

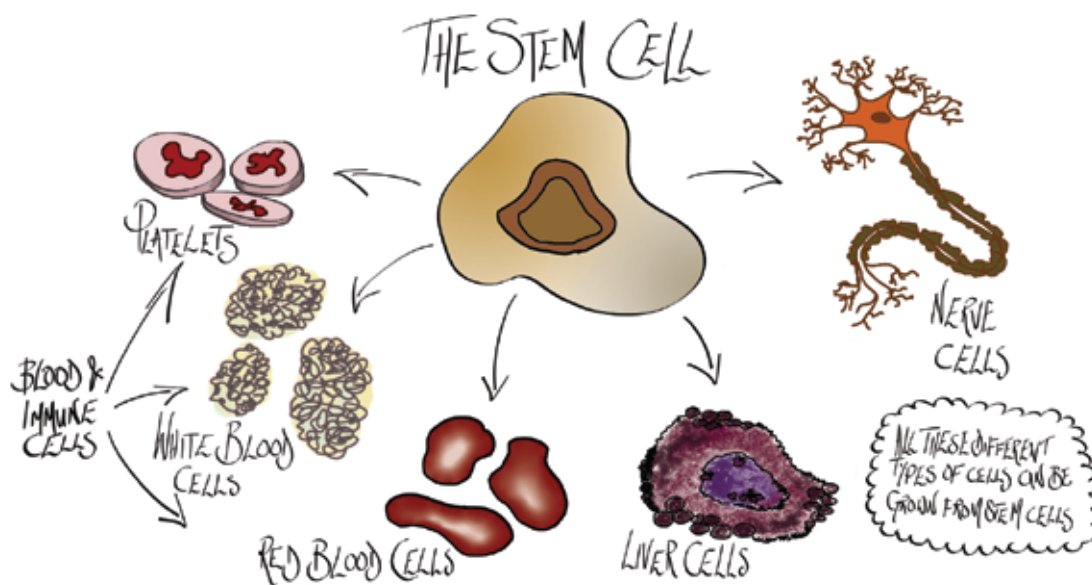


# **A Guide To Cord Blood Banking**

*For Families with Genetic Conditions*

## Cord Blood Banking

This leaflet is aimed at families who might be considering storing cord blood for the treatment of a child or other family member with a genetic condition. Some families may wish to consider donating cord blood for altruistic purposes – more information on how to do this can be found at <http://cord.blood.co.uk>.



### What is cord blood?

The blood that is in a newborn baby's umbilical cord and the placenta after birth and after the umbilical cord has been cut.

### What is cord blood banking?

The collection and storage of cord blood with the intention of using it to treat a medical condition.

### Why is cord blood useful?

Cord blood contains blood stem cells (also called haematopoietic stem cells), which can turn into the cells found in blood and the immune system. Blood stem cells can be used in transplants to treat diseases like leukaemia as well as some genetic conditions.

### Are stem cells only found in cord blood?

No. Many organs and tissues in the human body contain "adult stem cells". These can be found in people of all ages and can develop into a number of types of cells in the body, such as liver cells and nerve cells.

Cord blood stem cells are one type of adult stem cell. Blood stem cells, like those found in cord blood, are also present in bone marrow (inside the bone cavities, where blood is formed). Bone marrow stem cells can also be released into the peripheral blood (blood that is circulating in the body) under certain circumstances.

## What genetic conditions can be treated with cord blood?

You would need to discuss potential treatments with the doctor looking after the child/family member with the genetic condition, but in general terms, conditions that can be treated with bone marrow transplant can often be treated using a cord blood transplant, and the groups of genetic conditions for which cord stem cell transplant might be offered are:

- ◆ metabolic storage disorders
- ◆ some immune system disorders
- ◆ haematological disorders including haemoglobinopathies, e.g. thalassaemia and sickle cell disease. For these disorders it is important for families to know that the cord blood must be an exact tissue match ('HLA-identical') with the affected child - otherwise the cord blood cannot be used for a transplant. The chance of the cord blood being an exact match is around 25%. (A good HLA match is required for metabolic storage and immune system disorders but an exact match is not necessary for all of them.)

Claims have been made about treatments for other conditions but at present these potential treatments are still in the research phase. Further research is needed to confirm or refute these additional therapeutic applications. This leaflet reflects the current UK view. With more evidence, this may change in the future.

## Are there any advantages of cord blood transplants compared to other treatments?

According to the Royal College of Obstetricians and Gynaecologists, the advantages of a cord blood transplant, compared with a bone marrow transplant (the standard treatment) are as follows:

- ◆ 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.

(Source: '**Cord Blood Banking: information for parents**', Royal College of Obstetricians and Gynaecologists)

## Could there be any disadvantages?

- ◆ The cord blood that you're storing might contain the genetic condition that your family is affected by. This would mean that the cord blood would not be suitable for transplantation. If this is the case, there are other treatment options, including cord blood stem cells from an unrelated donor (please see overleaf).

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- ◆ The cord blood might not contain enough stem cells for a transplant, particularly if the transplant recipient is an adult. If this is the case, cord blood from unrelated donors can be used instead of or in addition to your stored cord blood.
- ◆ There could be practical drawbacks, for example in some hospitals it may be difficult to arrange for the cord blood to be collected. Also, the blood will not be collected if this will distract staff from caring for the mother in labour and the newborn baby.



- ◆ Cord blood transplant to treat genetic conditions is quite demanding for the patient. As is the case with bone marrow transplants, it would involve high-dose chemotherapy to suppress the immune system, followed by the patient being in isolation after the transplant has been given.

The potential risks and benefits should be discussed with your obstetrician and the doctor looking after the child/family member with the genetic condition. You should also try to seek specialist advice on risks and benefits from a centre that specialises in the genetic condition affecting your family.

### Who collects and stores cord blood?

In England, the NHS Cord Blood Bank can collect and store cord blood for families who are affected by genetic conditions where there's an indication that it is considered to be treatable by cord blood stem cell transplantation. In such cases, the blood is used for "directed donations", meaning that it is donated to someone you're related to.

In Northern Ireland, the Belfast Cord Blood Bank offers a service for directed donations for siblings who may require stem cell treatment. The service is offered throughout Northern Ireland, but mothers need to travel to one of two hospitals that are licensed to procure cord blood: the Royal Jubilee Maternity Hospital and the Mater Hospital.

In Scotland, the Scottish National Cord Blood Bank is due to be up and running in September 2009, and there are plans to set up a directed donation service.

Cord blood is not currently collected or transplanted by the NHS in Wales.

There are also a number of cord blood banks that are run by private companies. These can be found on the internet. Their services and fees vary. Make sure that if you use a private company that they are Human Tissue Authority (HTA) licensed. You should also ask how the bank processes the cord blood. Some banks might freeze the blood as it is, but most process the blood sample to reduce its volume before freezing. (this process might involve depleting the red blood cells and/or plasma, which are not needed in the transplant). So far successful transplants have only been done with 'reduced volume' cord blood.)



### **How would I arrange for my baby's cord blood to be collected?**

If you live in England or Northern Ireland and there is a genetic condition in your family that could be treated by cord blood stem cell transplantation, you may be told about directed donations of cord blood by the NHS. If you are not told about this but you would like information, you should ask your obstetrician and/or the doctor looking after the child/family member with the genetic condition.

If you have decided to use a private cord blood bank, you should also discuss this with your doctor or midwife. You would need to check what your hospital's policy is on cord blood collection, as not all hospitals permit cord blood collection for private cord blood banks.

If you are considering storing cord blood, this needs to be discussed with both your obstetrician and consultant at an early stage of pregnancy, in order to allow time for the necessary arrangements to be made.

### **Would my child be able to use their own cord blood later in life?**

If your child has a genetic condition, their own cord blood could not be used to treat them because the inherited condition will be present in the blood cells. However, if there is a genetic condition in your family that can be treated by cord blood stem cells and your child is born without that condition, their cord blood could be used to treat a sibling or another family member if the cord blood is fully matched to the affected sibling. For some genetic conditions, though, it could be beneficial to have an unrelated donor. If this is the case, the cord blood used in the treatment would be obtained from a public bank in the UK or abroad.

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### Will anyone else be able to use my child's cord blood?

If you store cord blood for directed donation through the NHS, it is only available for your family to use. Private cord blood banks' policies on this vary. With your consent, your cord blood might be used to benefit a patient who is not related to you.

### Is cord blood collection safe?

Yes. Strict new rules were introduced in the UK in July 2008 on the collection and storage of cord blood. By law, anyone collecting cord blood has to have a licence from the HTA, and this means that their staff and premises have to meet standards set out by the Government.

### Is it ethical?

Yes. Umbilical cord blood is routinely thrown away as hospital waste, so there are no ethical issues in terms of storing or using it.

### How much would it cost to store my baby's cord blood?

The NHS does not charge families with genetic conditions to store cord blood for directed donations.

Fees for using private cord blood banks vary, but are currently around £1,000. It's important to be clear about how much you will be charged and whether there might be any additional costs, such as annual storage charges. Private banks might store cord blood at no charge or at a reduced rate if a family had an immediate need for transplant, so it could be worth asking about this.

### If I do not store my baby's cord blood, are there any other treatment options?

Yes. You would of course need to discuss with the doctor looking after the child/family member with the genetic condition what treatments could be given, but these could include:

- ◆ Cord blood from a public bank in the UK or abroad.
- ◆ Bone marrow from a matched donor, either from a family member or a bone marrow registry in the UK or abroad.

### What else do I need to know?

If you are considering storing your child's cord blood, here are some questions that you may wish to ask your obstetrician and the doctor looking after the child/family member with the genetic condition:

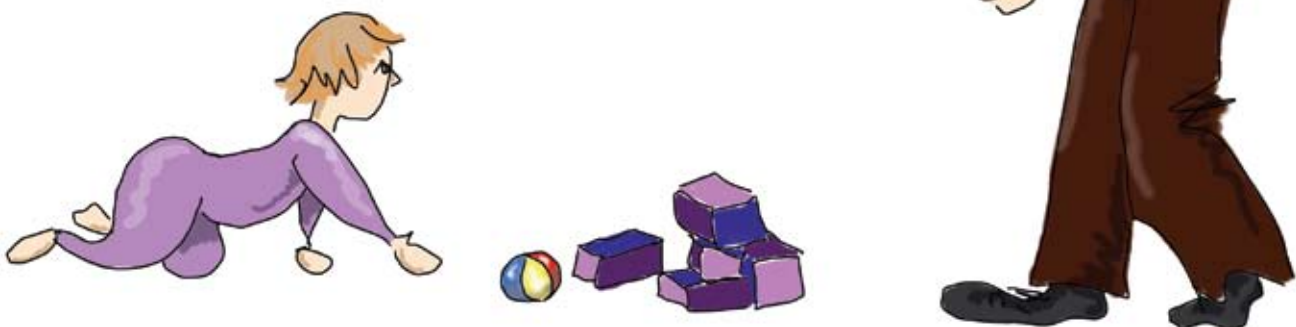
- ◆ Would cord blood storage be available to me on the NHS?
- ◆ If so, how do I access it?
- ◆ What technology does the NHS bank use to process the cord blood (is the cord blood stored whole or reduced volume)?
- ◆ Has any NHS cord bank had any successful cord blood transplants?
- ◆ Have the NHS staff had special training?
- ◆ Where will the blood be stored in an NHS bank?
- ◆ How long will the cord blood be stored for?
- ◆ How will the NHS bank ensure the correct labelling, tracking and security of my cord blood?

- ◆ What would happen to the cord blood if the NHS storage facility broke down?
- ◆ What would happen if the NHS Trust was declared bankrupt?
- ◆ How will the NHS safeguard the privacy of my information?
- ◆ Will the NHS bank use my child's cord blood for any other purposes, e.g. for research?
- ◆ Could there be any problems that I might need to bear in mind?
- ◆ Who are the bank's staff and what are their qualifications?
- ◆ Where will the cord blood be stored?
- ◆ How long will they store the cord blood for?
- ◆ How will they ensure the security of my cord blood?
- ◆ What would happen to my cord blood if the storage facility broke down?
- ◆ What would happen to my cord blood if the bank went out of business?
- ◆ How will they safeguard the privacy of my information?
- ◆ Will the bank use my child's cord blood for any other purposes, e.g. for research?
- ◆ Will there be any additional costs?
- ◆ Could there be any problems that I might need to bear in mind?

### If I decide to use a private cord blood bank, what questions should I ask them?

We have also listed some questions that you may wish to consider asking the cord blood bank, or finding out from their website:

- ◆ Is the bank licensed by the HTA to store cord blood?
- ◆ Can cord blood stored with the bank be used for transplants in NHS hospitals?
- ◆ Will my child's cord blood only be available for my family to use?
- ◆ What technology does the bank use to process the cord blood (is the cord blood stored whole or reduced volume)?
- ◆ Has the bank had any successful cord blood transplants?



## Cord Blood Banking

### Are there any other useful sources of information?

- ◆ NHS Cord Blood Bank, England - <http://cord.blood.co.uk>
- ◆ Belfast Cord Blood Bank: [www.nibts.org/cord.asp](http://www.nibts.org/cord.asp)
- ◆ Scottish Cord Blood Bank: [nss.scottishnationalcordbloodbank@nhs.net](mailto:nss.scottishnationalcordbloodbank@nhs.net)
- ◆ The Anthony Nolan Trust (which is setting up a cord blood bank for unrelated donors) <http://anthonymolan.org.uk/cordblood/cordbloodprogramme/>
- ◆ Human Tissue Authority (HTA): <http://www.hta.gov.uk/licensingandinspections/sectorspecificinformation/humanapplication/cordbloodcollectionfaqsforparents.cfm>
- ◆ 'Cord blood banking: information for parents', Royal College of Obstetricians and Gynaecologists [www.rcog.org.uk/womens-health/clinical-guidance/cord-blood-banking-information-parents](http://www.rcog.org.uk/womens-health/clinical-guidance/cord-blood-banking-information-parents)
- ◆ Condition-specific organisations, such as the UK Thalassaemia Society ([www.ukts.org](http://www.ukts.org)).
- ◆ If you are unsure which condition-specific organisation to contact, please feel free to ask the Genetic Interest Group ([www.gig.org.uk](http://www.gig.org.uk)).

The content of this leaflet has been produced independently of any third parties and the Genetic Interest Group has maintained full editorial control. No third party has requested the inclusion of any specific information in the leaflet. The leaflet has been reviewed by independent experts.



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