

GENERAL INFORMATION

❁ What is Bone Marrow?

Bone marrow is the soft tissue inside the bones that produce blood-forming stem cells. A healthy blood system is always making new blood-forming stem cells, which are necessary for survival.

❁ How can a blood stem cell transplant help a blood cancer patient?

Several fatal blood disorders including blood cancer can be cured by transfusing blood stem cells or bone marrow cells derived from a healthy volunteer donor. The healthy cells replace the diseased or depleted blood stem cells in a patient and thereby give the patient a second chance at life.

❁ What are the common blood disorders that can be treated with blood stem cell transplants?

Blood Stem Cells can be used to treat more than 100 blood disorders. Few of the common blood disorders that can be treated with blood stem cell transplant are listed below

- Acute Lymphoblastic Leukemia (ALL)
- Acute Myelogenous Leukemia (AML)
- Adrenoleukodystrophy (ALD)
- Chronic Lymphocytic Leukemia (CLL)
- Chronic Myelogenous Leukemia (CML)
- Hodgkin's Lymphoma
- Hurler Syndrome
- Krabbe Disease (Globoid-Cell Leukodystrophy)
- Metachromatic Leukodystrophy (MLD)
- Multiple Myeloma
- Myelodysplastic Syndromes (MDS)
- Non-Hodgkin's Lymphoma (NHL)
- Severe Aplastic Anemia
- Severe Combined Immunodeficiency (SCID)
- Sickle Cell Disease (SCD)
- Thalassemia
- Wiskott-Aldrich Syndrome (WAS)

❁ Why is it difficult for an Indian patient to find a match?

Two Reasons

- In an Indian population of 1.3 billion, only around four lakh people are registered as a blood stem cell donor.
- Ethnicity plays a key role in finding a match and India has a huge diverse ethnic background.

❁ What are the expenses incurred by DATRI?

• Cost of recruiting a donor

It costs DATRI INR 1800 to perform the HLA Typing for a donor to be added to the registry.

• Donation related expenses

After a match is found for a patient, DATRI does a Confirmatory typing along with detailed medical tests for the donor. We also incur expenses for the donation process, transportation of blood stem cells to the patient, lodging, food and travelling expenses of donors.

• Administration and operational cost of DATRI

❁ How much does it cost the patient?

This is dependent on the hospital, as all requests are received via the Doctor.

❁ I will donate blood stem cells only for a patient I know and not to anyone else.

In this case, you cannot register with DATRI. You can contact Histogenetics for more information

(Email: hospitalrelations@histogenetics.com or Phone: 044-22541053; Toll Free No: 18001023066).

❁ If I donate to someone and later I need blood stem cells, will the patient whose life I saved be able to donate back to me?

No, the patient can't donate as people who have been diagnosed with cancer cannot donate.

INFORMATION ON THE REGISTRATION

Does it cost me anything to register at DATRI?

It costs DATRI INR 1800 to perform the HLA Typing for a donor to be added to the registry. A donor who wishes to join the registry is requested to pay for his/her HLA typing. All donations to DATRI are 80G exempt.

Do I have to give blood to register as a donor?

No, a simple cheek swab sample along with completed registration and consent forms are all it takes to register as a blood stem cell donor.

What is a cheek swab / buccal swab?

A cheek / buccal swab, is a non-invasive way to collect cells from the inside of a person's cheek, which are used to do the HLA typing of a donor.

I just ate, drank tea / coffee, smoked can I swab?

Yes, the HLA typing is not affected by consuming food or by smoking. Please rinse your mouth thoroughly before the swab is taken.

Can I swab if I am chewing gum / paan?

Before swabbing, please remove the gum. If you are chewing paan, kindly rinse your mouth thoroughly before swabbing. Stained swabs can be difficult to process.

Is it ok if I don't know my height, weight and blood group?

Yes, but donors are requested to write an approximate height and weight. If there is a match with a patient these details would be helpful.

Why do you need contact information of a friend or family member for registration?

We need the contact information of another person in the case your contact information changes. We will only contact your friend / family member to get in touch with you, in case we are unable to reach you.

☼ If I am found to be a match, what next?

If your HLA matches with that of a patient, you will be contacted by a DATRI representative. Read 'Information on the Donation Process - FAQ's to know about the process in detail.

☼ What are the chances of my HLA matching?

Your HLA could match the patient's HLA, within few weeks of registration or it may take years. There is a chance that you may never match. But, if you do get matched, you are the **ONLY** one who can save the patient's life.

☼ Is it possible to register/donate with diabetes even though insulin injections are taken every day?

It depends on the diabetes type. Once there is a match a clearance from the physician is taken for further processing.

☼ I take medicines for heart disease. Can I register/donate?

Yes, you can register. Once there is a match, a clearance from the physician is taken for further processing.

☼ I am hypertensive (High BP). Can I register/donate?

Yes, you can register. Once you are a match, a clearance from the physician is taken for further processing.

☼ I am actively trying to get pregnant. Can I register/ donate?

Yes, you can register. If you are a match while you are pregnant, you cannot donate.

☼ Can Pregnant Women / Nursing Mothers register/ donate?

Yes, you can register. However, pregnant women and nursing mothers can't donate as the health of the donor is DATRI's priority.

☼ I have a history of miscarriages. Can I register?

Yes, you can register. If you are a match while you are pregnant, you cannot donate.

Will the donation impact my ability to have kids someday?

No, blood stem cell donation would not have any impact on your ability to have kids someday.

I am anemic. Can I register/donate?

Yes, you can register. Once you are a match a clearance from the physician is taken for further processing.

I had too much to drink last night. Can I still register?

Yes, you can register.

I am sick today. Can I register today?

Yes, you can register.

I have a rare blood group. Can I register?

Yes, you can register.

Once registered, can I refuse to donate when matched?

Being a donor is absolutely voluntary. Please remember that your refusal to donate could mean someone losing a chance to live!

Will a registered person be able to receive a copy of their HLA report?

The reports can be formally requested by the donor. The donor has to mail his/her name and barcode ID number (given in the Donor ID card) to info@datriworld.org after 45 days of registration.

If I have misplaced my donor card / forgotten my donor ID, what should I do?

Write to us at followup@datri.org or info@datri.org with your name and date of birth and we shall share the same with you.

INFORMATION ON THE DONATION PROCESS

☼ How does the Donation process work?

The various steps of the donation process are explained below

- **Confirmatory Typing(CT)**

A buccal swab /blood sample is collected to verify the HLA typing.

- **Master Health Check-up**

A series of tests are done to ensure that the donor is fit and does not have any infectious diseases like Hepatitis B, HIV etc.

- **Donation**

The donor will donate blood stem cells either by PBSC or Bone Marrow harvest methods whichever is discussed and consented for.

- **Transportation**

DATRI arranges to transport the blood stem cells to the patient anywhere in the world.

What is Confirmatory / Verification Typing (CT/VT)?

If your HLA type matches with any patient looking for a match, you will be called upon to donate your blood stem cells to save the patient. A cheek / buccal swab or a small sample of your blood is sent for Confirmatory Typing (CT) to verify your match with the patient

☼ Why is a health checkup required before donation?

There are two different methods of blood stem cell donation

- Bone Marrow Donation
- The Peripheral Blood Stem Cell Donation (PBSC Donation)

☼ What is Bone Marrow Donation?

This is a traditional method that has been in practice for more than 40 years. Bone marrow is extracted from the iliac crest (hip bone) under general anesthesia and may require one-day hospital stay.

☼ What is PBSC Donation and GCSF?

Peripheral blood stem cell (PBSC) donation is used for 80% of donations across the world. PBSC donation is done through a 4 to 5 hours nonsurgical outpatient procedure, called apheresis. Blood from

one arm of the donor flows into an Apheresis machine. The blood stem cells are separated and remaining blood is pumped back into the donor via the 2nd arm. PBSC donors are given a 5 days injection course of GCSF prior to PBSC collection.

What are the risks involved with the donation?

• Bone marrow donation

The most serious risk associated with donating bone marrow involves the use and effects of anesthesia during surgery. After the surgery, you might feel tired or weak and the area where the bone marrow was taken out might feel sore for a few days. You will be advised a pain reliever for the discomfort. You'll likely be able to get back to your normal routine within a couple of days, but it may take a couple of weeks before you feel fully recovered.

• Peripheral blood stem cell donation

The risks of this type of blood stem cell donation are minimal. Before the donation, you'll get injections of GCSF that increases the number of blood stem cells in your peripheral blood. GCSF may sometimes cause, bone pain, muscle aches, headache, fatigue, nausea or vomiting. These usually disappear within a couple of days. You will be advised to take a pain reliever for the discomfort by the DATRI physician.

Is it possible to donate where I live?

You can donate in the city where you live if there is an apheresis / bone marrow collection center. In case there is no apheresis / bone marrow collection center in the city, DATRI will make all the necessary travel and stay arrangements to facilitate donation.

How much blood stem cells will be collected during donation?

A maximum of 300ml of blood stem cells will be collected.

When will the donation take place?

In most of the cases the donation would take place 1 to 3 months after the confirmatory test. We always give notice and accommodate your schedule.

How often can a donor donate blood stem cells?

With DATRI the donor can only donate up to two times. This number is restricted because DATRI is focused on treating donors with care. However, there are no health restrictions involved with further donations.

Is the donor allowed to know the details of the patient and vice-versa?

As a standard practice across registries worldwide, the details of the donor and patient is kept confidential.

The donor/patient may be told the following details of the Patient/donor

- **Age group**
- **Gender**
- **Diagnosis**

Why can't I meet the patient now?

All registries across the globe follow a standard protocol. DATRI facilitates donor patient meeting after one year of donation at a mutually agreed time and place. This standard protocol is to support the donors' and the patients' privacy and discretion.

Why Me? Why not someone else?

You could be that 1 in 10,000 match! It is near impossible to find another alternative because your HLA is unique. 12 characteristics of the HLA are evaluated which have to match with the patient, which makes it so difficult. You are the only hope for the suffering life.

Will my religion permit?

Blood stem cell donation is similar to blood donation. So there are no religious interferences. Moreover, no religion restricts saving another life.

Will blood stem cell donation affect my fertility?

Irrespective of gender, there has been no reported cases or research evidence that suggest adverse effect on fertility. Stem cells donation does not influence or affect fertility.

❁ Won't I be deprived of blood or blood stem cells if I donate?

Your body will not be deprived of blood stem cells. The 5 days of GCSF injection increases the number of stem cells in your blood stream in your body. The 'extra' blood stem cells will be collected for the patient. During blood stem cell donation only stem cells are collected; the remaining components of blood (RBC, WBC, platelets) are returned to the body. The donated stem cells will be replaced within a few weeks.

❁ I am a woman, if I donate my blood stem cells/bone marrow, will it affect my state of pregnancy?

No. Before you can go on to donate, a pregnancy test is done and if it is positive you will not be permitted to donate. But you can be a blood stem cell donor one year after child birth.

❁ Can I opt for the type of donation (Bone marrow/PBSC) or do I have to follow the method that doctor advises?

Doctors will be the right judge to determine whether one can have a PBSC method or Bone Marrow method of donation. However, the final choice is that of the donor's.

❁ Does donating blood stem cells have short-term or long-term effects on my body?

There has been no long term side effects reported. Less than 10% of donors face flu-like symptoms. This is due to G-CSF which increases the number of white blood cells in the blood stream that in turn "attack" the already existing unwanted cells in your body as a protective mechanism. The symptoms are alleviated with a prescribed paracetamol.

❁ Will my medical condition interfere in me being a donor?

Potential donors who have tested positive for HIV, Type 1 diabetes, or have had epilepsy, or currently pregnant cannot donate. **To know more in detail about exclusion criteria please see [\(link\)](#).**

❁ Do I have to be on certain medication after donation?

No. It is not required. In case, if it is required then the doctor will advise.

☀️ What are blood stem cells?

Blood stem cells are immature primitive cells that have the capacity to multiply and mature into different types of blood cells such as

- Red blood cells, which carry oxygen to all parts of the body
- White blood cells, which help fight infection
- Platelets, which help control bleeding.

☀️ Why is it important to become a donor?

A patient has only 25% chance of finding a HLA matched donor within the family. Those who do not find a match within the family have to rely on a registry like DATRI to find a HLA matched unrelated donor willing to donate their blood stem cells. There are more than 1500 patients in the DATRI's database who are still waiting for a match. You could be a life-saving match to such a patient and gift them a chance to survive. If you are not registered with DATRI, chances are you might be a lifesaving match for someone and we will not be able to find you.

☀️ What is the difference between bone marrow and peripheral blood stem cell donation?

When blood stem cells are collected from the bone marrow, it is called bone marrow donation. If the blood stem cells are collected from the bloodstream, the procedure is called peripheral blood stem cell (PSBC) donation.

☀️ Is blood stem cell transplant a 100% cure for the patient/what are the survival chances for the patients?

The chances of survival for children is 80% and adults is 60%. It also depends up on the severity and the stage of the disease.

☀️ How is blood stem cell donation different from a cord blood transplant?

In a cord blood transplant the cord blood stem cells are collected and stored in a cord blood stem cells bank, but in a blood stem cell donation, blood stem cells are collected only when there is a matched donor and at the time of treatment.

What are my responsibilities as a donor?

Patients rely on the donor with a lot of hope to recover. So if you are found to be a match, willingly donate your blood stem cells, as you are the **ONLY** one who can save the patient's life.

Why does DATRI need monetary donations?

DATRI is a not-for-profit organization registered as a Section 8 company. We depend on monetary contributions to add potential donors to the registry, to help donation process and to support our operational expenses.

What are the eligibility requirements for potential donors?

There are 3 (three) requirements,

- You must be between the age of 18 and 50 years.
- You must fulfil the health guideline-free from diseases like HIV, Hepatitis, cardiac illness, auto immune disorders, chronic lung disease etc.
- Most important, you should have a kind heart to help someone in need.

What is a cheek swab / buccal swab?

A cheek / buccal swab, is a non-invasive way to collect cells from the inside of a person's cheek, which are used to do the HLA typing of a donor.

Is my data confidential? How is the data stored?

Yes, donor data is confidential. The data is encrypted and stored in a secure database.

How long does it take for my HLA information to be added to the DATRI registry?

It takes about 5 weeks for the HLA typing results to be added to the registry.

I am a regular blood donor? Can I donate blood stem cells?

Yes, you can donate.

☼ I am going to be married soon. Will donating blood stem cells affect my family life?

Donating blood stem cells does not interfere with your normal routine nor your family life. All our donors are leading a normal life.

☼ How do I update my personal details?

You can send a mail to followup@datri.org or info@datri.org with details to be updated along with the **Donor number** printed on your donor ID card.

☼ Are there any side-effects caused by the injection GCSF?

Some donors experience slight headache, nausea or body ache during the **5 days of the GCSF injection**. This decreases using a paracetamol prescribed by DATRI physician. No long- term side effects have been recorded.

ACT NOW. GIFT A LIFE.