

QUESTIONS ABOUT JOINING THE AUSTRALIAN BONE MARROW DONOR REGISTRY ("THE REGISTRY")

What is the eligibility criteria to join?

- If you are between the ages of 18-30 then you are in the ideal bracket to become a donor, but you can be aged up to 35
- Hold a valid Medicare card
- You'll also need to be able to answer "NO" to the following questions:
 - Have you ever been diagnosed with thalassaemia major?
 - Have you ever received an organ or bone marrow transplant?
 - Have you ever suffered a stroke or heart attack?
 - Have you ever had a positive test for HTLV or HIV?

There are also a few conditions that may or may not affect your eligibility. If you've ever suffered from any of the following conditions please contact our partner at info@strengthtogive.org.au.

- Cancer of any kind (except basal cell carcinoma of the skin or squamous cell carcinoma (SCC) of the skin)
- Pre-cancerous conditions, such as cervical abnormalities
- Auto-immune diseases (except minor conditions like psoriasis or vitiligo)

I joined The Registry in the past by giving blood, do I also need to do a cheek swab?

- No you do not need to do a cheek swab as this would result in a duplicate registration.

Does it cost me anything to join?

- There is no cost to join.



How do I join?

Joining is easy & free - simply swab your cheek & your saliva sample will be tested & added to The Registry!

1. Order your cheek swab kit online:

www.urthecure.com.au/swab

2. Once your kit arrives in the mail, swab your cheek. Fill in the forms and mail it back to The Registry.



We need people to join who are:

- Aged between 18 to 35 (up to 45 is OK)
- Have a culturally diverse background
- Males are ideal (any background is OK)
- Females with a culturally diverse background

I am already a blood donor, does this mean I am automatically added to The Registry?

If you already donate blood, this does not mean that you are automatically added to the bone marrow registry. You need to specifically request to join The Registry next time you donate blood OR join through a cheek swab.

QUESTIONS ABOUT JOINING THE AUSTRALIAN BONE MARROW DONOR REGISTRY (CONTINUED)

What information is being collected when I join?

- When you join the registry a sample of your DNA will be collected to determine your “HLA” – human leukocyte antigen. This is essentially your unique “code” which is cross-referenced with all the searching patient’s “codes” to see if you are match.

What happens to the saliva sample after it has been collected?

- Your saliva sample is not stored anywhere and it is destroyed after it has been tested, the only thing that remains is your HLA tissue type “code” with no identifying information.



Is my privacy protected?

- Strength to Give and the Australian Bone Marrow Donor Registry recognise the importance of respecting your privacy and protecting the confidentiality of your health information. They collect this information to ensure safe matching of potential donors and to maintain the quality of the registry database.

- The registry works closely with Red Cross Lifeblood and a network of health professionals and partner organisations, including registries in other countries.
- They do not provide information that would identify you to persons outside The Registry, The Blood Service or the health professionals involved in your care.
- If you are identified as a potential match your name will never be shared with the patient or their treating team. The information provided to other registries and treating doctors is solely to enable them to confirm your suitability as a match.
- If the match is confirmed and you agree to donate, only the hospital and health professionals involved in the collection process will know your identity. The Registry’s full privacy policy can be viewed on their website.
- Just think that joining the registry is more secure than many of the apps you probably have on your phone which gives a lot of your information to the developers and other 3rd parties!



QUESTIONS ABOUT WHO WE NEED TO JOIN

We all want to help, why don't you encourage everyone to join regardless of ethnicity?

- In an ideal world we could have anyone and everyone join! Our goal is to increase awareness about the cause amongst the entire public regardless of their cultural heritage, but we are aiming to target people with culturally diverse backgrounds to take action and join The Registry.
- The multicultural groups are under-represented on The Registry which means these patients are often the ones who struggle to find their match.
- Did you know that if we were to DOUBLE the number of people currently on The Registry as it is, it would only increase the chances of overall matching by 5%...and that's because it's heavily skewed to representing people with a North Caucasian background.
- Also with limited funding and a limited number of samples that can be collected each year, people joining who have a North Caucasian background essentially uses up funding to test a sample type that we already have plenty of and doesn't necessarily increase overall matching. So it becomes even more important to make sure the "right" type of samples are collected which are those with any sort of ethnic or indigenous heritage (as well as young males of all backgrounds aged 18 to 35).

Why is there an age restriction?

- Nobody likes to hear that they are "too old" in any circumstance! But in the case of stem cell donation, there is scientific evidence that younger stem cells perform better in a transplant which means a higher chance for a successful outcome for the patient.
- In addition to this, older donors are more likely to develop age-related conditions which may mean they cannot donate.



We need more young people aged between 18 to 30 to join The Registry

Why are male donors needed?

- Male donors are excellent candidates for stem cell donation. This is essentially due to biological reasons. They literally have more stem cells to give!
- Pregnancy in women create antibodies in their blood which can increase the likelihood of "graft vs host" disease for the patient receiving the stem cells. This can be a serious complication for the recipient where the donor cells attack the cells, organs and tissues of the patient after they receive the transplant.
- It's not that female donors are undesired candidates, but quite often males are chosen as ideal matches for patients!



We need more young males to join The Registry

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In partnership with the ABMDR
and Strength to Give



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QUESTIONS ABOUT DONATING YOUR STEM CELLS

How often will I be a match and asked to donate my stem cells?

- Only 1 in 1500 Australians are a match in any given year so you will not be receiving calls all the time that you are someone's match!

Does it hurt to donate my stem cells?

- It's not as scary as it sounds! These days your stem cells can usually be taken straight from the blood stream, much like in a blood donation. This is done 90% of the time.
- You will receive a small daily injection for 4 days prior to the stem cell collection day. It's safe and harmless and allows your stem cells to flow through your blood stream.
- On the stem cell collection day, the non-surgical procedure takes 3-4 hours and you can often watch TV or read a book during it and return to normal activities afterwards.

What's involved if I'm asked to donate my stem cells using the traditional method?

- If you are in the 10% of people who need to do a bone marrow donation, you will be placed under general anaesthetic so you will not feel any pain during the procedure. You may feel a dull ache at the base of your back near your pelvic bone afterwards and this can be relieved with paracetamol like Panadol. These aches will fade away usually within a few days.
- The procedure can take about 1 to 2 hours to complete. You can usually go home the same day or you may need to stay overnight. The aches that you may feel afterwards can take a few days to disappear.
- It is likely that if you are asked to donate your bone marrow in this way, then the patient receiving your bone marrow is a baby or child which makes it extra special knowing you can save a child's life!



This is Jack in the middle of his donation! Donating stem cells is not painful & it's similar to donating blood.

Do I lose my stem cells forever once they have been donated?

- Donating your stem cells does not mean you lose them forever. Your body replenishes these within 1 to 4 weeks

Are there any risks to my health?

- Your health is very important and your medical team will never put you through a procedure if they believe you are not healthy or fit enough. All the necessary checks are done before you donate your stem cells.

Am I obligated to donate once I receive that first call?

- It is important to know that when you receive that first call saying you may be someone's match you still have the opportunity to pull out. You are obligated to donate further along the process when the patient receives the high dose chemotherapy. From this point there is "no going back", because if someone pulled out at that point, the patient would die without the stem cells to re-build their immune system.
- Do not take your decision to join the registry lightly. ***You need to be prepared to show a level of commitment when you join as it is not fair for patients to receive false hope.***

QUESTIONS ABOUT DONATING YOUR STEM CELLS (CONTINUED)

Do I have to travel to donate my stem cells?

- If you match with a patient overseas this does not mean you need to travel to that country. You can donate your stem cells locally in Australia and they will be transported overseas.
- Stem cell donation occurs in most of the main cities in each State around Australia (except the Northern Territory). Travel expenses incurred to travel within Australia for a stem cell donation are reimbursed, they'll even cover the costs to bring a support person with you! Think of it as a free domestic holiday!



If I'm a match, can I donate my stem cell to a specific person?

- No. Although you may be inspired by your sick friend or family member to join, you can't ask to be specifically tested for a loved one who is sick (unless you are a sibling).
- When you join the registry you can potentially be matched with anyone, anywhere around the world.
- The chances of you matching with your loved one and also a complete stranger is extremely low. So don't worry, in the unlikely event that you are the match for your loved then you will be called!

OTHER QUESTIONS

Does my blood type need to match with the patient's blood type?

- No, your blood type does not need to match the patient's blood type. It is the other markers in the blood that are more important for matching, in some cases the patient will even have a new blood type (their donor's blood type) after the transplant!

Why do the stem cells/bone marrow need to be matched?

- There are lots of different markers in the blood that will determine if someone is your match or not. Your ethnic background plays an important role when looking at all of these markers and you are more likely to match someone who has a similar ethnicity or cultural background to you.
- Your blood can be "tissue typed" to find out what its unique "code" is and this is what is compared to the patient's "tissue type" or "code" to see if there is a match.
- If the cells are not matched then they will attack the patient's body because they detect the organs as foreign and the patient would die - transplants are never done unless the right match has been found.

