

Information on Public Cord Blood Donation

Dear expectant mother, dear parents,

Your child will soon be born, and you are considering a voluntary umbilical cord blood donation. Here we would like to explain how an umbilical cord blood donation works and what happens with the umbilical cord blood after donation.

On the following pages, we address the expectant mother directly, as she is the potential donor of the umbilical cord blood.

What is umbilical cord blood?

Umbilical cord blood is the blood that remains in the umbilical cord and placenta after a baby is born. During pregnancy, it provides the baby with important nutrients. Although it is often discarded as medical waste after birth, umbilical cord blood contains valuable cells that can be used to treat serious diseases.

Why is cord blood important and what is it used for?

Your cord blood donation can save lives! Cord blood is regularly used for blood stem cell transplantation and is stored in public cord blood banks for this purpose.

Blood stem cell transplantation

Cord blood contains many blood stem cells, which can form all types of blood cells. Healthy blood stem cells can replace sick blood cells and can be used to treat serious blood diseases such as leukemia (blood cancer) or immune system disorders. Blood stem cells from cord blood are an important alternative to stem cells from bone marrow and can give patients a chance for a cure.

Other clinical uses

The full potential of cord blood is not yet known and is currently being researched. In the future, cord blood could also be used for other medical treatments. For this, your additional consent would be required. The cord blood bank would inform you, and you could freely decide whether your cord blood can be used for other clinical purposes. You can choose whether the cord blood bank may contact you in the future if new clinical uses for your cord blood become available.

This information sheet refers only to the use of cord blood for blood stem cell transplantation.

How does the donation work?

If you and your baby are doing well after birth, a trained professional will collect the blood from the umbilical cord and placenta into a special bag. Cord blood is usually collected before the placenta is delivered, but collection after the placenta is delivered is also possible. After collection, the cord blood is sent to a public cord blood bank in Switzerland. There, it is processed, frozen, and safely stored until use. The use is anonymous, which means you will not know anything about the recipient, and the recipient will not know your or your child's identity.

What are the risks and benefits of a cord blood donation?

Collecting cord blood is safe. It does not affect the birth process, your health, or your baby's health.

The amount of blood taken for testing is small and does not affect your health. There is a small risk of mild pain, bruising at the puncture site, dizziness, and in rare cases, infection.

Although you do not directly benefit from the donation, you can help future patients and possibly save a life.

Is every cord blood donation collected and stored?

The requirements for a cord blood donation are very high. Therefore, not all donations can be carried out.

In certain situations – such as premature birth, multiple births, or medical emergencies – donation may not be possible. In rare cases, staff shortages may also mean that a donation cannot be carried out or processed.

For a donation to be suitable for medical treatment, it must meet strict quality criteria, such as containing enough blood stem cells. Only donations that meet all requirements are stored in public cord blood banks and made available for possible life-saving treatment.

What documents and blood tests are needed for a cord blood donation?

Cord blood donation is a voluntary decision that requires your consent. You can choose whether or not to donate. Your medical care will not be affected by your decision.

If you decide to donate, the most important steps are as follows:

1. The consent form

- Before birth, you will sign a consent form for cord blood donation, confirming that you agree to the donation and the contents of this document.
- You can withdraw your consent at any time before collection, without giving a reason and without any negative consequences.
- Additional document: *Consent to umbilical cord blood donation to a public cord blood bank*

2. The questionnaire about your health

- You will need to complete a questionnaire about your health and family history. This ensures that the cord blood is safe for patients.
- **It is important that you answer all questions truthfully to protect the health of the patients.**
- The collection will only take place if you and your baby are healthy and eligible to donate.
- Additional document: *Questionnaire for umbilical cord blood donation*

3. Blood tests for infectious diseases

- Your blood will be tested free of charge for transmissible diseases such as HIV, hepatitis, and syphilis. The tests are done in accredited laboratories within Switzerland.
- You have the right to access all test results and will be informed if any abnormalities are found.
- Please **inform us before birth about any possible risk situations that could cause an infection, such as HIV**. This is the only way we can guarantee the safety of the donated cord blood and protect the health of the patient.
- Before a blood stem cell transplant, additional tests for infectious diseases may be performed. For this purpose, some of your blood samples will be stored in a frozen state.

4. (Genetic) tests from the cord blood

- The blood type, cell count, and HLA tissue types will be determined.
- Additional tests may be performed before a transplant.
- Before a transplant, a genetic test (haemoglobinopathy test) is always performed. You can only donate cord blood if you agree to this test.
- Additional document: *Information Sheet on the Haemoglobinopathy Test*

How long is cord blood stored?

The cord blood and all related samples are frozen and stored as long as needed for the planned medical purpose – provided that the quality criteria defined by the cord blood bank are met. After a transplant, blood samples are stored for 10 years so they can be used to answer important patient-related questions if needed.

What happens with my personal data?

Your personal data is encrypted, which means your name is replaced by a code. This code allows communication with partner institutions. Only authorized staff at the maternity hospital and the cord blood bank can decode your identity. They are bound by professional confidentiality and may not share confidential information.

Personal data about you and your child is treated strictly confidentially. Only authorized personnel have access to unencrypted data. Your data is stored according to legal retention requirements – at least as long as the cord blood is stored. This ensures the quality and safety of the cord blood.

The cord blood bank may contact you regarding important matters.

All collected data is recorded, stored, processed, and retained in accordance with the Swiss Federal Data Protection Act (DPA) and the Data Protection Ordinance (DPO).

Swiss Transfusion SRC (Blutspende SRK Schweiz AG) and its authorized laboratories also use the samples and HLA data to evaluate how frequently certain HLA types occur in Switzerland. For this purpose, your data is used in anonymized form.

Encrypted data about you and your child may also be analyzed statistically by the cord blood bank.

Where can I donate cord blood?

In Switzerland, there are public cord blood banks in Basel and Geneva. These banks meet the highest international quality standards, are NetCord-FACT certified, and work exclusively with the following maternity hospitals:

- Cantonal Hospital Aarau
- University Hospital Basel
- University Hospital Bern
- University Hospital Geneva

A donation of cord blood to a public cord blood bank is therefore only possible at these hospitals.

How much does a cord blood donation cost?

Donating cord blood to a public cord blood bank is free of charge. You will not receive any payment for your donation.

Who owns the cord blood after donation?

After donation, the cord blood belongs to the public cord blood bank that stores it. By signing the consent form, you transfer ownership of your cord blood so that it can be used for transplants.

What is the difference between public, private, and hybrid cord blood banks?

Cord blood stored in public cord blood banks is intended for patients worldwide, not for private use. The public banks are located at University Hospitals in Basel and Geneva. The encrypted donation data is entered into the donor registry, a database operated by Swiss Transfusion SRC, which can be accessed by transplant centers worldwide. This allows patients around the world to receive your life-saving donation.

Alternatively, private or hybrid cord blood banks store cord blood for use within your family. If you choose the private option, you are responsible for organizing the collection and storage and for covering the costs. We recommend obtaining independent information if you are interested in this option.

What happens if the cord blood is not suitable for medical treatment?

We make every effort to process each cord blood donation and store it in the public cord blood bank for therapeutic use. Unfortunately, not all donations meet the high requirements.

Please indicate on the consent form what should happen to your donation if it is not suitable for therapeutic use. The following options are available:

- Use for **quality control** in the cord blood bank.
Your donation helps to monitor and maintain the high quality standards in the maternity hospital and cord blood bank. No genetic testing will be performed.
- Use for **research**
Your donation may be used for approved research projects, for example, to develop new cell therapies that can be used to treat serious diseases. All data and samples will be used in encrypted form.
Additional document: Information on the use of health-related data and samples
- **Disposal** of the donation
If you do not agree to the use of your data and samples for quality control and/or research, all samples related to the cord blood donation will be properly disposed of, and no health-related data will be analyzed.

What happens after a cord blood transplant?

After a blood stem cell transplant, genetic tests are performed on the patient to monitor the success of the transplant and the recovery. Very rarely, these tests may reveal information that could be important for your child. In this case, the cord blood bank will inform you.

What are my responsibilities after donation?

To protect the health of the patient, you must inform the cord blood bank if:

- You were ill at the time of donation or shortly afterwards.
- Your baby becomes ill shortly after birth.
- You or your child should develop a serious illness later in life.

To allow us to contact you if test results are relevant, please also inform the cord blood bank of any changes to your contact information.

How can I contact the cord blood bank?

If your child was born in Aarau, Basel, or Bern, please contact:

	<p>Cord Blood Bank Basel Universitätsspital Basel Petersgraben 4 4031 Basel E-Mail: cbb@usb.ch Website: usb.ch/cbb</p>	
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If your child was born in Geneva, please contact:

	<p>Banque de Sang foeto-placentaire de Genève Hôpitaux Universitaires Genève Rue Gabrielle- Perret- Gentil 4 1211 Genève 14 E-Mail: hematopoiese.laboratoire@hug.ch</p>
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Where can I find more information?

You can get **information about public cord blood donation** and its alternatives from the public cord blood banks, the maternity hospitals, and the donor registry of Swiss Transfusion SRC.

If you have questions about public cord blood donation, the staff at the maternity hospitals will be happy to help.

If you have questions about **data protection**, you can contact Swiss Transfusion SRC at: datenschutz@blutspende.ch

Cord Blood Bank Basel	Banque de Sang foeto-placentaire de Genève	Swiss Transfusion SRC	Data protection
			
Cantonal Hospital Aarau	University Hospital Basel	University Hospital Bern	University Hospital Geneva
			