



FREQUENTLY ASKED QUESTIONS

BONE MARROW / STEM CELL DONATION

About Anthony Nolan

Anthony Nolan is a pioneering charity that saves the lives of people with blood cancer who need a bone marrow, or stem cell, transplant. In 1974, Anthony Nolan's mother, Shirley, set up the world's first bone marrow register to match donors with people who desperately needed a transplant. Now, every day, we help three people in need of a potentially lifesaving transplant by using our register to find remarkable donors who are willing to give some of their bone marrow or stem cells to help a stranger. We are a UK charity with international reach, and we carry out world class research into stem cell matching and transplants to improve outcomes for all patients. There are currently almost 2000 people in the UK waiting for a stem cell transplant, and 37,000 worldwide.

About blood cancers

There are three main types of blood cancer; leukaemia, lymphoma and myeloma. Blood cancers are life-threatening partly because they prevent a person's immune system from working properly. When a person's immune system is badly damaged, they can die from an infection which their body would normally fight off. On average, one person every 20 minutes is diagnosed with blood cancer in the UK.

Treating blood cancers

All blood cells originate in the bone marrow from the same type of cell, called a blood stem cell. A blood stem cell transplant can replace a damaged immune system in a person with blood cancer - but only if the donor's cell type matches. A transplant works by taking blood stem cells or bone marrow from a healthy donor and giving them to the patient. The donor and the patient must have the same tissue type and, as there are millions of different combinations, finding a suitable match is very complicated. For many people with blood cancer, a transplant is their last chance of life.

The need for donors

We urgently need more people to join our register, so we can provide more matches and help save more lives. We also need more funds to increase our lifesaving work. Growing our donor register, our cord blood bank and our pioneering research all cost money. The more funds we have, the more lives we can help save.

We particularly need to recruit more young men. We also need more donors from a diverse range of ethnic backgrounds, as we often struggle to find matches for people with blood cancer in these groups

Currently, if you're white, northern European you have a 96% chance of finding a match. If you're from a BAME background, this drops to around 60%

We want all people with blood cancer to have the best possible chance of survival following a transplant. Currently, only 60% of transplant recipients receive the best

possible match (10/10). By building a more diverse register, we will be able to provide this best match to more people.

Joining the register

People in good health and aged between 16 and 30 years of age are eligible to register as new potential donors with Anthony Nolan. But we particularly need to recruit more young men, as they are most likely to be chosen to donate by transplant centres.

There are some medical criteria that exclude people from joining the register. They can be found by visiting www.anthonynolan.org or calling 0303 303 0303.

Registration involves completing a simple form – either at a donor recruitment event or via our website – and then providing a DNA sample with a simple home test kit.

Donating stem cells

Peripheral Blood Stem Cell (PBSC) donation

This is the most popular form of stem cell transplantation; around 90% of donations are made this way. A nurse will come to the donor's home or office to give them a series of injections over four days to stimulate the production of stem cells. The donation itself is carried out as an outpatient procedure at a London or Sheffield hospital. A needle is inserted into the donor's arm and their blood is passed through a machine which sifts off the stem cells. It's a similar sensation to giving blood and it takes around 4-5 hours. PBSC donors may have mild flu-like symptoms, such as headaches and muscle and bone pain while they're having the injections, but these will usually go away within 24 hours of the last injection.

Bone marrow collection

If a donor donates through a bone marrow collection, they'll come to a hospital in London or Sheffield where they'll spend two nights. The donor is given a general anaesthetic and doctors will take some of their bone marrow from the pelvis using a needle and syringe. Following the donation, they may experience some short term lower back discomfort. Usually donors can resume normal activities after two days.

Frequently asked questions about bone marrow / blood stem cell donation

What are stem cells?

When a stem cell divides, each new cell can either remain a stem cell or specialise into another type of cell, such as a muscle, skin or blood cell. These can divide to replenish other damaged cells, and in doing so, can act as a repair system for the body. Stem cells are made in the bone marrow.

If I donate, how long will it take my body to replace the donated stem cells?

The body begins to replace the stem cells immediately, with levels returning to normal after an average of 21 days.

What will they do with my stem cells?

Your donation of stem cells will be infused into the recipient's bloodstream the same day or day after you donate. If the recipient's body accepts them, the stem cells will start producing healthy blood cells. This will allow the body to do lifesaving activities like carry oxygen round the body and fight infection.

Is donating painful? Does it have side effects?

There is a common misconception that donating stem cells is painful, but it's not as bad as many people think. PBSC donors usually have flu-like symptoms while they are getting the injections to stimulate their production of stem cells. These will usually go away within 24 hours of the last injection.

Does PBSC donation have side effects or cause leukaemia?

There is no evidence to suggest that PBSC donation or the drugs used to stimulate stem cell production can cause leukaemia. Common side effects are outlined above.

Do I get paid?

No, we operate as a public service because we want to help any patient who needs a stem cell transplant.

Why do I have to be willing to donate in two different ways (PBSC and bone marrow collection)?

Either form of donation can be successful for transplant purposes but in certain situations the transplant doctor may specify that one method is the better option for their patient.

If I donate, will the person who gets my stem cells know who I am?

No, both you and the person you're helping will remain anonymous. This makes sure no one feels under pressure. Anthony Nolan operates a policy which allows donors and patients to communicate but only through messages sent via our team. After two years, and only if both sides agree, they will be able to exchange contact details.

Can I choose who my stem cells are given to?

No. If you are asked to donate your stem cells, it will be to help a person in urgent need of a potentially lifesaving transplant, who matches your tissue type.

Why can't you know who you have donated to?

It is important that the donor and patient are both anonymous so that no one feels under any undue pressure at any point in the process. Anthony Nolan operates a policy which allows donors and patients to communicate but only through messages sent via our team. After two years, and only if both sides agree, they will be able to exchange contact details.

If someone has a bone marrow or stem cell transplant, can you actually say you've saved their life? What are their chances?

For many people with blood cancer and other blood disorders, a bone marrow transplant is their only hope of a cure. Medical advances and vital research by Anthony Nolan mean survival rates for those who have received a transplant are going up all the time. But transplantation is a complicated procedure and the probability of long-term survival can range between 30 and 70%, depending on a variety of factors. Without a transplant to offer a potential cure, the chance of survival for these patients is very much lower. Whatever the outcome, donating to someone gives them a chance of life they would not otherwise have and can give people more precious time with their family and friends.

FREQUENTLY ASKED QUESTIONS ABOUT THE REGISTER**Who was Anthony Nolan?**

In 1971, Anthony Nolan was born with a rare condition called Wiskott Aldrich. The only known cure was a bone marrow transplant, but there was no process or system to find a matching donor. 1973 saw the first successful bone marrow transplant

between unrelated donors - previously, matches had only been made through relatives.

Anthony's mother Shirley had a vision: to start a bone marrow register that would connect potential donors with people like her son, who desperately needed a transplant. In 1974, the Anthony Nolan register was created. Anthony Nolan died in 1979, before a suitable match could be found for him, but, his legacy saved, and continues to save, thousands of lives.

How much of the money you raise goes on providing transplants?

For each pound we receive:

- 82p goes to help save lives. This 82p includes providing donors, finding overseas donors, recruiting new donors..
- 9p goes to research. This includes cord blood research, and finding ways to make stem cell transplantation more successful.
- 8p goes to raising more money. This includes fundraising activities.
- 1p goes to administration. This includes the day-to-day running of the charity.

How many people are on the Anthony Nolan register?

We currently have over 600,000 people on the Anthony Nolan register, but we urgently need more. Every day, we help three people in need of a potentially lifesaving transplant by using our register to find remarkable donors for patients in need. But there are still many more people who come to us in desperate need of a lifesaving transplant.

Why do you need more people on the register? Isn't 600,000 enough?

There are still many more people who come to us in desperate need of a lifesaving transplant. Many people with blood cancer die because a suitable match can't be found in time to help them.

Do I get paid for joining the register?

No, we operate our register as a public bank because we want to help any patient who needs a cord blood or stem cell transplant.

Do I have to be dead to donate?

No. We can only accept donations from living donors.

I'm already an organ donor – does that mean I'm automatically on the Anthony Nolan Register?

No it does not. Even if you are an organ or blood donor, you will still need to go through the Anthony Nolan donor recruitment process to join the register.

I'm already on the NHS Blood Service Bone Marrow Register or DKMS register – do I need to join the Anthony Nolan Register too?

No. You only need to be on one donor register.

Why can't you join if you're over 30?

You have a 1 in 790 chance of being a match and asked to donate in the next five years when you join the register.

But if you are a match, you're more likely to be chosen by the transplant centre to donate if you're younger.

Younger donors are the most likely to be selected by hospitals to donate, as they are less likely to have developed health issues which could prevent or delay donation.

Also, those younger donors will be on the Anthony Nolan register for the longest possible time, so it's more cost-effective for a charity like ours with limited funds. We do, however, have many alternative ways that people can help us which can be found on our website and we also regularly review our age criteria.

Why do you need to recruit more men than women?

Men are more likely to be chosen by hospitals to donate than women. Many of the stem cell donations we arrange come from young men, but they account for only 15% of those on the Anthony Nolan register. This is why we urgently need to recruit more.

Can women donate if they are pregnant or have had a baby?

Women are eligible to donate whether they have had children or not. If you are pregnant you may join the Anthony Nolan register, but will not be made active until your baby is one year old because of the antibodies your body produces in this period.

Do the donor and patient need to be of the same ethnicity? Would you need to be black to match a black patient, etc?

There are millions of different tissue types but the best match is likely to come from someone in the same ethnic group as the person needing a transplant. It can be much harder for people from black, Asian or other ethnic backgrounds to find a match because there are fewer people from these groups both on the Anthony Nolan register and registers abroad.

How much harder is it to find a match if you are from a minority ethnic background?

It is difficult to say exactly how much harder it is for different ethnic groups to find a match because there are so many different ethnic mixes and other factors to take into account. However, it is estimated that if you are white, northern European, you have as high as a 96% chance of finding a match but this falls to around 60% for a person from an ethnic minority background.

Can you join the register if you're gay?

Yes. Anthony Nolan believes that a person's sexuality in itself should not exclude them from joining our register. The criteria are the same for everyone. We ask all our donors to answer a full medical questionnaire, which includes several questions relating to lifestyle.