

CONSENT FORM – NEXT GENERATION SEQUENCING (NGS) CLINICAL INSTITUTE OF GENOMIC MEDICINE

PATIENT INFORMATION
Name and surname
Date of birth
Address
City and country of residence
Phone contact

LEGAL REPRESENTATIVE
Name and surname
Date of birth
Address
City and country of residence
Phone contact

Statement of the patient or legal representative.

1. I consent that DNA sample obtained from myself / my child / person under my legal representation is saved and analysed using next-generation sequencing for the following condition:

2. I understand that the next-generation sequencing is a test aimed to clarify the underlying genetic cause of the condition affecting me or my child. I understand that the test may also include testing of the genes, that are not directly associated with my current medical condition. I also understand that the report of this genetic test will only address those genes and variants that can be associated with my current medical problems.

3. I understand that the current medical knowledge of the function of genes and their association with disease in humans is constantly progressing. I understand that my report is based on the data that were available at the time of the testing, and that their significance may change in the future. A detected variant may thus currently have uncertain medical significance (variant of unknown or uncertain significance) but can be associated with my condition in the future. In cases, where a variant of unknown significance is identified, we will advise re-analysis of exome sequencing results after a period of two years after issuing the report.

4. I understand that the data obtained using next-generation sequencing in the DNA sample will be stored at Clinical institute of genomic medicine, UMC Ljubljana. I understand that data obtained with exome sequencing will be stored in a database at Clinical institute of genomic medicine, UMC Ljubljana and that they may be included in international databases, and included into medical publications in a limited form.

5. If analysis of a limited set of genes, associated with my condition does not reveal a likely cause of the disease, I consent to analysis of the whole set of sequenced genes:

YES / NO

I understand, that this expanded exome sequencing report also includes data on other genes and diseases that are not associated with my current medical condition but could nevertheless have a clear and immediate medical significance for my health and health of my family (incidental findings). I understand that I will be informed, if such findings are detected.

6. I understand, that I always have a possibility to freely withdraw this consent, without any further effect on medical managements of me or my child.

7. I was sufficiently informed about this genetic test and could ask any additional questions and I am satisfied with explanations provided.

Signature

Date

To be filled by the genetic counsellor:

..... confirm that I have informed the patient / parent / legal representative about the results and limitations of next-generation sequencing tests. I have presented the potential implications and procedures, associated with this test and the management of data

Signature

Date