Consent for genome sequencing analysis

RIBAKOOD
(puudumisel täita andmed käsitsi)

Patient name: ……..

Personal identification code: ……

Whole genome sequencing means sequencing all of a person's DNA. It is increasingly used in clinical medicine to diagnose genetic diseases. This test makes it possible to examine all of a person's genetic material at once, including all genes (over 20,000), with the goal of identifying a change in a gene that may cause the patient's condition. The test is usually performed on DNA extracted from a blood sample. Ideally, the child and both parents are analysed at the same time to achieve the best chance of finding a diagnosis.

Method:
☐ Whole genome sequencing of the patient (singleton analysis)
☐ Whole genome sequencing of the patient and both parents (trio analysis)
☐ Other method (as agreed with the laboratory): ……..

The analysis may take up to 6 months.

- I hereby give my consent for the genome sequencing analysis of my / my child's / my ward's DNA in order to identify a possible cause of disease.
- I understand the following:
  - Extracted DNA and genome sequencing data are stored at the Clinic of Genetics and Personalised Medicine of Tartu University Hospital.
  - There is a small chance that this analysis may identify genetic findings unrelated to the condition being investigated, but which could still be important for my / my child's / my ward's health. You will be informed only about those genetic changes for which preventive measures or medical interventions exist. The list of such genes is internationally agreed and endorsed by the American College of Medical Genetics and Genomics (ACMG). If I choose not to be informed of such incidental findings, I may miss useful information related to my / my child's / my ward's health risks.
    ☐ I would like to be informed about medically actionable incidental findings
    ☐ I do not wish to be informed about incidental findings
  - Knowledge about genetic conditions may improve in the future. I may be contacted again if new information becomes available about the results of my genome sequencing and their relationship to my / my child's / my ward's condition.
  - If genome sequencing is performed for biological parents or other relatives (trio analysis):
    - A written consent is required from both parents (or all family members analysed).
    - Results are reported only for the patient being investigated. Incidental findings, as described above, will be shared with all individuals whose genome was analysed, provided they have given consent.
    - The test may reveal that biological relationships differ from what is currently known.
- I understand that I may withdraw my consent for this test at any time without affecting other aspects of my / my child's / my ward's medical care. However, withdrawing may delay diagnosis and could reduce treatment effectiveness.
- I have had the opportunity to ask additional questions and I am satisfied with the explanations provided.

I agree to the performance of genome sequencing for myself / my child / my ward:
Patient / Parent / Guardian:

Name: …… Signature: …… Date ……

For trio analysis, consent from both parents is required:

Mother's name: …… Signature: …… Date ……

Father's name: …… Signature: …… Date ……

Clinician providing this information to the patient / parents / guardian:

Clinician's name: …… Signature: …… Date ……