

# **Guide for peripheral blood stem cell donors**

# Contents

Cover image: **Kuda Mandinyenya**, donating his blood stem cells to a UK patient.

# Congratulations!

You have been chosen to donate blood stem cells to a patient - congratulations!

It's exciting news as it's rare to be identified as a match. We understand that you may have questions. That's why we've produced this booklet, specifically for our donors undergoing PBSC donation.

As well as detailed information on the medical aspects, we also include information on our reimbursement policy and some information on how to share the amazing thing you are doing via social media, should you wish to, during your donation journey.

On behalf of DKMS UK, the patient 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 discuss anything you read in this booklet, please contact your DKMS coordinator on **020 8747 5660** or by email on **[workup@dkms.org.uk](mailto:workup@dkms.org.uk)**.

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



# Peripheral Blood Stem Cell (PBSC) donation

The medical team caring for the patient you are matched with has requested that you donate via the PBSC method. They have chosen this donation method based on a variety of factors, including the medical diagnosis, the patient's current condition and the stage of the disease. There are two methods of donation which collect slightly different types of cells. On this occasion, the cells collected through a PBSC donation will give the patient the best chance of recovery.



## Your medical assessment

Prior to the donation, you will undergo a medical assessment

to check you're physically fit and well to proceed with donating stem cells.

You can eat as normal on the day of your assessment. It is recommended to have a meal before you arrive at the hospital and to ensure you are well hydrated – this will help with access to your veins when taking blood samples. We recommend you wear comfortable clothes.

Please bring a valid form of identification with you, which the nurses will check. The doctor will have an in-depth discussion with you about the donation method and possible side effects and will answer any questions you may have. The doctor will then ask you to sign consent forms once you are comfortable with the information they have given you. By signing the forms, you are consenting to the procedure and that you understand what is involved and any possible side effects or risks. The decision to donate is yours and you can withdraw from the process at any point even after consent has been signed.

Your assessment will include the following checks:

## Physical examination and health history check

The doctor and nurses will undertake a basic physical examination – this will include measuring your height and weight, taking your blood pressure, checking your pulse and your temperature. The doctor will also listen to your heart and feel your abdomen. The nurse will also check your peripheral venous access (the veins in both your arms) to ensure there is suitable access for the needles when it comes to the day of donation.

You will also be asked a series of questions about your health history and asked to complete a questionnaire.

## An electrocardiogram (to check your heart)

This is to confirm there are no abnormalities in your heart rhythm.

## Urine and blood tests

The nurses will take urine samples, to test your kidneys, and blood tests – blood samples will be used to check your full

blood count, biochemistry, any infections and/or signs of infectious diseases. In some cases, some of the blood samples will be sent to the patient's hospital, so the medical team there can perform additional testing and confirm you match.

### **Additional tests**

These may include x-rays.

### **Pregnancy**

They will also carry out a pregnancy test (via blood or urine test) for all female donors at the medical assessment, as well as asking female donors to do a urine pregnancy test prior to starting G-CSF injections. The medical team at the hospital will advise further on when to do this. This is because DKMS would not ask a pregnant woman to donate as this has not yet been proven to be medically safe.

We therefore suggest that, if possible, female potential donors use contraception, as required, in the lead up to donation and for a month after their injections. If you have concerns about this or if one of the pregnancy tests after your medical assessment is positive, please contact your coordinator or the on-call emergency number (which you will be given shortly).



### **Your results and next steps**

The results from your medical assessment are usually available after a week, and these will be forwarded to your GP for their records. Providing the results show you are medically eligible to proceed with your donation, your coordinator will call you to inform you of the good news, make any arrangements prior to your donation and provide any other support you need. If there are any issues with your results,

the doctor from the hospital you attended will call you to discuss these and inform you of the next steps. On some occasions, your results may mean that you will not be able to proceed at all and will need to be removed from our stem cell donor register. On other occasions, the doctor may advise you of some repeat or additional testing that needs to be done, in order to identify whether you can proceed or not. After the doctor has spoken with you, your coordinator will then follow up and arrange the testing as needed.



### **G-CSF Administration**

In order to ensure that you are able to donate enough blood-forming cells for the transplant, you will receive two daily G-CSF (granulocyte colony stimulating factor) injections for four consecutive days before your donation. Your injections can be administered by a healthcare professional or you can do it yourself. G-CSF is a naturally occurring growth factor that stimulates the overall production of stem cells in your bone marrow and encourages your stem cells to move from your bone marrow, which is where they are usually stored, to your blood stream. This is important because it generates sufficient quantities of stem cells to be collected on the day of your donation.

If you would prefer that a healthcare professional administers the injections, your coordinator will arrange for a nurse to come to your home or place of work. The nurse will stay with you for an hour after the first injection, and for 15 minutes for the following three days of injections. If you are self-injecting we always advise you have someone present with you for each injection.

In very rare cases, donors can have an adverse reaction to the G-CSF injections. This is why the nurse stays with you to monitor you or why we advise you have someone with you if you are self-injecting.



### **Possible G-CSF side effects**

The possible side effects of G-CSF are comparable to flu-like symptoms. You may experience these during the course of your injections. These can include headaches, bone pain (especially in your larger bones, such as your breast bone, hips and legs), fatigue and, in rare cases, nausea and skin rashes.

Another potential side effect resulting from treatment with G-CSF is a temporary enlargement of the spleen, which donors cannot normally feel at all. But to ensure the spleen is not overstretched, donors should not do any weight training, contact sports or strenuous physical work from the first day they take G-CSF for up to two weeks after the donation.

All side effects usually disappear within 48 hours of donation. You can take paracetamol to ease any discomfort but please do not take any aspirin or aspirin-containing drugs.

You will have access to our on-call coordinator 24/7 via our emergency number if you have any concerns during the time you are receiving your injections.



### **Peripheral blood stem cell donation**

When you arrive for your first day of PBSC donation, you will be settled into a large reclining chair or a bed. A few blood samples will be taken, after which a nurse will insert a needle into each of your

arms which are connected to the apheresis machine. For approximately four hours, your blood will leave your body via one of the needles, and will circulate through the apheresis machine, which will separate your stem cells from the rest of your blood cells and plasma. These cells will be collected, along with some plasma, while the rest of your blood cells and plasma will be returned to you via the needle in your other arm.

After about four hours, you will be disconnected from the machine. The nurses will monitor you and ensure you are feeling well. Your cells will be taken to the lab, where cell processing and a cell count take place – this normally takes about an hour and a half. After the cell count has been confirmed, the nurses will then be able to advise you if you are needed for a second day of collection, and if so, they will administer an additional G-CSF injection.

The reason second day donations are sometimes required is because there is a minimum number of cells that are needed for the patient's treatment to be effective. If this is the case, you will have a hotel nearby booked for you, so you can rest, and the process the following day will be exactly the same.

Please note that during the donation, due to the needles in both your arms, you will have limited mobility. You may wish to bring something to read or a device on which to watch television or films. Don't forget your charger! Nurses will be nearby at all times to assist you with anything you need and to monitor you throughout your donation.



### **Possible donation side effects**

Broadly speaking, donation is a safe procedure, however, during your donation, you might experience some tingling (which is due to the donation method slightly depleting your calcium levels) as well as some bruising at the needle sites.

Other side effects can include chills, a temporary decrease in blood platelet count and light-headedness and, in rare cases, nausea. These side effects can be treated with a calcium infusion. Donors who experience light-headedness will be advised not to drive for the rest of the donation day.

Peripheral stem cell donation has been carried out since 1988, and DKMS has documented the use and long-term effects of G-CSF in more than 80,000 of our donors since the end of the 1990s. So far, on the basis of numerous international studies, there is no evidence to suggest that use of G-CSF may lead to lasting side effects.

Most donors are able to return to their usual activities within two days of donating. If your usual activities involve physical exertion, more recovery time may be necessary – possibly up to one week.



### **Central venous line**

As part of the donation process, a nurse will aim to insert a needle into a vein in both of your arms. Sometimes it can be difficult to do this. This can be for a number of reasons, such as if your veins are narrow or quite deep in your arm. If this is the case, the nurse, or another experienced medical professional, will use a central venous line (CVL) in order

to get access. A CVL is a short plastic tube, which will be inserted into a bigger vein close to your collarbone or next to your groin. If a CVL is needed, you would receive local anaesthetic before it is inserted to ensure you don't feel any pain.

The doctor will discuss a CVL with you at your medical assessment, and you will have the opportunity to ask any questions. CVLs are not frequently required by our donors. However, if you do require a CVL, and are needed for a second day of donation, you will be admitted into the hospital overnight between the first and second day. This is so the CVL doesn't have to be removed and reinserted the following morning.



### **Follow up care**

Within a week after your donation, a member of our follow up team will get in touch by phone. The purpose of this call is to check in with you after your donation, to see how you are feeling and also to find out how your donation experience was. In the very rare case that you require any additional medical care following your donation, your follow up coordinator will liaise with our medical adviser and the hospital where you donated to support you with this. One month following your donation, a follow up health questionnaire will be sent to you along with a letter to your GP requesting a blood test to ensure all your blood counts have gone back to normal. We will then follow up 6 months post donation, then yearly for up to 10 years. This is optional and you can request to not take part in the Follow Up programme. Separately, donors are advised not to donate blood for 6 months following their PBSC donation.



### **Potentially meeting your patient**

During the follow up call, we will also be able to share some information about the patient you have donated your stem cells to, if you would like to know about them. As per international standards, we can share their age group, their gender and the country in which they are receiving treatment. We will also be able to advise you on possible communication/contact options for you, if you would like to correspond via us with the patient. These options depend on the standards set by the country where the patient is based and can vary, including needing to wait for a couple of years post-transplant before making direct contact. The patient will need to agree to communicating with you before you can start to do so.



### **Subsequent donations**

Occasionally, a patient may be in need of a second donation, which can occur for a variety of reasons.

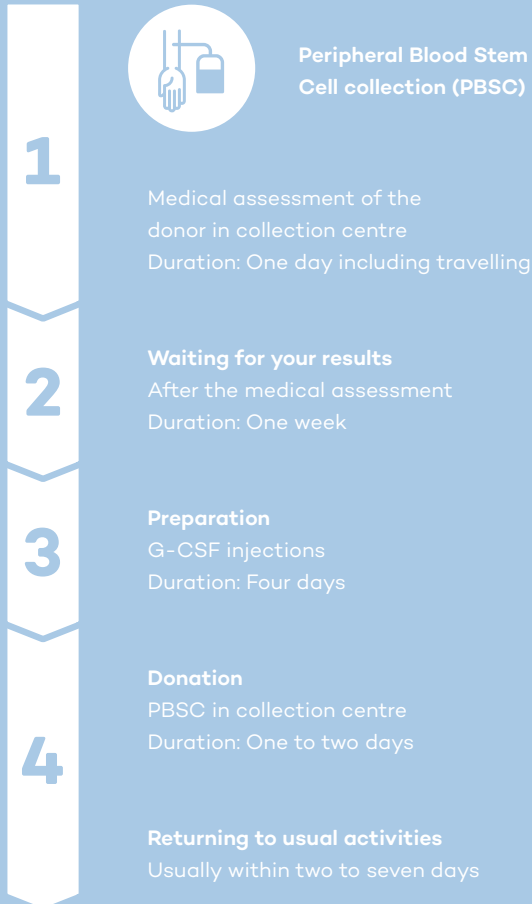
- The transplanted stem cells have not yet multiplied and developed successfully in the patient's body.
- The patient has suffered a relapse.
- The patient's body is rejecting the transplanted stem cells.
- The patient needs another stem cell donation, or stem cell boost, to accelerate the restoration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

For this reason, after your donation, we will keep you 'reserved' for two years for the patient you donated your cells to. If the patient's medical team think the patient requires additional cells, we will be in touch to check if you are willing and available to donate again. Depending on the reason the patient needs the additional cells, you may be asked to donate via PBSC collection again, via a bone marrow donation, or via a donor lymphocyte collection, which is similar to PBSC but without the injections. We have other booklets on these types of collection should you be interested.

As always, the decision to donate remains yours. The process would involve going for a medical assessment again, and discussing the donation method in-depth with the doctors to ensure you are happy to proceed.



# PBSC timeline



# Social media guidelines

We encourage you to share your experience, as showing what it is like to be a blood stem cell donor can help motivate others to take action and register as potential donors too. Raising awareness is a huge part of winning the fight against blood cancer. If you decide to publish your experience, please read the following guide. These guidelines refer to social media channels like Facebook, Instagram, Tiktok, Youtube, LinkedIn, and Twitter – as well as personal blogs, TV, radio, newspapers, and magazines.

## Why are these guidelines important?

Our goal is to protect the data and privacy of our donors and patients. According to national regulations, the stem cell donation must be anonymous. This means you are not allowed to meet, make direct contact with, or even know who the patient is - at least for a period of two years (depending on the rules of the country). This is for several important reasons:

- After a successful donation, you are reserved for the patient for two years, in case another stem cell donation is necessary. Anonymity allows you to make this decision free from emotional pressure
- While the patient is focusing on recovery, it might be too much of an emotional burden to know or meet the person who donated the stem cells.

With these guidelines we want to ensure that information shared on social media cannot be used to identify you or the patient.

## What can I talk about?



### Do share

- Your experience and talk about how it feels to give another person a second chance at life!
- General information about the patient (e.g. the age range and country of the patient)
- Your name
- Your country
- Your age
- Your stem cell donation and your support of DKMS
- That your donation took place in a hospital or collection center



### Don't share

- Your location or exact date of the donation by “checking in” on social media
- Specific and confidential details about your patient (e.g. exact age, gender, or exact location)
- Your donor number
- Your exact address, specific regions, or landmarks that would identify where you are
- Your date of birth
- The date of your donation or the date of your journey to the collection center (paraphrase it, e.g. weeks ago/last month)
- The name or exact location of the collection center

## What does this mean for my photos and videos?

The same rules apply to photos and videos – they should not provide information on your identity or the identity of the patient. Please consider the following:

- Photos and videos should not be published on the same day as the donation.
- Please do not publish photos which identify the date or location (e.g. hospital name/logo, landmarks, or wall calendars).
- Please do not publish photos of personal data (e.g. donation number, ID stickers, label on stem cell bag, hospital documentation, or any specific information about the patient.)

### Photo & video tips

- Close and centered: Please try to capture the expression on your face, get as much (day)light as possible and ensure you are in focus.
- Originals without filters: If we ask for your photos to share on the DKMS social accounts, please send us the original images at full dimensions (without filters!)
- Mix it up: Take a selection of photos and videos both vertically and horizontally, with and without flash.
- Try different angles and poses and express what it feels like to be a donor!
- You can easily make a video of a compilation of photos or a mix with small video snippets from your donation day.
- High resolution: If possible, try and send us photos with the highest resolution you can get.

- Please tag us in your content and use hashtags like #deletebloodcancer. We are happy to like and share it.



### Giving an interview or have further questions?

Thank you for supporting us and spreading our message! Please contact us if you receive an interview request so we can help you prepare and ensure you have all the information you might need. The main contact person before and during donation is your case manager.

Unsure if your social media post meets the guidelines? Our social media team will be happy to help you and will often share posts on our DKMS channels.

In addition, our social media team is always happy to receive your photos or videos to share on DKMS' own channels.

**You can find us and some inspiration here:**



# Reimbursement of personal expenses

DKMS will reimburse any reasonable personal expenses related to your medical assessment and donation. Please bear in mind that we can only reimburse costs evidenced by itemised receipts and these should be provided with your reimbursement claim. We have included some guidelines below to help you understand which expenses we can and can't cover. Details on how to claim your expenses will be sent to you by your coordinator. All information is correct as at June 2023, but is subject to change.



## Food and drink

Food and drink expenses can be reimbursed up to £35 per day, plus £35 per day for your companion on your donation day. We cannot reimburse any costs for alcoholic drinks.



## Public transport

CT Travel, our trusted travel partner, will arrange 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 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 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 on 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. Note NI and tax will be applied and deducted from this sum.

We encourage you NOT to take annual leave for the procedure, wherever possible, and will support you in recovering certain costs incurred. If your employer asks you to take unpaid leave in order for you to attend your medical assessment and donation, please provide the following information in your reimbursement claim:

- 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 recent invoices.







# A previous donor's story

Pria, a doctor from Crawley, registered with DKMS in 2020, having been inspired by a message on social media.

She was then contacted by DKMS just five months later, informing her that she was a potential match for a stranger in need of a lifesaving blood stem cell transplant.

The mum of two said: "I received a call from a lady at DKMS. She said I was extremely close to being a match, but there were also eight other people who were identified as possible matches too. As it was nine of us in total, you never expect you'll be chosen."

"My actual donation was really nice, especially as there were other donors in the room at the same time donating for other patients. They really go out of their way to look after you. We were treated to a lovely lunch. You can't really complain because the treatment you receive when you are there is amazing. I've remained terrific friends with one of my fellow donors."

Pria, who is happy to share her story to help others, said: "It was really sweet to receive a letter from DKMS thanking me for being a lifesaver, especially in the midst of a pandemic. It almost brought tears to my eyes. I don't know anything about my patient other than she is a woman. She really is a stranger, but I hope my blood stem cells help her to live a long life."

# Thank you for your support

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