PG-E INFORMED CONSENT

## Genetic Laboratory Testing



Child         Surname:         Forenames:         Date of birth:         Place of birth:         Gender:	Material         EDTA blood:       []         Hepar. blood:       []         Other specimen:       []         Quantity:
Referring Paediatrician           Surname:           Forenames:           Telephone:           E-Mail:	Hospital*: Adress:
* if applicable By signing this form we declare that we have received comprehensive information regarding the genetic background related to the disease/ disorder in question, as well as the possibilities and limitations of genetic laboratory studies. We hereby request genetic analysis and testing: We hereby consent that results of the genetic analyses performed are being transmitted to the referring paediatrician, and in addition to the following physicians/ individuals: Surname: Forename: Hospital: Address: Hospital: Address:	<ul> <li>We would like to be informed about the results of the genetic analyses only insofar as practically relevant regarding the disease/ disorder in question. With regard to secondary findings we wish NOT to be informed.</li> <li>[]yes []no</li> <li>We would like to be informed about secondary findings as far as there are practical consequences for my child's and/ or our health, and treatment options.</li> <li>[]yes []no</li> <li>We consent to the storage of the samples for re-evaluation and quality management purposes as well as for further investigations – if necessary – and for scientific purposes in an encoded (pseudonymized) way.</li> <li>[]yes []no</li> <li>We have been informed, and agree that our personal data and the data obtained in the analysis will be recorded, evaluated or stored in an encoded (pseudonymized) way in scientific databases, and that further – in accordance with data protection and medical confidentiality – the request, or parts of thereof, may be transmitted to a specialised cooperating laboratory.</li> <li>We have been informed, and agree to the electronic storage, processing, use, and transmission of all data collected by Praxis für Humangenetik Tübingen/ CeGaT. For more datailed information on data privacy as well as your rights please refer to www.cegat.de/en/privacy-policy.</li> <li>We have been informed that we have the right to withdraw this consent, or parts of thereof, at any stage without giving reasons. We have been informed that we also have the right, not to be informed about test results at all (right not to know). We are aware that we have the right to halt the processing of the samples, and even demand them being discarded, at any time including all the results obtained hereofore.</li> </ul>
Mother of the child:	Physician:
Date Signatures of the child's parents	Date Signature