



EACH NEW LIFE COULD SAVE ANOTHER

CONSENT LEAFLET

How you and your baby could save the life of someone with blood cancer by donating your umbilical cord.

**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer

HELLO, LIFESAVER. ✕ HELLO, LIFESAVER'S MUM. ♥

Yes, you heard us right. After the safe birth of your baby, you could save the life of somebody with blood cancer or a blood disorder by donating your umbilical cord.

At Anthony Nolan, we save the lives of people with blood cancer. We do it with the help of over 620,000 adult potential donors, who've volunteered to give their stem cells to a stranger in need. We do it with the help of our researchers and fundraisers. And we do it with the help of heroic mums like you – and your little ones, too.

Wow! How?

The blood in your baby's placenta and cord is rich in stem cells. These can be used in stem cell transplants and/or cell therapy to give the chance of life to people with blood cancer or blood disorders – but usually, they're just thrown away after the birth.

Anthony Nolan's cord blood programme is a pioneering initiative to save more lives. We collect donated cord blood and tissue, and then store them in our cord blood bank until needed.

Transplant recipients will usually need stem cells that are a genetic match for them – which means we need to have a greater variety of cord blood available from people from different ethnic backgrounds. Combined with our adult donor programme, you and your baby can help us to ensure that we find the best match for as many people as possible.

You probably have some questions about donating. We'll gladly get in touch with you to discuss any issues,

but here are some of the most common questions that arise:

WHAT IS CORD BLOOD?

It's the blood that remains in the placenta and umbilical cord after you give birth. Following your baby's birth, the cord is clamped and cut. Then, along with the placenta, it's usually thrown away.

Why is cord blood important?

Every year, around 2,000 people in the UK will need a stem cell transplant from a stranger – including more than 300 children.

The stem cells in cord blood can be used for transplants, as an alternative to finding a stem cell donor. One of the many advantages of cord blood stem cells is that they are immediately available for patients who need them.

Time is often a crucial factor for a person who needs a stem cell transplant, so it could mean the difference between life and death.

What happens when I donate my cord blood?

It's a simple, safe, and swift procedure. Once your baby has been safely born, the umbilical cord will be clamped as normal. Then the cord and placenta, once delivered, will be passed to one of our cord collectors who will take it to a separate room to extract the blood.

To complete your donation we will require a maternal blood sample from you following birth and will also need you to sign our formal consent paperwork and answer some questions on your medical history before the cord blood can be processed and used for a person who needs a stem cell transplant.

Are there any risks?

No. Collecting your baby's cord blood is a risk-free, painless procedure which does not interfere in any way with giving birth. The safety of you and your baby always takes priority.

The maternal sample is taken following birth. This carries the same risk of bruising or discomfort as any of the blood tests you might have during your pregnancy.

What happens to the cord blood?

After collection, we process the cord blood to make sure it can be used for a transplant. About a quarter of the units we collect will be suitable. We store these until needed. Sometimes donated cords aren't suitable for transplant; for example, if the amount of blood collected is too small. If it isn't suitable, we'll dispose of it as clinical waste or use it in research that's been approved by an Ethics Committee. If it's used for research, your identity and your baby's identity will remain unknown.

If you donate, you will be agreeing to let us to use your donation for either a stem cell transplant or research. You have the right to withdraw consent at any time, unless the donation has already been used.

If it turns out that we can only use your baby's cord blood for research, your donation could still help us save lives. Our researchers are working tirelessly to understand the different properties of cord blood, which will help us to ensure that stem cell transplants are more effective than ever.

Research is also being undertaken to create new therapies for other conditions such as strokes, heart attacks, and brain injury. The cord blood will not be cloned.

Can you always carry out a collection?

Sadly, we can't guarantee that your cord blood will be collected and stored. This may be because a collector is unavailable, or because of other situations which could arise during your labour.

Why do I need to consent?

Consent is central in all forms of healthcare and tissue donation in the EU, and a legal requirement of cord blood collection. Without your consent we can't process your cord blood donation and it will be thrown away.

Will my taking part be confidential?

Yes. Authorised personnel from this hospital and from Anthony Nolan may look at parts of your medical records, or your baby's medical records, and the data collected. But they will not disclose any details outside the programme.

WHAT NEXT?

If you'd like to give your consent, just peel off the sticker on the opposite page and attach it to the front of your medical notes.

Then fill in the pre-consent form on the opposite page, fold this leaflet back up into an envelope, and send it back to us via freepost. You can also pre-consent to donate online via our webform: anthonymolan.org/cord

STILL INTERESTED IN DONATING?

Here is some further important information you need to be aware of.

Public/private information-alternatives

Anthony Nolan has a public cord blood bank meaning that everyone can benefit from your donation. There is no cost to donate, nor is any money paid for your donation. Your donation is seen as a voluntary goodwill gesture for unrelated use. Following donation you will no longer have ownership of the cord blood so it may not be available for your use in the future.

Alternately there are private banks that you can pay to store the cord blood for your own purposes.

Legal requirements

We are governed by the Human Tissue Authority (HTA) whose role is to protect the public. Collection of cord blood can only be carried out under a HTA licence and by somebody who has had specialist training or it would be breaking the law. We work under the Anthony Nolan HTA licence and all the cord blood team has had this training.

Consent

Only the mother of the baby can give consent. Any pre-consent form, online registration or verbal consent signed by your health care professional will only give us permission to collect the cord blood. We require a formal full informed consent before we can send off the cord blood for processing and long term storage.

Full consent comprises of having read this leaflet and had an opportunity to speak to one of our collection team to make sure you have understood

the information and had an opportunity to ask questions. You will then sign a consent form.

Once the cord blood is processed it is frozen and stored in our cord blood bank. Maternal and cord blood samples and cord tissue samples are stored for future testing.

Your consent for this donation is seen as enduring (i.e. has no time limit) and will be for both transplant and for research. It is possible to consent for one scheduled purpose only. You can withdraw your consent at any time without prejudice by contacting programme staff – unless we have already used it.

Donor data recording/linkage

Your cord blood donation will be anonymised, however the linkage between you and your donation will always remain in place in order that we can identify it if you want to withdraw your consent.

Collection procedure

A piece of placental/umbilical tissue will be collected also – potentially for research. The collection takes place at the point at which the placenta would normally be thrown away. The procedure is risk free.

Research

All research is ethically approved by Anthony Nolan. It could go abroad, involve animals or commercial companies. The samples collected and stored for research purposes will be used in human biomedical research projects only. In some cases payment is received by the programme from researchers for blood and tissue received. This is used to help the charity keep the cord programme running.

Analytical tests

Your blood will be tested for a wide range of infections for the safety of any potential recipient of a transplant. This includes tests for HIV, hepatitis, syphilis and HTLV as well as tests for some other blood borne infections. Also we do DNA analysis to obtain your tissue type (HLA) to help find a better match. The cord blood is also tested for infections, is tissue typed and tested for genetic conditions (duplicating the NHS neonatal screening test e.g. haemoglobinopathies).

If any result comes back positive we will contact you and your GP. However we may not always perform the tests, so if you do not hear from us you cannot assume that the results are negative.

As a donor you have a right to receive any analytical test result so contact us if you are concerned (Anthony Nolan or collection staff).

Data protection

We are also governed by the 1998 Data Protection Act and from 25 May 2018 the General Data Protection Regulation (GDPR) 2016 so only collect data that is required for the purposes of the cord blood programme. Any data is held securely. If suitable for transplant the cord blood and donor eligibility details will be listed on national and international registries. We require your permission to review your maternity records to gather demographic and health data. You have a right to see your own health records and correct information held about you.

Your details are safe with us. We promise to protect and respect your privacy. Please refer to our Privacy policy for more information about how we process your data. You can update your preferences at any time by emailing support@anthonymolan.org

Follow up

We may contact you in the future to check on you and your baby's health. It is an important safety check before the sample is sent out for transplant so it is important that you respond. If you do donate please let us know if your baby develops a serious disease in the future.

Questions

If you do not understand any of the information in the leaflet or the consent form or if you feel there may be any conflict with your cultural or religious needs, please do not hesitate to ask the collection team any questions before you make a decision to donate. You can also call us on **0303 303 0303** or visit anthonymolan.org/cord

We ask that any information you provide to us should be as accurate as possible to the best of your knowledge.

You cannot donate your cord blood if you have ever:

- had malaria
- received a blood transfusion or blood derived product since 1980
- injected drugs for non-medical reasons
- received money or drugs in exchange for sex
- been diagnosed with HIV, hepatitis B or hepatitis C
- or if you are under 16

Or if, in the last 12 months, you have had sex with:

- a partner who has had sex with someone in exchange for money or drugs
- a partner who injects drugs for non-medical reasons
- a partner who has been diagnosed with HIV, hepatitis B or hepatitis C
- a man who has had sex with another man

PRE-CONSENT FORM

Donating your cord blood costs you nothing, but it could save a life. If you're interested in donating, just complete this form and return it to us free of charge. However, if you have printed this form then it's not possible to send via Freepost so either just hand it in or send via Royal Mail.

Alternatively, visit anthonymolan.org/cord and register online.

PLEASE PRINT IN CAPITALS.

First name(s)

Surname

Your DOB

Address

Postcode

Phone

Email

Maternity hospital

Hospital number

Baby's due date

Signature

Date

Please tick as appropriate

☐ I give Anthony Nolan permission to collect and evaluate my cord blood and place it in short term storage at the hospital if I have my baby prior to completing formal consent.

Anthony Nolan will hold your personal details including your medical data, securely within our organisation. This includes us having access to your NHS maternity records. All personal data will be processed in accordance with Data Protection Laws (including the Data Protection Act 1998 and from 25 May 2018 the General Data Protection Regulation (GDPR) 2016.

We would love to keep in touch with you about our life saving work, including news, fundraising activities and how you can support us.

Please let us know if you would like us to contact you by

Email

☐ Yes

☐ No

Telephone

☐ Yes

☐ No

Mobile (SMS)

☐ Yes

☐ No

From time to time, we will also send you information about our lifesaving work, including news, fundraising opportunities and how you could support us by post. Please tick this box if you would prefer not to get post from us. ☐



MY BABY AND I WANT TO SAVE LIVES

Please hand you in your form or send via Royal Mail affixing a stamp here.

Anthony Nolan Cord Collection
Ward 64
2nd Floor
Saint Mary's Hospital
Oxford Road
Manchester
M13 9WL



'IT'S AMAZING. ON
THE DAY YOU GIVE
LIFE, YOU COULD
ALSO SAVE A LIFE.'

Katherine, cord blood donor

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**ANTHONY
NOLAN**

**saving the lives
of people with
blood cancer**