

# Cord Blood Donation





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## UMBILICAL CORD BLOOD DONATION

The stem cells found in umbilical cord blood can be used for stem cell transplants, for people with leukaemia, for example.

That's why your midwife or gynaecologist has asked you to consider donating cord blood after delivery.

In this brochure, you can learn more about cord blood donation. The brochure is accompanied by a questionnaire and consent form.





### **Sanquin Umbilical Cord Blood Bank**

The first successful umbilical cord blood transplant took place in 1988. Since then, umbilical cord blood banks have been established all over the world. There have been more than 35,000 successful transplants using stem cells from umbilical cord blood worldwide. In the Netherlands, the national Umbilical Cord Blood Bank was established in 1994. This later became the Sanquin Umbilical Cord Blood Bank (CBB). The CBB is a non-profit public umbilical cord blood bank.



## WHAT IS UMBILICAL CORD BLOOD?

Umbilical cord blood contains blood-forming stem cells. These stem cells are the foundation for forming cells for our blood and immune system. Normally, umbilical cord blood is discarded along with the placenta after delivery.

Why donate umbilical cord blood?

Unfortunately, not every patient with a life-threatening illness has a matching stem cell donor available. In that case, umbilical cord blood is a good alternative. The stem cells from umbilical cord blood can be used for stem cell transplants, giving people with serious blood diseases such as leukaemia a chance of recovery. The donated umbilical cord blood can also be used for patients who need a different form of cell therapy. The cells from umbilical cord blood are then used to create a drug. If you decide to donate your child's umbilical cord blood, the stem cells will be stored in an international donor bank. The stem cells can then be used for the treatment of a patient. Dutch patients obviously also benefit from this.





## DONATING UMBILICAL CORD BLOOD IN STEPS

## Step 1

Congratulations, you're pregnant! From 20 weeks of pregnancy, the midwife or gynaecologist will ask if you would like to donate umbilical cord blood.

## Step 2

Yes, I would like to donate umbilical cord blood.
You can sign up from 20 weeks of pregnancy until the end of your pregnancy. Complete the questionnaire and sign the consent form. Submit the form to the midwife or gynaecologist as soon as possible!

## Step 3

After giving birth.

After your baby is born and the umbilical cord has been clamped, the umbilical cord blood will be collected. Some blood samples will also be taken from you. The umbilical cord blood will be transported to the Umbilical Cord Blood Bank as soon as possible. An employee from the CBB will assess the cord blood

- → Suitable: The umbilical cord blood will be processed and stored in the bank.
- → Not suitable: The umbilical cord blood will be used for scientific research.
- → Not suitable and no permission for scientific research: The umbilical cord blood will be destroyed.

#### Step 4

Up to 6 months after giving birth.

If the umbilical cord blood is suitable for patient treatment, you will receive a postpartum questionnaire and return envelope after giving birth. Complete and return the questionnaire to Sanquin in the enclosed return envelope. Sanquin will review the questionnaire. No irregularities? The stem cell product will be made available for patient treatment.

Good to know: no digital versions of the questionnaire, consent form or postpartum questionnaire are currently available. As soon as they become available, they can also be submitted digitally.



## HOW UMBILICAL CORD BLOOD DONATION WORKS

#### Before the birth

If you would like to donate umbilical cord blood, please complete the questionnaire and consent form provided with this brochure. You can submit the signed set of forms to the midwifery practice or hospital.

It is important for us to have a good understanding of your health and that of the biological father of the child. Therefore, we ask questions about your medical and obstetric history. For example, we want to know if you or the biological father of the child is a carrier of an inherited disease because we want to eliminate the risks of transmitting diseases as much as possible.

In the consent form, we ask you to agree to blood tests and the long-term storage of data and blood samples. The stem cell product can be stored indefinitely. We will inform you if any significant findings emerge from the blood tests that are relevant to your or your child's health.

#### Good to know:

You can still decide not to donate umbilical cord blood up to and including the birth.

### **During the birth**

The umbilical cord blood is collected after the birth of your child, after the cord has been cut. This is entirely painless and without risk. The health of you and your newborn always takes precedence, so the obstetric process is not disturbed. You and your midwife decide on the exact moment of donation and takes place at a suitable time between birth and afterbirth. Donation does not necessarily need to start immediately after birth. It is possible to wait a few minutes before collecting the cord blood.

The cord blood is collected in a special bag. A small piece of the umbilical cord is sent to the Umbilical Cord Blood Bank. Several tubes of blood are also taken from you to test for infectious diseases. Some of this blood is stored in case additional tests are needed later. If any abnormalities are found during the blood tests, we will notify you immediately. Sometimes it is necessary to donate blood again for more extensive testing.

Good to know: If any problems arise during delivery, umbilical cord blood will not be collected.



#### After the birth

At the Umbilical Cord Blood Bank, it is assessed whether your donation is suitable for treating patients. If so, the umbilical cord blood is processed and stored in the international donor bank. If the umbilical cord blood is not suitable for stem cell transplantation or the manufacture of medication, it can be used for scientific research in recognised research institutes.

Research can further improve the quality of umbilical cord blood transplants. New treatments for diseases can also be discovered or researched on how certain diseases can be better detected. Sometimes a sample of maternal blood is needed for this research.

Direct use can be made of the cells from umbilical cord blood during scientific research, or cell lines can be made from the cells from the umbilical cord blood. In making cell lines, the cells are modified so that they can continue to divide and multiply indefinitely, making them theoretically immortal.

#### Good to know:

On the questionnaire and consent form, you can indicate what you do and do not consent to. If the umbilical cord blood is not suitable for treating patients, and you have not given consent for scientific research or the creation of cell lines, the umbilical cord blood will be destroyed.

If the umbilical cord blood is suitable for treating patients, you will receive a questionnaire about your and your child's health within six months of collection. Based on your answers, we can then determine if the umbilical cord blood can be used safely.

If your child has a serious illness or inherited disorder in the future, please let us know. This is important information for us.

Sanquin stores the donated umbilical cord blood until it is needed by a patient with a suitable profile somewhere in the world. The umbilical cord blood is then additionally tested for certain inherited disorders (hemoglobinopathies). You will immediately be informed if there are any special circumstances.



## PRIVACY & COMPENSATION

All data relating to you and your child, as well as the results of blood and umbilical cord blood tests, are treated in the strictest confidentiality. Data is only accessible to designated Sanquin employees and legal entities (such as the GGD) to which the Umbilical Cord Blood Bank reports. We adhere to applicable laws and regulations. The donated material and medical data are shared with doctors and researchers without disclosing the identity of you or your child. The donated material and medical data are labelled with a code, so the recipient or research institute cannot identify its origin from you or your child.

## **Costs and compensation**

As with regular blood donations, the donor does not receive compensation. Sanquin incurs costs for processing and storing the materials. The midwife receives a small compensation for the costs incurred for collection. If a stem cell product is supplied from our stem cell bank, the requester pays a fee for it.

## **Transfer of stem cell products**

If Sanquin decides to close the Umbilical Cord Blood Bank in the future, we are legally obliged to transfer the stem cell products to another non-profit public umbilical cord blood bank. Careful transfer with the corresponding protection of your data is guaranteed in this regard.







When can you not donate umbilical cord blood?

- If you do not wish to be informed of the results of blood tests that are important for the health of you or your child.
- If you do not agree to the indefinite storage of data and blood from you or your child.
- If your pregnancy was achieved through egg donation.
- If the information about the biological father of your child is unknown, unless sperm is donated through a recognized sperm bank.
- If you or the biological father of the child has a disease or condition that can be transmitted through umbilical cord blood.



Do you have any questions after reading this brochure? Please contact the midwife, the gynaecologist, or the Umbilical Cord Blood Bank of Sanquin.

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