Hannover Medical School

Department of Human Genetics
Accreditation DIN EN ISO 15189 (D-ML-13168-01-00)
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Consent Form for Unaffected Parents
(to be signed by each parent separately)

"Predicting the clinical outcome of non-muscle actinopathies"

Study Principal Investigator: Prof. Dr. med. Nataliya Di Donato

ID Family_____

Research participant	Name Date of birth Contact information
Index patient	Name Date of birth

A) General

I confirm that I have read the information sheet and fully understood the above mentioned research study. I had the opportunity to ask questions and was provided with a copy of the study information sheet and the consent form. I had sufficient time to decide whether I want to take part in this study.

I understand that I have rights as a research study participant and by signing this consent form I do not give up any of my legal rights.

B) Blood draw and usage of blood samples

I agree to provide a venous blood sample (5-10ml) for the study, which will be stored for an unlimited time.

I agree that the taken blood samples are used to examine the disease mechanisms of actin mutations under the responsibility of the Department of Human Genetics at Hannover Medical School (MHH). This includes the generation of cell lines for molecular-biological, biochemical and biophysical analysis.

- I agree to provide a blood sample and voluntary donate the sample to the Department of Human Genetics at MHH.
  ☐ Yes / ☐ No

Information about the results of the study

- There is interest in an explanation of the overall results of the study.
  ☐ Yes / ☐ No

Cost compensation

I understand that there will be no expenses to me or my insurance company associated with this study.

[If you or your insurer does pay a bill for services we have requested, we can reimburse you after receiving a receipt for service.]

Furthermore, I understand and agree that my samples could be used to make new products, tests or findings. These may have value and may be developed and owned by the research team and/or others. I understand that if this happens no money will be provided to me.

Withdrawal of consent to sample usage

I understand that I can withdraw my participation in the study any time without explaining my reasons to the research team.

I understand, that if I choose to withdraw, it will neither affect my medical care nor would I lose any benefits.

I am informed that I can ask to have my samples and related information to be destroyed.

I understand that it will be difficult to retrieve or destroy my data once it has been anonymized as linking the information to me will no longer be possible or extremely expensive and time consuming.

C) Data Storage

I agree to the analyses, use and sharing of my health information for research purposes at the Department of Human Genetics at MHH.

I understand that the data might be used for publications and presentations of the study and I am aware that the publications will exclude names, addresses, dates of birth or other personal data that can identify me.

Permission withdrawal

I am informed that if I withdraw, no other health information will be collected for this research.

I am aware that if legal regulations permit I can request for the deletion of information that can identify me.

Research participant

_____
Printed name of research participant

_____
Relation to index patient

_____
Signature of research participant

Researcher / provider obtaining permission

_____
Printed name

_____
Signature

Place / Date _____