EBERHARD KARLS UNIVERSITÄT TÜBINGEN

Consent Form

Universitätsklinikum Tübingen

for the collection and storage of biomaterial (blood, DNA and/or RNA samples), for the performance of genetic tests, and for the processing of the collected genetic and personal data within the framework of the scientific study described in the information letter (HNE_2022-Vers. 09.02.2022)

„Elucidation of the genetic causes of hereditary retinal diseases" and Data Protection

Patient Information

.....

Name Surname Date of Birth

.....

Tel Email

.....

Street, ZIP Code, City

Please read this consent form carefully and cross any point that does not apply:

I have received, read and understood the information letter (HNE-2021-Vers.09.02.2022) on participation in the study "Elucidation of the genetic causes of hereditary retinal diseases" and on data protection.
With my signature I give my consent to the genetic examinations necessary for the clarification of this question, to the blood sampling necessary for this purpose, as well as to the collection and storage of my personal and clinical data.
I have had sufficient opportunity to discuss any open questions.

I consent to the analysis of my DNA/RNA samples by high throughput sequencing (e.g. panel, exome and/or genome sequencing).

I would like to be informed about the results of genetic testing related to my retinal disease.

I agree that the findings of the genetic examination(s) may be sent to the following physicians / persons:

Dr. .....
Attending or Referring Physician

I consent that my attending and/or referring physicians collect my personal data, in particular information about my health including medical records, and that such data are sent to and stored together with my biomaterials at the Molecular Genetics Laboratory, Institute for Ophthalmic Research, Centre for Ophthalmology, University Tübingen to support this study.
I declare that I agree with the collection and processing of data and their encrypted (pseudonymized) transfer taking place within the framework of the study.
I agree that authorized personnel may inspect my personal medical record for the purpose of reviewing the data and release the attending physician from his medical confidentiality obligation in this respect.

German legislation stipulates that your personal data and medical and genetic results and findings must be completely destroyed after 10 years. However, this information may still be relevant to you or your relatives (e.g. your children) after that time. With your consent, we may also keep this data beyond the legally required period of 10 years.
I agree to my data / documents being stored for an unlimited period.

My biomaterials (blood/DNA/RNA samples) may be used indefinitely for medical research projects.

My biomaterials (blood/DNA/RNA samples) may be passed on pseudonymously to universities, research institutes and research companies for medical research purposes.

The collected data also serve to gain scientific knowledge.
I agree that collected genetic and clinical data and results about the disease in question may be used in encrypted (pseudonymized) form for scientific purposes and may be used anonymously for teaching purposes and in scientific publications, as well as published in scientific journals.
I declare that I have been adequately informed about the collection and processing of my data collected in this study and my rights, and I consent to the use of the data collected in this study in the manner described.

I was informed that I can request information about my stored data and the correction of incorrect data at any time.
I have been informed that I may withdraw my consent in whole or in part at any time without giving reasons, without incurring any disadvantages, and that I have the right to request test results at any time, but also not to learn about them.
In case of withdrawal, the remaining biomaterials will be destroyed upon my request and the collected data will be deleted or anonymized. Data from analyses already performed cannot be removed.
I have received a copy of the patient/proband information and consent form. The original remains with the Department of Ophthalmology, University of Tübingen or your treating or referring physician.

…….. City, Date	…… Signature Patient or Legal Guardian	…… …… …… For Legal Guardian: Name, Address