

GENE DONOR CONSENT FORM

This document contains essential information about the rights of a gene donor in order to help me decide whether to become a gene donor. The Human Genes Research Act regulates the rights of gene donors. Further information about becoming and being a gene donor is given in the gene donor information kit. This consent form, the law and information kit shall be explained to me by a specialist and I may ask questions at any time.

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

1) The aim of the Estonian Genome Project is to establish the Gene Bank, a database that contains data on the health and genes of the people of Estonia. The Gene Bank enables scientific and applied gene and health research to be carried out in order to determine genes that influence the development of diseases. Research carried out with the help of the Gene Bank shall not be limited to the present scientific level.

2) I give my consent to become a gene donor entirely voluntarily. No one may discriminate against me on the basis of being or not being a gene donor. No one may force me to become a gene donor.

3) I may not demand a fee for providing a tissue sample, for the description of my state of health or 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 research and development institutions as well as commercial enterprises may receive anonymous data about gene donors. The right of ownership of the tissue sample, of the description of my state of health and of other personal data and genealogy shall be transferred to the University of Tartu, the chief processor of the Estonian Genome Project.

4) If I wish, I may submit additional information about myself to the chief processor. The chief processor of the Gene Bank has the right to receive information about my state of health from other databases. I have the right to prohibit the supplementation, updating and verification of descriptions of my state of health stored in the Gene Bank.

5) I have the right not to be aware of my genetic data, hereditary characteristic and genetic risks obtained as a results of genetic research

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 have the right to genetic counselling upon accessing my data stored in the Gene Bank. I can access my data stored in the Gene Bank free of charge.

7) No one has the right to access my data stored in the Gene Bank unless the data have been coded (anonimised). I may grant consent to my doctor to access my decoded data contained in the Gene Bank. Decoding is performed by the chief processor of the Gene Bank in cases and pursuant to the procedure provided by law.

8) The chief processor of the Gene Bank may give out tissue samples, descriptions of DNA and descriptions of the state of health from the Gene Bank only in coded form so that the identity of the gene

donor remains unknown to the receiver of the data.

9) I have the right to apply to the chief processor of the Estonian Genome Project at any time for the destruction of the data which enable me to be identified. Upon unlawful disclosure of my identity, I have the right to claim compensation for damage and apply to the chief processor of the Estonian Genome Project for the destruction of my tissue sample, description of DNA and description of my state of health.

10) I may withdraw my consent to become a gene donor until my tissue sample or the description of my state of health is coded.

11) I am aware that in the case of the University of Tartu as the chief processor ending its activities, the ownership of the tissue samples, the data, and also the written consent forms of the gene donors is transferred to the Republic of Estonia in accordance with the Human Genes Research Act.

By signing this document, I give my free and informed consent to:

- 1) Become a gene donor;
- 2) Give a 50 ml venous blood sample using single-use equipment
- 3) Have a description of my state of health and genealogy drawn up;
- 4) Have the tissue sample, description of my state of health and my genealogy entered in the Gene Bank in coded form;
- 5) The use thereof for genetic research, public health research and statistical and other purposes in accordance with the law.

The gene donor keeps a copy of this consent form.

Gene donor

Full name: _____
ID Code or Date of Birth _____
Sex _____
Place of Residence: _____

Legal representative

Full name: _____
ID Code or Date of Birth _____
Sex _____
Place of Residence _____

Date: _____

Signature: _____

Information concerning the health service provider who is to take the tissue sample:
