

GENERAL ASSEMBLY OF NORTH CAROLINA  
SESSION 2003

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HOUSE BILL 1256

Short Title: Voluntary DNA Database. (Public)

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Sponsors: Representatives Miller and Walend (Primary Sponsors).

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Referred to: Science and Technology, if favorable, Finance.

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April 24, 2003

A BILL TO BE ENTITLED

1 AN ACT TO DIRECT THE SECRETARY OF COMMERCE TO ESTABLISH A  
2 DNA DATABANK FOR THE VOLUNTARY SUBMISSION BY INDIVIDUALS  
3 OF DNA SAMPLES LINKED WITH THE INDIVIDUAL'S MEDICAL RECORD.  
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5 The General Assembly of North Carolina enacts:

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

8 "Part 19. Voluntary DNA/Medical Records Database.

9 **§ 143B-472.85. Voluntary DNA Database established; purpose.**

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

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

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

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

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

5 **"§ 143B-472.86. Collection of DNA samples.**

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

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

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

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

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

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

29 **"§ 143B-472.87. Access to Voluntary DNA Database information.**

30       (a) The Secretary shall adopt rules:

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

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

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

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

39           (1) A population statistics database.

40           (2) Identification research and protocol development.

41           (3) Quality control.

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

1 **"§ 143B-472.88. Confidentiality of DNA records.**

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

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

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

8 **"§ 143B-472.89. Segregation of records.**

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

12 **"§ 143B-472.90. Fees.**

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

23 **"§ 143B-472.91. Definitions.**

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

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

35 **SECTION 2.** There is appropriated from the General Fund to the  
36 Department of Commerce the sum of three hundred thousand dollars (\$300,000) for the  
37 2003-2004 fiscal year and the sum of three hundred thousand dollars (\$300,000) for the  
38 2004-2005 fiscal year. These funds shall be used to establish the Voluntary DNA  
39 Database, including the purchase of computer equipment, in accordance with Section 1  
40 of this act.

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