

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2003

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HOUSE DRH60294-LN-105A (3/25)

Short Title: Voluntary DNA Database. (Public)

Sponsors: Representatives Miller and Walend (Primary Sponsors).

Referred to:

A BILL TO BE ENTITLED

AN ACT TO DIRECT THE SECRETARY OF COMMERCE TO ESTABLISH A
DNA DATABANK FOR THE VOLUNTARY SUBMISSION BY INDIVIDUALS
OF DNA SAMPLES LINKED WITH THE INDIVIDUAL'S MEDICAL RECORD.

The General Assembly of North Carolina enacts:

SECTION 1. Article 10 of Chapter 143B of the General Statutes is amended by adding the following new Part to read:

"Part 19. Voluntary DNA/Medical Records Database.

"§ 143B-472.85. Voluntary DNA Database established; purpose.

(a) The Secretary of Commerce shall establish a DNA database for the recording of DNA data and related medical records submitted voluntarily by individuals for the purposes authorized in this Part. DNA data and related medical records stored in the database shall be stripped of all information that would personally identify the individual submitting the data. The Secretary may maintain the database in the Department of Commerce or another suitable location. The Secretary shall appoint the Director of the DNA database.

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

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

(d) The principal purpose of the Voluntary DNA Database is to advance scientific study of the links between genetics and common diseases in order to improve diagnosis and treatment of the diseases, provided that DNA samples and related medical records may only be stored in the database if all personal identifying information is removed. The information contained in the database may not be collected, analyzed, or

1 stored to obtain information about human physical traits or predisposition for disease
2 unless the purpose for obtaining the information is authorized by this subsection.

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

7 **"§ 143B-472.86. Collection of DNA samples.**

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

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

15 (c) The Director of the DNA database may not accept a blood sample or other
16 specimen taken from a person that is submitted voluntarily unless the sample or
17 specimen is collected in a medically approved manner by a physician or registered nurse
18 or other person who is trained to properly collect samples or other specimens and
19 supervised by a licensed physician. A person collecting a blood sample or other
20 specimen under this section shall not be liable in any civil action if the person collects
21 the sample or specimen in a reasonable manner according to generally accepted medical
22 or other professional practices.

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

27 (e) A person who collects a blood sample or other specimen under this section
28 shall send the sample or specimen to the Director of the DNA database.

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

31 **"§ 143B-472.87. Access to Voluntary DNA Database information.**

32 (a) The Secretary shall adopt rules:

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

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

36 (3) Relating to the internal disclosure, access, or use of a sample,
37 specimen, or DNA record in the Department of Commerce DNA
38 laboratory.

39 (b) The Director may release a DNA sample, analysis, or record, only if
40 personally identifiable information is removed, for:

41 (1) A population statistics database.

42 (2) Identification research and protocol development.

43 (3) Quality control.

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

4 **"§ 143B-472.88. Confidentiality of DNA records.**

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

7 (b) A person who knowingly discloses information in a DNA record or
8 information related to a DNA analysis of a blood specimen except as authorized by this
9 Part is guilty of a Class 1 misdemeanor.

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

11 **"§ 143B-472.89. Segregation of records.**

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

15 **"§ 143B-472.90. Fees.**

16 The Director may collect a reasonable fee for providing population statistics data or
17 other research data as authorized by this Part. The Director shall charge to North
18 Carolina-based biotechnology corporations and research institutions an equal portion of
19 the cost to store and retrieve information in the database. The annual fee for each
20 biotechnology corporation or research institution shall be twenty-five thousand dollars
21 (\$25,000) for the first year of operating the database. Thereafter, the charge to each
22 corporation or research institution shall be based on the actual cost of maintaining the
23 system, divided by the number of biotechnology corporations and research institutions
24 that represents one half of the total number of biotechnology corporations and research
25 institutions in the State.

26 **"§ 143B-472.91. Definitions.**

27 As used in this Part, unless the context clearly requires otherwise:

- 28 (1) 'Database' or 'DNA database' means the Voluntary DNA Database
29 established under this Part for the recording of DNA samples and
30 related medical records voluntarily submitted by an individual.
31 (2) 'Director' means the Director of the Voluntary DNA Database
32 established under this Part.
33 (3) 'DNA' means deoxyribonucleic acid.
34 (4) 'DNA record' means DNA identification information stored in the
35 Voluntary DNA Database for the purposes stated in this Part.
36 (5) 'DNA sample' means a blood sample or other specimen voluntarily
37 submitted to the database by an individual."

38 **SECTION 2.** There is appropriated from the General Fund to the
39 Department of Commerce the sum of three hundred thousand dollars (\$300,000) for the
40 2003-2004 fiscal year and the sum of three hundred thousand dollars (\$300,000) for the
41 2004-2005 fiscal year. These funds shall be used to establish the Voluntary DNA
42 Database, including the purchase of computer equipment, in accordance with Section 1
43 of this act.

1 **SECTION 3.** This act becomes effective July 1, 2003. Section 1 of this act
2 becomes effective only if funds are appropriated to implement this act.