**Ein Bild, das Schrift, Grafiken, Text, Grafikdesign enthält.

Automatisch generierte Beschreibung**

Additional Genetic Findings in Minors

Informed Consent Material for Parents

It is possible that we discover findings that are not related to your child’s disease but to other, possibly inherited and/or hereditary characteristics. These are so-called **additional findings** that indicate a more or less strong predisposition to other diseases.

For some predispositions there are **preventive programs and/or treatment options**, but for others there are not. Some predispositions can alreadylead to a disease in **childhood**, some only in **adulthood**. If there are preventive programs and/ or treatment options for the respective disease, these can also be carried out in part during child- hood. If there are no preventive programs and/ or treatment options for the respective disease, knowledge about the predisposition to the dis- ease can be relevant for your child’s **life planning**. An additional finding can also reveal a so-called **disease carrier status**. This is not medical rele- vant for your child him- or herself but may be relevant for its offspring and siblings or for you as parents. In the case of the other categories of additional findings listed above, there is also the possibility that not only your child but also your- self or your child’s siblings may be affected by the possible disease. We will not actively search for additional findings, and there is no obligation to collect them.

**Types of additional findings:**

* Additional findings regarding diseases for which **preventive programs and/or treatment options** already exist in **childhood or adolescence**.
* Additional findings regarding diseases for which **preventive programs and/or treatment options** exist in **adulthood**.
* Additional findings regarding diseases that occur in **childhood or adolescence** and for which **neither** **preventive programs nor treatment options** exist.
* Additional findings regarding diseases that do **not occur until adulthood** and for which neither preventive programs nor treatment options exist.
* Additional findings regarding a **disease carrier status**.

**How do we deal with additional findings?**

* We will **always inform** you of additional findings concerning diseases that are **very likely** to occur and for which, according to the current state of medical knowledge, there are **successful preventive pro- grams and/or treatment options already in childhood**.
* Additional findings that are **relevant** to the **treatment** of your child’s **current condition** will **always be shared with you**.
* **If you wish**, we will also provide you with additional findings on diseases that are **very likely to occur** and for which, according to the current state of medical knowledge, there are **successful preventive programs and/or treatment options in adulthood** (e.g., familial breast and ovarian cancer).
* **If you so wish**, we will provide you with additional findings on the **disease carrier status** if such knowledge is useful for **yourself or other family members**.
* Furthermore, **if you wish**, we will provide you with additional findings on diseases that are **very likely to occur** **in childhood** but for which there are **no successful preventive programs and/or treatment options** according to the current state of medical knowledge, provided that these additional findings are relevant to **your child’s life planning**.

**We do not evaluate and communicate:**

* Genetic alterations that, according to the current state of science, are **not** associated with an **increased likelihood of disease**.
* Genetic alterations that are associated with a **disease** that is **not life-threatening** but have a **low probability** of causing that disease.
* Genetic alterations that have a **high probability** of leading to **disease in adulthood** but for which there are **no successful preventive programs and/or treatment options** based on current medical knowledge.
* Genetic alterations that are **highly likely** to be related to **childhood disease** for which there is **no successful screening and/or treatment** options and which are **not relevant to future life planning**.

**Consent Form**

I agree

that I would like to be informed of medically relevant findings about my child that are not related to his or her current illness and for which there are targeted *preventive programs and/or treatment options in adulthood.*

* yes

Additional findings regarding diseases for which **preventive programs and/or treatment options** exist in **adulthood**.

* I do not want to know details about the finding at this time but would like to be informed if there is a finding that will be relevant to my child at a later date.
* no. I disagree, I do not want to be informed about such findings.

I agree,

that I would like to be informed of medically relevant findings about my child that are not related to his or her current illness and which, according to the current state of scientific knowledge, are insignificant for my child him- or herself but which indicate hereditary diseases that may possibly be passed on to offspring or which may possibly be relevant for siblings or myself.

Additional findings on a **disease carrier status**.

* yes
* no. I disagree, I do not want to be informed about such findings.

I agree

that I would like to be informed of medically relevant findings about my child that are not related to his or her current illness, that are *important for my child’s or our family’s life planning,* and that are highly likely to lead to an illness still in childhood for which there are no *preventive programs and/or treatment options* according to the current state of knowledge.

* yes

Additional findings regard- ing diseases that occur in **childhood or adolescence** and for which **neither preventive programs nor treatment options** exist.

* no. I disagree, I do not want to be informed about such findings.