

WEST VIRGINIA LEGISLATURE

2024 REGULAR SESSION

Introduced

House Bill 5512

By Delegates Kimble, Butler, Horst, Worrell, Jeffries,
Phillips, McGeehan, Hott, C. Pritt, Ridenour, and
Foster

[Introduced February 07, 2024; Referred to the
Committee on Health and Human Resources then the
Judiciary]

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

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

§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. The
5 consent form must use easy to understand language that does not threaten to penalize the
6 parents or claim that the child will be hurt in any way for refusing to consent to the retention of the
7 newborn bloodspots. If a parent or legal guardian consents to the retention of newborn blood spots
8 or samples, the blood spots may not be disseminated, shared, analyzed, or used for test
9 development, public health studies, newborn studies, genetic or medical research, forensics, law
10 enforcement, or any other purpose without the express, separate, written, voluntary, informed
11 consent of the parent or guardian, or the express, separate, written, voluntary, informed consent of
12 the adult who was a minor at the time the newborn dried bloodspots were retained. A general
13 consent permitting treatment, signed by the parents or guardian for a home birth or at admission to
14 a birthing or other health care facility, does not fulfill this requirement. This requirement for
15 voluntary consent shall not be abrogated or 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. The consent form must use easy to
5 understand language that does not threaten to penalize the parents or claim that the child will be
6 hurt in any way for refusing to consent to the retention of newborn genetic screening test results. If
7 a parent or legal guardian consents to the retention of newborn screening test results, the test
8 results may not be disseminated, shared, analyzed, or used for test development, public health
9 studies, newborn studies, genetic or medical research, forensics, law enforcement or any other
10 purpose without the express, separate, written, voluntary, informed consent of the parent or
11 guardian, or the express, separate, written, voluntary, informed consent of the adult who was a
12 minor at the time the newborn screening test results were retained. A general consent permitting
13 treatment signed by the parents or guardian for a home birth or at admission to a birthing or other
14 health care facility does not fulfill this requirement. This requirement for voluntary consent shall not
15 be abrogated or superseded.

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.