

Human Genes Research Act

Passed 13 December 2000

(RT I 2000, 104, 685),

Entered into force 8 January 2001.

Chapter 1

General Provisions

§ 1. Purpose and scope of application of Act

(1) The objectives of this Act are to regulate the establishment and maintenance of a Gene Bank, to organise the genetic research necessary therefor, to ensure the voluntary nature of gene donation and the confidentiality of the identity of gene donors, and to protect persons from misuse of genetic data and from discrimination based on interpretation of the structure of their DNA and the genetic risks arising therefrom.

(2) The following are provided for in this Act:

- 1) the conditions for processing tissue samples, descriptions of DNA, descriptions of state of health and genealogies in the Gene Bank;
- 2) the rights and obligations of gene donors, the chief processor and authorised processors of the Gene Bank and genetic researchers relating to tissue samples, descriptions of DNA, descriptions of state of health and genealogies;
- 3) the conditions for the establishment and maintenance of the Gene Bank;
- 4) the restrictions on the use of tissue samples, descriptions of DNA, descriptions of state of health and genealogies collected in the Gene Bank;
- 5) the conditions for genetic research relating to the Gene Bank and the organisation of supervision thereof.

§ 2. Definitions

In this Act, the following definitions are used:

- 1) “DNA” means a molecule of deoxyribonucleic acid which contains the genetic information of a human being;
- 2) “tissue sample” means cells, intercellular substance and body fluids taken from a human being for the purposes of genetic research;
- 3) “description of DNA” means a digital model of DNA created as a result of genetic research;
- 4) “gene donor” means a person who provides a tissue sample in accordance with this Act and with regard to whom a description of state of health and genealogy are prepared;
- 5) “description of state of health” means data collected for use in genetic research which reflects the state of health of a gene donor, illnesses he or she has suffered from and treatment thereof, and his or her lifestyle, physical and social environment and hereditary characteristics;
- 6) “genealogy” means information in the Gene Bank concerning the names, dates of birth and blood relationships of the ascendants and descendants of a gene donor;
- 7) “genetic research” means the scientific study and description of DNA, other constituents of tissue samples, descriptions of state of health and genealogies and determination of the links between them with the purpose of obtaining data on the genes, gene products and hereditary characteristics of human beings;
- 8) “genetic researcher” means a natural or legal person or a state or local government agency who performs genetic research;

- 9) “genetic data” means data concerning the genes, gene products or hereditary characteristics of a human being, including a description of DNA or a part thereof, which is obtained as a result of genetic research;
- 10) “Gene Bank” means a database established and maintained by the chief processor consisting of tissue samples, descriptions of DNA, descriptions of state of health, genealogies, genetic data and data enabling the identification of gene donors;
- 11) “coding” means the replacement with a unique code of such data of a tissue sample, description of DNA, description of state of health or genealogy which enables the identification of the person;
- 12) “decoding” means the reverse identification of a gene donor through the unique code given to a tissue sample, description of DNA, description of state of health or genealogy or the identification of the tissue sample, description of DNA or description of state of health of a gene donor based on the identity of the gene donor.

§ 3. Chief processor of Gene Bank

- (1) The chief processor of the Gene Bank is a non-profit foundation founded by the Republic of Estonia on the basis of the Foundation of and Participation in Legal Persons in Private Law by the State Act (RT I 1996, 48, 942; 73, correction notice; 1998, 59, 941) within the area of government of the Ministry of Social Affairs which has the right to organise the taking of tissue samples, to prepare descriptions of state of health and genealogies, to code, decode, store, destroy and issue descriptions of state of health and genealogies, to perform genetic research and to collect, store, destroy and issue genetic data.
- (2) The objectives of the chief processor are to:
- 1) promote the development of genetic research;
 - 2) collect information on the health of the Estonian population and genetic information concerning the Estonian population;
 - 3) use the results of genetic research to improve public health.
- (3) In order to achieve its objectives, the competence of the chief processor includes the establishment and maintenance of the Gene Bank. The chief processor has the right to delegate the rights of processing, except for coding and decoding, to an authorised processor on the basis of a contract in the cases and under the conditions prescribed in this Act.

§ 4. Supervisory board of chief processor of Gene Bank

- (1) The supervisory board of the chief processor of the Gene Bank shall consist of nine members. The Riigikogu² shall, on the proposal of the Social Affairs Committee of the Riigikogu, appoint three members of the supervisory board. The Government of the Republic shall appoint three members of the supervisory board. The Board of the Estonian Academy of Sciences shall appoint three members of the supervisory board.
- (2) The term of authority of a member of the supervisory board is from one year to five years. The due date for termination of the authority of a member of the supervisory board shall be determined upon appointment of the member of the supervisory board. If a member of the Riigikogu or the Government of the Republic is appointed to the supervisory board, the authority of such member of the supervisory board shall terminate upon the termination of his or her authority as a member of the Riigikogu or the Government of the Republic.
- (3) The body which appointed a member of the supervisory board may remove the member of the supervisory board with good reason, which is, above all, failure to perform his or her duties to a material extent, a constant conflict of interests or

inability to participate in the work of the supervisory board or the causing of significant damage to the interests of the chief processor of the Gene Bank in any other manner, and also the commencement of bankruptcy proceedings against the member of the supervisory board.

§ 5. Authorised processor of Gene Bank

An authorised processor of the Gene Bank is a natural or legal person or an Estonian state agency or local government agency who may receive all processing rights, except the right to code and decode, from the chief processor on the basis of a contract. The requirements for authorised processors shall be established by the Government of the Republic.

§ 6. Genetic research and genetic testing

(1) Genetic research relating to the Gene Bank is permitted in order to study and describe the links between genes, the physical and social environment and the lifestyles of people, to find medicinal products or methods of treatment on the basis thereof, to assess individual health hazards and to prevent illnesses.

(2) Genetic testing to which the provisions of Chapters 2, 3 and 4 of this Act do not apply may be performed pursuant to the procedure and for the purposes provided by law. Tissue samples taken from people in the course of genetic testing and the results of research performed on such samples shall not be added to the Gene Bank.

§ 7. Application of provisions which regulate processing of personal data

(1) The provisions of the Personal Data Protection Act (RT I 1996, 48, 944; 1998, 59, 941; 111, 1833; 2000, 50, 317; 92, 597) which regulate the processing of personal data, together with the specifications provided for in this Act, apply to the taking of tissue samples, preparation of descriptions of state of health, coding, decoding, and the maintenance of databases by the chief processor.

(2) The provisions regulating the processing of personal data do not apply to the processing of coded tissue samples, coded descriptions of DNA and coded descriptions of state of health if such tissue samples, descriptions of DNA and descriptions of state of health are processed as a set of data and on the condition that the set of data to be processed contains DNA samples, descriptions of DNA or descriptions of state of health of at least five gene donors at a time.

Chapter 2

Rights of Gene Donors

§ 8. Confidentiality of identity of gene donors

(1) The identity of a gene donor shall remain classified after coding.

(2) A gene donor has the right to permit disclosure of his or her identity.

(3) The fact of a person being or not being a gene donor shall remain classified. Only a person himself or herself has the right to disclose the fact of being or not being a gene donor and the circumstances thereof, unless otherwise prescribed by law.

(4) Coding and decoding shall be performed in accordance with the requirements of this Act.

§ 9. Voluntary nature of gene donation

- (1) It is prohibited to take a tissue sample and prepare a description of state of health or genealogy without the specific knowledge and voluntary consent of the person.
- (2) It is prohibited to influence a person's decision to become a gene donor, including by threatening the person with negative consequences, promising material benefits or providing subjective information.
- (3) The chief processor and authorised processors are permitted to disseminate only general information concerning the Gene Bank and genetic research.

§ 10. Right to apply for destruction of material

- (1) Pursuant to the provisions of § 21 of this Act, gene donors have the right to apply, at any time, to the chief processor for the destruction of data which enables decoding.
- (2) If the identity of a gene donor is unlawfully disclosed, the gene donor has the right to apply to the chief processor for the destruction of the tissue sample, description of DNA and description of the state of health pursuant to the provisions of § 21 of this Act.

§ 11. Other rights of gene donors

- (1) Gene donors have the right not to know their genetic data.
- (2) Gene donors have the right to access personally their data stored in the Gene Bank. Gene donors do not have the right to access their genealogies.
- (3) Gene donors shall not be charged for accessing their data stored in the Gene Bank.
- (4) Gene donors have the right to genetic counselling upon accessing their data stored in the Gene Bank.
- (5) Gene donors have the right to submit additional information on themselves to the chief processor.
- (6) Gene donors have the right to prohibit the supplementation, renewal and verification of descriptions of their state of health stored in the Gene bank.

§ 12. Consent to become gene donor

- (1) A person's consent to provide a tissue sample, to have a description of the state of health or the genealogy of the person prepared, to entry of the description of the state of health or the genealogy in the Gene Bank in coded form and to use thereof for genetic research, public health research and statistical purposes shall be prepared in writing and shall be signed by the person who becomes a gene donor.
- (2) Partial or conditional consent is not valid.
- (3) A document specified in subsection (1) of this section shall, in addition to an expression of consent and the signature of the person who becomes a gene donor, set out the following information:
 - 1) the name and personal identification code or, in the absence thereof, sex, date of birth and residence of the person;
 - 2) information concerning the medical institution or family physician who is to take the tissue sample;
 - 3) the part of the body from which and the manner in which the tissue sample is to be taken;
 - 4) the date on which consent is granted.
- (4) The chief processor or authorised processor shall inform a person, prior to the person granting consent, of the following facts:

- 1) grant of the consent specified in subsection (1) of this section is voluntary;
 - 2) the gene donor is not entitled to request a fee for providing a tissue sample, preparation and study of a description of his or her state of health or genealogy, or use of the research results;
 - 3) data on hereditary characteristics and genetic risks obtained as a result of genetic research may be unpleasant for the gene donor;
 - 4) the gene donor has the right not to know his or her genetic data;
 - 5) the gene donor has the right to know his or her genetic data, except genealogy;
 - 6) the gene donor has the right to apply to the chief processor for the destruction of data which enables decoding or, upon unlawful disclosure of his or her identity, for the destruction of the tissue sample, description of DNA and description of his or her state of health;
 - 7) a gene donor has the right to withdraw his or her consent until his or her tissue sample or the description of his or her state of health is coded.
- (5) The chief processor or authorised processor to whom a person who is about to become a gene donor submits his or her consent is required to provide the gene donor promptly with a copy of his or her written consent.
- (6) The chief processor shall preserve the written consent of a gene donor for as long as the tissue sample, description of state of health or description of DNA are stored, except in the case provided for in subsection 10 (1) of this Act.
- (7) The format of written consent to become a gene donor and the procedure for the completion and preservation thereof shall be established by the Minister of Social Affairs.

§ 13. Persons with restricted active legal capacity and persons without capacity to exercise will

- (1) The consent of a person with restricted active legal capacity to become a gene donor shall be deemed valid if the following conditions are met:
- 1) the person with restricted active legal capacity and his or her legal representative or guardian have been given the information provided for in subsection 12 (4) of this Act;
 - 2) the legal representative or guardian has expressed the consent provided for in subsection 12 (1) of this Act;
 - 3) the person with restricted active legal capacity is not opposed to providing a tissue sample or to the collection of descriptions of his or her state of health.
- (2) Persons who are unable to understand the content and meaning of consent shall not be gene donors. In the case of doubt, it is presumed that the person is temporarily unable to understand the content and meaning of consent.

Chapter 3

Processing of Gene Bank

§ 14. Taking of tissue samples and preparation of descriptions of state of health

- (1) The chief processor shall organise the taking of tissue samples and the preparation of descriptions of state of health itself or through an authorised processor.
- (2) The medical procedure of taking a tissue sample shall be performed by a health care professional of the Republic of Estonia.
- (3) A description of state of health shall be prepared and supplemented by the chief processor or authorised processor on the basis of statements by the gene donor and data on the gene donor stored in medical institutions. Only data on illnesses

suffered from by the gene donor himself or herself may be collected from a gene donor. A gene donor may be asked questions about habits or illnesses which have occurred in his or her family. Such questions shall not enable the identification of a certain person or generation.

(4) The chief processor or authorised processor may prepare a genealogy on the basis of the results of questioning a gene donor and on the basis of other databases and genetic research.

(5) A person taking a tissue sample and a person preparing a description of state of health shall maintain the confidentiality of the identity of the gene donor, his or her tissue sample, the description of his or her state of health and his or her genealogy and shall deliver the personal data of the gene donor, the tissue sample, the description of his or her state of health and his or her genealogy to the chief processor or an authorised processor designated by the chief processor as soon as possible.

§ 15. Right of ownership of tissue samples, descriptions of state of health and genealogies

(1) The chief processor's right of ownership of a tissue sample, description of state of health, other personal data and genealogy is created from the moment the tissue sample or personal data is provided or the moment the state of health or genealogy is prepared.

(2) Tissue samples and uncoded information in the ownership of the chief processor and written consent of gene donors are not transferable.

(3) A gene donor is not entitled to request a fee for providing a tissue sample, preparation and study of a description of his or her state of health or genealogy, or use of the research results.

§ 16. Permission to use Gene Bank

(1) The Gene Bank may be used only for scientific research, research into and treatment of illnesses of gene donors, public health research and statistical purposes. Use of the Gene Bank for other purposes, especially to collect evidence in civil or criminal proceedings or for surveillance, is prohibited.

(2) The doctor of a gene donor has the right, pursuant to clause 24 (2) 7) of this Act, to obtain the decoded description of the state of health of the gene donor from the Gene Bank in order to treat the gene donor.

§ 17. Permission to use genealogy

(1) Genealogies may be used only within the Gene Bank for structuring tissue samples, descriptions of DNA and descriptions of state of health on the basis of blood relationships.

(2) The chief processor may issue, to a gene researcher, the link between coded tissue samples, coded descriptions of DNA and coded descriptions of state of health based on blood relationships in adherence with the requirements provided for in subsection 22 (4) of this Act.

§ 18. Storage of tissue samples, descriptions of DNA and descriptions of state of health

(1) Tissue samples, descriptions of DNA and descriptions of state of health shall be stored by the chief processor or an authorised processor.

(2) Coded DNA samples, coded descriptions of DNA and coded descriptions of state of health may also be stored by a gene researcher who has the resources and

conditions necessary for storage. The conditions for storage shall be established by the Minister of Social Affairs.

(3) In order to organise storage, the chief processor shall enter into a contract with an authorised processor or gene researcher which shall set out the following:

- 1) the tissue samples, descriptions of DNA and descriptions of state of health handed over for preservation;
- 2) the time of delivery of the tissue samples, descriptions of DNA and descriptions of state of health to the authorised processor or gene researcher and the manner of supplementing the tissue samples, descriptions of DNA and descriptions of state of health;
- 3) the place and term of storage;
- 4) the method of storage;
- 5) the security measures to be applied by the storer;
- 6) the procedure for the copying, distribution, destruction and issue of tissue samples, descriptions of DNA or descriptions of state of health and for the return thereof to the chief processor or authorised processor;
- 7) the liability of the authorised processor or gene researcher.

(4) All tissue samples shall be stored in the territory of the Republic of Estonia. The Government of the Republic may, at the request of the chief processor and if good reasons therefor become evident, grant permission for tissue samples to be stored outside the territory of the Republic of Estonia if it is ensured that the chief processor has effective control over the tissue samples and that the tissue samples cannot be used in a manner prohibited by Estonian law.

§ 19. Rights related to results of genetic research

(1) An authorised processor or gene researcher shall unconditionally deliver descriptions of DNA or parts thereof to the chief processor. The chief processor may grant an authorised processor or gene researcher the right to use a description of DNA or a part thereof for a charge or without charge. The chief processor shall grant gene researchers who are legal persons in public law or state agencies of the Republic of Estonia the right to use descriptions of DNA or parts thereof without charge.

(2) Results of genetic research not specified in subsection (1) of this section and intellectual property rights related thereto shall be provided by law.

§ 20. Issue of tissue samples, descriptions of DNA and descriptions of state of health, and records of issue

(1) The chief processor shall issue tissue samples, descriptions of DNA and descriptions of state of health from the Gene Bank only in coded form, except upon the issue of data on a gene donor to the gene donor or to the doctor of the gene donor in the cases provided for in subsections 11 (2) and 16 (2) of this Act.

(2) Upon the issue of a tissue sample, description of DNA or description of state of health, the issuer shall prepare a record of issue in which the tissue samples, descriptions of DNA and descriptions of state of health issued and received and the manner and date of delivery are indicated. The record of issue shall be signed by the representatives of the issuer and receiver.

(3) If the issuer is an authorised processor, the issuer shall promptly send a copy of the record of issue to the chief processor.

(4) The procedure for issuing tissue samples, descriptions of DNA and descriptions of state of health, including the format of the record of issue and the

procedure for the completion and preservation thereof shall be established by the Minister of Social Affairs.

§ 21. Destruction of data which enables decoding, tissue samples, descriptions of DNA and descriptions of state of health, and records of destruction

(1) If a gene donor applies to the chief processor for the destruction of data which enables decoding, the chief processor is required to destroy the data which enables decoding within two weeks as of the receipt of the corresponding written application from the gene donor.

(2) If a gene donor applies to the chief processor for the destruction of a tissue sample, description of DNA or description of his or her state of health due to unlawful disclosure of his or her identity, the chief processor is required to organise the destruction of the tissue sample, description of DNA and description of state of health within one month as of the receipt of the corresponding written application from the gene donor unless the chief processor proves that the identity of the gene donor was disclosed as a result of the gene donor's own behaviour.

(3) The chief processor may organise the destruction of tissue samples, descriptions of DNA and descriptions of state of health on the basis of records of issue prepared pursuant to § 20 of this Act, in which case the chief processor shall issue a destruction order to the receiver specified in the record of issue.

(4) All persons who have a specific tissue sample, description of DNA or description of state of health in their possession are required, on the order of the chief processor, to destroy the specific tissue sample, description of DNA or description of state of health promptly and at their own expense.

(5) Upon the destruction of data which enables decoding, tissue samples, descriptions of DNA or descriptions of state of health, the destroyer shall prepare a record of destruction which sets out the destroyed object and the manner, place and date of destruction. If the destroyer is not the chief processor, the destroyer shall promptly send a copy of the record of destruction to the chief processor.

(6) The procedure for destroying data which enables decoding, tissue samples, descriptions of DNA and descriptions of state of health, including the format of the record of destruction and the procedure for the completion and preservation thereof shall be established by the Minister of Social Affairs.

Chapter 4

Data Protection

§ 22. General requirements for data protection

(1) Data in the Gene Bank shall be processed in compliance with the highest standard of data protection.

(2) Data enabling identification of gene donors shall not be available through the external computer network of the Gene Bank.

(3) The chief processor shall appoint the specific persons who perform coding or decoding, who have access to the consent of gene donors, to the collection of tissue samples and descriptions of DNA, to descriptions of state of health and to genealogies, and who issue coded or uncoded tissue samples, descriptions of DNA or descriptions of state of health.

(4) The chief processor may issue tissue samples, descriptions of DNA or descriptions of state of health from the Gene Bank only in coded form, as a set of data and on the condition that samples or data concerning at least five gene donors are

issued at a time. The cases provided for in subsections 11 (2) and 16 (2) of this Act constitute an exception.

(5) In order to verify the authenticity of data to be entered in the Gene Bank before coding, the chief processor and authorised processor are permitted to compare such data with data stored in other databases.

§ 23. Coding

(1) The chief processor shall give each tissue sample, description of DNA, description of state of health and genealogy a unique code consisting of at least sixteen random characters immediately after receipt of the tissue sample, description of DNA, description of state of health or genealogy in the Gene Bank. The chief processor shall obtain the approval of the data protection supervision authority for the method of generating the codes.

(2) The chief processor shall replace with a code all data concerning a tissue sample, description of DNA and description of state of health which enables the reverse identification of the gene donor, including the name, personal identification code, date of birth and residence.

(3) The chief processor shall indicate the code given to a tissue sample, description of DNA, description of state of health or genealogy on the written consent of the gene donor. The chief processor shall store the written consent together with the code indicated thereon in the database of the Gene Bank and it shall be the only possible key for decoding.

(4) In the interests of greater security, the chief processor may give an additional code to a coded tissue sample, coded description of DNA, coded description of state of health or coded genealogy and this code shall replace the initial code given to the tissue sample, description of DNA, description of state of health or genealogy. The chief processor shall make a record of the link between an initial code and an additional code in a database used solely for that purpose.

(5) The chief processor, authorised processors and genetic researchers are required to encode tissue samples, descriptions of DNA, descriptions of state of health and genealogies only with the code given to the tissue samples, descriptions of DNA, descriptions of state of health or genealogies by the chief processor.

§ 24. Decoding

(1) Only persons appointed pursuant to subsection 22 (3) of this Act may gain access to written consent with a code indicated thereon and have the technical possibility to decode data.

(2) The chief processor is permitted to decode data only in the following cases and for the following purposes:

1) in order to destroy a tissue sample, a description of DNA or a description of state of health or data which enables decoding;

2) in order to enable access to data on a gene donor stored in the Gene Bank, except genealogies, at the written request of the gene donor;

3) in order to renew, supplement or verify a description of the state of health of a gene donor without contacting the gene donor unless the gene donor has prohibited the supplementation, renewal or verification of the description of his or her state of health;

4) in order to identify a gene donor on the proposal of the chief processor and with the consent of the Ethics Committee, to contact the gene donor and to renew,

supplement or verify a description of his or her state of health with his or her written consent;

5) in order to identify a gene donor and, with the gene donor's written consent, to take a new DNA sample if a tissue sample has been destroyed or does not contain sufficient DNA;

6) in order to identify a gene donor within the Gene Bank and amend his or her genealogy if the results of DNA research contradict the previously known genealogy or provide new information concerning the genealogy;

7) in order to issue a description of the state of health of a gene donor to the doctor of the gene donor at the request of the doctor of the gene donor and with the consent of the gene donor or, in urgent cases where a gene donor is unable to grant consent and has no legal representative or guardian or if the legal representative or guardian of the gene donor is unavailable, without the consent of the gene donor but in his or her interests and according to his or her presumed intentions.

Chapter 5

Prohibition on Discrimination

§ 25. Prohibition on discrimination

(1) It is prohibited to restrict the rights and opportunities of a person or to confer advantages on a person on the basis of the structure of the person's DNA and the genetic risks resulting therefrom.

(2) It is prohibited to discriminate against a person on the basis of the person being or not being a gene donor.

§ 26. Discrimination in employment relationships

(1) Employers are prohibited from collecting genetic data on employees or job applicants and from requiring employees or job applicants to provide tissue samples or descriptions of DNA.

(2) Employers are prohibited from imposing discriminatory working and wages conditions for people with different genetic risks.

§ 27. Discrimination in insurance relationships

(1) Insurers are prohibited from collecting genetic data on insured persons or persons applying for insurance cover and from requiring insured persons or persons applying for insurance cover to provide tissue samples or descriptions of DNA.

(2) Insurers are prohibited from establishing different insurance conditions for people with different genetic risks and from establishing preferential tariff rates and determining insured events restrictively.

Chapter 6

Supervision and Resolution of Appeals

§ 28. Data protection supervision authority

Supervision over the collection of descriptions of state of health and genealogical data, the coding and decoding of tissue samples, descriptions of DNA, descriptions of state of health and genealogical data, and the processing of tissue samples, descriptions of DNA, descriptions of state of health and genealogical data shall be exercised by the data protection supervision authority.

§ 29. Ethics Committee

(1) The processing procedures of the Gene Bank. The assessment of the Ethics Committee is not binding, except in the case provided for in clause 24 (2) 4) shall be assessed by the Ethics Committee.

(2) The Ethics Committee shall act pursuant to generally recognised ethical rules and international conventions.

(3) Each member of the Ethics Committee shall be an Estonian citizen with active legal capacity whose permanent residence is in the Republic of Estonia. Each member of the Ethics Committee shall be a recognised specialist in his or her field with the necessary expertise to perform the duties of a member of the Ethics Committee and shall have an impeccable reputation.

(4) The members of the Ethics Committee shall be appointed and the number of members shall be determined by the supervisory board of the chief processor of the Gene Bank. The term of authority of a member of the Ethics Committee is five years.

(5) The supervisory board of the chief processor of the Gene Bank may remove a member of the Ethics Committee prior to expiry of the term of authority of the member with good reason, which is, above all, failure to perform his or her duties to a material extent, inability to participate in the work of the Ethics Committee or the causing of significant damage to the interests of the chief processor in any other manner, and also the commencement of bankruptcy proceedings against the member of the Ethics Committee.

§ 30. Resolution of appeals arising from employment and insurance relationships

(1) Complaints concerning discrimination occurring in employment relationships due to genetic risks shall be adjudicated by the Labour Inspectorate, if necessary with the assistance of the chief processor or experts from the data protection supervision authority in investigating and deciding the matter.

(2) Complaints concerning discrimination occurring in insurance relationships due to genetic risks shall be adjudicated by the Insurance Supervisory Authority, if necessary with the assistance of the chief processor or experts from the data protection supervision authority in investigating and deciding the matter.

Chapter 7 Implementing Provisions

§ 31. Amendment of Criminal Code

The Criminal Code (RT 1992, 20, 287 and 288; RT I 1999, 38, 485; 57, 595, 597 and 598; 60, 616; 97, 859; 102, 907; 2000, 10, 55; 28, 167; 29, 173; 33; 193; 40, 247; 49, 301 and 305; 54, 351; 57, 373; 58, 376; 84, 533; 92, 597) is amended as follows:

1) section 124⁴ is added to the Code worded as follows:

"§ 124⁴. Inducing persons to become gene donors

Inducing a person to consent to providing a tissue sample for the purposes of genetic research by offering material remuneration or by causing damage or threatening to cause damage to the person is punishable by a fine, detention or up to one year imprisonment.";

2) section 124⁵ is added to the Code worded as follows:

"§ 124⁵. Illegal conduct of human research

Conduct of medical or scientific research on a person who has not granted his or her valid consent thereto is punishable by a fine, detention or up to one year imprisonment.";

3) section 128¹ is amended and worded as follows:

"§ 128¹. Disclosure of confidential data which became known due to professional activity

Disclosure by a doctor, medical assistant, nurse, midwife, psychologist, advocate, notary or other person of confidential data relating to the descent, genetic data, artificial insemination, family or health of a person which became known to the offender due to his or her professional activity, if such disclosure violates legislation regulating the professional activity or other legislation, is punishable by a fine or deprivation of the right of employment in a particular position or operation in a particular area of activity or by detention or up to one year imprisonment.";

4) section 134² is added to the Code worded as follows:

"§ 134². Discrimination based on genetic risks

Unlawful restriction of the rights of a person or conferral of unlawful preferences on a person based on the genetic risks of the person is punishable by a fine, detention or up to one year imprisonment."

§ 32. Amendment of Personal Data Protection Act

The Personal Data Protection Act (RT I 1996, 48, 944; 1998, 59, 941; 111, 1833; 2000, 50, 317; 92, 597) is amended as follows:

1) clause 4 (3) 3) is amended and worded as follows:

"3) data relating to state of health, genetic information or sexual life;"

2) subsection 9 (2) is amended and worded as follows:

"(2) Processing of sensitive personal data revealing ethnic or racial origin, state of health, genetic information or sexual life is permitted without the consent of the person if the processing is carried out:

1) for performance of obligations prescribed by law;

2) for protection of the person's life, health or freedom;

3) for performance of a task in the public or general interest which is assigned by law to a chief processor or a third person to whom the data are disclosed."

§ 33. Amendment of Estonian Academy of Sciences Act

Clause 5¹) is added to subsection 9 (3) of the Estonian Academy of Sciences Act (RT I 1997, 35, 539) worded as follows:

"5¹) appoint three members of the supervisory board of the chief processor of the Gene Bank;"

§ 34. Establishment of chief processor

The Government of the Republic shall decide on the establishment of the non-profit foundation specified in subsection 3 (1) of this Act within two months as of the entry into force of this Act.

¹ RT = *Riigi Teataja* = *State Gazette*

² Riigikogu = the parliament of Estonia