies, genetic or medical research, forensics, law enforcement, or any other purpose
12 without the express, separate, written, voluntary, informed consent of the parent or guardian, or
13 the express, separate, written, voluntary, informed consent of the adult who was a minor at the
14 time the newborn dried bloodspots were retained. A general consent permitting treatment, signed
15 by the parents or guardian for a home birth or at admission to a birthing or other health care facility,
16 does not fulfill this requirement. This requirement for voluntary consent shall not be abrogated or

17 superseded.

§16-4G-4. Consent for retention, sharing and use of newborn genetic screening test results.

1 Notwithstanding any other state or federal law or regulation, the test results of newborn
2 genetic screening may not be retained by any health care facility or any state or county agency,
3 office, or archive longer than three weeks from the testing, and must be destroyed unless express,
4 separate, written, voluntary, informed consent is received no sooner than 14 days from the date
5 when both the mother and child have been discharged from a health care facility or the birth of the
6 child, whichever is later. The consent form must use easy to understand language that does not
7 threaten to penalize the parents or claim that the child will be hurt in any way for refusing to
8 consent to the retention of newborn genetic screening test results. If a parent or legal guardian
9 consents to the retention of newborn screening test results, the test results may not be
10 disseminated, shared, analyzed, or used for test development, public health studies, newborn
11 studies, genetic or medical research, forensics, law enforcement or any other purpose without the
12 express, separate, written, voluntary, informed consent of the parent or guardian, or the express,
13 separate, written, voluntary, informed consent of the adult who was a minor at the time the
14 newborn screening test results were retained. A general consent permitting treatment signed by
15 the parents or guardian for a home birth or at admission to a birthing or other health care facility
16 does not fulfill this requirement. This requirement for voluntary consent shall not be abrogated or
17 superseded.

§16-4G-5. Consent revocation from newborn screening, retention, and sharing use.

1 The Secretary of Health and Human Services must make publicly available a form to allow
2 a parent, legal guardian, or adult who was a minor at the time consent was given, to revoke their
3 consent for further storage, sharing, or use of newborn blood spots and newborn genetic
4 screening results. A health care facility or health care provider must share information about this
5 form if a parent or guardian gives consent for newborn screening testing.

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

NOTE: The purpose of this bill is to require the express consent of a parent or guardian to conduct a genetic screening of a newborn infant, to retain blood samples from the infant, and to retain and share results of the genetic screening of the infant.

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