

SEARCHING FOR A BONE MARROW DONOR



Angela received a bone marrow transplant from an unrelated donor to treat her non-Hodgkin's lymphoma.

INFORMATION FOR PATIENTS AND THEIR FAMILIES

For patients who need a bone marrow or blood stem cell transplant, tissue type matching is an important factor for the success of the transplant.

We inherit our tissue typing from our parents. This means that the first step in finding a suitable donor is within the immediate family, typically the patient's siblings.

It is not necessary for all family members to be tissue typed. A tissue typing scientist needs to evaluate which family members should be tested and which unrelated donors also have the best chance of matching the patient.

INTRODUCTION

Each year, many people worldwide are diagnosed with cancer of the blood, such as leukaemia. Some of these patients can be treated with chemotherapy and/or radiation without requiring further treatment. Other patients do require further treatment. They may need a bone marrow/blood stem cell transplant. With a transplant, these patients have the best chance of achieving remission or, in some cases, a cure.

Bone marrow/blood stem cell transplants can also treat other blood and immune system disorders.

A bone marrow/blood stem cell transplant is a serious and complicated procedure. This brochure aims to simplify the most vital information to give answers to transplant patients and their families about the donor search process.

WHAT IS BONE MARROW?

Bone marrow is the soft, spongy part in the centre of bones where blood cells are produced. The bone marrow contains stem cells, which develop into the mature cells in our blood: red blood cells, white blood cells and platelets. It is these stem cells that are used for transplantation. They can be found in bone marrow, blood or umbilical cord blood.

WHAT IS A BONE MARROW/BLOOD STEM CELL TRANSPLANT?

A bone marrow or blood stem cell transplant is a treatment option for some people who have life-threatening blood or immune system diseases. The procedure replaces blood stem cells in people whose bone marrow has been destroyed by large doses of chemotherapy or radiotherapy.

The healthy blood stem cells from a suitable donor are given to the patient intravenously and find their way into bones to become healthy marrow. Transplantation of these healthy blood stem cells means that the patient's bone marrow can produce new red and white blood cells and platelets. It also means that the patient can have ongoing chemotherapy and/or radiotherapy as directed by their clinician.

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WHO CAN BE A DONOR?

For the transplant to have any real chance of succeeding, there needs to be a precise tissue-type match. The most suitable donor for a bone marrow/blood stem cell transplant is a fully matched family member but only around one person in three has such a donor. If a suitable donor is not found in the immediate family, a wider family search and/or unrelated donor search may be needed.

WHAT IS TISSUE TYPING?

Tissue typing, also known as HLA typing, is done to check how closely the patient's cells match the potential donor's cells. HLA stands for human leukocyte antigen. HLA markers are found on almost all cells in our body. They are one of the main ways our immune system can tell the difference between our own cells and foreign cells such as bacteria, which our body should attack.

The closer the match in HLA types, the better the chance of a successful transplant.

If the donor's HLA markers are not similar enough to the patient's, the immune system of the patient may attack the donor cells. This is called rejection.

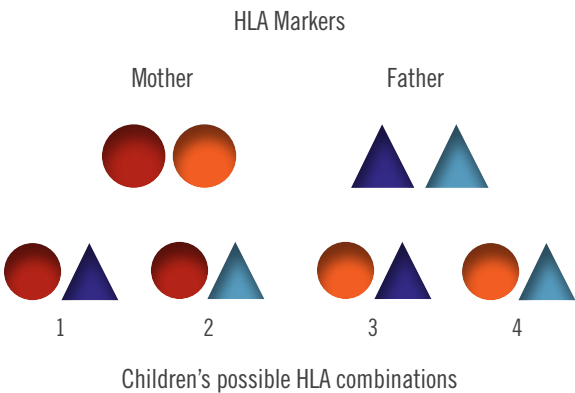
Likewise, the cells from the donor's immune system which accompany the blood stem cells may recognise the HLA mismatch and attack vital organs of the patient. This is known as graft versus host disease (GvHD). The more compatible the donor-patient match, the less likely there will be rejection or severe GvHD.

HOW LONG DOES TISSUE TYPING TAKE?

A blood sample is needed to perform HLA typing. Testing is done using the white blood cells and DNA. Testing is performed with the strictest of confidentiality and DNA is not used for any reasons other than tissue typing. Initial results are found at about two weeks. Further high resolution, detailed tissue typing takes an additional two to four weeks.

SCREENING DONORS

How we get our HLA type:



We inherit HLA from our parents. There are four possible combinations of the parents' HLA marker sets, so each sibling has a one in four chance of being an HLA match with the patient.

THE RESULTS

HLA typing is reported as a series of numbers and results will be reported to the patient's clinician.

There are two main groups in an HLA type.

Class I antigens are:	Class II antigens are:
<ul style="list-style-type: none">• HLA-A• HLA-B• HLA-C	<ul style="list-style-type: none">• HLA-DR• HLA-DQ• HLA-DP

The results reported for compatibility will generally include six numbers:

Two A antigens, two B antigens and two DR antigens, as a minimum

Example:

Patient	A3, 32	B7, 37	DRB1*01:01, 15:01
Donor	A3, 32	B7, 37	DRB1*01:01, 15:01

HLA typing is not related to blood group, gender, appearance or personality. The likelihood of finding an HLA match does depend on ancestry, so a patient is therefore more likely to find a match among potential donors of the same ethnicity.

SEARCHING FOR A DONOR

A donor search is started by the patient's referring hospital. Either the hospital donor search coordinator or the Australian Bone Marrow Donor Registry (ABMDR) search coordinator will manage the family donor searches in close collaboration with the HLA scientists.

The hospital will inform you who is coordinating the donor search and provide you with their contact details.

Tissue typing (or HLA typing) is a process to check how closely a patient's cells match a potential donor's cells.



SIBLING SEARCH

- Best first approach
- Match found for about 30% of patients



EXTENDED FAMILY SEARCH

- An HLA expert decides if this is of benefit
- May involve parents and other close relatives



UNRELATED DONOR SEARCH

- Search Australia and worldwide for one of the millions of registered donors

A search for a suitable donor may include a sibling search (brothers and sisters), an extended family search (other close relatives) and/or an unrelated donor search (volunteer donors from around the world).

TYPING FAMILY AND FRIENDS

To assist with the family search, the Donor Search Coordinator needs a designated contact person within the family and a family tree showing relationships, gender, age and number of children of family members willing and available for tissue typing.

If a match is not found among the patient's brothers and sisters, it may be beneficial to search the patient's extended family but this decision will be made by an HLA expert based on the tissue type of the patient. In many cases an extended family search may not be recommended and the best option at this stage may be an unrelated donor search.

We encourage all family and extended family members who have been typed to consider joining the registry as they may be able to save the life of another patient.

If an unrelated person or friend wishes to be typed, they must be willing to join the Australian Bone Marrow Donor Registry and may be called upon to donate bone marrow / blood stem cells for any patient in need, even if not a match with their friend. Volunteers must be in good health and between the ages of 18 and 45. They will be retired from the registry on their 60th birthday. Donors can make a life-saving difference to someone in need.

If friends and family wish for more information on joining the registry, they can call the Australian Red Cross Blood Service on 13 14 95 or visit abmdr.org.au

HOW ELSE CAN FAMILY AND FRIENDS HELP?

The patient will need a lot of help physically, emotionally and psychologically for many weeks, particularly once they leave hospital. Many patients also require blood products such as platelets. So donating blood to help someone in need is one of the best ways to make a difference.

Further information can be found on the Blood Service website, www.donateblood.com.au

UNRELATED DONORS

Millions of bone marrow/blood stem cell donors from dozens of countries are listed worldwide on bone marrow donor registries. As well, blood collected from the umbilical cord and placenta of newborns is a rich source of blood stem cells suitable for transplantation in some patients. These donations are stored in cord blood banks.

Patients may be considered for an unrelated donor transplant, dependent on their diagnosis and other factors. The clinician asks the search coordinator to search for donors across Australia and worldwide. All information is handled confidentially. If an initial match is found between a patient and a donor, further high resolution and verification typing is performed.

The search and matching process is highly detailed. Patients should allow a minimum of one or more months to find a suitable donor but depending on their tissue typing some patients may not easily find a matched donor.

Millions of people have voluntarily joined bone marrow registries and hundreds of thousands have donated cord blood units around the world.

COLLECTION OF THE DONOR'S BONE MARROW/ BLOOD STEM CELLS

There are two ways a donor can donate your bone marrow and blood stem cells. The actual donation method is based on both the patient's needs and the donor assessment.

1. Peripheral blood stem cell donation

Normally the number of stem cells circulating in the blood is low. To increase the number of blood stem cells, a hormone-like substance called Granulocyte Colony Stimulating Factor (G-CSF) is injected under the skin daily for 4 days prior to the collection. The stem cells are then collected by a procedure called leukapheresis. During this procedure a needle is inserted into a vein in the donor's arm and the blood passes into a cell separator machine, which selectively removes the stem cells.

The remaining blood components are immediately returned to the donor's body. This procedure is performed at a hospital or apheresis centre, does not require a general anaesthetic and takes approximately 3 to 4 hours. After the procedure the donor may leave but a subsequent donation the following day may be necessary if not enough cells are collected.

2. Bone marrow blood stem cell donation

Blood stem cells found in the bone marrow can also be collected under general anaesthetic. Using a needle and syringe, the marrow is extracted from the pelvic bone cavity. This procedure can take up to two hours.

The time needed for complete recovery varies, but generally the donor can go home the same or next day, and resume their normal activities after two or three days. Normal bone marrow will re-grow rapidly to replace the collected bone marrow.

For more information, potential donors should refer to the information brochure 'Joining the bone marrow registry' or visit the donor pages on www.abmdr.org.au.

DID YOU KNOW?

There are over 170,000 potential donors registered with the ABMDR but more are always needed, particularly from different ethnic backgrounds as similar ethnic backgrounds increase the chance of a match.

THE TRANSPLANT

The transplant team will determine the urgency of a bone marrow/blood stem cell transplant depending on the disease of the patient and their clinical condition. It can take up to several months for the transplant to occur.

The patient's clinician will give more detailed information on what to expect. In short, the transplant will take place in a hospital room, not in an operating theatre. The healthy blood stem cells are infused through a central line. The procedure usually takes between 30 and 60 minutes, and then patients have many weeks of waiting for the new bone marrow cells to grow.

New cell growth is called engraftment. It takes place after the bone marrow/blood stem cell transplant when there is a sustained rise in new blood cell production.

In terms of how successful the procedure is likely to be, this will depend on the original disease, the stage of it and the patient's general condition at the time of the transplant. The transplant clinician is the best person to ask about this to find out more.

Peter has joined the bone marrow registry to help others in the community.



SUPPORT NETWORKS

Leukaemia Foundation

www.leukaemia.org.au | Phone 1800 620 420

Provides accommodation, transport, information, education and emotional and practical support to people living with leukaemias, lymphomas, myeloma and related blood disorders, while funding research into better treatments and cures.

CanTeen

www.canteen.org.au

Support for young people with cancer aged between 12 and 24.

Cancer Council

www.cancercouncil.com.au

Cancer helpline, information and support to people with cancer and their carers.

Look Good...Feel Better

www.lgfb.org.au

Look Good...Feel Better is a free national community service program dedicated to teaching cancer patients - through hands on experience - techniques to help restore their appearance and self image during chemotherapy and radiation treatment.

Michael feels proud that he may be able to help a total stranger one day.



DEFINITIONS

Bone Marrow

The soft, spongy part in the centre of the bones where blood cells are produced. The bone marrow makes blood stem cells.

Bone Marrow Collection

A procedure in which bone marrow is collected from the donor.

Bone Marrow / Blood Stem Cell Transplant (BMT)

A treatment option for some people who have life-threatening blood or immune system diseases. It is the process of replacing unhealthy bone marrow cells with healthy cells.

Central Line

A catheter that is inserted under the skin of the chest into a vein. It is a long, hollow tube with two or three passages and stays in place during BMT and is used to collect blood samples and give medications and fluids.

Engraftment

New cell growth. It takes place after the bone marrow/blood stem cell transplant when there is a sustained rise in new blood cell production.

GvHD

Graft versus host disease. When cells from the donor's immune system which accompany the blood stem cells recognise an HLA mismatch and attack vital organs of the patient.

Leukapheresis

A process in which blood stem cells are collected from the donor's blood using an apheresis cell separator machine.

Platelets

A type of blood cell that helps blood to clot and people to stop bleeding.

Rejection

When the donor's HLA markers are not similar enough to the patient's, the immune system of the patient attacks the donor cells.

Stem Cells

Early-stage cells that produce other cells. Tissue in the body contains stem cells that renew and replace that tissue when needed due to damage or wear and tear. Blood stem cells generate all blood cells in the body, including red cells, white cells and platelets.

Tissue Typing

A process to check how closely the patient's cells match the potential donor's cells. Also known as HLA typing.

HLA

Human leucocyte antigen. HLA markers are found on almost all cells in our body.

White cells

A type of blood cell that fights infection and protects the body against foreign organisms.

For more information
call 13 14 95 or visit
abmdr.org.au

