

AN ACT

ENTITLED, An Act to require written informed consent before genetic testing.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF SOUTH DAKOTA:

Section 1. Terms used in this Act mean:

- (1) "Genetic information," information derived from a genetic test about a gene, gene product, or inherited characteristic;
- (2) "Genetic test," a test of human DNA, RNA, chromosomes, or genes performed in order to identify the presence or absence of an inherited variation, alteration, or mutation which is associated with predisposition to disease, illness, impairment, or other disorder. Genetic test does not mean a routine physical measurement; a chemical, blood, or urine analysis; a test for drugs or HIV infection; any test commonly accepted in clinical practice; or any test performed due to the presence of signs, symptoms, or other manifestations of a disease, illness, impairment, or other disorder;
- (3) "Predictive genetic test," a genetic test performed for the purpose of predicting the future probability that the person tested will develop a genetically related disease or disability.

Section 2. No person may order or perform a predictive genetic test without first obtaining the written, informed consent of the person to be tested. For purposes of this section, written, informed consent consists of a signed writing executed by the person to be tested or the legally authorized representative of the person to be tested that includes, at a minimum, all of the following:

- (1) The nature and purpose of the predictive genetic test;
- (2) The effectiveness and limitations of the predictive genetic test;
- (3) The implications of taking the predictive genetic test, including, the medical risks and benefits;
- (4) The future uses of the sample taken from the person tested in order to conduct the

predictive genetic test and the information obtained from the predictive genetic test;

- (5) The meaning of the predictive genetic test results and the procedure for providing notice of the results to the person tested; and
- (6) A listing of who will have access to the sample taken from the person tested in order to conduct the predictive genetic test and the information obtained from the predictive genetic test, and the person's right to confidential treatment of the sample and the information.

Section 3. If a person to be tested or the person's legally authorized representative signs a copy of the informed consent form developed pursuant to section 2 of this Act, the person obtaining the informed consent shall give the person to be tested a copy of the signed informed consent form and shall include the original signed informed consent form in the medical record of the person tested.

Section 4. Nothing in this Act alters the ability to perform genetic tests done in pursuance of a lawful criminal investigation or court order.

An Act to require written informed consent before genetic testing.

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I certify that the attached Act  
originated in the

SENATE as Bill No. 1

\_\_\_\_\_  
Secretary of the Senate

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\_\_\_\_\_  
President of the Senate

Attest:

\_\_\_\_\_  
Secretary of the Senate

\_\_\_\_\_  
Speaker of the House

Attest:

\_\_\_\_\_  
Chief Clerk

Senate Bill No. 1  
File No. \_\_\_\_\_  
Chapter No. \_\_\_\_\_

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Received at this Executive Office  
this \_\_\_\_ day of \_\_\_\_\_ ,

20\_\_ at \_\_\_\_\_ M.

By \_\_\_\_\_  
for the Governor

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The attached Act is hereby  
approved this \_\_\_\_\_ day of  
\_\_\_\_\_, A.D., 20\_\_

\_\_\_\_\_  
Governor

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STATE OF SOUTH DAKOTA,  
SS.  
Office of the Secretary of State

Filed \_\_\_\_\_, 20\_\_  
at \_\_\_\_\_ o'clock \_\_ M.

\_\_\_\_\_  
Secretary of State

By \_\_\_\_\_  
Asst. Secretary of State