Bone marrow stem cell donor recruitment – quick reference page

Thank you for enquiring about becoming a bone marrow stem cell donor on the South African Bone Marrow Registry (SABMR). Please read this information carefully.

To become a bone marrow donor you need to be:

- Committed to help anyone (not just the person who motivates you to join)
- Between 18 – 50 years of age
- In general good health (with no history of hepatitis or sexually transmitted diseases)
- Weigh over 50 kg

Do not register as a bone marrow stem cell donor if:

- You think you might need a test for HIV, Hepatitis –B or C.
- You have injected yourself (even once) with illegal or non-prescription drugs.
- You have taken money or drugs for sex.

Registration process

Joining the registry is simple: You need to call The Sunflower Fund Toll Free Number 0800 12 10 82 weekdays 9am-1pm or 2-4pm so that we can make sure that you meet the criteria and will then complete your Sunflower/SABMR Registration Form with a Reference Number. If you are not able to pay for your blood test (R300 for AB level or R1000 for DR level testing), you will be added to the waiting list and when funds become available we will forward your form and direct you to the closest Donor Recruitment Clinic. There you will give them the completed form and they will take a small blood sample – about two teaspoons. Your blood sample is then analysed (called “tissue typing”) and put on the national database.

Registered donors will in due course be sent a donor card by the SABMR. Donors will only be called back to donate stem cells if they are ever a perfect match for a patient. The odds of being a match are about 1: 100 000 which is why we need as many donors as possible. The donation procedure is minor with little discomfort – a full description can be found in the information below.

Thank you for being prepared to "Share a little, to Save a Life".
Bone marrow stem cell donor recruitment – more information

An important consideration when becoming a donor

It is vital that prospective donors realise that by joining the South African Bone Marrow Registry they could be called for **anyone needing a transplant, and not just the patient who first motivated them to join**. People are often keen to join the registry when they know the patient or when they become emotionally involved through press articles. However, some donors who have been perfect matches for someone else are unwilling to donate, saying that they only joined the registry for one person! This is tragic, not only because money to test and register the donors was wasted, but those donors may have been the other patients’ only hope for survival. Please think seriously about joining the registry as it is an important commitment. Note that if you sign up and drop out at a later stage, it costs time and money and could cost lives.

Donor confidentiality

All sensitive personal information is strictly confidential and can only be accessed by authorised staff. In compliance with **international agreement, strict anonymity is maintained between donor and patient**.

Our payment policy

Regrettably neither the SABMR nor The Sunflower Fund receives any government funding towards the cost of tissue typing the samples and depend solely on donations from the public. Tissue typing at the internationally accepted DR level costs around R1000 per person. We ask potential donors to pay towards the tissue typing costs, either R300 at the AB level or R1000 at the DR level. After completing their application form, donors will be asked to deposit their donation in The Sunflower Fund’s bank account and fax proof of payment to 021 701 6790. Their form will then be sent to them so that they can go for the blood test. Anyone not able to pay for their test will be placed on a waiting list and when funds become available their forms will be sent to them.

Please donate financially

Bank details: THE SUNFLOWER FUND
Bank: ABSA 4051 834 719
Branch code: 632005
Ref: Sunflower Ref. Number (To obtain this please call 0800 12 10 82)

Call 0800 12 10 82 should you have any queries or should you wish to register.

Thanks again for being prepared to **Share a little, to Save a Life**. Please have a look at our website for more information at www.sunflowerfund.org.za
Frequently asked questions and important information

(Please read and understand the information below when making your decision)

The Sunflower Fund is a registered charity formed in 1999 by a group of parents whose children had contracted leukaemia, and in some cases had lost their battle against it. Together with other concerned citizens and members of the medical profession, they formed The Sunflower Fund in support of the South African Bone Marrow Registry.

**How would I help?**

Every year thousands of South Africans of all ages and races are diagnosed with diseases such as Leukaemia, Aplastic anaemia or some rare genetic disorders. 75% of these patients are under the age of 25. Their only hope of survival is a blood stem cell transplant from a donor who shares the same tissue type. Without this transplant it would mean certain death. It all depends on ordinary people like you, ordinary people who wish to give the amazing GIFT OF LIFE.

YOU could be that MATCH for someone with leukaemia or other life threatening blood disorders. The chances of finding a match are about 1:100 000 and it could be you! You may well be the only one in the world who can provide that match and save someone’s life.

**What happens if I am a perfect match?**

The medical procedure for obtaining stem cells from the blood is called a harvest. If you were asked to donate, you would be required to attend a specialist harvest centre in South Africa. A full medical examination will be carried out and if you are still agreeable, growth factor (G-CSF)* injections will be administered. These will increase the production of the stem cells in the bone marrow. These excess stem cells enter the bloodstream from where they are harvested using a cell separator machine. This minor medical procedure with minimal discomfort entails you being connected to the machine by an intravenous line (similar to donating blood or platelets) for 4 – 6 hours, possibly on two consecutive days. The precious bone marrow stem cells are filtered out of your blood and your own blood then returned to you. Thus you are able to go home immediately afterwards.

The harvest will take place in a private ward and the donor is often admitted for the night preceding the harvest as this has proved to be most comfortable and convenient, particularly if the donor is from out of town.

* Granulocyte colony stimulating factor (G-CSF). This is a protein which also occurs naturally in the body. It is given in order to mobilize the stem cells out of the bone marrow and into the circulating blood, where they can be collected for transplant. All individuals are at risk for developing cancer, including leukemia, lymphoma or other blood diseases throughout their life time. G-CSF stimulates normal cell growth. In some patients with cancer or abnormal blood cells, it has been shown to stimulate leukemic blood cells. It is unknown whether G-CSF increases or decreases an individual’s risk of developing cancer. Based on available data from healthy people who have received G-CSF, no long-term risks have been found so far. The data being collected during follow-up of donors worldwide will help establish if there are any or long-term effects from receiving G-CSF. Approved: SABMR Board - 23 November 2007.

**Are there any side effects for the donor?**

Sibling transplants have been taking place for over 10 years; a short term side effect is flu-like symptoms during G-CSF stimulation; some donors have also reported mild bone pain.
Why are unrelated donors needed?
Although family members – brothers and sisters in particular – may offer the closest matches, unfortunately 75% of patients will not have a suitable sibling, so have to search elsewhere.

How are donors and patients matched?
In the same way as red cell blood groups exist, so white cells can be categorised into groups known as “tissue types”. Thousands of tissue types exist, so finding the correct match depends upon having a very large register of donors. Because people’s genetic makeup is so varied and their tissue types are inherited characteristics, the chance of finding a suitable match can be slim. The likelihood of finding a matching donor will be considerably greater in donors from the same ethnic background as the patient.

Ethnic Donors
In South Africa we have even more unique combinations of tissue types. Therefore it is very important that we have own registry and the larger that registry, the greater and faster the chance of finding a perfect match. We desperately need donors from all ethnic groups and mixed ethnic backgrounds.

Keep in contact
Your details are kept on the registry until you are 60 years old and it is therefore vitally important that you keep us updated with your current contact details – so that you can be found when you are needed. All information that you supply is kept strictly confidential. Registered donors can also update via the SABMR website (www.sabmr.co.za/contact.html).

Can I change my mind?
Most donors are delighted to hear that they have been chosen to donate - after all, that's why they joined the Registry. A potential donor may decline at any time. There is however, a point of no return for the patient.

When is the point of no return?
This stage is reached about a week before the actual donation when the patient’s own bone marrow is destroyed with high doses of chemotherapy in preparation for receiving the harvested stem cells. At this point the donor is seen to have a moral obligation to proceed because without the donation of stem cells the patient will die.

Please do not hesitate to contact The Sunflower Fund should you require any further information or assistance.

Email: donorqueries@sunflowerfund.org.za Website: www.sunflowerfund.org.za
Toll free number: 0800 12 10 82

Thank you for being prepared to “Share a little, save a life.”