

Cord blood banking: information for parents



Royal College of
Obstetricians and
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Setting standards to improve women's health

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Key points

- Cord blood is the baby's blood that remains in the placenta and umbilical cord after birth.
- Cord blood contains stem cells.
- Blood stem cells from cord blood can be used for transplants for children and young adults. This is known as a cord blood or stem cell transplant.
- A cord blood transplant can treat many blood diseases, immune diseases and metabolic diseases.
- It is not yet known if stem cells from cord blood can be used to treat other conditions.
- Stem cells from cord blood can be collected and stored for future use.
- Cord blood is not usually collected as a routine.
- Cord blood must be collected safely and in a way that minimises contamination and infection.

- It is best if a trained technician who is not involved in the care of a woman or her baby collects cord blood.
- There are two types of cord blood bank:
 - (a) private (commercial) banks
 - (b) public banks.
- Private banks are generally for-profit organisations which store cord blood for possible future use by an individual's own family for a fee.
- Each hospital should have its own policy on private banking and make this policy available to prospective parents.
- A public bank, such as the NHS cord blood bank, stores donated cord blood for use by patients anywhere in the world who need a transplant.
- A public bank may also store cord blood for families with a known genetic or other disease.
- The Royal College of Obstetricians and Gynaecologists (RCOG) supports public banking and donation to the NHS cord blood bank.
- The RCOG remains unconvinced about the benefit of storing cord blood with a private bank for families who have no known medical reason to do so.

About this information

This information is for you if you are deciding whether to use a private (commercial) cord blood bank. It is based on the Royal College of Obstetricians and Gynaecologists (RCOG) Scientific Advisory Committee (SAC) Opinion Paper on **Umbilical Cord Blood Banking** published in 2006 (www.rcog.org.uk/index.asp?PageID=545). This Statement is due for revision in 2008.

This information aims to help you and your healthcare team make the best decisions for you and your family. It is not meant to replace specific advice from a doctor or midwife about your own individual situation.

Some of the information here may not apply to you. Your doctor, midwife, or another member of your healthcare team will discuss any further issues with you.

What is cord blood?

Cord blood is the baby's blood that remains in the placenta and cord after birth. After the baby is born, the blood in the placenta and cord is no longer needed and is usually disposed of carefully.

Cord blood contains many different types of cells including very small numbers of a particular type of cell, known as stem cells. These cells are the building blocks of all the other cells in the body. Different parts of the body are made up of different types of cells: the heart is made up of heart cells, the liver is made up of liver cells, blood is made up of blood cells, and so on. Stem cells can grow into these different kinds of cells in the body.

Why is cord blood useful?

Cord blood is currently used in the treatment of:

- blood related disorders, such as leukaemia, sickle cell anaemia and thalassaemia (also known as haemoglobinopathies)
- some immune system disorders
- metabolic storage disorders, such as Hurler syndrome (an inherited condition caused by an enzyme deficiency).

Some scientists have claimed that cord blood could potentially be used to cure diseases such as Alzheimer's disease, Parkinson's disease and conditions such as diabetes. They also claim that cord blood could be used to treat diseases affecting the brain, heart and spine.

Other scientists argue that there is not enough evidence to back up these claims. It may be that in the future more diseases will be treated with cord blood. At present, however, much more research is needed.

How is cord blood used?

Blood stem cells are stem cells that grow into new blood.

A cord blood transplant uses blood stem cells to replace diseased cells with healthy new cells and rebuild an individual's blood and immune system. For the transplant to be a success, the new cells must match the individual's own cells as closely as possible. There have been over 6000 successful cord blood transplants (between relatives and non-relatives) worldwide.

Cord blood transplants can be used as an alternative to bone marrow transplants to treat some disorders. This has mainly been successful in treating young patients for leukaemia.

The advantages of a cord blood transplant, compared with a bone marrow transplant, are that:

- there are fewer complications with a cord blood transplant.
- it is easier to find a match from stem cells than from bone marrow. This, in turn, leads to increased access to transplantation, particularly for patients from ethnic minorities.
- cord blood can be frozen and stored for years so it is more readily available.
- there are fewer delays with a cord blood transplant. Delays are inevitable in the case of bone marrow transplants because of the need to search registers, contact would-be donors and the bone marrow retrieval procedure itself.

The disadvantages are that:

- a cord blood transplant may not be possible. There may not be enough cells from one cord for a transplant, especially to an adult.
- for some blood conditions, such as certain leukaemias, a transplant using a child's own blood may be harmful. This is because the stored stem cells may contain the same abnormality and risks that caused the child to become ill in the first place. In this case, a donation from another source would be better.

What is cord blood banking?

Cord blood banking is when cord blood is collected and stored for treating a disease or illness.

Types of cord blood bank

Public banks

If you give birth in one of three hospitals in the south east of England, you can donate cord blood to a public bank, such as the NHS cord blood bank. There is also a small NHS public bank in Belfast in Northern Ireland (see section **Is there anything else I should know?**). Donation is voluntary and collection and storage is free of charge. A public bank stores cord blood for use by anyone anywhere in the world, thus ensuring fair access for all patients requiring stem cell transplantation. It is an alternative to a volunteer bone marrow donor registry.

The RCOG supports public banking and donation to the NHS cord blood bank.

If there is a known genetic condition in your family or you already have a child with leukaemia or blood related disorder, your clinician may recommend that you consider banking your baby's cord blood. Your clinician may be able to arrange for cord blood to be collected and stored in the NHS cord blood bank for future use by your family. You should also discuss this with the doctor looking after the person in your family who is ill.

Private (commercial) banks

People can store cord blood with a private bank in the hope that, in the future, cord stem cells may be useful, should a member of their own family develop a disease treatable by stem cell therapy.

The chances of your child ever needing to use his or her own cord blood are extremely small, so there is no guarantee that the cord blood will ever be needed. Nevertheless, you may feel this is worthwhile, like an insurance policy.

There is a fee for collection and long-term storage of up to £1,500. Depending on circumstances, some private banks may store cord blood free of charge for certain families where there is a known genetic condition.

If you have not banked with a private bank and your child develops a blood related disorder, immune system disorder or metabolic storage disorder in the future, then you still have other options. These are:

- cord blood from a public bank in the UK or internationally.
- use of other sources of therapy such as bone marrow transplants. There is worldwide collaboration with international bone marrow registries to find suitable matches for patients who require a bone marrow transplant.
- treatment from a sibling who matches a family member who can give bone marrow.

Full written information on the private banking policy at your hospital should be given to you at your antenatal booking appointment. This information may not be given routinely, so you may need to ask if you would like to find out more.

The RCOG remains unconvinced about the benefit of storing cord blood with a private bank for families who have no known medical reason to do so.

How is cord blood collected safely?

Cord blood must be collected safely. It is important that:

- a trained technician who is not involved in your or your baby's care collects the cord blood. It is important that neither your obstetrician nor your midwife should be distracted from looking after you and your baby during and immediately after childbirth.
- there should be no alteration in your 'usual management' of labour, such as the delivery of the placenta or clamping of the cord. Some evidence indicates that immediate cord clamping may be harmful to babies. However, delaying cord clamping can prevent a successful cord blood collection.
- cord blood should be collected after the placenta has been delivered in a clean

environment using methods and facilities, which meet the required regulations including the EU Tissue and Cells Directive.

Cord blood collection may not be advisable or possible if:

- the baby is premature
- you have a multiple pregnancy
- the cord around the neck needs to be cut early to deliver the baby
- you are delivered by emergency caesarean section
- you are being prescribed certain medication
- you or the father of the baby have tested positive for a transmissible infection(s).

Making an informed decision

If you are considering private banking you should discuss this with your doctor or midwife. You may wish to consider the following points:

- Not all hospitals allow collection by private banks. You should ask about the private banking policy at your hospital during your antenatal booking appointment. Once you have made a decision about banking, you should let your doctor or midwife know.
- You may find that your midwife or obstetrician has been advised by their professional organisation not to collect blood for a private bank.
- There are a number of uncertainties surrounding cord blood storage. For instance, who owns the cord blood legally? What are your rights if the facility storing the cord blood breaks down and the cord blood becomes unusable?
- Private banks are run by private companies. If you decide to bank through a private company, you will enter into a contract between yourself and the company. It is your responsibility to check that you are happy with all the terms and conditions of the contract. Some private companies make additional charges to screen for bacterial diseases.
- Since April 2006, all UK cord blood banks come under the EU Directive on Tissue Cells 2004/23/EC and are required to be licensed by the Human Tissue Authority (HTA). Cord blood should be collected and banked in accordance with this. If you choose to use a private bank, it is your responsibility to check that the private bank is approved and follows correct procedures.

Some questions to ask are as follows:

- ❑ Is the bank accredited/licensed for storage of cord blood?
- ❑ If it is a UK bank, has it been licensed by the Human Tissue Authority (HTA)?
- ❑ Does the bank follow proper collection procedures?
- ❑ What happens if no stem cells are collected?
- ❑ Does the bank follow best practice testing regimens?
- ❑ Does the bank follow best practice sample storage?
- ❑ Where is the cord blood stored?
- ❑ Is the transportation to the storage facility checked to ensure the blood is kept appropriately?
- ❑ When is the stored cord blood no longer useful?
- ❑ What happens to the cord blood when it is no longer needed?
- ❑ Who is responsible for screening the blood to ensure that HIV/hepatitis-positive cord blood is stored separately?
- ❑ Could my child or any of my children use the cord blood, if I am not around?
- ❑ What will happen to my cord blood, if the bank is no longer functioning in the future?

Useful additional information

A Parent's Guide to Cord Blood Banks

www.parentsguidecordblood.com

The Society of Obstetrician and Gynaecologists of Canada patient information leaflet

www.sogc.org/health/pdf/cord-bloodfinal_e.pdf

The Anthony Nolan Trust is a charity that recruits and registers bone marrow donors

www.anthonynolan.org.uk/

Is there anything else I should know?

- The commercial company advertising itself as the UK Cord Blood Bank <http://cordbloodbank.com/uk/about.php> is not the same as the NHS Cord Blood Bank.
- The hospitals that routinely collect cord blood for storage in a public bank are Northwick Park Hospital in Middlesex, Barnet Hospital in Hertfordshire, the Luton and Dunstable Hospital NHS Trust in Luton and the Mater Hospital Trust in Belfast

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