Hannover Medical School

Department of Human Genetics
Accreditation DIN EN ISO 15189 (D-ML-13168-01-00)
Prof. Dr. med. Nataliya Di Donato

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Consent Form for Patients/ Parental Permission form for affected Individuals

"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

Mother

Name
Date of birth
Contact information

Father

Name
Date of birth
Contact information

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.

I agree that my child can take part in this research study.

B) Blood draw, skin biopsy and usage of the samples

I agree that my child can provide a venous blood sample (5-10 ml) and a skin biopsy (Ø 3 mm) for the study, which will be stored for an unlimited time. I agree that the taken blood and skin 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 that my child can provide a blood sample and voluntarily donate the sample to the Department of Human Genetics at MHH.
  ☐ Yes / ☐ No

- I agree that my child can provide a skin biopsy and voluntarily donate the sample to the Department of Human Genetics at MHH.
  ☐ Yes / ☐ No

Information about the results of the study

- If there are results within the above mentioned study that are of importance for my / my child's health according to current knowledge, I would like to be informed.
  ☐ Yes / ☐ No

- 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 for me or my child's insurance company associated with this study.

[You or your insurance company will be reimbursed upon receipts if you do have to pay for any services we requested.]

Furthermore, I understand and agree that my child's samples could be used to make new products, tests or findings. These may be valuable and may be developed and owned by the research team and/or others. I understand that if this is the case, no money will be provided to me, my child or other family members.

Withdrawal of consent to sample usage

I understand that I can withdraw my child's participation in the study at any time during the research without giving any reasons to the team. I understand that withdrawing will not affect the medical care provided to me or my child, nor will it result in the loss of benefits. I am informed that I can ask for my child's samples and related information to be destroyed. I understand that it will be difficult to retrieve or destroy my child's data once it has been anonymized as linking the information to my child will no longer be possible or extremely expensive and time consuming.

C) Data Storage

I agree to the analyses, use and sharing of my child's 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 my child.

Use of Photographs Statement

I understand that facial photographs can identify my child. I indicate below my preferences for the usage and storage of the photographs:

- I agree that the researchers may use my child's photographs for presentations at conferences/seminar talks.
  ☐ Yes / ☐ No / ☐ I want to decide later

- I agree that the researchers may use my child's photographs for publications in specialized journals including their online-versions (without mentioning of names, addresses, or other identifiable personal data).
  ☐ Yes / ☐ No / ☐ I want to decide later

Permission withdrawal

I am informed that if I withdraw, no other health information about my child 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 my child.

Research participant (if legally competent)

Printed name of research participant

Signature of research participant
(if developmental age 14 years or older)

Mother

Printed name

Signature

Father

Printed name

Signature

If applicable legal guardian

Printed name

Signature

Researcher / provider obtaining permission

Printed name

Signature

Place / Date