



## Declaration of Consent for participation in the study

### Mosaicism and Risk Prediction in Parents of Children with *de novo* Variants (MORNOVA)

Institute of Human Genetics Medical Centre Leipzig AöR

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Information on Proband / medical ID-stickers

#### Personal Data of Probands

##### Proband:

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surname, name

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date of birth

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address, phone number, E-Mail-address

##### Mother:

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surname, same

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date of birth

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address (if different from proband), phone number, e-mail address

##### Father:

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surname, name

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date of birth

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address (if different from proband), phone number, e-mail address

#### General Information

I have received and read the information on the study and the declaration of consent and have had enough time to think about participating in the study. My decision to participate has been made independently. The study's aim, the process, the meaning and advantages and potential risks have been adequately

explained to me. Questions I had could be answered to my full satisfaction. Participation in the study is voluntary and at no charge upon which no claims to financial compensation can be made by me.

I agree that the priorly mentioned doctors and members of the study gain access in personal medical reports. Here, data and information on my medical history and health will be anonymised and saved to servers of the University Hospital Leipzig. I give my consent that such information can be used in anonymous form to support findings of the study in a later publication. On top of that, I agree to the transfer of such anonymised data to cooperating institutes and working groups. I agree to the sampling, usage and storage of my samples and those of my legal guardians by the prior mentioned doctors, members of the study group and institution.

#### Data Protection

An insight into the data protection concept of this project is available upon request. Access to, deletion, and modification of data (e.g., in the event of a name or address change, etc.) is also possible at any time without providing reasons, and without any disadvantages resulting from this. Additionally, a data transfer can be requested if the signatory wishes to have the data transferred to a third party (for further studies or physicians in other specialized institutions). Data will only be shared with third parties without a scientific research background with a corresponding written request to the above-mentioned study team. Consent for the use of the collected and generated data can be withdrawn at any time without providing reasons to the institution or person mentioned at the beginning. This does not affect any further medical treatment. I am aware that I can revoke this consent at any time in writing without providing reasons, and without any disadvantages resulting from this. Data will only be shared with third parties who are not associated with the above-mentioned study with a corresponding postal request. I agree that the collected and generated pseudonymized data will be securely stored indefinitely until revoked.

#### Protection of Minors and Dependents

I have been informed that I must inform the individuals I legally represent who are 14 years of age or older about the study and, if they wish, introduce it to the project leader or a project staff member in person or by phone to answer all questions. If the participating child turns 18 during the course of the study, a new briefing and consent must be obtained. For participants who are unable to consent independently (the majority of participants), this decision will continue to be made by the parents or legal representatives.

If results are obtained within the above-mentioned study that are of immediate importance to me or my relatives, I **Yes  / No**  would like to be informed. No additional findings will be made

I agree that copies of reports from genetic preliminary examinations of mine may be reviewed and requested if necessary (if "No," participation in the study is not possible). \* **Yes  / No**

I agree that already collected DNA samples of mine may be used and requested. **Yes  / No**

I agree that already collected DNA samples of mine may be further stored, e.g., for supplementary examinations. \* The samples will be transferred to us. **Yes  / No**

I agree that already collected DNA samples of my child may be used as a control sample and that copies of reports may also be requested (if "No," participation in the study is not possible). **Yes  / No**

\* If yes, please provide the laboratory where the genetic diagnostics were performed (name, address, and contact person, if applicable):

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place, date

signature proband or legal guardian

In the case of shared custody, both legal guardians are generally required to sign. If only one legal guardian is able to give consent, they confirm by signing this consent that they are acting on behalf of and with the authorization of the other legal guardian.

Any notes or comments from the informing physician or from the participant or their relatives:

name and stamp of the consulting physician

place, date and signature of the consulting physician