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| YOUR OWN LETTER HEAD |  |
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**Information sheet on the further processing of health-related personal data for research**

# Dear parent,

We hereby invite you to contribute to medical research.

# Background

Every hospital is required to make and store records for its outpatients and inpatients. This documentation contains health-related data collected during treatment (e.g. blood pressure readings, lab results, responses to questionnaires).

We would like to use all of these data for medical research once they are no longer needed for your treatment. For this reason, we ask that you consent to the use of these data for research purposes under strict conditions (compliance with the Human Research Act, data privacy). By doing so, you will be making a valuable contribution to advancements in medical research, and we thank you for this.

# Your rights

The release of data in encrypted or unencrypted form for further processing for research purposes is voluntary (the only exception is the further processing of your non-genetic personal information in anonymized form, which does not require your consent or approval by the cantonal ethics commission). No one will pressure or persuade you to do so in any way. If you opt to release the data and materials, you are entitled to withdraw your consent at any time. You are not required to disclose your reasons for refusing or revoking this release. Your decision will not affect your treatment.

If the findings from a research project are relevant to your child’s health and we are able to trace the data back to you, we will be pleased to inform you of these findings if you request this.

# Confidentiality and protection of your data

Your data is treated with strict confidentiality. This data is part of the hospital information system, which is highly secure and has strictly regulated access.

Your consent therefore permits research to be carried out using non-genetic data in unencrypted form. Only the few people working on the project and who absolutely need this data to carry out their work have access to this data. If requested, the non-genetic data can also be provided in encrypted/unencrypted form to third parties outside of the hospital for research purposes provided this is done in compliance with the applicable data privacy regulations.

In the case of encrypted data, we replace this information (e.g. name, age, address) with a code and provide only the code to the researchers. The key (the list that connects the code with the name) is kept under secure and strict safekeeping conditions at the Hospital. Researchers cannot link the data to your identity. This encryption can be removed in specific cases only, e.g. for the protection of your child’s health, your rights or when required by law.

1 of 2 / please turn over

# Support in research

The data is permitted to be provided for research purposes only. Research is permitted to be carried out only when approved by a cantonal ethics commission in accordance with the Human Research Act. We therefore make data available exclusively for approved research projects. These projects may lead to improvements in the treatment of future patients.

# Contact

Please contact your attending physician if you have any other questions concerning the further processing of data for research purposes or if you wish to revoke your consent.

Written revocation of your consent can be sent to the following address:

< Clinic Address >

page 2 of 2

**Declaration of consent**

for the further processing of non-genetic personal data in unencrypted form for research purposes.

Last name/

first name:

Date of birth:

I hereby consent to

* health-related non-genetic data about my child in encrypted or unencrypted form – made available through medical treatment or otherwise – being further processed for research purposes.

**Yes**

**No**

I acknowledge that

* I have received the clarification document accompanying this declaration of consent;
* I have been informed that my consent is voluntary;
* I have been sufficiently informed of the further processing of health-related data for biomedical research;
* I know that the non-genetic data can be used for research unless I revoke this consent;
* I know that I am permitted to revoke this consent at any time without providing a reason;
* I know that the data is protected;
* I know that the data may be passed on to third parties for research purposes.

I wish to be informed about the research findings if they provide conclusions about my child`s health and/or treatment.

**Yes**

**No**

Place, date, legally valid signature of the parent or his / her authorized representative: