

Please send a **copy** of this document with official request for investigation and probe material back to:

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Klinik für Kinder- und Jugendmedizin

Ärztlicher Direktor: Prof. Dr. K.-M. Debatin

**Diagnostische Laboratorien der Universitätsklinik für
Kinder- und Jugendmedizin**

Molekulardiagnostisches Labor

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Informed Consent to Perform Genetic Testing

I was informed about the aims, comprehensiveness, implications, and consequences of the genetic testing that is planned for me, as well as about my legal rights by [please print]:

(Mrs./Mr. Dr. [MD]) _____

A reasonable time for my consideration was provided.

I agree that sample material (eg. blood) will be taken from

☐ me ☐ my child ☐ my ward, the person for whom I am guardian: _____

and I want the following genetic test(s)

(eg. chromosome analysis, molecular tests of the gene(s) *ATXN1*, *HD*, other) _____

used for diagnosis of the following disease(s)

(e.g. Dysmorphic syndrome, Spinocerebellar Ataxia, Huntington Disease, other) _____

The results of the investigations should be reported to the above-mentioned physician, and to the attention of:

(Mrs./Mr.) _____ (Address) _____

I want to be informed about the results: ☐ Yes ☐ No

I can request the cancellation of the whole investigation or parts of it and/or its results at any stage and time.

Unused material for the investigation

☐ may be used in an anonymous way as a laboratory quality control sample or for scientific purposes.

☐ should be stored for 10 years

Further genetic testing requires a new request for investigation and again my permission.

☐ should be destroyed after completing the tests

If nothing is declared here the material must be destroyed after completing the test.

I have the right to abrogate this consent any time in a written or oral way, without any disadvantages to me or members of my family.

Location, date _____

Patient, legal representative (Please print: last name, first name, DOB, gender [M/F]):

Signature

Signature of the responsible doctor: _____

The German law (**Gendiagnostikgesetz – GenDG**) defines under which circumstances genetic testing of a human individual is legal. *Diagnostic* testing can only be conducted with the patient's informed consent which requires documented consultation with a doctor. *Predictive* testing requires genetic counselling by a human genetics specialist prior to and after the investigation, or the patient's written renunciation.

Allocation

original patient's records in the responsible doctor's office; **copy**: please send with request and probe material to the investigating laboratory; **copy**: to patient itself