

ENROLLED HOUSE
BILL NO. 1368

By: Boyd and Pope (Clay) of the
House

and

Brown and Williams of the
Senate

An Act relating to health; creating the Genetic Research Studies Nondisclosure Act; providing definition; requiring all records from genetic research studies to be confidential; prohibiting release of records for certain purposes; limiting application of act to life, disability income, or long-term care insurance; allowing certain tissues to be used for genetic research; requiring informed consent for such use; providing for obtaining informed consent; allowing the use or publishing of genetic research results; allowing identification of individuals when informed consent has been obtained; providing for codification; and providing an effective date.

BE IT ENACTED BY THE PEOPLE OF THE STATE OF OKLAHOMA:

SECTION 1. NEW LAW A new section of law to be codified in the Oklahoma Statutes as Section 3614.4 of Title 36, unless there is created a duplication in numbering, reads as follows:

A. This section shall be known and may be cited as the "Genetic Research Studies Nondisclosure Act".

B. For purposes of the Genetic Research Studies Nondisclosure Act, "genetic research study or studies" shall mean those genetic research studies approved by an institutional review board as defined in 21 CFR, Section 50 or conducted subject to the requirements of the federal common rule at 21 CFR, Section 50 and Section 56, and 45 CFR, Section 46.

C. All research records of individual subjects in genetic research studies shall be confidential, meaning the records shall not be subject to subpoena or discovery in civil suits, except in cases where the information in the records is the basis of the suit. The records shall not be disclosed to employers or health insurers without the informed consent of the subject.

D. Notwithstanding any language in this section to the contrary, this section shall not apply to an insurer or to an individual or third party dealing with an insurer in the ordinary course of underwriting, conducting or administering the business of

life, disability income or long-term care insurance or in connection with any judicial, legislative or administrative proceeding relating to life, disability income or long-term care insurance. Nothing in this section is intended to govern an insurer or to govern an individual or third party dealing with an insurer in connection with the obtaining, maintaining, use, disclosure or redisclosure of genetic information or the results of a genetic test, including but not limited to records of individual subjects in genetic research in connection with life, disability income or long-term care insurance or in connection with any judicial, legislative or administrative proceeding relating to life, disability income or long-term care insurance.

E. All stored tissues, including blood, that arise from surgery, other diagnostic or therapeutic steps, or autopsy may be disclosed for genetic or other research studies if informed consent has been obtained. Informed consent may be included in a section of the consent for treatment, admission to a hospital or clinic, or permission for an autopsy and no other consent shall be required.

F. It shall be permissible to publish or otherwise use the results of genetic research studies for research or educational purposes if no individual subject is identified. If specific informed consent from the individual has been obtained, the individual may be identified.

SECTION 2. This act shall become effective November 1, 1999.

Passed the House of Representatives the 23rd day of February,
1999.

Speaker of the House of
Representatives

Passed the Senate the 6th day of April, 1999.

President of the Senate