

### **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 and I am aware of the following:**

- 1) The aim of the Estonian Genome Project Foundation is to establish the Gene Bank, a database that contains health and gene data of the people of Estonia. The Gene Bank enables scientific and applied gene and health research to be carried out in order to find genes that influence the development of illnesses. Research carried out with the help of the Gene Bank shall not be limited to the present scientific level.
- 2) My consent to become a gene donor is entirely voluntary. 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 request a fee for providing a tissue sample, for describing my state of health or genealogy, or for the use of my research results. I am aware of the fact that my tissue sample may have some commercial value and that commercial entities 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 Estonian Genome Project Foundation. The foundation has been established and it is controlled by the Republic of Estonia. The foundation is financed by commercial entities.
- 4) If I wish, I may submit additional information on myself to the Estonian Genome Project Foundation. The Estonian Genome Project Foundation 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) Data on hereditary characteristics and genetic risks obtained as a result of genetic research may be unpleasant for me. I have the right to not know my genetic data.
- 6) I have the right to know my genetic data and other data about me stored in the Gene Bank, except my genealogy. I have the right to genetic counseling 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 if the data have been decoded. I may grant consent to my doctor to access my decoded data contained in the Gene Bank. Decoding is performed by the Estonian Genome Project Foundation in cases and pursuant to procedure provided by law.

- 8) The Estonian Genome Project Foundation may issue 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.
- 9) I have the right to apply at any time to the Estonian Genome Project Foundation for the destruction of my data that can be decoded. Upon unlawful disclosure of my identity, I have the right to claim compensation for damage and apply to the Estonian Genome Project Foundation for the destruction of my tissue sample, description of DNA and description of my state of health.
- 10) I can withdraw my consent to become a gene donor until my tissue sample or the description of my state of health is coded.

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

- 1) Become a gene donor;**
- 2) Provide a 50 ml venous blood sample from my arm using single-use equipment;**
- 3) Have a description of my state of health and genealogy prepared;**
- 4) Enter the tissue sample, description of my state of health and my genealogy in the Gene Bank in coded form;**
- 5) The use thereof for genetic research, public health research and statistical purposes in conformity with the law.**

A copy of this consent form remains with me.

**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:

\_\_\_\_\_