



Commit to a lifesaving
procedure now...

You may have a rare and priceless gift

Every year thousands of people die from fatal blood and bone marrow diseases. A blood stem cell donor whose tissue type matches a patient could quite simply make the difference between life and death for that patient. **You could be that match.**

“ In order to save more lives, the Anthony Nolan Register needs to continually increase the number of donors, in particular young donors, more males and individuals from black and minority ethnic groups. ”



Photograph by Jake Green — Response photographic

PHAP005 version 004/0309

The Anthony Nolan Trust...

was established in 1974 by Shirley Nolan, to try to find a bone marrow donor for her son Anthony. Sadly, Anthony died aged 7 without a donor being found. However, the unique work of The Anthony Nolan Trust has continued. The Anthony Nolan Trust is the first, and one of the largest independent registers of potential blood stem cell donors in the world; and the most successful in the UK.

Linked to other registers worldwide, The Anthony Nolan Trust carries out thousands of new searches each year to find donors for patients throughout the world.



“A year after I donated I was asked if I wanted to go back on the Register. I had no doubts about going back on.

The experience was incredibly upbeat and I would go through it again in an instant if I were selected as another match.”

Andy Sallnow

Why me?

Did you know?

By the time you have finished reading this leaflet, someone, somewhere, will have been diagnosed with leukaemia or another form of life threatening bone marrow disease.

Amazingly, the total number of tissue types that may exist is greater than the world population. **You may well be the only person**, either now or in the future, who could save the life of someone who urgently needs this lifesaving treatment.

Blood and bone marrow disorders can affect both children and adults but only around a third of patients will find a tissue type match within their family. The remainder of patients rely on the generosity of an unrelated donor.



If you love life - you could give life

By reading this you are taking the first step towards joining the Anthony Nolan Register; thereby giving hope to many patients in need of a transplant.

Route to joining the Anthony Nolan Register

- 1 Read this booklet
- 2 Check the donor criteria (see right hand panel 'Donor criteria for joining')
- 3 Make sure you read and understand pages 5-8
- 4 Happy to proceed? Complete the medical questionnaire
- 5 Postal applications; return the completed medical questionnaire to The Anthony Nolan Trust

OR

Clinic applications; proceed to the donor counselling area with your completed medical questionnaire

If you meet our criteria for joining and are:

a) applying by post, you will receive a blood sample kit to take to your GP;

OR

b) at a clinic, a blood sample will be taken by our trained personnel.

Donor criteria for joining

In order to join the Anthony Nolan Register you should:

- be aged between 18-40
- be in excellent health (please discuss any ongoing medical conditions with us before proceeding)
- weigh at least 8 st (51kg). Please check our maximum weight for height chart if you are attending a clinic
- reside in the UK (for the next three years minimum)
- be willing and able to take time off work to undergo a medical and the donation in a London hospital (loss of earnings are reimbursed)
- be committed to the responsibility of being on the Anthony Nolan Register until your 60th birthday.
- be prepared to donate anonymously to any patient worldwide.

Please discuss your decision to join the Anthony Nolan Register with your family and friends.

Keeping safe

There are a number of general health exclusions which could prevent you from joining the Anthony Nolan Register. Please read below to see if any of the listed criteria apply to you.

Our guidelines are consistent with the criteria used by other registers in Europe, North America and Australasia and also by the Department of Health (UK).

It is vital that individuals are honest and exclude themselves from the Anthony Nolan Register if they believe they could be at an increased risk of transmitting a blood-borne disease through their lifestyle, travel or medical history.

You cannot join the Register if...

- you or your partner are HIV or HTLV positive or carry the Hepatitis B and/or Hepatitis C virus
- you think you might need a test for HIV, Hepatitis B or Hepatitis C
- you have in the last twelve months injected yourself with illegal or non-prescription drugs, including body building drugs
- you are involved in high risk sexual practices that may increase your risk of exposure to transmissible diseases.

Please remember, you may be at ongoing risk of HIV or Hepatitis B or Hepatitis C after sex with ...

- any individual you think may be HIV, HTLV positive or a Hepatitis B or Hepatitis C carrier
- any individual who has in the last twelve months participated in high risk sexual activities including unprotected sex with multiple partners
- any individual who has ever injected or has been injected with illegal or non-prescription drugs
- any individual who has had unprotected sex with partners from areas of the world where AIDS/HIV is very common, including some countries in Africa. The main route of HIV infection in Africa is through heterosexual sex.

If you have any questions or concerns regarding keeping safe – these can be discussed confidentially with Anthony Nolan staff either at the donor recruitment counselling session or by phone.

You've got this far... now what?

Before we ask you to complete the medical questionnaire we would like to explain what we need and what would happen should you be found to be a match for a patient. Currently approximately one in every thousand people on the Anthony Nolan Register is selected as a match for a patient each year!

Blood stem cells are produced in bone marrow which is found in the centre of all large bones. These cells develop into mature blood cells – each having an important role:

- white blood cells help fight infection
- red blood cells carry oxygen to tissues throughout the body
- platelets help to control bleeding.

When essential bone marrow is destroyed by disease or by treatment to eradicate leukaemia and other blood disorders, a transplant from a tissue type matching donor offers the greatest chance of recovery.

A donor's healthy blood stem cells are transfused into a patient where they have the potential to regenerate, producing the healthy blood cells needed by the patient to stay alive.

“
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”

The donation process...

If you are selected as a possible match for a patient, we will contact you using the details you give us when you join the Anthony Nolan Register, and we will request another blood sample for confirmatory testing which includes virology screening. These tests are required to confirm whether you are an appropriate match for a particular patient.

Are you aware?

Matching for bone marrow transplantation is much more complex than simply matching blood group types. It is based on the analysis of genetic markers that are found on most of our cells in our bodies. These markers are our tissue types.

Should you be selected as a donor, there are two ways in which your blood stem cells can be collected. Ideally volunteers should be willing to donate by either method. Both options will be discussed with you prior to the procedure taking place, and greater detail will be provided in order for you to make an informed decision about your choice. As part of the donation process, every donor has a comprehensive medical examination in London to ensure their fitness to undergo the collection. This takes place approximately 2-3 weeks prior to the actual donation.

The costs of the medical as well as the donation (including travel, accommodation and subsistence) are covered by The Anthony Nolan Trust.

It is vital that you only join the Anthony Nolan Register today if you are really committed to donating your blood stem cells should you match.



Bone marrow harvest

Blood stem cells are produced in bone marrow which is found in the centre of all large bones. These cells develop into mature blood cells – each having an important role:

- white blood cells help fight infection
- red blood cells carry oxygen to tissues throughout the body
- platelets help form blood clots to control bleeding.

Step 1 The donor is given a general anaesthetic and bone marrow is withdrawn from the pelvic bones using a sterile needle and syringe.

Step 2 The donor will spend three days and two nights in a London hospital and is usually able to return home 24 hours after donating

Step 3 Short term effects will include tiredness and may include localised discomfort in the lower back or bruising.

Step 4 Most donors are able to resume normal activities after 7-10 days.

Step 5 Donors are required to have a full blood count four weeks after donation to ensure normal levels have returned. (The bone marrow cells will replace themselves within 4-6 weeks).

Potential risks of the donation

- infection, or injury at the needle insertion sites
- adverse reaction to the general anaesthetic

All risks are very rare and certainly no greater than undergoing any minor operation.

Peripheral blood stem cell (PBSC) collection

Blood stem cells are also found in the blood stream (peripheral blood), but in much smaller numbers.

Step 1 On consecutive days, donors receive three of the 4/5 day series of injections of synthetic growth factor (G-CSF) at work or at home given by a trained nurse. This growth factor stimulates production and movement of blood stem cells to the peripheral blood.

Step 2 Donor has a blood test and the fourth course of injections in London the day before the first collection

Step 3 A needle is inserted into veins in each of the donor's arms and the blood is passed through a leucapheresis machine which removes white blood cells and a small amount of plasma only. The donor undergoes this procedure as an outpatient (7-8 hours total in a London hospital).

Step 4 There may be one or two collections on successive days. If a second collection is required this will involve 4-5 hours in hospital on the second day.

Step 5 The donor is usually able to resume normal activities after two days.

Potential risks of the donation

Side effects may include mild flu-like symptoms such as headaches, muscle and bone pain which are normally alleviated by a non-aspirin containing medication. Symptoms usually disappear within 24 hours of the last injection.

Protection of your data

We (The Anthony Nolan Trust and Anthony Nolan Marketing Limited, collectively 'the Trust') have a legal obligation under the Data Protection Act 1998 to ensure that all information about you held by us is processed in accordance with the Act. The uses of such information are covered by our notification under the Data Protection Act 1998.

- We will not collect information about you except where you specifically and knowingly provide it or give us your consent to obtain it.
- Your personal details (eg name, postal and e-mail addresses) as well as sensitive personal information (tissue type, ethnic origin and pertinent medical details) are held on a central database by The Anthony Nolan Trust.
- We will use such data to administer our relationship with you as a member of the Anthony Nolan Register and to keep in touch with you concerning our activities as a fundraising charity, blood stem cell register and scientific research institute. We will not supply your data to any third party except where a) this is necessary for us to carry out our activities or b) we are required to do so by law.
- All sensitive personal information is handled as strictly confidential, and can only be accessed by authorised Trust staff. Any authorised individual working with data held by The Anthony Nolan Trust has a legal duty to keep information confidential.
- When you join the Register we will assign you a unique donor ID. This will be used for the purposes of providing information anonymously to transplant centres and other registries around the world for the matching and donation process.
- You have a right under the Data Protection Act to obtain from us a description of the personal information that we hold on you, and a right to have that information provided to you. Should you wish to know what information we hold on you, or to see it (we may charge a fee for this), please write to our Data Protection Officer at The Anthony Nolan Trust, Royal Free Hospital, London NW3 2QG.



Photograph by Glasgow Evening Times.

“Johanna campaigned ferociously to raise awareness of the need for people to join the Anthony Nolan Register. The Anthony Nolan Trust gave us hope for 12 years, the Charity never failed to find her a match – her match simply just didn't join the Register.”

Angela MacVicar, Johanna's mother

Joining the Register?

We are delighted that you are now making the decision to help The Anthony Nolan Trust take back lives from leukaemia.

If you are attending one of the Anthony Nolan clinics, please fill in the medical questionnaire. One of The Anthony Nolan Trust staff will discuss the process with you before arranging to take a small blood sample.

If you are reading this at home, then please fill in the medical questionnaire and return it to us in the envelope provided. We will assess your questionnaire and contact you with further instructions.



There are many other ways you can help us save lives. As an independent charity, The Anthony Nolan Trust continually relies on financial and other voluntary support from the general public. Without those funds the Charity could not carry on its lifesaving work.

**For further information please call 020 7284 1234
or visit www.anthonynolan.org.uk**

FAQs

If I join the Register will I definitely be asked to donate?

You are only called on to donate if you have a similar tissue type to that of a specific patient in need of a bone marrow transplant. However, each and every individual on the register could be called upon to donate at any time over a period of many years. If you are found to be a suitable donor and decide not to donate this could be devastating news to the patient facing a life-threatening illness.

Does it cost me anything to join the Anthony Nolan Register?

No, joining our bone marrow register is free. The Anthony Nolan Trust will also reimburse any expenses you incur as a result of donating your blood stem cells. These expenses include travel, accommodation, loss of earnings and any other out of pocket expenses. However, as a charity with limited funds, we have to stress that potential donors should fully consider the implications of joining the Anthony Nolan Register and be fully committed to being a donor as it is costly for us to add each new donor to the Register.

Could I be a donor more than once? If so, how often?

After the first donation, the donor is asked if they would like to stay on the Register and donate again. Although this is unusual, The Anthony Nolan Trust has had several donors who have donated three times. Current policy permits a volunteer to donate blood stem cells up to a maximum of four times.

Do I need to join more than one register worldwide?

No, you only need to join one bone marrow register. Joining more than one registry would cause duplication of records and waste valuable resources. Should you relocate to another country, you may ask for your records to be transferred to the registry of that country.

FAQs

What if I have medical complications following my donation?

Although we do not anticipate claims, all donors are covered by insurance that is taken out on their behalf against death and physical or mental disablement.

Why do you need to recruit more men than women?

For a number of clinical reasons, men are the preferred donors. In recent years 70% of matched donors who went through the procedure were men. Yet only 45% of donors on the Anthony Nolan Register are men.

I am 41 and in good health. Why can't I join the Register?

The possibility of becoming a donor is small, and we incur high costs to register and maintain an active donor register. We concentrate on recruiting younger donors (who are more likely to be selected by transplant centres) because they are likely to remain on the Register for a longer time.

If I donate, will the patient know my identity?

The Anthony Nolan Trust maintains a two year period during which correspondence between patient and donor, if any, is anonymous. After two years, and only if both patient and donor are in agreement, their details may be exchanged. Some registries and transplant centres have different policies and in those cases we abide by the most stringent policy.

FAQs

Why do you need to know my ethnic origin?

Is it important?

Ethnic origin is important when matching donors and patients. The tissue types that are tested when searching for a suitable blood stem cell donor are genetically inherited and often unique to a particular race. A patient in need of a transplant is more likely to discover a suitable donor amongst groups of people who share a similar genetic history to them. In practice this means that an African-Caribbean patient, for example, has the greatest opportunity of finding a donor within their own ethnic community.

How long will I be on the Register?

Donors may remain on the Register until they turn 60 unless they wish to be removed or other criteria arise that makes them no longer a suitable candidate for donation.

I would like to donate to a specific person only.

Should I still join?

Donors on the Register will not be provided with identification details on their potential recipient so they must be prepared to donate to anyone, anywhere regardless of their nationality, ethnic origin, religion or other persuasion.

Please join the Anthony Nolan Register and make someone else's hope become a reality.



Photographs by Allan Jones.

The information in this booklet is correct at time of going to press.

“It is good to be alive”

Jonathan, a blood stem cell recipient.