



ABOUT THE SABMR

Our job is to match bone marrow stem cell donors with patients who are in urgent need of transplants. In most cases, bone marrow transplants can help patients to recover from serious illnesses, such as Leukaemia and Non-Hodgkin's lymphoma.

Who can make use of our services?

If you are diagnosed with a blood disorder that requires a stem cell transplant, your family members will be tested first. If no matches are found within your family, your doctor and/or transplant centre will reach out to us to find a suitable donor.

Why choose us?

We are the only registry in Africa that has been accredited by the World Marrow Donor Association (WMDA). This allows us to search among the 76 000 donors on our local database, as well as international databases, which gives us access to more than 39 million donors worldwide.

Other South African registries search within a much smaller donor pool and might not initially provide patients with all the possible donor matches. In contrast, we present you and your physician with all the potential donor matches from every single search to give you the best choice.

Counselling patients and/or their loved ones or caregivers also forms a vital part of what we do. We are mindful of the emotional rollercoaster that comes with the diagnosis of a life-threatening illness, but there are ways to cope, and we are here to help you get through this.

What fees are involved?

A preliminary search is conducted for free, however there is a cost involved for additional services. If you have medical aid, make sure that you can cover any costs that your provider doesn't cover. If you don't have medical aid, we can assist you with a breakdown of the fees, to ensure that you are aware of how much you will have to pay.

What if you can't afford the costs?

The search for a matched unrelated donor and verification process can get expensive and many may not be able to afford it, which is why we introduced the SABMR's Patient Assistance Programme (PAP). Depending on your financial situation, we can either partially or fully cover the costs of the search, testing and verification of a matched unrelated donor at no cost to the patient. If a donor is found, we can also direct the funding towards the 'stem cell procurement process', which is the procedure through which healthy donor stem cells are collected for transplant purposes.

The Patient Assistance Programme is intended for patients without medical aid who are from areas where raising the necessary funds are unlikely. It is also for patients who have medical aid, but whose provider does not cover unrelated donor searches, testing or procurement, even after an appeal.

The goal of the programme is to fill the monetary gap for patients in regard to donor search, testing and procurement, which means that it doesn't cover the cost of the patient's actual transplant. The transplant cost is usually covered in one of three ways:

1. If the procedure is completed at a state facility with an active transplant programme, the state covers the cost.
2. Several medical aids will cover the transplant procedure, but not the cost of the donor search or any other donor costs.
3. Some patients can fundraise enough for the transplant, but not enough for the donor search. That's where the Patient Assistance Programme can help fill the gap by facilitating and funding all the steps leading up to the actual transplant.

We also assist the transplant centres in their motivation for medical aid funding or for Patient Assistance Programme funding.

NEED TO FIND AN UNRELATED
DONOR MATCH?

THE SOUTH AFRICAN BONE MARROW
REGISTRY (SABMR) CAN HELP.





STEP 1: PRELIMINARY SEARCH FOR POTENTIAL MATCHING DONORS

Once a physician refers a patient to the SABMR, the process begins with a computer-based search, called a 'preliminary search' in our own database, as well as those abroad. The purpose of the preliminary search is to get a general idea of how many possible donors there are for you. This step is completely free, but from step 2, costs apply.

STEP 2: ACTIVATED SEARCH

At this point, we share the preliminary search results with your physician and possible donors are asked to have blood tests done in order to find the best donor for you. Donors from our own, local database are approached first to save costs, and only if a possible match isn't found, international donors are contacted through our worldwide partner network. This is called the 'activated search' phase as the potential donor plays an 'active' role in the process by having a blood test done to see how closely they match your tissue type.

STEP 3: FORMAL SEARCH

Once we have shared the donor testing results with the transplant centre, they will narrow down the list of suitable donors and give an indication of when they can accommodate the donation and transplant procedures. This phase is termed, the 'formal search', which involves contacting the short-listed donors to assess their availability and willingness to proceed with the donation process. The transplant centre and/or your doctor will discuss their decisions with you and inform you whether it is likely to proceed.

STEP 4: VERIFICATION TYPING OF POTENTIAL DONOR(S):

While newly recruited donors are fully typed, those who registered a few years ago may have to undergo a series of laboratory tests to further establish their suitability. Once a donor's human leukocyte antigen (HLA) typing shows there is a match with the patient, the donor's typing must be verified by an EFI/ASHI accredited laboratory. At this point, tests are also done for infectious diseases.

STEP 5: STEM CELL DONATION

The matched donor will undergo a full medical examination to determine their health status and assess whether they are at any risk during the donation process. Once medically cleared, the donor will receive a five-day course of daily injections (G-CSF: Granulocyte Colony Stimulating Factor) to increase the quantity of stem cells in their bloodstream. On the fifth day of injections, the donor will be admitted to a medical facility and connected to a cell separator machine. While taking blood from the donor, the machine removes important stem cells needed for the transplant. Once done, it returns the remaining cells to the donor's body. In some cases, it may be necessary for the stem cell collection to be repeated again on the following day, to ensure sufficient stem cells have been collected.

A Donor Visitor, appointed by the SABMR, will accompany the donor throughout the day of the donation to provide support. Prior to the stem cell donation, the patient too will undergo a conditioning regimen of chemotherapy with or without radiation in preparation of the transplant.

The SABMR is responsible for the donation process and the transport of the bone marrow stem cells to the transplant centre. It is important that the stem cells are transplanted within 72 hours to ensure the most optimal conditions for the stem cell survival and engraftment for the patient.

Once you start the search journey with the SABMR and your search is activated, we ask that you continue with us in order to eliminate confusion between registries, which may hamper the process.

POST-TRANSPLANT

Once you have undergone the transplant, the long journey of recovery begins. We ask that you keep the information regarding the transplant private for three months. Please do not share information about the timing or location of the procedure to the media or on social media. The reason for this is that we do not want any assumptions to be made about who the donor is as this would breach their right to anonymity, nor do we want any attention diverted from your recovery.

CONTACTING YOUR DONOR

Our policies aim to protect both the patient and the donor's safety, privacy and dignity. We give donors and patients basic information about each other (for example, whether they are an adult or a child, male or female and which country they are from).

We cannot tell you who the donor is or share personal or contact details between you. Following your transplant, you may anonymously correspond with your donor through the SABMR if you wish to say thank you.

Direct contact with your donor is subject to the conditions imposed by the donor's registry. However, direct contact with a donor registered on the SABMR is permitted three years after the transplant.

HOW TO BECOME A POTENTIAL DONOR?

Even if your family members are not suitable matches for the bone marrow transplant you need, they may be a match for someone else. If friends and other relatives want to show support and register as potential stem cell donors, they can visit our website, www.sabmr.co.za and complete the four simple questions online to start the application process.

GIVE THE GREATEST GIFT OF ALL, A SECOND CHANCE AT LIFE.

CONTACT US:

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