



ACT NOW. GIFT A LIFE.
www.datri.org

YOU ARE
A LIFE
SAVING
MATCH!



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Congratulations!

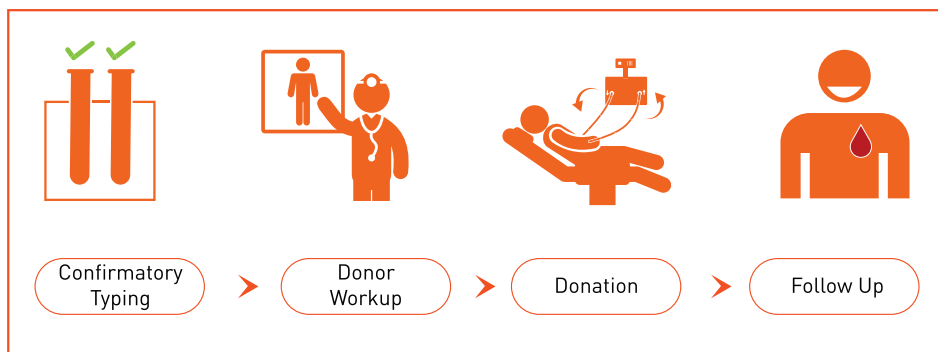
You are a life-saving MATCH!

Thank you for signing up as a Blood Stem Cell donor and being part of DATRI Blood Stem Cell Donors Registry. You will remember the first step was to provide us with a cheek swab sample - this was tested and your HLA (Human Leukocyte Antigen) type stored in our database.

You have been matched for a patient. As you know the chance of finding a match is around 1 in 10,000 to 1 in over a Million, so this is a fantastic news!

This booklet is to help you understand the next steps on your journey to continue through this life-saving donation. You will be supported by your Donor Coordinator who will keep you fully informed about the process. He/she can introduce you to other donors who can share their experience first-hand.

Before you donate, we want to confirm that you the same donor and you are fit/eligible to donate. Here is a brief infographic on the donation process for your reference.



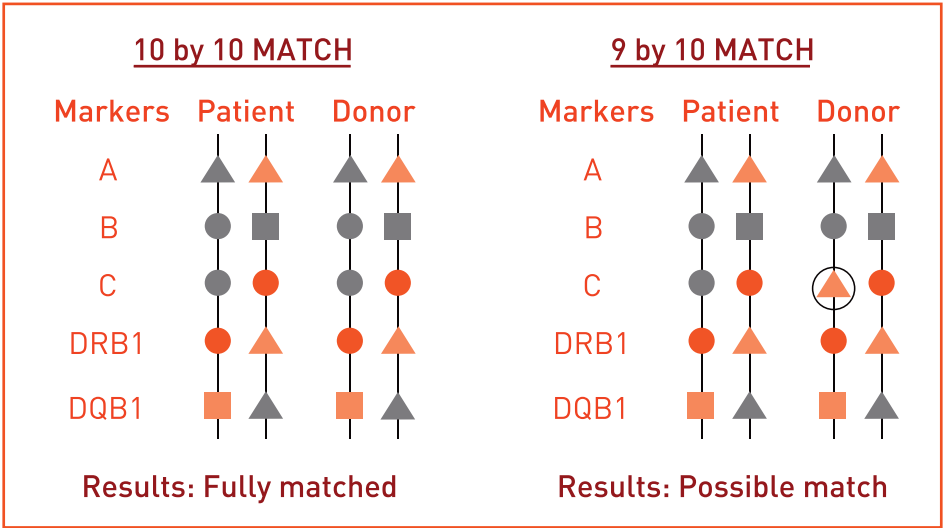
Who needs a blood stem cell transplant?

Blood stem cell transplants are used to treat patients whose bone marrow is not producing healthy blood cells. Nearly 100 potentially fatal blood disorders, including several types of Blood Cancer and Thalassemia, are treated with bone marrow transplants taking the support of unrelated donor like you. The unhealthy cells of the matched patient will be destroyed with Chemotherapy and healthy blood stem cells collected from a donor will be transplanted.

What is meant by a match?

The cells that manage the body's immune system come from the bone marrow and therefore a bone marrow (also known as blood stem cell) transplant essentially introduces a new immune system to a person. The donor and the patient have to have the same genetic markers or identity for the patient's body to accept the new cells. These markers are called the Human Leukocyte Antigens (HLA). HLA is important in matching patients and donors for a blood stem cell transplant.

Most transplant centres look at 10 HLA antigens, A, B, C, DRB1 and DQB1 to select a donor. While a 9/10 match between a patient and a donor may be suitable, a full 10/10 match is ideally required.





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DONATION PROCESS



1. CONFIRMATORY TYPING

You have been selected through an initial search of the database as a potential match and contacted by your Donor Coordinator for an information session. This is an opportunity for you to ask any questions. We recommend that you get your parents and other important members of your family involved so that they can fully understand and support your decision to Gift a Life.

During the briefing session, you will be asked to answer a simple questionnaire on your current health status. You will then provide us with a small sample of blood or a cheek swab that will be used for the confirmatory typing. This is to reconfirm that you are the perfect match for the patient.

The choice in your hands

It is your decision to participate in confirmatory typing. Costs incurred for facilitating the donation will be covered by DATRI. Your Donor Coordinator is available to answer any questions or concerns. This is also a good opportunity to talk with other donors so that once you are confirmed as a match for the patient, you move onto the next stage.

After Confirmatory Typing

The donor coordinator will let you know the outcome of your confirmatory typing in seven (7) days.

If you are a confirmed match, you will be briefed on the next stages of donation. Your Donor Coordinator and one of the panel of doctors are available to assist you during this time.



2. DONOR WORKUP

We will introduce you to your doctor who will complete a donor health questionnaire and also evaluate you and your family's medical history. At this time more information will be shared about the donation process and any potential risks and side effects. You are invited to have a family member or friend to attend this session with you.

Once you agree to proceed, you will be asked to sign few documents, including a "consent to donate" document. This confirms that you have understood what will take place during the donation process.

Master Health Checkup

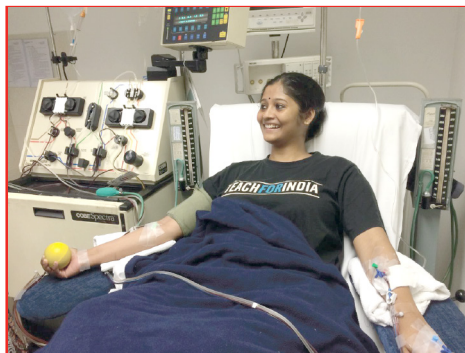
You will be given a thorough physical examination to make sure you have no pre-existing medical conditions that could pose any special risks to you or the patient. This will include a chest x-ray, ECG and ultrasound scan. At the same time, some blood sample will be collected to test for infectious diseases to avoid any disease transmission to the patient through donation. The results of the above tests will help determine your eligibility to donate.





3. DONATION

Once the doctor gives a medical clearance, you will proceed to the donation process. Donation will be carried out in our nearest collection centre. There are two methods to donate blood stem cells.



PBSC (Peripheral Blood Stem Cell) Donation

PBSC donation (a non-surgical procedure) is similar to blood donation except that in PBSC donation only blood stem cells are collected. This is carried out as an outpatient procedure usually taking between 4-5 hours.

To stimulate bone marrow to produce stem cells and release them into the blood stream, you will receive an injection called G-CSF (Granulocyte Colony Stimulating Factor) for five days. G-CSF is a type of growth factor and growth factors are proteins made in the body. The collection of Blood Stem Cells will be scheduled on the fifth day with 2 sterile needles inserted one in each arm that will be connected to an Apheresis machine. Your blood will be taken out from one arm and processed through an apheresis machine that separates out the blood stem cells.



We recommend you not to go to crowded places during this period to avoid any infections. Vitamin supplements may be recommended by the doctor based on your reports. You may experience flu-like symptoms of headache, bone or muscle aches for the few days before the collection. Doctor may prescribe pain-killers to alleviate the aches, if required. After donating, you are recommended not to do any physical strenuous activity for at least 1 day.

Marrow Donation

Based on the patient's disorder and the transplant doctor treatment plan, few donors may be requested to donate bone marrow. Marrow donation is a procedure that takes place in a hospital under general anesthesia. You check-in the evening before the donation and the following morning, doctors will collect liquid marrow from the hip bone (pelvic). This takes around one hour and usually you will be required to stay-in overnight to allow the effects of the anesthesia to wear off. You can then go home the following day.

Most donors will feel some soreness in the lower back for a few days but usually they resume their routine in a few days. You should be back to do your normal physical activities in a few weeks and your own marrow is completely replenished within 4-6 weeks.





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4. FOLLOW UP

After you donate Blood Stem Cells, a DATRI Coordinator will contact you for follow-up at periodic intervals of day 2, 1 week, 1 month, 6 months and 1 year after the donation. Your marrow/ blood stem cells are completely replaced within four to six weeks of donation. After 1 month, we shall get a detailed CBC done to ensure you are healthy. DATRI Blood Stem Cell Donors Registry cares about your well-being and wants to support you throughout your journey - after all, only few people like you are able to gift the hope of life.

Privacy

DATRI considers privacy very seriously for both our donors and the patients that we are supporting. Essential details of the patient and donor will be shared only with the intention of finding the possible match. We do this in order to protect both parties from unwelcome attention or contact.

In case of any need to use and share the photos of patients and donors, we would do it only after taking written consent from both patients and donors.

Patient and Donor Communications:

When you are identified as a match we provide you with some basic information of the patient such as their gender, age and the diagnosis.

After one year, if both the patient and the donor are willing to get in touch or meet, DATRI will share the contact information with respective parties. After that, it will be up to the donor and the recipient to start the communication as they choose. We understand that every individual is different and while most parties want to meet, it is absolutely acceptable not to and to remain anonymous.

Here are the glimpses of few meet-ups of Donors and Recipients

Donor
Maresh
with Recipient
Gauri





Donor
Shabas T.S
with Recipient
Manasvi Karamchedu



Donor
Amit Mohite
with Recipient
Paul Surya



Donor
Dr Kanmani
with Recipient
Shreemali



Donor
Gopal Vachhani
with Recipient
Neerali



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FAQs

1) Do I get to choose the donation method?

The best method of Blood Stem Cells collection i.e. Bone Marrow Harvest or Peripheral Blood Stem Cell Donation would be determined by the transplant physician based on the needs of the patient. Donors can indicate their preferred method of donation and they will also be advised of the transplant doctor's preference.

2) Is it true that donating bone marrow is very painful?

Bone marrow harvest is not painful as you will be under General Anesthesia during collection. Most donors say they feel some discomfort or stiffness the following day.

3) Will there be any long term effects on my health after donation?

All of our donors have returned to their normal routine after donating. None have had any long term side effects. Bone marrow is fully replenished within 4-6 weeks. There is a possibility that a donor may be slightly tired than usual during this phase. However, it differs for each donor and many of them have returned their normal routine within a day.

4) Do I have to pay for the tests and bear any other costs?

You do not have to pay. You will be reimbursed for all expenses relating to the donation including any travel expenses or unpaid leave. Although most employers are very supportive and will allow additional time to attend medical check-ups. Please understand that donating your blood stem cells is a voluntary action and you will not be compensated for the donation.

5) Can I change my mind and withdraw my consent to donate?

There must be genuine reasons for saying "no", including illness/health conditions, the risks involved or even anxiety. While DATRI respects the decision of the potential donor, uncommitted donors give false hope to patients awaiting a transplant. Once a donor gives his or her consent on the "Consent to Donate" form, the patient is actually put on a pre-transplant treatment to clear off the diseased marrow. So, if a donor decides to back out at any stage after the consent, the patient will most likely die without a transplant. DATRI hopes that you will be committed to your participation as a life-saving donor and we will ensure that you are fully informed and are supported throughout the procedure.

6) Will I be able to have a family after donating

Yes, many donors (male & female) have had children after they have donated. Blood Stem Cell donation has no lasting adverse impact on your health.

7) Media consent - Why is it required?

Spreading awareness on the Blood Stem Cell Donation is an essential step to recruit donors. For this, we create many printed and digital materials to reach out to the masses. We may use donors' photographs and details to make these materials comprehensible and appealing. These materials will be shared on all printed and digital media platforms to reach larger public. We need your media consent to carry out this activity unhindered, as it includes sharing personal details.

Glossary

Blood Components - Human blood is composed of *Red blood cells* (RBC), *White blood cells* (WBC), Platelets and Plasma.

Blood Stem Cells - Blood stem cells are produced in the bone marrow, which is present in the cavity of the bone. The sources of the blood stem cells used for transplant are: Bone marrow and peripheral blood stem cells (PBSC) and blood collected from the umbilical cord. They are also called as hematopoietic stem cell.

Bone Marrow - Found in the cavity of all large bones. It is where Blood Stem Cells are produced. Blood Stem Cells develop into all the blood cell components like *Red blood cells* (RBC), *White blood cells* (WBC), Platelets and Plasma.

Bone Marrow Transplant (BMT) - The process of giving healthy marrow to a patient whose marrow is damaged or diseased.

Collection Center/Apheresis Center - A hospital associated with DATRI that is qualified to collect bone marrow and Blood Stem Cells and care for donors before and after the donation procedure.

Confirmatory Typing - A stage of testing to make sure that a potential donor is the best match for a patient. This is also referred to as Verification Typing.

G-CSF - If a donor chooses to donate their peripheral blood stem cells they receive an injection of Granulocyte Colony Stimulating Factor (G-CSF). G-CSF is a type of growth factor and growth factors are proteins made in the body. G-CSF will activate and increase the blood stem cell production and move the cells from the bone marrow to the circulating blood, where they will be collected for transplant to a patient.

HLA - Human Leukocyte Antigen - Human Leukocyte Antigen are proteins on the surface of our cells that helps the immune system to identify the cells that belongs to our body. The best transplant outcome happens when a patient's HLA and Donor's HLA closely match. This refers to the white blood cell (leukocyte) blood group. Just as red blood cells have A, B and O group, white blood cells have the HLA types and the success of a transplant depends mainly on HLA matching. There are at least 10 important HLA groups for bone marrow transplantation. Each of these groups in turn may have hundreds to thousands of variations. Hence there is a need to have as many donors in the registry as possible to offer the best chance of finding a match.



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Match - In a marrow or Blood Stem Cell transplant, the match refers to how much alike the donor's and patient's tissue types are.

Peripheral Blood Stem Cells (PBSC) - The blood stem cells that circulate in the blood.

Registry - A Registry, such as DATRI, is an organisation that registers adult unrelated Blood Stem Cell Donors. It also spreads awareness about Blood Stem Cells and how their donation can cure blood cancer and other severe blood disorders. The registry enrolls / registers voluntary donors, willing to donate their blood stem cells to a matched patient, and maintains a confidential database of these potential life-savers. When the registry receives a request for a match from the patient's doctor, it searches for an HLA matched donor from its database. Registries like DATRI also facilitate the collection of Blood Stem Cells and transportation of the same to the patient location. Almost all registries, worldwide, are a part of the global World Marrow Donors Association, which enables them to search for HLA matched donors worldwide.

Tissue-type - An individual's tissue-type is defined by 10 to 12 characteristics (A, B, C, DRB1, DQB1 and DPB1), collectively known as the human leukocyte antigen group (HLA). Testing for HLA groups, known as "tissue-typing", is usually performed on a small blood sample or cheek swab sample.

Workup - The process that a matched potential donor goes through to make sure he / she is healthy and fit to donate marrow or blood stem cells. Workup includes a detailed information session with donor center staff, a physical examination and collection of blood samples for testing and screening for Infectious disease markers.

NOTES:

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

Donor coordinator details:

Name: _____

Phone Number: _____

E-mail id: _____



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Proud to be part of a noble drive and feeling delighted & Blessed to be the tool of almighty to gift a life.

Eldho Varghese | CEO, Rajasthan Marbles | Ernakulam

Value of life is not in its duration but it's in donation. You are not important because of how long you live, you are important because of how effective you live.

Hemant Sonthalia | Bank Employee-HSBC House | Kolkata



The purpose of life is not to be happy. It is to be useful, to be honourable, to be compassionate, to have it make some difference that you have lived and lived well.

Shruti Kakkar | Assistant Professor | Delhi

An act of kindness, one at a time that is all that it takes to rebuild faith in humanity.

Bharti Sharma | Software Engineer | Gurgaon



After this stem cell donation. I visualised that I have the power to save a life. Giving life to some is not a simple task. I could do it.

Ajasudheen | Assistant Professor | Ernakulam

I never thought I could save someone's life until I donated my Blood Stem cells.

Naresh Gokinapalli | Graphic Designer | Khammam



I feel Very fortunate to get an opportunity to save a life and get their blessings. I can only say that "Think of giving not as a duty but as a privilege". I served my privilege and will continue serving

Sudha Jyothsna Shrey | Software Engineer | Hyderabad

Little pain doesn't matters if your concern is to save someone's life, saving a member of a family.

Nirmal Kumar | Senior Accountant | Chennai





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DATRI Blood Stem Cell Donors Registry, Module No:1207 & 1208, 12th Floor,
Ticel Bio Park - Phase II, CSIR Road, Taramani, Chennai - 600 113. India.
+91 44 2254 1283, 4079 5300, Toll free: 1-800-300-DATRI (1-800-300-32874)

Spread the word

