

Guide for stem cell donors via bone marrow



DKMS is one of the most significant non-profit organisations in the world dedicated to the fight against blood cancer. We encourage more people to join the stem cell register, work to ensure everyone who needs a stem cell transplant has equal access to one, and conduct research focused on continually improving the survival and recovery rate of people with blood cancers or disorders.

Founded in Germany in 1991 by Dr Peter Harf, DKMS and the organisation's over 1,200 employees have since relentlessly pursued the aim of giving as many patients as possible a second chance at life. With more than **12.5 million registered donors**, DKMS has succeeded in doing this over **120,000** times to date, by providing stem cell donations to those in need. This accomplishment has led to DKMS becoming the global leader in the facilitation of stem cell transplants.

DKMS has offices in Germany, the US, Poland, Chile, and South Africa as well as the UK. In India, DKMS has founded the joint venture DKMS-BMST together with the Bangalore Medical Services Trust. International expansion and collaboration are key to helping patients worldwide because blood cancer knows no borders.

dkms.org.uk

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Congratulations!

You have been chosen to donate stem cells to a patient needing a transplant.

It's exciting news, as it's rare to be identified as a match. Of course, we understand that you may have questions. That's why we've produced this booklet specifically for our donors who are undertaking stem cell donation via bone marrow. The booklet covers all aspects of your journey through the process – medical assessment, possible side effects and subsequent recovery, along with information on DKMS reimbursement for donors. On behalf of DKMS UK, the patient you have been matched with and their medical team, we would like to thank you for your commitment to the process so far.

More information

If you would like to chat to us about anything you read in this booklet, please contact your DKMS coordinator on **020 8747 5660** or by email on workup@dkms.org.uk

Your coordinator will be your main point of contact and will be on hand to support you through your donation journey.



Bone marrow donation

The medical team caring for the patient you have been matched with has asked that you donate stem cells via a bone marrow donation. Bone marrow donation, or harvesting, is a medical technique used to collect stem cells from your bone marrow for transplantation. It is a type of surgery done in an operating room. Cells collected using this method will give the patient you have been matched with the best chance of recovery. The use of this method is based on a variety of factors including the patient's medical diagnosis, their current condition and the stage of their disease, as well as the donor's medical history.



Your medical assessment

Before donation, you'll have a medical assessment at the stem cell collection centre where your donation will take place, to check you're physically fit and well enough to proceed. This is also a good opportunity for you to meet the medical team who will be responsible for your care and ask them any questions you may have.

Your assessment will include the following checks:

Counselling on the donation method and your consent as a donor

Your medical team will have an in-depth discussion with you about the donation method and possible side effects. Once you're comfortable with the information provided, you'll be asked to sign some consent forms.

Physical examination and health history

This will include measuring your height and weight and checking your blood pressure and vital signs. You will also be asked questions about your general health as well as any personal or relevant family medical history.

Electrocardiogram (ECG)

This non-invasive test records your heart's electrical activity to rule out any abnormalities.

Urine and blood tests

A nurse will ask you to supply a urine sample. Blood samples will be taken to check your full blood count, biochemistry and for any infections or signs of infectious diseases. If you have spent time abroad, there may be some additional samples requested.

Pregnancy test

Anyone who could become pregnant will be asked to carry out a pregnancy test during the medical assessment. An additional home pregnancy test will be supplied for use at a later date. Your coordinator will advise you on when this test should be taken as it will vary from donor to donor. This is because donors cannot proceed with donating stem cells via bone marrow if they become pregnant.

We therefore ask anyone who could become pregnant to take precautions to avoid getting pregnant in the time between being identified as a match and the donation of your stem cells. If you have concerns about this or if you do become pregnant during this time, please contact your DKMS coordinator as soon as possible (**020 8747 5660** or **workup@dkms.org.uk**).



Medical clearance and next steps

The results from your medical assessment will be available between one to two weeks after your appointment. Providing they show you are medically eligible to proceed with the donation, your DKMS coordinator will call you with

the good news and confirm arrangements for your donation.

If there are any issues with your results, the doctor will call you directly to discuss next steps. The doctor will advise you of any repeat or additional testing that may be required, in order to identify whether you can proceed as a donor. In this case, your DKMS coordinator will follow up with you to arrange any testing needed. You will receive a copy of your medical report for your own records.

Approximately one to two weeks prior to the donation, the patient you are matched with will start a conditioning regimen, also known as pre-transplant treatment. Most often this will include high doses of chemotherapy and/or radiation therapy. This intense therapy is required to effectively destroy as many of the patient's diseased cells as possible – making room in the bone marrow for the new, transplanted cells to grow. The patient's immune system is weakened by the treatment, minimising the risk that their body will reject the new cells.



Bone marrow collection

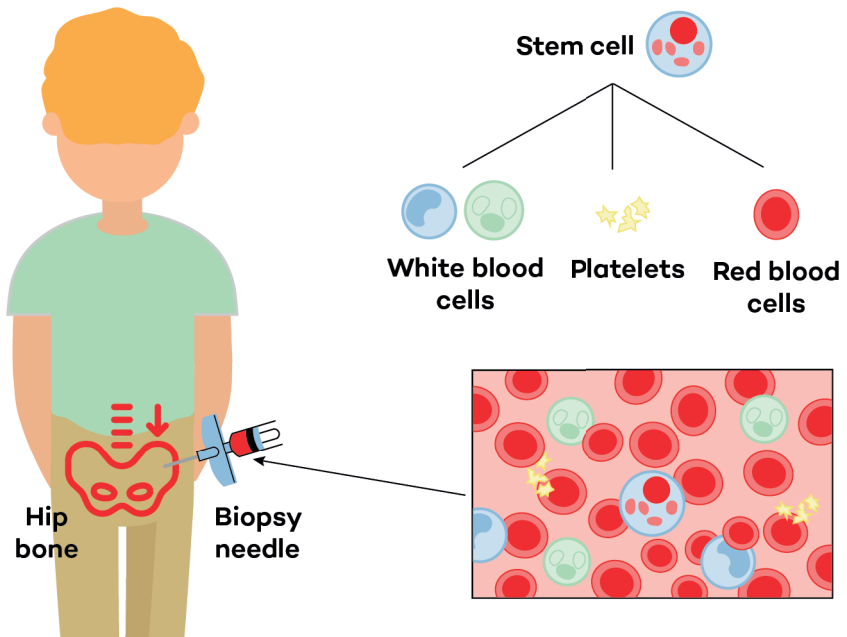
The day before the procedure, you will be admitted to the stem cell collection centre. Both pre-operative and post-

operative evaluations will be needed, so we ask that you stay at the collection centre for two nights. This will also ensure that you receive the necessary care and attention during the initial stages of your recovery.

The procedure will take place early in the morning. General anaesthesia will be administered, meaning you will be asleep and pain-free throughout the procedure, which will take between 30 minutes to one hour.

The doctor will make one or two small superficial incisions in each side of your lower back and then guide a needle through the skin and into the pelvic bone. Cells collected from within this cavity provide a rich source of stem cells that, once transplanted, will start to produce new healthy blood cells. Each incision will be about 5 millimetres and as such won't usually require stitches. No more than five per cent of your total bone marrow will be removed and this will be replenished naturally within a few weeks.

Bone Marrow Donation





Recovery and possible side effects

Following your bone marrow donation, it is common to experience some discomfort including tiredness, bruising, and mild back or hip pain that can last up to two to three weeks. You may have some minor bleeding at the incision site. Discomfort can be managed with over-the-counter painkillers such as paracetamol, but please avoid taking ibuprofen or anything that contains aspirin for two to three days post-donation. When you're discharged from the stem cell collection centre, the doctor may prescribe you some additional painkillers, if required.

While bone marrow donation is generally safe, there are some risks associated with any medical procedure, especially those involving general anaesthesia. Potential side effects of general anaesthesia may include a sore throat, lowered blood pressure, headaches, fatigue and, in rare instances, nausea or vomiting. The medical team may request that you stay an additional night in the collection centre depending on your symptoms.

To aid in your recovery, we advise avoiding heavy lifting, bending

and intense physical activity for about two weeks. It's also a good idea to take a week off work after the procedure. If your job or daily routine involves significant physical effort, you may need more than a week to fully recover. We will provide a letter for your employer with all the necessary details to request this time off.

'If it meant giving someone a chance, it seemed a small thing to do. DKMS were absolutely brilliant, they made it so easy, and arranged everything. I would definitely do it again. There was nothing complicated or difficult about the donation process.'

Debbi Long, stem cell donor by bone marrow. Read more of Debbi's donation story on [page 11](#)



Follow-up care

In the days following your donation, a member of DKMS' Donor Follow-up team will be in touch to check on your recovery and hear about your donation experience. In the unlikely event that you require any additional medical care after your donation, the Follow-up team will coordinate

with our medical adviser and the medical team at the stem cell collection centre, to ensure you receive the necessary care.

One month after your donation, we will send you a health questionnaire and a letter for a blood test at your GP surgery, to confirm that your blood counts have returned to normal. We will also follow up with you at six months, and then annually for up to ten years. Participation in this follow-up programme is optional, and you can choose to opt out at any time.

Additionally, please note that it is recommended not to donate blood for 12 months after your bone marrow donation. If you have any questions or concerns at any stage, please don't hesitate to contact us (**020 8747 5660** or **workup@dkms.org.uk**).



Patient updates and potential contact

During our follow-up call with you after your donation, we can share with you the age range and sex of the patient who received your stem cells, and the country in which they are receiving treatment. We will also be able to advise you on any possible communication/contact options available to you if you would like to

correspond with the patient. These options depend on the rules and standards set by the country where the patient is based and can vary. It's entirely up to you whether you want to contact them or not.

DKMS has also created a Donor Club on Facebook – to bring our stem cell donors together to connect, chat and share stories. It is a safe place for you share any excitement, worries or questions you have about the post-donation journey.

Subsequent donations

Occasionally, a patient may need a second donation, which can occur for a variety of reasons:

- the transplanted stem cells have not yet multiplied and developed successfully in the patient's body
- the patient has suffered a relapse
- the patient's body is rejecting the transplanted stem cells
- the patient needs a stem cell boost, to accelerate the restoration of their immune system.

For this reason, provided you are happy for us to do so, we will keep your DKMS profile 'on hold' or 'reserved' for two years specifically for this patient.

Depending on the reason for a secondary donation request, you may be asked to donate via bone marrow collection (BMH) again, via a peripheral stem cell collection (PBSC), or more likely via a lymphocyte (white blood cells) collection (MNC). Full details of these methods will be provided by

your coordinator and our medical team if a subsequent request is made. You can also find additional information regarding these methods on our website.

As always, the decision to donate remains yours.

Stem cell donor Poonam met Viren, the recipient of her stem cells, and now calls him 'Uncle Viren'.



'I'm here because of the kindness of a stranger.'
For Ivor, meeting his stem cell donor Mark was like winning the lottery.

Daniel travelled to Dallas for an emotional, once-in-a-lifetime meeting with Payton, who had received his stem cells anonymously in 2018.



Giving someone a second chance at life: Debbi's story

Debbi Long, 51, from Swindon, did something amazing. She offered a total stranger with blood cancer a second chance at life by selflessly donating stem cells, after signing up to the stem cell register held by blood cancer charity DKMS.

'I first heard about the stem cell register through **'Finn the Fabulous'** on Facebook – he's a young boy who has had two successful stem cell transplants and is now campaigning to encourage more people to register as stem cell donors,' explains Debbi. 'I was so moved that I decided to register with DKMS.'



Debbi was then contacted by DKMS because she was a match for someone needing a transplant. Debbi was asked to donate via bone marrow. 'If it meant giving someone a chance, it seemed a small thing to do,' explains Debbi. 'DKMS were absolutely brilliant, they made it so easy, and arranged everything. I would definitely do it again. There was nothing complicated or difficult about the donation process.'

Strict regulations protecting the anonymity of donors and recipients immediately following a donation mean that Debbi knows almost nothing about the patient her stem cells went to – only that he is a young boy from South Africa.

'It's quite emotional to think about his family and what they're going through,' she says. 'I'm going to get a card and present to send him and I would love to know more about my recipient, when I'm allowed to.'

Now, like Finn the Fabulous, Debbi's joined forces with DKMS to encourage more people to join the register.

Reimbursement of personal expenses

DKMS will reimburse any reasonable personal expenses related to your medical assessment and donation. Our online Webexpenses platform is easy to use and makes keeping track of expenses uncomplicated. You will need to upload images of your itemised receipts to accompany the reimbursement claim.

Here are some guidelines to help you understand which expenses we can and can't cover. Details and instructions on how to claim your expenses will be sent to you by our dedicated DKMS Reimbursements team.



Food and drink

Food and drink expenses can be reimbursed up to £35 per day. This will also apply to your companion on the days of donation.



Public transport

CT Travel, our trusted travel partner, can arrange any travel for you in advance. However, should there be any unexpected additional expenses when you

travel to your medical assessment or your donation, we will reimburse any claims relating to standard class public transport costs (e.g. trains, taxis). This will also apply to your companion when travelling to and from your donation.



Mileage and parking

Any mileage undertaken in your personal vehicle relating to travel to and from your medical assessment and/or your donation can be reimbursed at the current tax valid amount of 45 pence per mile.

For example:

Home to airport/station/hotel/hospital and return trip (e.g. 10 miles @ 45p per mile = £4.50 to be reimbursed).

Any parking costs directly relating to your travel to and from your appointments can also be reimbursed.



Driving in London

If your appointment is in Central London, we will reimburse the Congestion Charge and the Ultra-Low Emission Zone (ULEZ)

charge, if applicable. Please follow payment instructions provided on the TFL website: <https://tfl.gov.uk/modes/driving/pay-to-drive-in-london>

It's important that you ensure all charges are paid in full to avoid penalties. Penalty fee or default charges will not be reimbursed. Please note the Congestion Charge/ULEZ needs to be paid only for the days the car is in use, so if, for example, you drive into London on Monday, do not use the car on Tuesday and drive out again on Wednesday, you would not need to pay Congestion Charge/ULEZ charges for the Tuesday.



Loss of earnings

Up to £200 per day (depending on your normal daily wage) can be reimbursed, if you are not granted paid leave. Please note that National Insurance and tax

will be applied and deducted from this sum.

If your employer asks you to take unpaid leave in order for you to attend your medical assessment and donation, you will need to provide the following:

- Confirmation of dates of unpaid leave, signed by your manager and on company headed paper or by an official work email.
- Your three most recent payslips, which would be used to calculate your daily wage.






If you are self employed, please provide the following:

- Evidence of self-employed status (e.g. UTR/tax reference number, business name and address).
- Evidence of loss of earnings, for example three months' worth of invoices and bank statements.



Would you like to continue to support DKMS?

Donating your stem cells is an amazing thing to do. Following your donation, if you would like to, there are lots of ways to get involved with DKMS, helping us give more people with blood cancers or disorders a second chance at life. You could:

-  Register potential lifesavers
-  Join or start a DKMS volunteering hub
-  Raise awareness in your community or workplace
-  Fundraise for DKMS
-  Like and share our social media posts.

Find out more at dkms.org.uk/get-involved

Last but not least, a very big 'thank you' from everyone at DKMS!



'Without his stem cell donor, Finn wouldn't be here today!'

Jo Hill, mum to stem cell transplant recipient Finn

Our front cover star

Alex Reeves from Cirencester donated his stem cells by bone marrow to a young woman in the United States.

'What you're doing can help someone,' he says simply, inspired by a deeply personal, family connection. 'My mum's friend's brother survived leukaemia because of a stem cell transplant. I've seen the impact first-hand.'



'It's amazing how becoming a stem cell donor can connect you to anyone across the world. What you're doing can really help someone. Hopefully my recipient now has a lot more life to look forward to.'

Alex Reeves, stem cell donor by bone marrow

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