

Be The Cure Registry

(by Jeevan Stem Cell Foundation)

Registered Public Charitable Trust since 1995

22, Wheatcrofts Road, II Floor, Nungambakkam, Chennai 600 034

Mobile : +91 89399 99216, +91 97908 97918 • Email : bethecure@jeevan.org • Website: www.bethecure.in

Information to Adult Stem Cell Donors

Annually 120,000 Indians are diagnosed with blood cancers. Over 30,000 of these could hope for a cure from transplantation of blood forming stem cells from adult donors like you.

One in four of these patients might have a sibling as potential donor. All others have to depend on registry like Be The Cure by Jeevan Stem Cell Foundation to find a matching donor.

Hence, we need 100,000 Indians to register as potential Adult Stem Cell donors. Only 1 in 1,500 donors will be a match and asked to donate for a patient requiring a transplant in any given year.

To join the Be The Cure Registry you must answer yes to these two questions:

Have you read the donor information materials of Be The Cure Registry or at www.bethecure.in?

Are you between 18 and 50 years old?

Who cannot donate Stem Cells?

If any of the following apply to you unfortunately **you will not be eligible** to join the registry:

- You are aged under 18 or over 50
- You weigh under 50kg or are severely overweight (a BMI of more than 40)
- You (or your partner) are, or think you are, HIV or Human T-cell lymphotropic virus (HTLV) positive or believe you may carry the Hepatitis B or C virus
- You have ever been injected with non-prescription drugs including body-building drugs (includes one off use)
- You have **EVER** had any of the following:
 - Cancer (including leukaemia)

- Heart disease or heart surgery
- Stroke
- Epilepsy
- Diabetes (unless this is controlled by diet alone)
- Rheumatoid arthritis

- You ever suffer/suffered from any chronic illness?

As a volunteer of the Be The Cure Registry we want you to understand and commit that:

1. You are willing to donate to any patient who needs your stem cells
2. You are willing to give a blood sample / Cheek swabs for HLA typing and addition to the registry
3. You will be listed in the registry till the age of 61 and you will inform Be The Cure Registry, if you are unwilling or unable to continue in the registry for any reason
4. Keep us updated if there is any change in your contact details
5. In the event of you being a match,
 - a. You will respond quickly
 - b. You will be asked to give an additional blood sample for testing
 - c. You will receive injections of a drug to increase the number of blood forming cells in the blood stream
 - d. You will donate your stem cells in an approved institution and the procedures might take approximately 6 hours.

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Frequently Asked Questions

Q: What is the Be The Cure Registry?

The Be The Cure Registry is a database of adult donors between the ages of 18 and 50 yrs who have volunteered to donate their stem cells for the treatment of people suffering from blood related illnesses treatable with stem cells

Q: Why should I join the Be The Cure Registry?

Every year over 120,000 Indians are diagnosed with blood cancers and another 10000 children are born with diseases like Thalassaemia. They can hope for a 60 to 80% chance of cure, if they find matching stem cell donors. The chance of finding a donor in the family is less than 30%. The match is highly ethnicity dependent and hence the chance of finding a match in an Indian registry is over 70%.

Q: If I am a match, will I be paid for the donation?

No. By registering in BPCR, you are committing to be a voluntary non remunerated stem cell donor.

Q: When I donate, will the patient be charged for stem cells?

The patient will not be charged for the stem cells you donate. However, there is a cost involved in the medications provided to you, HLA typing, testing for other infectious agents and counting the number of stem cells in your donation. The patient will reimburse these, if he/she can afford.

Q: What is the process of stem cell donation?

You can donate your stem cells in two ways.

More than 90% of people donate their stem cells by a process similar to donating platelets. This is called peripheral blood stem cell collection (PBSC). The other 10% donate through bone marrow, where they give cells from the bone marrow in their pelvis.

Q: How does the PBSC donation work?

It is a relatively simple process.

You will receive injections of granulocyte colony-stimulating factor (G-CSF) over four days. This is a naturally-occurring hormone which increases the number of blood forming stem cells your body produces. Possibly on the fourth day you will receive the injection in the hospital and a blood sample is

collected for counting the number of cells in the blood. The PBSC donation will start the next day.

A nurse or doctor will insert a tiny tube into the vein in your arm. The tube will be connected to a machine to collect the stem cells. Donation only takes about 4-5 hours. Occasionally we will need to collect more cells the following day. You will not need a general anaesthetic or to stay in hospital overnight.

Q: Will I experience any side effects for the drug (G-CSF) administered?

You might experience side effects including flu-like symptoms and muscle pains, but they are usually mild and only last a couple of days.

Q: How is “Be The Cure Registry” different from other registries in India?

There is a cost involved in HLA typing, collecting stem cells from a donor, testing and transport to the hospital where the patient is admitted. Be The Cure Registry will recover the actual cost from the patient’s family. We will endeavour to keep it below Rs. 3 lakhs as against the current cost of Rs. 7-10 lakhs.

Q: How do I join the Be The Cure Registry?

The process is simple, all it involves is that you fill in a form and hand it over to our donor support manager. A blood sample will be taken from you for Human Leucocyte Antigen (HLA) Typing and after this you are free to leave. You will be contacted when a request is received from someone of your HLA Type who requires a transplant.

Q: Why do I need to provide ONLY my Aadhar Card number or PAN Card number as ID proof?

In case you are a match for someone, after a few years, this will be the only way we can reach you.

Q: What if anyone needs stem cells?

Please ask them to contact us at stemcell@jeevan.org with their HLA typing report and we will help to find a suitable match for them.

If you need more information, please feel free to talk to one of us at **Be The Cure Registry** on +91 89399 99216, +91 97908 97918 or send us a mail at bethecure@jeevan.org

Thank you for your interest