
Information sheet for cord blood donation

Public Cord Blood Bank

Dear expecting mother, dear parents

You will soon give birth and you are considering donating your child's cord blood. This information sheet will tell you all you should know about the collection process for cord blood and storage of your child's cord blood in a public cord blood bank (CBB).

Introduction

The blood that remains in the child's umbilical cord and placenta after birth is known to contain a relatively large amount of potentially life-saving cells called blood stem cells. Blood stem cells from cord blood can be used for transplants to treat blood cancer (such as leukemia), other severe blood diseases or rare immunologic disorders. With a blood stem cell transplant, the patient's diseased blood and immune system is replaced by healthy new blood stem cells.

Cord blood can be collected from the umbilical cord and placenta after delivery of the child and clamping. This is a procedure which is safe for you and your child. Cord blood storage in a public cord blood bank makes the donated blood stem cells available for the treatment of all patients requiring blood stem cell transplantation worldwide. The probability that the donated cord blood will be used for a recipient depends on the unit's HLA characteristics and their compatibility with those of the recipient.

Storage of blood stem cells from cord blood has the following advantages

- The collection process is safe for mother and child
- Cord blood can be easily frozen and stored for a practically unlimited length of time (cryoconservation) without the cells losing their potential for later use
- Cord blood is rapidly available for treatment (transplantation)
- Blood stem cells from cord blood are less likely to cause transplant rejection than other types of blood stem cells, hence the necessity of compatibility (HLA-matching) between donor and recipient is less stringent than for blood stem cell transplantations with bone marrow or peripheral blood stem cells

However, the quantity of blood stem cells in a cord blood unit (CBU) is limited; therefore, cord blood is preferably used for children as the quantity may not be sufficient for a transplant in an adult.

Cord blood donation is voluntary, anonymous and non-remunerated.

Up until the birth of your child you are entitled to withdraw your consent to donate your child's umbilical cord blood.

As alternatives to the public CBBs, cord blood can be stored in a private or hybrid cord blood bank (hybrid banking is only possible from collections in Inselspital Bern). In these cases, it is your responsibility to take the necessary steps and you must bear the full costs for collection and storage of your cord blood yourself.

Requirements for donation

A medical evaluation is required before donation in order to ascertain the health of mother and child, and to assess donor eligibility and thus to protect the recipient from transmissible diseases.

This entails:

- Filling in a medical questionnaire on the state of health and medical history of the mother and father. The questionnaire also includes questions on known diseases or disorders in the family, which could be transferred to the recipient via the cord blood. The medical questionnaire should be filled in before the onset of active labour. A cord blood collection can only be performed if all the eligibility criteria are met
- Signing an informed consent form before cord blood donation

- Excluding transmissible viral or bacterial infections. For instance, it is mandatory to test for HI-Virus, Hepatitis-B- and -C-Virus and Syphilis (Screening-Tests)

However, in the initial period of an infection, an infectious disease may not be detectable and could be transmitted to the recipient of the cord blood stem cells. It is therefore of the utmost importance to mention any risk situation and fill in the medical questionnaire truthfully.

Should the screening tests reveal any abnormal results, you would be informed immediately. Of course, you have the right to view all the test results.

Apart from the usual screening tests mentioned above, samples of the maternal donor's blood and of the child's cord blood are stored for later analysis (such as haemoglobinopathy testing), which may be necessary in the context of transplantation. The haemoglobinopathy test is a genetic test. We kindly ask you to read the "Information Sheet on the Haemoglobinopathy Test".

All data collected in context with a cord blood donation are pseudonymised. "Pseudonymised" means that the name will be replaced by a pseudonym (generally a multi-digit letter or numeric code) to make it impossible to determine the identity of the person concerned. CBBs only can link the pseudonym to your and your child's identity. All data collected are stored in accordance to the current law as long as they are relevant for the security, quality and traceability of the CBU, but at least for the entire storage period which is set to indefinite. Only authorized personnel have access to the data collected, all of whom are bound to medical confidentiality.

How is cord blood collected?

The cord blood stem cells are collected from the residual blood, which remains in the placenta and the umbilical cord after delivery of the child and clamping. A minimum amount of cord blood is necessary for further processing and banking. Unfortunately this amount is not always reached.

The cord blood collection is performed by the qualified staff caring for the mother during delivery. The collection is performed under sterile conditions to minimise the risk of contamination and infection of the unit and in order to ensure the highest possible quality and safety of the future transplant product.

The care for mother and child always has first priority. A cord blood collection does not interfere with the birth process.

In rare cases, it may turn out that a planned cord blood collection is not advisable or not possible, notably in critical medical situations such as a premature delivery or an emergency.

Storage of the cord blood unit

The collection, processing and storage of cord blood units for public banking are performed according to the international quality standards of FACT-NetCord (International Standards for Cord Blood Collection, Processing, Testing, Banking, Selection and Release). In Switzerland, these standards are only implemented in a limited number of maternity units which is why cord blood collections for public banking are only possible in these clinics (see list below). The cord blood unit is then registered in the Swiss Transfusion SRC database and is available for patients worldwide.

Should the cord blood you donated not fulfill the quality requirements and therefore not be suitable for clinical use, it will either be discarded, or, in certain centers - with your consent - it can alternatively be used for quality control tests in the cord blood bank, or for scientific research projects.

By voluntarily donating your child's cord blood, you will transfer the ownership of the donated cord blood unit to the public cord blood bank.

Costs

You will bear no costs for the collection and storage of the donated cord blood in the public CBB.

Genetic tests on the recipient after transplantation

After transplantation, the recipient undergoes genetic testing in order to monitor the function of the transplanted blood stem cells, or - on the other hand - to follow the initial disease. In very rare cases, these tests could produce results that may be relevant for you or the child. You will be informed, if the CBB becomes aware of any such results and if the CBB is required to do so by law.

Duty to supply information post donation

Certain illnesses or infectious diseases, as yet unknown at the time of donation, can pose a risk for the recipient of a cord blood unit. Any health problems occurring in the perinatal period or later in your child's life could affect the quality of the unit and the safety of the future recipient. The cord blood bank must be informed of any such health issues. The parents are requested to contact the cord blood bank or the maternity unit should this case/situation arise.

To ensure reachability of parents / child in case of available test results, you are further requested to communicate any changes in contact details to the cord blood bank or the maternity unit.

List of clinics in Switzerland where cord blood donation for public banking is possible:

- [Kantonsspital Aarau](#)
- [University Hospital Basel](#)
- [University Hospital Bern](#)
- [University Hospital Geneva](#)

If you are considering a cord blood donation, these hospitals can provide further information.

The two public cord blood banks in Switzerland are located at the University hospitals of Basel and Geneva.

Link

https://www.blutspende.ch/de/blutstammzellspende/blutstammzellspender_werden/wenn_es_zur_spende_kommt/wie_spende_ich_blutstammzellen/nabelschnurblutspende



Consent to umbilical cord blood donation Public Cord Blood Bank

I consent to voluntarily donate my child's umbilical cord blood for storage in a public Cord Blood Bank (CBB). The blood stem cells from this cord blood can be used to treat a patient in Switzerland or abroad who needs a blood stem cell transplantation.

In particular, I confirm the following points:

- I have read the **Information Sheet for Cord Blood Donation – Public Cord Blood Bank** and understood its contents. I have had the opportunity to ask questions and all my questions have been satisfactorily answered. I have had enough time in which to reach a decision
- I am aware that the requirements and obligations stated in the Information Sheet (e.g. donor eligibility and notification of any changes in my health) are mandatory and I duly agree thereto
- I have been informed about the tests needed (in particular for communicable infectious diseases such as HIV, hepatitis B, C and E, and syphilis) and I consent to a blood sample being taken for this purpose between seven days before and seven days after delivery
- I consent to an umbilical cord blood sample being taken for HLA typing
- I have read the Information Sheet on the Haemoglobinopathy Test and understood its contents.
- I consent to a genetic test being performed on a sample from my child's cord blood, if needed before the umbilical cord blood is released to the transplant center, to confirm the presence or absence of haemoglobinopathy
- I have been advised of my right to access the test results
- I consent to notify the obstetric department of any relevant changes in my health that could affect my eligibility to donate. I undertake to inform the obstetric department immediately if I fall ill in the next few days or shortly after giving birth, or if a close contact or my child falls ill
- I also undertake to notify the CBB and/or obstetric department of any changes in health occurring later in my life or the life of my child that could affect the quality and safety of the stored cord blood unit (CBU) or that could potentially affect the recipient
- I have been informed that in the event of a transplant with the donated cord blood, some blood samples will be stored for long after the transplant in order to resolve any issues that may later arise concerning this specific transplant and that could be important for the recipient
- It has been explained to me that after a transplant the recipient will have genetic tests to monitor the growth of the transplanted blood stem cells or track the development of the original disease. In rare cases, these tests may yield results that could be relevant for my child or me. The CBB will inform me if it learns of such test results and is required to do so by law
- To ensure reachability of parents / child in case of available test results, parents are requested to communicate any changes in contact details to the cord blood bank or the maternity unit.
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- I consent to Swiss Transfusion SRC Inc. and its accredited laboratories using the sample material and HLA data for the purpose of statistical analysis of population variability in HLA and of the distribution of the various HLA combinations. My data will be anonymized when used for this purpose. Such studies involve no risks for me and my child
- I am aware that up until the birth of my child I am entitled to withdraw my consent to donate my child's umbilical cord blood
- I am providing my child's blood stem cells free of charge
- In voluntarily donating my child's umbilical cord blood, I agree to transfer ownership of the CBU donation to the Public CBB
- I consent to my and my child's pseudonymized data being entered into the Swiss Transfusion SRC Inc. database. Only authorized personnel have access to the collected data, all of whom are bound to medical confidentiality.

Swiss Transfusion SRC is subject to the Swiss Federal Act on Data Protection (FADP). I have been informed that pseudonymized data relating to both my child and me will be used in connection with the search for an unrelated cord blood donor for patients both nationally and internationally, i.e. including in countries that do not have data protection legislation comparable to that of Switzerland and in which data protection is not ensured to the same degree. This data includes a cord blood identification number, information about my state of health and about the child's sex, date of birth and tissue markers. I can find more information on data protection at www.blutstammzellspende.ch/de/datenschutz-blutstammzellspende (QR Code: see below). If I have any questions, I can also contact datenschutz@blutspende.ch at any time.

Further information on the data protection provisions:





I have understood all the above information. I consent to donating my child's cord blood for storage in the Public CBB. In particular, I consent to the harvesting, processing, analysis and long-term storage of the CBU along with the associated data and documentation. Furthermore, I consent to the transmission of the personal data specified above to international recipients for the purposes described.

Yes No

I consent to my child's blood stem cells being used, identified only by a pseudonym, for the following purposes if unsuitable for transplant storage:

- Research (with the approval of the competent institutional review board)

Yes No

- Quality control in the CBB

Yes No

Mother:

Surname: First Name:

Date of birth (dd mm yyyy):

Date: Signature:

Father (optional):

Surname: First Name:

Date: Signature:

Attestation by medical personnel trained in cord blood donation:

I attest that I have explained the nature and importance of a cord blood donation to the mother.

Surname: First Name:

Date: Signature: