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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

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- 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.

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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

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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 no 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:

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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: .....

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Medical Questionnaire
Umbilical Cord Blood Donation

You have read the **Umbilical Cord Blood Donation Information Sheet** and would like to become a cord blood donor. Thank you for providing truthful answers to the following questions by checking the requisite boxes. You will be helping to keep safe not only yourself but also the patients who will be receiving your child's cord blood. The questions concern you, the child's mother. Where information about the child's father, siblings (brothers and sisters) or other relatives is required, it will be specifically mentioned.
At the end of the questionnaire (section D) there is space for further information, comments on individual questions or other relevant information.

A. CHILD'S MOTHER'S DETAILS

Surname	
First name	
Date of birth	
Street	
ZIP / City	
Phone / E-Mail	

B. PARENTS' ETHNICITY DETAILS

Which ethnic group do you belong to? Please check.

African	AFNA	North Africa	Child's mother ☐	Child's father ☐
	AFSS	Sub-Saharan Africa	Child's mother ☐	Child's father ☐
Asian	AS	Central Asia: Russian Far East, Kazakhstan, Uzbekistan, Kyrgyzstan, Tajikistan	Child's mother ☐	Child's father ☐
		North-East Asia: Japan, North and South Korea	Child's mother ☐	Child's father ☐
		Oceania: Pacific islands except Japan, Australia, New Zealand, Taiwan, Aleutian Islands	Child's mother ☐	Child's father ☐
		South-East Asia: China, Mongolia, Myanmar, Laos, Cambodia, Thailand, Vietnam, Taiwan	Child's mother ☐	Child's father ☐
		South-West Asia: Middle East, Turkey	Child's mother ☐	Child's father ☐
		South Asia: India, Pakistan, Bangladesh, Sri Lanka, Bhutan, Nepal	Child's mother ☐	Child's father ☐
Caucasian	CAU	Europe, Greenland, Iceland, Russia, Australia, New Zealand, North America (USA, Canada)	Child's mother ☐	Child's father ☐
Hispanic	HI	Central America, South America, Caribbean	Child's mother ☐	Child's father ☐
Mixed	MX		Child's mother ☐	Child's father ☐
Other	OT		Child's mother ☐	Child's father ☐
Unknown	UK		Child's mother ☐	Child's father ☐

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C. HEALTH QUESTIONNAIRE

			Yes	No
1.	a)	Were you and/or the baby's father adopted as a child?	☐	☐
	b)	Did you become pregnant using donor eggs or donor sperm, or as a surrogate mother?	☐	☐
	c)	Do you know or can you find out the medical history of the child's father?	☐	☐
2.		Have you been ill in the last 4 weeks or had a fever over 38.5°C? If so, please specify the cause (if known)	☐	☐
3.	a)	Have you taken medication during your pregnancy (e.g. tablets, injections, suppositories)? Please specify	☐	☐
	b)	In the last 3 years have you taken Acitretin (Neotigason® / Soriatane®), e.g. for psoriasis?	☐	☐
4.	a)	Have you ever received immunotherapy (e.g. medication derived from human or animal plasma, cells or serum)? If so, please specify	☐	☐
	b)	Have you been vaccinated in the last 4 weeks against any of the following? Flu ☐ Hepatitis B ☐ Whooping cough ☐ ☐ Tetanus ☐ Rabies ☐ Other vaccination(s) ☐ ? Please specify German measles..... When?	☐	☐
5.		Do you have or have you had any of the following illnesses or symptoms? If so, please specify (diagnosis, date, treatment, stating whether resolved or still present)	☐	☐
	a)	High blood pressure before or during pregnancy (e.g. pre-eclampsia, HELLP syndrome):	☐	☐
	b)	Cardiovascular disease:	☐	☐
	c)	Respiratory disease:	☐	☐
	d)	Gastrointestinal disease:	☐	☐
	e)	Kidney, bladder and urinary or genital tract disease:	☐	☐
	f)	Neurological disease:	☐	☐
	g)	Immune system disease (e.g. allergy, chronic inflammatory disease, autoimmune disease):	☐	☐
	h)	Infectious disease:	☐	☐

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		Yes	No
i)	Contact with a person with a contagious or infectious disease? Which disease? ..... Date	☐	☐
j)	Blood disease:	☐	☐
k)	Cancer:	☐	☐
l)	Diabetes: Type I ☐ Type II ☐ Gestational ☐	☐	☐
m)	Thyroid disease: Hashimoto's thyroiditis ☐ Hyperthyroidism ☐ Other ☐ Please specify: ..... Treatment? ..... From when to when?	☐	☐
n)	Other disease:	☐	☐
6.	In the last 12 months have you had:	☐	☐
a)	An accident ☐ Surgery ☐ If so, please specify:	☐	☐
b)	A blood transfusion (e.g. packed red cells, platelet concentrate, plasma)? If so, when? ..... Why? ..... In which country?	☐	☐
7.	Creutzfeldt-Jakob disease risk		
a)	Have you or a blood relative been found or suspected to have Creutzfeldt-Jakob disease? Child's mother ☐ Child's father ☐ Other relative ☐	☐	☐
b)	Have you ever had a human tissue transplant? If so, please specify:	☐	☐
c)	Have you ever had an animal tissue transplant? If so, please specify:	☐	☐
d)	Have you ever had brain or spinal cord surgery? If so, please specify:	☐	☐
8.	Tropical virus risk (including Chikungunya, Dengue, West Nile and Zika virus)		
a)	Have you traveled outside Switzerland in the last 6 months? If so, where? ..... When did you get back? ..... Did you have symptoms (e.g. fever) during your stay or have you had any since your return?	☐	☐
b)	During your pregnancy were you ever diagnosed with Chikungunya, West Nile or Dengue infection?	☐	☐
c)	Have you or your partner been diagnosed with Zika infection in the last 4 months?	☐	☐

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			Yes	No
9.		Malaria risk		
	a)	Have you ever had malaria? If so, when?	☐	☐
	b)	Have you visited a malaria risk area in the last 3 years? If so, where? ..... When?	☐	☐
10.		Chagas disease risk		
	a)	Have you ever had Chagas disease?	☐	☐
	b)	Were you or your mother (the child's grandmother) born or raised outside Europe or have you lived outside Europe for more than 6 months? If so, which or both of you? ..... In which country?	☐	☐
11.		Have you ever had:	☐	☐
		☐ Tuberculosis ☐ Lyme disease ☐ Brucellosis ☐ Osteomyelitis ☐ Q fever ☐ Toxoplasmosis ☐ Babesiosis ☐ Leishmaniasis If so, when?	☐	☐
		Does any close contact (e.g. carer or member of the same household) have open tuberculosis?	☐	☐
12.		In the last 2 months have you had:	☐	☐
		☐ A tattoo ☐ Gastroscopy / colonoscopy ☐ Acupuncture ☐ Permanent make-up ☐ Piercing ☐ Microblading ☐ Contact with another person's blood (via needle stick injury or splatter in the eye, mouth or other) If so, when? ..... Were sterile instruments used? ☐ Yes ☐ No	☐	☐
13.	a)	Have you ever had jaundice or hepatitis? If so, please specify: Hepatitis A ☐ B ☐ C ☐ E ☐ Jaundice:	☐	☐
	b)	Has your partner had hepatitis or jaundice in the last 12 months? Please specify: Hepatitis A ☐ B ☐ C ☐ E ☐ Other:	☐	☐
14.	a)	Have you spent at least 6 of the last 12 months in a country with a high HIV rate? If so, where?	☐	☐
	b)	Did you incur a risk of HIV during your stay (e.g. through sex or medical or paramedical procedures such as blood transfusion, tattooing or piercing)?	☐	☐

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		Yes	No
15.	Do one or more of the following risk situations apply to you?	☐	☐
a)	Change in sexual partner in the last 4 months	☐	☐
b)	Sex in exchange for money, drugs or medicaments in the last 12 months	☐	☐
c)	Sex with a partner who had had sex with men in the previous 12 months	☐	☐
d)	Intravenous drug use in the last 12 months	☐	☐
e)	Positive test for HIV, syphilis or hepatitis C	☐	☐
16.	In the last 12 months have you had sex with partners who have:	☐	☐
a)	incurred any of the risks itemized in Question 15?	☐	☐
b)	had a blood transfusion in a country with a high HIV rate?	☐	☐
c)	incurred any other HIV risk (e.g. through sex, tattooing or piercing) in a country with a high HIV rate?	☐	☐
17.	In the last 12 months have you had symptoms of, or been treated for, chlamydia, genital herpes, syphilis, or any other sexually transmitted disease? Please specify:	☐	☐
18.	Do any of the following diseases run in your family? If so, please indicate their relationship to the child	☐	☐
a)	Red blood cell disease (e.g. thalassemia, sickle cell anemia etc) Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐
	Aplastic anemia Child's father ☐ Child's sibling ☐	☐	☐
b)	Platelet disease (e.g. immune thrombocytopenia purpura) Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐
c)	Genetic bleeding disorder (e.g. hemophilia, von Willebrand disease, factor V Leiden mutation) Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐
d)	Metabolic and lysosomal storage disease (e.g. cystic fibrosis, gout, Tay-Sachs, Fabry's disease, Gaucher's disease, Niemann-Pick disease) Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐
e)	Diabetes type I: Child's father ☐ Child's sibling ☐ Diabetes type II: Child's father ☐ Child's sibling ☐	☐	☐
f)	Congenital or acquired immunodeficiency Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐

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		Yes	No
g)	Malignant blood disease (e.g. leukemia, multiple myeloma, myelodysplastic syndrome, essential thrombocythemia etc.) Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐
h)	Cancer Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐
i)	Other disease Please specify ..... Child's father ☐ Child's sibling ☐	☐	☐

D. COMMENTS ON THE QUESTIONNAIRE (Mother)

Question: .....

.....

Question: .....

.....

Question: .....

.....

Question: .....

.....

Question: .....

.....

I confirm that my personal details are correct and that I have been truthful in completing the questionnaire

Mother

Surname: .....First name: ..... Date of birth: .....

Date: .....Signature: .....

Father (optional)

Surname: .....First name: ..... Date of birth: .....

Date: .....Signature: .....

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Questionnaire review by qualified staff

E. TO BE COMPLETED AT RECRUITMENT

Comments on Section C “Medical Questionnaire”:

Question: .....

.....

.....

Question: .....

.....

.....

Question: .....

.....

.....

Question: .....

.....

.....

Questionnaire reviewed (at recruitment): Date: ..... Signature .....

Maternity Unit (please check):

Aarau: ☐ Basel: ☐ Bern: ☐ Geneva: ☐ Tessin: ☐

F. TO BE COMPLETED AT UMBILICAL CORD BLOOD COLLECTION

Having reviewed the pregnant patient’s medical questionnaire and medical history, I hereby certify that there is currently no physical evidence of present or past HIGH RISK BEHAVIOR for communicable infectious disease (HIV, HTLV, hepatitis B or C, or sexual communicable disease). Based on the documentation / medical history available to me, I confirm that this donor is able to donate her baby’s umbilical cord blood at birth. Should fresh health information emerge that could impact this donation, I undertake to forward it to the umbilical cord blood bank.

Physician:

Surname: ..... First name: .....

Date: ..... Physician’s signature: .....

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Information Sheet on the Haemoglobinopathy Test

What are haemoglobinopathies?

Haemoglobinopathies are diseases caused by disorders of the red blood pigment (haemoglobin) in red blood cells. Haemoglobinopathies are usually inherited diseases and result in disease patterns of variable severity depending on the specific genetic defect involved.

The World Health Organization (WHO) estimates that about seven per cent of the world's population carry a gene mutation that manifests clinically as a haemoglobinopathy. According to WHO estimates, around 300,000 to 500,000 children are born with a severe form of haemoglobinopathy every year.

Several different diseases make up the group of haemoglobinopathies, the most significant of these being the **thalassaemias** and **sickle cell disease**. These are inherited diseases.

Why might a haemoglobinopathy test be necessary in connection with cord blood donation?

Blood stem cell transplants are sometimes used to treat severe forms of these diseases, so it is important that the frozen cord blood units be tested for these diseases before their use. This can be done with a haemoglobinopathy test, which is a genetic test that indicates whether someone has a a genetic disposition for these diseases.

These genetic tests need not be performed on all frozen umbilical cord units, but only on those that match a particular patient according to the tissue typing results. Thus, they are performed only at the time when the frozen umbilical cord unit is requested for transplantation. Haemoglobinopathy testing can yield results that are of significance for your child and your child's descendants. There is no need to take an additional blood sample for this test. It can be performed using a sample stored for this purpose at the time of donation. The test would not involve any costs for you.

The samples are preserved and examined in accordance with current scientific and technological standards.

What does this haemoglobinopathy test mean for my child and for me?

We distinguish between two forms of thalassemia and sickle cell disease:

1. **Affected persons** (homozygous^{+}) usually produce only abnormal haemoglobin. This results in severe medical conditions. Affected persons need regular and lifelong medical assistance.
2. **Carriers** (heterozygous*) have both normal and abnormal haemoglobin. Under normal circumstances, this will not affect the structure of their red blood cells and the disease will not become manifest. However, carriers can pass on the defect to their children. When a carrier has a child with someone who is also a carrier, there is a chance that the child will inherit a severe form of the disease.

What happens if the results of the haemoglobinopathy test are abnormal?

1. If your child is **not** capable of judgement at the time of the test (we will assume this to be the case if your child has not yet reached the age of 14)

and is an affected person:

Due to the significance that this result has for the health of your child and of your child's descendants, the law requires us to notify you of the result and requires you to acknowledge it. You will be offered a genetic counselling from a medical specialist after receiving the results. This genetic counselling would not involve any costs for you.

and is a carrier:

Although this result is not of direct significance for the health of your child, it may be of significance for your child's descendants. When the test is requested, you will be asked whether you wish to be notified if the test reveals that your child is a carrier. You will have the option of genetic counselling from a medical specialist at the time of the test as well as after receiving the results. This genetic counselling would not involve any costs for you.

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2. If your child is **capable** of judgement at this time (we will assume this to be the case if your child is 14 years old or older)

Your child will receive the required information about haemoglobinopathies at the time of the test. Directly thereafter, your child will decide whether he or she wishes to be notified of the test results. Children capable of judgement are entitled to decide for themselves as to whether they wish to know the results. They have a right "not to know", even if the result is of significance for their own health. Your child will have the option of genetic counselling from a medical specialist at the time of the test as well as after receiving the results. This genetic counselling would not involve any costs for you and/or your child.

Unfortunately, a cord blood donation will not be possible if you do **not** consent to a genetic test of this kind.

[+]homozygous: homozygous individuals have the gene defect in both genes.

*heterozygous: heterozygous individuals have the gene defect in only one gene.