

THE BONE MARROW DONOR PROGRAMME: BUILDING A NATIONAL ASSET FOR SINGAPORE

Across all cultures and throughout history, the blood has been identified as the very essence of life taking centre stage in much of our art and literature. Diseases of the blood, which we today can identify as leukaemia and lymphoma among others, inevitably led to an early death.

In the early 1800's the first blood transfusions were carried out, often with disastrous results and only improved after 1901 when the discovery of the blood groups introduced the concept of a match between donor and recipient. In the 1950's a major step forward saw the world's first blood stem cell or bone marrow transplant to cure leukaemia. Carried out between identical twins, this pioneering procedure replaced the diseased blood "factory" cells of the patient with blood-producing cells taken from his healthy sibling donor.

Known as Haematopoietic Progenitor Cells, (HPC) these early stage cells are found in the bone marrow, blood stream and the umbilical cord discarded after childbirth. Once transplanted into a patient, they are capable of growing into the three main components of the blood; red and white blood cells and platelets.

Today we know a successful transplant requires a genetic match between donor and patient. For the treatment of a blood disease, compatibility is critical as the white blood cells are the body's first line of defence in fighting infection and disease. A mis-match between patient and donor will result in the new donor cells attacking the patient they were meant to cure.

FINDING A MATCHING DONOR

The odds of two people having compatible DNA suitable for a blood stem cell transplant is 1 in 4 among siblings but 1 in 20,000 among the general population and usually a match will only be found within the same racial group. As transplants have become the standard treatment for many blood diseases, the demand for donors has grown and today, registers of volunteer bone marrow donors, who have each provided a DNA sample for genetic typing, are the blood stem cell source for most patients needing a transplant.

In Singapore, this is the work of the Bone Marrow Donor Programme.

The BMDP was established in 1993 to save the lives of patients who need a bone marrow transplant through building a register of volunteer bone marrow donors. As an independent charity, the cost of building this register, which is an asset for the whole Singapore community, is supported through funds raised from the public.



SINGAPORE'S MULTI-RACIAL CHALLENGE

Six Singaporeans a day are diagnosed with a blood disease and while not all of them will need a transplant, for those who do, they need to find a matching donor. This means patient and donor must share the same genetic markers known as Human Leucocyte Antigens, or HLA. When a volunteer donor signs up to join the BMDP register, they provide a small tissue sample, collected as a buccal swab from inside the cheek, and this goes to the lab for tissue typing. Each volunteer donor is then "tissue typed" into a sequence of 12 HLA markers or codes, which are then searched on a daily basis against the HLA type of the patients who desperately need a donor. The cost of adding each new donor onto the register in 2016 was around \$180.00.

In multi-racial Singapore, expansion of the BMDP register over the past five years, to more than 75,000 potential volunteer donors, has significantly improved the chance of finding a local matching donor although our diversity still means that around half our patients depend upon a donor from overseas. To try and help more patients with a local match, the BMDP is rolling out an aggressive plan to add another 50,000 new donors before 2018.

DONOR SEARCH AND SELECTION

Once a patient is diagnosed with a blood disease and the best option for treatment is a bone marrow or blood stem cell transplant, the search for a donor begins. The first option is a matching brother or sister who will have a 1 in 4 chance of being a match but when this fails, the patient's doctor will reach out to the BMDP.

Search services are provided at no charge and part of the BMDP's charitable contribution to the Singapore community. Patient-specific incurred costs are billed to the patient together with an administrative fee which covers out-of-pocket expenses such as laboratory and medical fees, overheads and staff time. Charges are usually levied in two stages:

VERIFICATION TYPING	HPC PROCUREMENT
<p>Step 1: donor counselling and information session carried out by qualified nursing / counselling staff from the BMDP</p> <p>Step 2: Collection of DNA sample to be sent to the laboratory for HLA typing and Infectious Disease testing</p>	<p>Step 3: a full medical examination, chest x-ray, ECG, additional blood tests and other health screening</p> <p>Step 4: Stem Cell Collection carried out as an outpatient or inpatient procedure in a hospital close to the donor. The cost includes hand-carried transportation either across Singapore or in-bound from overseas.</p>
COST: \$1,400 (BMDP) - \$4,500 (INTERNATIONAL)	COST: \$20,000 (BMDP) - \$37,000 - \$63,000 (INT)

The advantages of finding a local donor are significant; less time from search to transplant which gives the patient a better chance of survival and significant cost savings. In support of this, the BMDP is committed to grow the local donor base and ensure a better chance of finding a match for all Singapore in the context of the highly diverse Singapore community.

BMDP ACTIVITIES @ A GLANCE



DONOR REGISTER	SEARCH AND SELECTION SERVICES	BMDP DONOR MANAGEMENT
<ul style="list-style-type: none"> Public education on blood diseases and the need for a bone marrow donor register Donor recruitment activities - roadshows and events with education, company and government partners. Swab processing for HLA typing Data verification, donor and database management Marketing and fundraising activities 	<ul style="list-style-type: none"> In-coming requests for individual patients from the local hospitals Local / global database searches to identify a match Data analysis and donor recommendations based on transplant centre and doctor preferences Donor activation instructions and liaison Case management, follow through to procurement 	<ul style="list-style-type: none"> Activation of BMDP donors and information sessions for consent Liaison with the Collection Centres for transplant dates Donor counselling and support throughout the medical procedure 12 months follow up Transportation of stem cell products from Collection Centre to Transplant Centre
RECRUITMENT PARTNERS	HOSPITAL CLIENTS	INTERNATIONAL DONORS
<ul style="list-style-type: none"> Junior Colleges, IB Schools, ITE and Polytechnics Universities Corporate Sector Public Sector Religious and Affiliated Groups 	<ul style="list-style-type: none"> NUH SGH KKWCH Mt Elizabeth Hospitals Raffles Hospital, CHCC Ampang Hospital / UMMC 	<ul style="list-style-type: none"> Out-going donor activation instructions Coordination with local Transplant Centres International transportation and local courier activation
<p>17, 174 new donors recruited at \$180.00 each bringing the BMDP register to 75,000. The total direct cost was \$2,486,543.00.</p> <p>Register growth was funded through public donations and direct funding from the Tote Board while the 2016 public education was funded through an SG50 grant from Care and Share.</p>	<p>BMDP received a search request for 171 Singapore patients and submitted a Donor Recommendation Report for each.</p> <p>In addition, the local register was searched for 408 international patients with 10 local donors providing HPC for overseas patients</p>	<p>191 BMDP donors were called for Verification Typing to confirm if they were the best match for a patient.</p> <p>49 Singapore patients had a transplant; 21 had a local donor and 28 needed donors from overseas.</p> <p>Income from HPC Procurement was \$2,108,506.00.</p>

With no Medisave/Medishield coverage for HPC procurement-related charges, the BMDP assists Singaporean and PR patients through subsidies on the Verification Typing. Patients unable to pay the HPC procurement fees can apply for funding from the BMDP. A total of \$170,000 was paid out to assist 50 patients in 2016.



BMDP VALUES AND CONSTITUTION

The BMDP was established more than 20 years ago and our vision is to “provide hope for patients with leukaemia and other blood-related diseases”. We do this by finding a matching transplant donor for every patient giving them that one last chance of a cure.

The BMDP Constitution clearly sets out the organisation’s mandate which can be summarised in the following key areas:

- to set up and maintain a register of bone marrow donors making these part of a global collaboration
- promote understanding of blood diseases among the public and educate on the need for bone marrow donors
- provide financial and other assistance to patients suffering from blood diseases
- provide professional services to the transplant hospitals to scientifically identify the best donor match for their patients
- counsel and support volunteer donors going through the stem cell donation procedure

Again, supporting Singapore’s diverse community, success in finding donor matches is highly dependent upon global and regional collaboration. In support of this, the BMDP engages with other registers around the world to improve transplant outcomes by way of sharing outcomes and knowledge with the international transplant community.

AN IPC AND SINGAPORE CHARITY

Like any other charity in Singapore, the Bone Marrow Donor Programme is governed by the Charities Act and regulations. A fundamental principal is that our work must be for the benefit of the community in Singapore and no specific individual or group. Our operations fall into three distinct areas:

- **Building the National Donor Register** of volunteer donors and making these volunteers globally accessible through a network of collaborating registers. **All this work is funded by money raised from the public and our fund-raising activities.** Access to the BMDP register and where necessary the global database together with our Search Selection Services is available with no charge for all Singaporeans who need to find a matching bone marrow donor. **International collaboration is critical as less than half our Singapore patients can find a match locally.**
- **Search, Donor Selection and Stem Cell Procurement** activities which are **patient-specific and are paid for by the patient** are on a full-cost recovery basis. An administrative fee built into the procurement costs covers out of pocket expenses such as medical fees and laboratory tests plus overheads and manpower.
- **Funding transplants** is available for those patients who are Singaporeans or PRs and unable to pay for the HPC procurement. This is managed in collaboration with the Medical Social Workers from the public hospitals who have the facilities to undertake the financial due diligence on our behalf. All applications are submitted for review and approval by the Board of the BMDP.