

Donating Cord Blood, Umbilical Cord and Placental Tissue Frequently Asked Questions



Blood and Transplant

NHS Cord Blood Bank
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This document provides answers to questions most frequently asked by donors and may help you decide if you want to donate your baby's umbilical cord, placental tissue and cord blood. If you choose to help us and agree to donate to the NHS Cord Blood Bank please sign the consent form provided.

Where can I donate my cord blood to the NHS cord blood bank?

We can only collect from: Luton & Dunstable Hospital, St George's Hospital and University College Hospital. Collection is not always possible, and many donations are not suitable to be banked for clinical use when they are evaluated, and so you should never transfer to one of these hospitals just for the chance to donate.

What is cord blood?

Cord blood is the blood that remains in your placenta and umbilical cord after you give birth. It is normally thrown away as clinical waste but, as it is rich in stem cells, it can be stored and used to treat patients. Stem cells are special cells that can either remain a stem cell or specialise into other specialised cells, such as muscle, skin, liver, nerve or blood cells. They can divide to renew damaged cells, and in doing so act as a repair system for the body. Cord blood is rich in haematopoietic stem cells that can make new red and white blood cells, and platelets which are needed to help blood clot. Cord blood, cord and placental tissue also contain other stem cells such as mesenchymal stem cells which can repair other tissue in the body. It is possible we could use your donations to make new biological therapies by selecting certain cells and allowing them to grow and multiply under laboratory conditions.

Why is cord blood important?

The stem cells found in cord blood can be used to treat a variety of diseases including:

- Blood cancers, such as leukaemia and lymphoma
- Some immune disorders, such as Aplastic Anaemia and Severe Combined Immunodeficiency (SCID)
- Metabolic disorders, such as Duncan's Syndrome (also known as X-linked lymphoproliferative disease – a disease which often leads to death from bone marrow failure, irreversible hepatitis, and malignant lymphoma in boys) and Hurler's Syndrome (a lysosomal storage disease which causes developmental deformities, vision problems, organ damage and death)

These stem cells can be given to patients as a cord blood transplant and are essentially an alternative to bone marrow transplantation. The cells can be stored frozen for many years and have the advantage of being immediately available when required for a patient.

Why do you need to collect cord blood?

We aim to store 20,000 cord blood units, this will complement a UK public bank of 30,000 cord blood units in collaboration with another UK cord blood bank held by the Anthony Nolan charity. A public bank of this size would allow the UK to provide life-saving cord blood transplants for a large number of patients who currently can't find a donor and reduce the need to import cord blood from banks overseas.

How do I give consent?

Without your consent we are unable to collect your cord blood, cord and placental tissue following the birth of your baby. The consent process is regulated by the Human Tissue Authority to ensure it has been done properly. We will talk through the process with you where you will have an opportunity to ask questions at any time during the consent process. If you decide to donate your baby's umbilical cord, placenta and cord blood you will need to sign the consent form. Even if you have signed the consent form you can still change your mind and withdraw consent at any time before or after your baby is born. If you change your mind after donating your cord blood the cord blood collection, remaining samples and any paperwork bearing your personal identification data will be discarded. Where the donation has been used already it may not be possible to withdraw consent for the use of the cells and you will be informed if this is the case.

Am I eligible to donate my cord blood and tissue?

Most mothers are able to donate their cord blood and tissue, but we will need to ask a few questions about your lifestyle and medical history to confirm that the donation would be safe for any patient.

Do I need to change my birth plan if I wish to donate my cord blood and tissue?

No. We do not interfere with your choice of birth plan or the actual delivery of your baby which will be supervised by your attending midwife/doctor. The safe delivery of your baby is the absolute priority and any consideration of collecting your cord blood will only be carried out once this is achieved. If you have consented to cord blood donation we will attempt to make a collection regardless of method of delivery. Some birth plans may yield less blood e.g. physiological third stage, however, this does not always mean that we cannot make a successful collection, as this often depends on the concentration of stem cells within the blood. We can still attempt a collection after delayed clamping if you have consented to donate your cord blood and tissue.

How is my cord blood collected and what will happen to it?

Once your baby has been born, the umbilical cord is clamped and cut. When the midwives have checked the cord and placenta to make sure everything is OK they will pass it to a member of our team who will do the collection in a dedicated room nearby. This dedicated NHSBT collector will collect the blood using a specially designed sterile collection kit. The donation is labelled with a unique donation number and information about you and the cord blood donation will be entered onto the NHS Blood and Transplant database. The donation will then be sent to the NHS Cord Blood Bank laboratories where it will be evaluated and, if it is suitable for clinical use processed. If the donation is not suitable for clinical use, it will either be disposed of according to UK regulations or, if you have given consent for research, we will use it for ethically approved research. It is possible your donations (cord blood, cord and placental tissue) could be sent abroad to researchers in other countries.

Is all cord blood collected and stored?

We can't guarantee that your cord blood will be collected and stored. It may not be collected because the collection staff may not be available to make the collection, or there may be a medical or technical reason why the cord can't be collected. If a collection is obtained, they frequently do not contain enough cells for clinical use and these won't be processed or stored. In addition, some cord blood donations with lower cell counts are used for research, quality control purposes so we can monitor the quality of our processes and to make sure they are fit for purpose or alternatively to validate new procedures.

Will donating cord blood affect my baby or me?

No. The safe delivery of your baby takes priority. We have worked with midwives and doctors since 1996 to develop procedures that are entirely safe for you and your baby and do not interfere with the birth in any way. We use dedicated collection staff so that your midwife is free to concentrate on taking care of you and your baby both during and after delivery.

What tests are performed on the blood samples taken from me?

Following your donation we need to take a blood sample from you. Although we don't require blood samples from your baby we may occasionally detect your baby has low platelets (a blood factor important in clotting) by testing directly on the cord blood at our laboratory. As it is not always routinely carried out on all new-borns in hospitals, we will inform your maternity team accordingly if this is the case. In the same way that blood from blood donors is checked for infections, we must check your blood to confirm the cord blood is safe for transplantation. In the unlikely event that any test proves positive, you will be informed and offered appropriate advice. In exceptional circumstances, for instance if your baby is at risk, your GP, obstetrician or baby's doctor may be informed. As for blood donors the requirement for testing will not affect your ability to obtain life assurance, health insurance or a mortgage.

We may also use your blood to develop rare blood panel tests or other diagnostic purposes.

What tests are performed on my cord blood?

We will test your blood only to make sure it is safe to be transplanted into any patient. Specifically, we will test for blood borne diseases including viruses and other diseases, such as sickle cell and hepatitis. We will also carry out haematology tests to count the stem cells to make sure there are sufficient for clinical use. In addition, we will tissue type (termed HLA type) your blood and the cord blood donation. The HLA type is used by transplant centres to match donations with patients. Where the transplant patient has a good HLA match with the cord blood donation there is a much better chance the transplant will be successful. The maternal HLA type can also help with matching the donation to a patient.

We also carry out routine tests for infectious diseases on both your samples and the cord blood unit both at the time of banking and at reservation of the cord blood unit. Therefore, some of these results might not be completed until years after collection. Hence please be aware that there may be a long delay in the provision of what would have been a diagnostically useful positive result, at the time of your donation.

If your donations are used for research it is possible that other genetic (DNA) tests could be performed.

Is my personal information, including my test results, kept confidential?

Yes. We'll store your information on our cord blood donor database, where it will be given a unique donation number. We'll then refer to this donor number when reporting to other institutions such as transplant centres, without identifying either you or your baby. Your personal information will not be shared with a third party unless you give express consent we can do so. All information provided to NHSBT is used in accordance with the General Data Protection Regulation (GDPR) and all other relevant privacy and data protection laws. To find out more about your privacy rights please visit our website www.nhsbt.nhs.uk or call us on **0300 123 23 23**.

Will you contact me again?

Possibly, we may contact you again after 6 or 12 weeks just to make sure you and your baby are well and that there are no reasons why we shouldn't transplant your cord blood. The interview is by telephone and will only take a few minutes. If a patient needs your cord blood we will endeavour to contact, you or your GP before the cord blood is released to the transplant doctors caring for the patient. Again, this is only to make sure that you and your baby are still well and that there are no reasons why your cord blood should not be used.

Does it cost me any money? Do I get paid?

No, there is no cost to you in donating your cord blood to the NHS Cord Blood Bank. Your donation will be on a voluntary basis only and we are not able to offer any payment to mothers for donating their cord blood. This includes your donations for research, cell line or new therapy creation.

How long is my cord blood stored for?

Cord blood donations are stored below -190°C where we can keep them indefinitely. Cord blood donations over 15 years old have been successfully used for transplants.

Will my cord blood be available to my own family should it be needed in the future?

We operate our cord blood bank as a public resource making donations available for any patient anywhere in the world and do not store cord blood for private family use. In the extremely unlikely event, a member of your family requires a cord blood transplant in the future, a search will be made of public cord blood registries around the world to identify the best cord blood unit available. It is possible that your donation may be available, but the transplant centre may prefer to use another donation from a different individual.

How does the NHS Cord Blood Bank differ from private banking?

The NHS Cord Blood Bank is publicly, or government funded and only collects cord blood from public hospitals. The potentially lifesaving product is then stored for any patient that needs a transplant anywhere in the world. There is no charge to the donor, but the product is not stored specifically for that person or their family.

There are several commercial cord blood banks that charge a fee to collect and store cord blood for private family use only. If you wish to use one of these companies, you need to contact them directly. To fully understand the potential of private storage we would advise you to research the claimed benefits thoroughly and seek out independent advice from institutions such as the EU and/or various medical bodies representing doctors and professional medical opinion.

The Human Tissue Authority has produced a parental guide on cord blood banking available at:

<https://www.hta.gov.uk/guidance-public/cord-blood-banking-guide-parents>.

Why does the NHS Cord Blood Bank only collect cord blood and tissue in certain hospitals?

The NHS Cord Blood Bank is funded entirely by the Department of Health and funding constraints mean we are only able to collect at a few hospitals in and around London. These have been chosen to have a high birth rate and a diverse population. London has the highest incidence of Black and Minority Ethnic communities in the UK and, having the collection centres close together in one city reduces the infrastructure costs.

Will my cord blood or tissue be used for research?

We endeavour to store every cord blood donation to the NHS Cord Blood Bank for clinical use. However, donations will frequently, through no fault of your own, not meet the very high specifications required to ensure it is suitable for transplantation or use in a clinical trial. If this is the case and you have given specific consent for research, the donation may be used for ethically approved research purposes instead and consequently will not be wasted. Provision of cord blood, cord or placental tissue for research is governed by our approvals under the National Research Ethics Committee to protect your safety, rights, wellbeing and dignity.

Traditionally patients requiring a transplant to treat blood diseases such as leukaemia have been treated using bone marrow cells from a relative or a nonrelated donor. Research has revealed that the stem cells found in cord blood can be just as effective in treating these patients as bone marrow stem cells. Research is now being carried out to see how and why these cells are so effective, how to improve their effectiveness and the range of potential treatments for which they may be suitable.

Other research being done includes studies on the way different types of cells are made or work in the body. This research can lead to better prevention or treatment of diseases such as blood diseases, cancer, and heart disease. This work may involve growing cells in the laboratory for prolonged periods of time as so-called cell lines and may involve the storage and testing of DNA. It is possible animals could be used in this research. Tests may be done on other components of your donated cells, tissue or blood. All research will always be done on an anonymised basis.

It is also possible NHS Cord Blood Bank could provide your research donations to private / commercial companies in the UK or abroad. We also recover the cost of collecting and supplying these materials that you have so kindly donated for research, to these companies.

Cord blood or tissue will under no circumstances be released for use in cosmetics safety or related testing, nor other consumer (non-biomedical) product related research.

Why is my cord tissue needed?

Your cord tissue is a valuable source of Mesenchymal Stromal / Stem Cells (MSC). These are an amazing kind of cell that can differentiate into a variety of cell types, including osteoblasts (bone cells), chondrocytes (cartilage cells), myocytes (muscle cells) and adipocytes (fat cells which give rise to marrow adipose tissue). These cells also can have a profound effect on the immune system. NHSBT, many companies and researchers are trying to produce new novel therapies by perfecting the growing of MSCs in laboratories to get enough of them in a pure form to use in clinical trials. If researchers can use your donated cord tissue to grow enough Mesenchymal Cells, we can use them to treat many diseases. For example, we may be able to use MSCs as a cell therapy for primary sclerosing cholangitis (PSC), a liver disease for which there is currently no treatment. Like most liver diseases, PSC involves inflammation that leads to liver damage. In the absence of effective treatment, damage from the disease means that patients often need liver transplants. It is believed MSCs could be a better treatment by dampening down the immune response that is at the root of the problem in PSC.

For further information, queries or complaints, contact the NHS Cord Blood Bank as detailed below.

NHS Cord Blood Bank is part of NHS Blood and Transplant, a special health authority within the NHS.

Freephone **0800 783 5870** E-mail: cordblood.donation@nhsbt.nhs.uk