

## GENE DONOR CONSENT FORM

This document contains information about being a gene donor in order to help me decide whether or not I wish to become a gene donor. The rights of a gene donor are regulated by the Human Genes Research Act and the legislation concerning personal data protection. Further information about becoming and being a gene donor is given on the gene donor fact sheet. I can contact the data controller or processor of the Gene Bank if I have any questions.

### **I have been informed of and am aware of the following:**

1. The objective of the Gene Bank is to collect information about the health and genes of the Estonian population and to use this information to establish and update the Gene Bank database. The Gene Bank may only be used for scientific research, research and treatment of the diseases of the gene donor, public health research and statistical purposes. Using the Gene Bank for other purposes, especially for collection of evidence or surveillance in civil or criminal cases, is prohibited. The research carried out with the help of the Gene Bank is continuing and not limited to the current level of science.
2. The granting of consent is voluntary. Nobody may be discriminated against for being or not being a gene donor. Nobody may force me to grant consent to becoming a gene donor.
3. Health and genetic data are special category personal data, i.e. sensitive data. They are stored in the Gene Bank in pseudonymised format, i.e. health, genetic and personal identification data are kept separately in the Gene Bank.
4. I may not demand payment for providing a tissue sample, for the description of my state of health, for the preparation and research of my genealogy or for the use of the research results. I am aware of the fact that my tissue sample may have some commercial value and that research and development institutions as well as commercial enterprises may receive data about pseudonymised gene donors.
5. The controller acquires the right of ownership to the tissue sample as of the moment it is taken. The controller acquires the right to use the description of the state of health, genealogy and written consent of the gene donor and the right to process the personal data they include as of the moment they are prepared.
6. I have the right to be aware of my genetic data and other data about me stored in the Gene Bank, except my genealogy. I can access the results of the genetic research concerning me that are stored in the Gene Bank, which are given to me free of charge. I have the right to not know the results of the genetic research.
7. I have the right to counselling when accessing my data stored in the Gene Bank.
8. The controller of the Gene Bank may give out tissue samples, descriptions of DNA and descriptions of the state of health from the Gene Bank for research and development only in pseudonymised format so that the identity of the gene donor remains unknown to the recipient of the data.
9. De-pseudonymisation means reconnecting the non-personal data with the data that identify a person. De-pseudonymisation makes it possible to connect the personal data, description of the state of health and genetic data of a specific gene donor. De-pseudonymisation is carried out by the controller of the Gene Bank in the cases and pursuant to the procedure stipulated in the Human Genes Research Act. A detailed explanation of this is given on the gene donor's fact sheet.
10. I may submit additional information about myself to the controller of the Gene Bank at any time.
11. I can determine the following when making the choice below:
  - I may grant consent for my doctor to access the results of the genetic research concerning me that

are stored in the Gene Bank. The doctor can access the data free of charge.

- I can grant my consent for the controller of the Gene Bank to obtain my personal data and health data from other databases.
- I may prohibit the controller of the Gene Bank from supplementing, renewing and verifying the description of my state of health stored in the Gene Bank.

Note: If I decide not to grant the aforementioned consent with this form, I can do so later if I wish to.

Below, I can make choices based on the information above. I will tick **one** of the following boxes that is suitable to me in order to express my will:

- I allow my doctor to access the description of my state of health. I understand that I can withdraw this consent later.
- I do not allow my doctor to access the description of my state of health.

Below, I can make choices based on the information above. I will tick **one** of the following boxes that is suitable to me in order to express my will:

- I allow the controller of the Gene Bank to supplement, renew and verify the description of my state of health stored in the Gene Bank. I understand that I can withdraw this consent later.
- I do not allow the controller of the Gene Bank to supplement, renew and verify the description of my state of health stored in the Gene Bank. I am aware that if I do not allow the controller of the Gene Bank to supplement, renew or verify the description of my state of health, it will not be possible to carry out accurate research and development on the basis of the data stored in the Gene Bank or to assess my health risks accurately.

12. I may withdraw my consent to become a gene donor at any time. Until the pseudonymisation of the tissue sample and the description of the state of health, this means that the collected data and tissue sample will be destroyed. If I withdraw my consent to become a gene donor after the pseudonymisation of data, but do not demand the destruction of my tissue sample, the description of my DNA and the description of my state of health, then the data which make it possible to identify the gene donor will be destroyed in such a manner that they cannot be recovered. I can submit the relevant expression of will to the controller of the Gene Bank at their location or with a digital signature.

13. If my identity, the fact that I am a gene donor and other personal data are unlawfully disclosed, I have the right to demand compensation for damage and the destruction of my tissue sample, the description of my DNA and the description of my state of health.

14. I am aware of the fact that upon the termination of the operations of the controller of the Gene Bank, the right of ownership in the tissue samples and the right to use and process the descriptions of the state of health, genealogies, the written consent of gene donors and the personal data related thereto will transfer from the controller to the Republic of Estonia.

**By signing this document I grant my free and informed consent for the processing of my personal data and for becoming a gene donor, as well as to:**

- 1) provide a venous blood sample of up to 50 ml;
- 2) have the description of my state of health prepared;
- 3) have my genealogy prepared;
- 4) enter the tissue sample, description of the state of health and genealogy in the Gene Bank in pseudonymised format;
- 5) use these for genetic research, public health research and statistical purposes.

The signed consent form will be stored by the controller of the Gene Bank. The gene donor will retain a signed copy of the consent form.

Information regarding person who takes tissue sample:

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Data of processor:

Name \_\_\_\_\_

Address \_\_\_\_\_

Registry code \_\_\_\_\_

Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

Data of controller:

Name \_\_\_\_\_

Address \_\_\_\_\_

Registry code \_\_\_\_\_

Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

**Gene donor:**

First name and surname \_\_\_\_\_

ID code or date of birth \_\_\_\_\_

Gender \_\_\_\_\_

Place of residence \_\_\_\_\_

Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_

**Representative of gene donor:**

First name and surname \_\_\_\_\_

ID code or date of birth \_\_\_\_\_

Gender \_\_\_\_\_

Place of residence \_\_\_\_\_

Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

Date \_\_\_\_\_

Signature \_\_\_\_\_