PG-E

INFORMED CONSENT



Genetic Consultation

Child Surname: Forenames: Date of birth: Place of birth:	Gender:
Mother Surname: Forenames: Date of birth:	Address*:
Place of birth:	Telephone :
Father Surname: Forenames: Date of birth:	Address*:
Place of birth:	Telephone :

* If different from the child

You have registered interest in an Online Genetic Consultation. We are happy to assist you with all questions you might have on genetic issues depending on your clinical symptoms, or the symptoms/features of your child respectively, your family history, and previous medical findings.

A genetic consultation and diagnostics is supposed to assist you in making informed choices concerning the disease/ disorder inquestion, your health or the health of your child respectively. To what extent genetic consultations and diagnostics may be helpful depends on the particular disease/ disorder and your personal specific questions. Both will define the topics in the consultation and the kind of genetic testing proposed. In the event of information being obtained during the consultation pointing to additional genetic issues you haven't yet been aware of, we will discuss with you your options. It remains your personal decision if and to which extent to proceed with a possible genetic diagnostic strategy.

Please notice that it is impossible to obtain information on all conceivable genetic disorders or diseases influenced by genetic factors respectively. It is equally not possible to assess or exclude all conceivable health risks for yourself, for family members and especially your children. In some cases no risk estimates or likelihoods can be given for a particular disease/ disorder, striking features in the appearance of an individual (phenotypic abnormalities) or a developmental delay/ intellectual disability. Even if chromosome analyes and further genetic testing were uneventful, a genetic cause can't be ruled out with certainty. In these instances, the genetic evaliuation and assessment is based on scientific publications, literature cases and the comparison with other, likewise affected individuals. This also means that in the case of a pregnancy, there are cases – even after extensive genetic diagnostics and testing as well as thorough literature search – there are no definitive answers on whether the child will be healthy or not.

Previous medical findings, clinical symptoms to date as well as the family history are a prerequisite for the genetic consultation and diagnostics.

A genetic consultation and diagnostics comprises usually:

- $\bullet\,$ the clarification of your personal reasons, motivation and purpose for the consultation,
- a structured medical and family history including,
- · an assessment and evaluation of all medical reports and results to date,
- an assessment of physical findings, and pictures taken for diagnostic purposes, if applicable
- initiating the genetic lab investigations/ testing,
- · an assessment of specific genetik risks,
- a detailed Medical Genetics Report with the relevant findings including all lab results explaining possible health consequences and/ or treatment options respectively.

Genetic diagnostics and testing will not be performed without your consent. It is your decision to make, and completely up to you whether to go ahead with the proposed genetic testing after the consultation. We understand that the relevance of proposed genetic strategies may depend on very personal factors. Equally, it remains your decision to which extent to take the advice given regarding the results of the genetic diagnostics. Genetic testing may reveal findings with no known health effects to date. We would communicate such findings only, if they were relevant for the enquiry/ your questions.

After completion of the genetic diagnostics you will be receiving a Medical Genetics Report with the most important topics of the consultation and the relevant findings including all lab results. Please don't hesitate to contact us should you have remaining questions.

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physicians/ indiv vant findings incl Surname:	ent that the referring physician/ specialist, and in addition the following iduals may receive a copy of the Medical Genetics Report with the releuding all lab results:	genetic testing may be s	data and photographes obtained in the consultation, and in the nared with colleagues/specialists in an encoded (pseudonymized) h data protection and medical confidentiality – if necessary for ire []yes []no
Hospital: Address: —		genetic testing may be s	data and photographes obtained in the consultation, and in the shared in an encoded (pseudonymized) way – in accordance with ical confidentiality – for training purposes of medical staff
Surname: Forenames: Hospital: Address:		ding genetic consultation Genetic Consultation. We hereby release my re	declare that we have received comprehensive information regar- n and diagnostics, and wish to make an appointment for an Online ferring physician and other treating physicians from confidentia- n advising on behalf of CeGaT GmbH.
Druckbuchstaben)		Physician: (Block letters)	
Date	Signatures of the child's parents	 Date	Signature