

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2005

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HOUSE BILL 2795

Short Title: Voluntary DNA Database/Funds.

(Public)

Sponsors: Representative Miller.

Referred to: Appropriations.

May 30, 2006

A BILL TO BE ENTITLED

AN ACT AUTHORIZING THE SECRETARY OF COMMERCE TO ESTABLISH A VOLUNTARY DNA AND MEDICAL RECORDS DATABASE SIMILAR TO THE ENVIRONMENTAL POLYMORPHISMS REGISTRY ESTABLISHED BY THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES AND TO APPROPRIATE FUNDS TO IMPLEMENT THIS ACT.

The General Assembly of North Carolina enacts:

SECTION 1. Chapter 130A of the General Statutes is amended by adding the following new Article to read:

"Article 23.

"Voluntary DNA/Medical Records Database.

"§ 130A-490. Definitions.

The following definitions apply in this Article:

- (1) Database. – The Voluntary DNA Database established under this Article for the recording of DNA samples and related medical records voluntarily submitted by an individual. The term also includes DNA database.
- (2) Director. – The Director of the Voluntary DNA Database established under this Article.
- (3) DNA. – Deoxyribonucleic acid.
- (4) DNA record. – DNA identification information stored in the Voluntary DNA Database for the purposes stated in this Article.
- (5) DNA sample. – A blood sample or other specimen voluntarily submitted to the database by an individual.

"§ 130A-490.1. Voluntary DNA Database established; purpose.

(a) The Secretary of Commerce shall establish the Voluntary DNA Database for the recording of DNA data and related medical records submitted voluntarily by individuals for the purposes authorized in this Article. DNA data and related medical records stored in the database shall be stripped of all information that would personally

1 identify the individual submitting the data. The Secretary may maintain the database in
2 the Department of Commerce or another suitable location. The Secretary shall appoint
3 the Director of the DNA database who shall be responsible for marketing the database
4 to potential donors and companies that may wish to access the database. The Secretary
5 shall select a public research institution to develop, implement, and maintain the
6 database.

7 (b) The DNA database must be capable of classifying, matching, and storing the
8 results of analyses of DNA and other biological molecules.

9 (c) The DNA database may contain DNA records and related medical records of
10 individuals who have volunteered to provide the DNA sample and medical records. The
11 Secretary may receive, analyze, store, and destroy a record, blood sample, or other
12 specimen for the purposes described in subsection (d) of this section.

13 (d) The principal purpose of the Voluntary DNA Database is to advance
14 scientific study of the links between genetics and common diseases in order to improve
15 diagnosis and treatment of the diseases, provided that DNA samples and related medical
16 records may only be stored in the database if all personal identifying information is
17 removed. The information contained in the database may not be collected, analyzed, or
18 stored to obtain information about human physical traits or predisposition for disease
19 unless the purpose for obtaining the information is authorized by this subsection.

20 (e) The Director may publish educational materials on the Voluntary DNA
21 Database for dissemination to the general public. The materials shall describe the
22 purposes for which data in the database will be used, who will have access to the
23 database, the confidential nature of samples in the database, and other information.

24 **"§ 130A-490.2. Collection of DNA samples.**

25 (a) The Secretary shall adopt rules establishing procedures for the collection,
26 preservation, analysis, and use of blood samples or other specimens in a manner that
27 permits the exchange of DNA samples between DNA laboratories and the use of the
28 data for the purposes authorized under this section.

29 (b) The Director of the DNA database may contract with a laboratory, other State
30 agency, private entity, or institution of higher education for services to perform DNA
31 analyses.

32 (c) The DNA database may not accept a blood sample or other specimen taken
33 from a person that is submitted voluntarily unless the sample or specimen is collected in
34 a medically approved manner by a physician or registered nurse or other person who is
35 trained to properly collect samples or other specimens and supervised by a licensed
36 physician. A person collecting a blood sample or other specimen under this section shall
37 not be liable in any civil action if the person collects the sample or specimen in a
38 reasonable manner according to generally accepted medical or other professional
39 practices.

40 (d) The Director shall provide at no cost to the individual the specimen vials,
41 mailing tubes and labels, report forms, and other instructions for collection of blood
42 samples or other specimens from individuals voluntarily submitting DNA to the
43 database.

1 (e) A person who collects a blood sample or other specimen under this section
2 shall send the sample or specimen to the DNA database in accordance with instructions
3 provided by the Director.

4 (f) A DNA laboratory may analyze a blood sample collected under this section
5 or other DNA specimen only for the purposes authorized under this section.

6 **"§ 130A-490.3. Collection of medical history.**

7 The Director of the DNA database shall make available on the Internet a medical
8 history questionnaire that shall be required as part of every voluntary submission to the
9 database. Information from the questionnaire shall be automatically entered into the
10 DNA database and shall be coded in a manner that links it to the DNA record of the
11 volunteer. The medical history questionnaire shall be developed by the Director, in
12 consultation with the following persons, or their designees:

13 (1) The Director of the Genomic Science Program, North Carolina State
14 University.

15 (2) The Chair of the Department of Genetics, University of North Carolina
16 School of Medicine.

17 (3) The Director of the Biomedical and Biotechnology Research Institute,
18 North Carolina Central University.

19 (4) The Chair of the Department of Pediatrics and Genetics, East Carolina
20 University School of Medicine.

21 (5) The Director of the Genomic Science Program, Western Carolina
22 University.

23 **"§ 130A-490.4. Access to Voluntary DNA Database information.**

24 (a) The Secretary shall adopt rules:

25 (1) To prevent unauthorized access to the DNA database.

26 (2) To release DNA records, specimens, or analyses from the DNA
27 database for authorized purposes.

28 (3) Relating to the internal disclosure, access, or use of a sample,
29 specimen, or DNA record in the Department of Commerce DNA
30 laboratory.

31 (b) A DNA sample, analysis, or record may be released only if personally
32 identifiable information is removed for:

33 (1) A population statistics database.

34 (2) Identification research and protocol development.

35 (3) Quality control.

36 (c) The Director may release a record of the number of requests made for a DNA
37 record and the name of the requesting person. The Director shall maintain a record of
38 requests made under this section.

39 **"§130A-490.5. Confidentiality of DNA records.**

40 (a) A DNA record stored in the Voluntary DNA Database is confidential and is
41 not subject to disclosure except for the purposes authorized in this Article.

42 (b) A person who knowingly discloses information in a DNA record or
43 information related to a DNA analysis of a blood specimen except as authorized by this
44 Article is guilty of a Class 1 misdemeanor.

1 (c) A violation of this section constitutes official misconduct.

2 **"§ 130A-490.6. Segregation of records.**

3 The Secretary shall adopt rules providing for the segregation of DNA records
4 created under this Article from records created under Article 13 of Chapter 15A of the
5 General Statutes.

6 **"§ 130A-490.7. Fees; other funds.**

7 The Director may authorize a twenty dollar (\$20.00) payment for each sample an
8 individual donor gives. In addition, the Director may accept grants, contributions,
9 devises, bequests, and gifts, which shall be kept in a separate fund, which shall be
10 nonreverting, and shall be used to fund the implementation and continuing operation of
11 the Voluntary DNA Database. The Department may also accept donations of equipment
12 and storage facilities from a State, private, or public research institution to be used for
13 the purposes of the DNA Database."

14 **SECTION 2.** There is appropriated from the General Fund to the
15 Department of Commerce the sum of five million dollars (\$5,000,000) for the
16 2006-2007 fiscal year to implement Section 1 of this act.

17 **SECTION 3.** Section 2 of this act becomes effective July 1, 2006. The
18 remainder of this act becomes effective October 1, 2006.