DKMS

WE DELETE BLOOD CANCER



DONOR HANDBOOK

CONFIRMATORY TYPING

“Thank you for being an important part in our key mission and the cause of working towards providing all blood cancer patients with a potential donor.

We believe that no blood cancer patient should be denied a second chance at life.”

— DKMS Foundation India

AT YOUR SIDE ON YOUR LIFE SAVING JOURNEY

Dear Potential Donor,

If you are reading this handbook, it is likely you have received the great news that a request has been made on behalf of a patient who needs some of your stem cells. With this handbook, we want to guide you through the following steps and help you feel secure in your decision. Here, you can find answers to your questions and information on the processes and support offered to you by our team at DKMS Foundation India.

We thank you for making the important commitment to potentially saving someone's life. Our commitment is to support you at every step on the way of your lifesaving journey.

Together we can save lives.

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“Whenever you get a chance to do good for someone, just go for it!”

Jeethesh, Blood stem cell donor

THERE ARE SURVIVORS BECAUSE THERE ARE LIFESAVERS

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CONFIRMING THAT YOU ARE A MATCH

You've been identified as a match because you have the same tissue type of the patient. This patient is desperately in need of a stem cell transplant now. When you registered with DKMS Foundation India, you submitted a cheek swab sample that was tested to determine your tissue type (HLA-Human Leukocyte antigen). Your tissue type has now been found to be a match for this patient.

Donating blood stem cells is a serious commitment to the patient, who is in critical need of the stem cells that might potentially save their life. This decision is a personal one and it is completely voluntary.

This section of the booklet explains the Health and Availability Check, Peripheral Blood Stem Cell (PBSC) donation process and how we will support you throughout your journey.

“It feels good to help others but it feels awesome when you are a reason for someone’s life”!

Dr. Shaina, Blood stem cell donor



CONFIRMATORY TYPING

GET INFORMED

Once you have been found to be a match to the patient, we will get in touch with you to share this good news. A detailed information session will be conducted by our coordinator. You will be asked a few important health questions during this stage just to ensure you are fit and healthy. The coordinator will explain the peripheral blood stem cell donation procedure in detail. All your questions and concerns with regard to PBSC donation will be addressed by the coordinator.

DONOR RIGHTS AND PATIENT SAFETY

At DKMS Foundation India, our donors' health and safety is our top most priority. We pull out all stops to ensure the blood stem cell donation process is comfortable and easy for the donors.

Your committed decision is of prime importance. Donation is entirely voluntary and this is an important decision for you. On the other hand the patient will receive high dose chemotherapy and radiation therapy a few days before your donation to prepare for the transplant. If you are unable to donate after the patient's intensive treatment has begun, this would be fatal for the patient and the patient will be denied a second chance at life. If you have any concerns please let us know as soon as possible. However, you have the right to withdraw at any stage of the procedure.

Talk to your family and friends, as they can help you think it through. Please ask us for a leaflet designed exclusively for your family and friends. If you would like to talk to somebody who has already donated their stem cells, we may be able to put you in touch with someone.

SUBMIT THE HEALTH HISTORY QUESTIONNAIRE AND CONSENT FORM

Once you confirm your willingness to go ahead with the donation process, you will be asked to fill in a health history questionnaire (HHQ). The HHQ ensures there are no health issues preventing you from donating your blood stem cells. Your consent enables us to move forward with the Peripheral Blood Stem Cell donation process.

Any medical condition will be thoroughly reviewed by our medical team and if donating poses any additional risk to you, you will not be asked to proceed as a donor. Depending on your health status, it is possible that you may be temporarily deferred to donate, or need to be permanently removed from the registry.

SCHEDULING BLOOD DRAW

During this step, we will schedule a blood draw at your residence as per your convenience, during working hours. A small amount of blood sample is collected to re-confirm you are the perfect match for the patient and also to check a few infectious diseases such as HIV, hepatitis, malaria, etc. This process is called **Confirmatory Typing**.

KEEP US UPDATED AND BE READY

Once you are eligible as a donor, complete your health history questionnaire and give your consent to proceed, you will have already become an essential part of the patient's search for a donor and may well be their only opportunity for a second chance at life.

It can take anywhere from one week to three months to schedule the final phases of your donation. Once it is determined that you are the best match and the patient is ready to proceed, we will schedule a medical assessment and the PBSC donation. The following section of the handbook will discuss PBSC donation.



Sri Harsha,
Blood stem cell donor

AT A GLANCE

GET INFORMED, CONFIRMATORY TYPING

Info session with coordinator, complete health history questionnaire, blood draw

KEEP US UPDATED AND BE READY

Waiting period – 1 to 3 months

INFO SESSION

Discussion of PBSC donation process and scheduling

MEDICAL ASSESSMENT

Health check by collection center physician, blood test and diagnostic study

G-CSF ADMINISTRATION

Administration of G-CSF by a professional nurse

PERIPHERAL BLOOD STEM CELL DONATION

Collection of stem cells, Outpatient procedure, 3-4 hours

DONOR FOLLOWUP

Post donation followup at regular intervals

STEPS IN PERIPHERAL BLOOD STEM CELL DONATION - WORKUP

1. INFO SESSION

- Once it is determined that you are the best match, the DKMS Foundation India coordinator will contact you again to prepare a time schedule and explain the Peripheral Blood Stem Cell donation in more detail.
- You will receive information regarding date, time, and venue of donation.
- All the expenses incurred including transport and medical assessment will be borne by DKMS Foundation India.
- Once you have agreed, we will begin scheduling your medical assessment and peripheral blood stem cell donation. This whole process is know as **Workup**.

2. MEDICAL ASSESSMENT

The medical assessment takes place at an authorized hospital/blood bank - Collection Center (CC) where the stem cells are collected.

The purpose of the medical examination is to assess your suitability as a stem cell donor.

Following steps are involved:

- You will meet the blood bank physician or the Collection Center physician where you donate the stem cells. The physician once again explains the PBSC procedure in detail, reviews your health history questionnaire, answers your queries, and does a basic physical exam (health check).
- You will go through detailed lab tests such as complete blood count, liver function, renal function, thyroid function, etc. to check if you are healthy and free of any infections to donate stem cells.
- You will also undergo diagnostic studies such as chest x-ray, ultrasound abdomen and ECG at this stage.

3. DONOR FINAL CLEARANCE

- In this step, the CC physician reviews your complete lab and diagnostic reports and clears you to donate stem cells, confirming that you are medically fit for the Peripheral Blood Stem Cell donation.
- Occasionally, you may need some additional testing to be cleared, based on the opinion of CC physician.
- You may not be cleared too if it is deemed that you are not fit enough to donate stem cells.

4. G-CSF ADMINISTRATION

- G-CSF is a Granulocyte colony stimulating factor (protein) which is naturally produced in our body.

- Usually, G-CSF stimulates production of blood stem cells and mobilizes them into the blood stream as and when needed.
- Administration of G-CSF helps to increase the number of blood stem cells and mobilize them into the blood stream. The stem cells in the blood stream are then collected through Peripheral Blood Stem Cell donation.
- You will receive G-CSF injections for five consecutive days before your donation. On the first four days, a nurse visits your house and administers the G-CSF injection and on the fifth day, the injection will be given to you at the Collection Center prior to your donation.
- The injection will be administered through a tiny needle under the skin as prescribed by the CC physician.
- Rarely, you may encounter some temporary discomforts during the time of G-CSF administration. These discomforts are similar to cold/flu-like symptoms, such as: headache, bone pain and muscle aches. These discomforts disappear shortly after donation. Donors will be prescribed Paracetamol / Ibuprofen for pain relief by the CC physician.
- Donors should refrain from any strenuous activities like lifting heavy weights, contact sports, and gym during G-CSF administration and for 2 weeks post donation.

5. PERIPHERAL BLOOD STEM CELL DONATION PROCEDURE – COLLECTION

- PBSC donation is generally scheduled on a weekday, but we will check availability.
- It is an outpatient procedure which lasts about 3 to 4 hours. This procedure does not need any anaesthesia or hospitalisation.
- Blood is drawn through a tiny sterile needle in one arm and passed through an apheresis machine. A sterile, single-use disposable kit is used for PBSC collection. The apheresis machine separates the stem cells from the blood, collects it in a bag and rest of the blood is routed back to the body through the other arm.
- The CC physician and the nurse will keep monitoring you during the PBSC procedure and you will be observed until you are physically stable and ready to go home.
- Occasionally, a second day donation may be required if your stem cell yield is low.
- We will follow up with you regularly to check on your recovery after the donation.

6. DONOR FOLLOWUP

- Donor's care is our priority and we will contact you on a regular basis after your donation to ask about your physical condition. It is important to contact us directly if you have any concerns.
- You should expect a phone call the day following your donation and then weekly until you report a full recovery. As part of our donor followup process, we will be in contact with you at regular timeframe for the next ten years.



DONOR EXPERIENCE

As they say, real heroes don't wear a cap, this came true when a dedicated Army personnel from India took a step ahead to save a blood cancer patient. Sandipan is a doting father, a loving husband, and a passionate Army personnel. He is a simple man who is always ready to help others. From being a regular blood donor to serving his country, he does it all, a real hero!

- Sandipan, Blood stem cell donor

FREQUENTLY ASKED QUESTIONS

Here you will find all the questions we regularly get asked at DKMS Foundation India. If you can't find the answer to your question here, or elsewhere in this booklet, please feel free to contact our donor support team members at medical@dkms-india.org

THE THINGS YOU MAY WANT TO KNOW

WHERE WILL MY STEM CELLS BE COLLECTED?

Your stem cell collection will be scheduled at a hospital or a blood bank in Bangalore or another major city in India depending on where you live. We will cover all your travel expenses.

WHO COVERS THE EXPENSES?

There will be no cost to you. When a donor is matched with a patient, we will cover the costs (including any travel, meals, or accommodation expenses that may be necessary). DKMS Foundation India will also cover the costs for a companion to travel with you to the hospital or for the donation. Your personal health insurance will never be used. Whilst it is extremely rare to require followup care, if it is ever needed, the donor's costs would also be covered by DKMS Foundation India. Other than that, we are not legally permitted to make any payments or rewards for the provision of tissues, including blood stem cells for transplantation.

WILL I PERMANENTLY LOSE MY STEM CELLS?

For the PBSC procedure, the amount of stem cells collected is only a fraction of the body's total stem cells. The amount donated does not weaken your own immune system. Your stem cells will be naturally replenished within a few weeks.

WILL MY EXISTING MEDICAL CONDITION PREVENT ME FROM DONATING?

We take the health and safety of our donors very seriously. All donors are required to complete a health history questionnaire before proceeding. Any medical concerns are reviewed by a doctor to fully assess your ability to continue as a donor. Depending on your health status, it is possible that you may be deemed temporarily unavailable to donate, or need to be permanently removed from the registry.

WILL I BE COMPENSATED FOR THE TIME I TAKE OFF FROM WORK?

If you are not covered by your employer, DKMS Foundation India has a financial assistance programme that deals with lost wage compensation.

WHEN WILL MY DONATION TAKE PLACE?

It is hard to say exactly when your donation will take place, since it depends strongly on the patient's condition. In most cases, you would be asked to donate anywhere between 1-3 months once we receive your duly-filled health history questionnaire. We will always give you 3-4 weeks advance notice. If there are any important dates when you cannot donate, we will always try to accommodate to your schedule.



EVERY 5 MINUTES SOMEONE IN INDIA IS DIAGNOSED WITH BLOOD CANCER OR A BLOOD DISORDER SUCH AS THALASSEMIA OR APLASTIC ANEMIA

WILL I BE ASKED TO DONATE AGAIN?

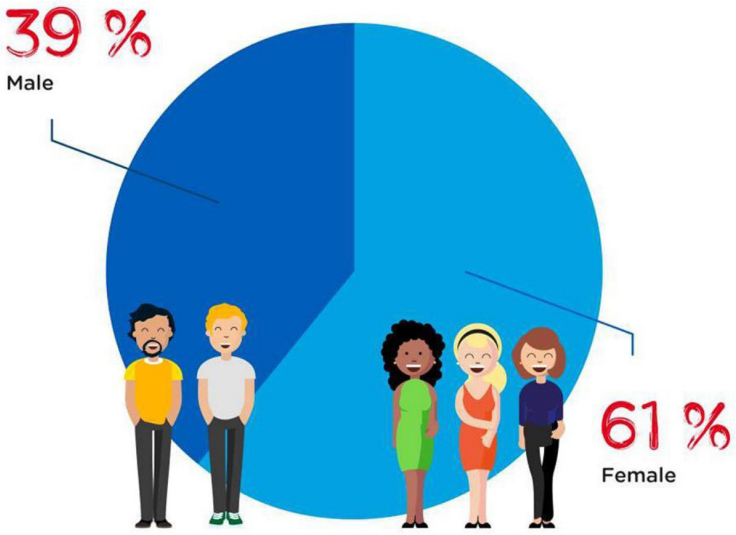
There is a possibility you will be asked to donate again for the same patient. If a patient's immune system does not accept the transplant, the patient might relapse, meaning second stem cell transplantation could be necessary. In very rare cases, you might be a matching donor for another patient in need. In both cases, your donation is always completely voluntary.

WILL I BE ABLE TO MEET THE PATIENT I HAVE DONATED MY STEM CELLS FOR?

We are often asked by donors if they can find out more about the person they donated their stem cells to, or even meet them. Depending on the country where the transplantation takes place, different rules apply. As per confidentiality and legal policy, the patient's age group, gender and location of treatment will be shared with the donor post donation. Depending on which country the patient was transplanted in, it might also be possible to write to the patient anonymously following donation. Few countries allow patient and donor meet following a period of 2 years post donation, with prior consent. Your Foundation India coordinator can provide further information on the specific policies that are in place at the hospital where your specific patient is being treated.

UPDATES ABOUT THE PATIENT

The patient's doctor may provide updates within the first year after the donation. We will contact you once an update is available. It is important to note that, due to confidentiality, some transplant centers are unable to provide patient updates. You should be prepared for the possibility that you may not receive any updates on the patient's recovery.



DID YOU KNOW?

We do not have equal representation in our team. More females continue to respond to our call to register than males and our research shows that men often register when their friends and family encourage them to.

TOGETHER WE REALLY CAN SAVE LIVES!












OUR SUPER














HEROES

DKMS

WE DELETE BLOOD CANCER

GET IN TOUCH WITH US

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ASK A QUESTION:

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