THE LITTLE GUIDE FOR RECRUITMENT VOLUNTEERS

saving the lives of people with blood cancer

anthony.nolan.org
WHO ARE WE?

About Anthony Nolan
Anthony Nolan finds matches for people with blood cancer who need lifesaving blood stem cell transplants. For someone with blood cancer, such as leukaemia, a stem cell transplant can be their only chance of life. We use our register, cord blood bank and research to find remarkable people who can give them that chance.

About Marrow
Marrow was set up in 1998 by students at Nottingham University. Since then, students all over the country help us carry out our lifesaving work by recruiting their peers and raising awareness of Anthony Nolan. Marrow recruit 28% of people who go on to donate, so these volunteers really are crucial to saving lives.

WHO ARE WE LOOKING FOR?

We're looking for particular types of donor to help us double the number of lives we save.

Young donors
We recruit 16-30 year olds because they make the best donors.

Male donors
Young men are the most likely to be chosen to donate (39% of those who donated in last two years are young men) but they only make up 12% of the register.

Minority ethnic groups
Tissue type is an inherited characteristic passed on from parents to children so someone from a similar ethnic background to the recipient will make the best donor.

WHY ARE RECRUITMENT VOLUNTEERS AWESOME?

The volunteers at a recruitment event are absolutely crucial to our work. They guide the potential donor through the implications of joining the register and what donation entails.

Without these volunteers, we wouldn’t be able to recruit healthy 16-30 years olds to our register. But more importantly, we wouldn’t be able to recruit well informed and totally committed healthy 16-30 years olds to our register. And without that understanding and commitment, the risk of dropping out is huge. Dropping out of the register means less lives saved and more hopes dashed. You help us to save lives. It’s as simple as that.

WHAT HAPPENS AT A RECRUITMENT EVENT?

Welcome
There is a reception desk where the recruitment event routine is explained and the potential donor is given an application form and an information leaflet.

Filling in the form
The potential donors fill in their forms and any initial questions and queries are answered.

Counselling
The potential donor has a confidential individual information session with a trained volunteer who will advise them through the process. This session is used to aid the donor’s understanding and allow them to make an informed choice about joining the register. The application form is also checked to make sure that the potential donor is eligible to join the register.

Taking the saliva sample
A trained volunteer will guide the donor through giving their saliva sample.

THE DONATION PROCESS

Stage 1
The saliva sample is sent to our laboratories, where the basic tissue-typing is determined. Most people don’t progress from this stage but if they’re found as a potential match, they will be contacted and asked to progress to stage two.

Stage 2
Blood samples are taken for more detailed testing, to confirm the accuracy of the match. About 10% of this group will be asked to donate.

Stage 3
Final blood samples are taken and lots more tests occur to confirm the accuracy of the match. The donor also undergoes a self-administered medical assessment.

Stage 4
Donors go to London for a comprehensive medical assessment which lasts around two hours. At this stage, the donor is reminded of their commitment as the recipient’s preparation is dependent on the outcome of the medical. Then it gets exciting…

Stage 5
The date is set for the donation and the method is decided. Very infrequently (less than 5% of cases) mobilisation of stem cells in PBSC fails. If this happens and the donor cannot or is unwilling to donate marrow through a bone marrow collection method then the patient has been medically prepared for transplant but may not receive healthy blood stem cells which can be fatal. In order to avoid this situation we only recruit donors who can and will donate marrow by either method if required.

Stage 6
Then comes the big day! Our staff team at Anthony Nolan will follow up with questionnaires and support for the next five years. The donor is also asked if they would like to stay on the register and donate again. People can donate up to four times.

<table>
<thead>
<tr>
<th>Time</th>
<th>Bone marrow collection</th>
<th>PBSC collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before donation</td>
<td>Attend harvest centre for medical examination (one day max.)</td>
<td>Attend harvest centre for medical examination and venous assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Receive G-CSF injections for four days, the first three at home</td>
</tr>
<tr>
<td>At donation</td>
<td>Admitted for two nights, marrow collected under general anaesthetic</td>
<td>Outpatient procedure (one/two days), PBSC by apheresis in three/four hour long session(s)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5th G-CSF administered if second day collection required</td>
</tr>
<tr>
<td>After donation</td>
<td>Recommended to take seven to ten days off work/university and energetic physical activity</td>
<td>Recommended 1 day off work</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoid energetic physical activity</td>
</tr>
</tbody>
</table>
THE ADVICE SESSION
Please use the Event Quick Check Guide for thorough instructions. These are the issues you'll need to address when you guide your applicant.

Consent
You need to make sure that each application is given and consents to the following information.
• Their donation will be anonymous
• They need to let us know of any change of address or status
• They will stay on our register until they're 60
• They could donate to a person anywhere in the world
• They're willing to donate through either method

PBSC – through the blood
• Injections are given over 4 days then the stem cells are taken from the circulating blood
• Can feel achy and tired when having the injections

Bone Marrow Harvest – through the bone marrow
• Take the stem cells directly from the pelvic bone using a needle and syringe
• Done under general anaesthetic
• Have achy lower back for a couple of days

Permission
Always ask permission to check the application form. It is important to ensure the suitability of donors at this stage and make sure all the required information is supplied. (Details about the application form itself are below)

Ethical implications of registering
If a blood stem cell transplant is the only chance of survival for a patient, a potential donor should not be considering the implications of donation after being found to be a match – the time when someone's life is in the balance. Donors need to be aware that they may hold the key to someone's survival.

Although only 0.96% of those registered actually go on to donate, ideally all recruits should be prepared to be within that 0.96%. A potential donor could be called on tomorrow or in 30 years time.

Financial implications of registering
The initial tissue typing costs Anthony Nolan £100. That expense is wasted if the potential donor does not honour the commitment they have made when they are called up to donate in the future.

Anonymity and worldwide recipients
Many potential donors may ask about contact between donor and recipient following a successful transplant. The majority of Anthony Nolan donors and patients never meet. It is essential for the success of stem cell donation programmes that strict anonymity for donor and patient is maintained, both prior to the donation and for a period of two years after the transplant. This ensures that there can be no suggestion of an unrelated donor being coerced or induced to donate for financial or other reward and protects the right to privacy of both the patient and donor. Donors may correspond with their recipient through Anthony Nolan two years post donation at the instigation of the recipient and the incidence of this is very rare.

The chance to withdraw
It is essential to stress that the decision to join the register is not binding; as a volunteer they can back out at anytime in the proceedings. If potential donors are having doubts about joining the register then answer any questions they may have and encourage them to think carefully about it.

Informing family
The potential donor’s parents or alternative contact person must be aware of their decision to join the register, especially as this is likely to be the address we will contact them at. Suggest that they show the Anthony Nolan logo to someone who lives at this address so any post may be forwarded to them as soon as possible.

Notifying Anthony Nolan of change in status
It is vital that donors are contactable at any time while they remain on the register as it is not possible to predict when they might be called up for donation. Donors must keep us informed if they change their details or if their health status changes – including pregnancy. Other lack of availability such as lengthy stays overseas should also be noted where possible.

The positive aspects of registration
It is important to emphasise the positive aspects of joining the register. They are joining almost half a million people willing to help cure cancer.

Questions
All questions from potential donors must be treated with respect. It is important that the donor feels comfortable to ask you anything. If they ask you anything that you are not comfortable answering or are unsure about, refer them to a senior volunteer.

All happy and content? Collect their saliva sample and your work is done!

THE APPLICATION FORM
What to look out for
It's vital that the application form is filled in correctly.
• Is the form filled in correctly? Are all boxes ticked?
• Is the form legible?
• Check that the date of birth, height/weight and donor signature are all completed
• Have they fully completed and signed the consent form?
• Have they given an acceptable height and weight? Please check the height/weight chart

Address to which kits should be sent
• Should be the donor's home address. If the donor is a student then the address should ideally be the student's home/family address
• They must inform family members that they have joined the register
• They must inform Anthony Nolan if their contact details change

Alternative address
This should be a close friend or relative who is aware of where the donor is and has a permanent UK address.

International students
• Accepted if they are based in the UK and intend to remain for three years or more
• A contact with a permanent UK address is needed
• If not accepted, encourage them to register in their home country www.bmdw.org

GP details
• GP details are very important. Please ensure this section is completed
• NHS number is not vital

WHAT ABOUT DIFFICULT ISSUES?
Rejecting potential donors
There will be a very small number of times when you will have to tell people that they cannot join. This is because they could put either themselves or the recipient at risk if they were to donate.

Usually the reasons for turning someone away are straightforward. It will be because of the risk donation would be to them, rather than posing a risk to the recipient. People usually find this type of rejection quite acceptable.

Potentially sensitive issues
Very infrequently, you may need to turn someone away due to a very sensitive issue. Perhaps they are overweight, they are at risk of contracting an infectious disease or they can't make an informed decision.

The volunteer should always review the entire application form before communicating any problem to the donor. There may be multiple issues and this then gives you the option of communicating the least stigmatising one to the potential donor.

The reasons for ineligibility should be clearly explained. In explaining the reasons, responsibility for the decision is firmly placed with us at Anthony Nolan. You as a volunteer are not rejecting the potential donor; you are following the guidelines laid down by Anthony Nolan. That should make things slightly easier for you.
FREQUENTLY ASKED QUESTIONS
Here’s a list of the most commonly asked questions. Remember, if you are unsure of any medical conditions please take as much information as possible and enter it into the application form within the boxes provided.

Who needs stem cell transplants?
Blood stem cell or bone marrow transplants can be used to help individuals who are affected by blood cancers, such as leukaemia.

What happens first?
You will be asked to complete an application form and give a saliva sample which will be taken for tissue-typing.

Do you take my marrow at the recruitment event?
No, only a saliva sample is taken to be sent off for tissue typing. Blood stem cells are only collected if you’ve been confirmed as a match for a specific recipient.

How do I join the register?
Come to a Marrow recruitment event, complete an application form and give a saliva sample. Alternatively you can apply online at www.anthonynolan.org.

What happens after I have given my saliva sample?
The sample will be sent to Anthony Nolan labs in London to be tissue typed. You will then be called up for secondary testing only if you are ever found to be a potential match.

Who will have access to my tissue type?
Tissue type is held confidentially on a secure database. The only time anyone will have access to your tissue type is when the register is being searched for a potential match.

What stages must I go through before having the donation?
Before the donation there will be a blood test to ensure the accuracy of a match. You will undergo a medical assessment in London to certify you are fit to donate. You’ll also receive more advice to increase your understanding of the procedure and you can ask further questions.

What does the cell collection involve?
Cells are donated either by bone marrow or peripheral blood stem cell collection.

Where would it be done?
Both methods take place in hospital in London.

Is it painful?
There is short-term discomfort in the lower back after bone marrow donation. PBSC donors usually experience flu-like symptoms.

Do I have to be put to sleep?
Bone marrow collection usually takes place under general anaesthetic. However, it is possible to have spinal anaesthetic. PBSC requires no anaesthetic.

Would I have to miss work/university?
Time away from normal duties is required for both procedures. After bone marrow collection donors are recommended to take seven to 10 days off work. Donation is arranged at a mutually convenient time within a fixed time period.

What are the risks involved?
The biggest risk involved in bone marrow donation is from the general anaesthetic. Several years of donor follow-up in the UK and around the world have not shown any evidence of long-term health problems from donation. However, we continue to monitor the health of our donors for ten years after donation.

What will they do with the blood stem cells?
A donor’s healthy blood stem cells are infused into the patient’s bloodstream and if accepted (engrafted) begin producing normal blood cells and help fight off any cancer cells left behind after the transplant procedure.

Will I ever get to meet the recipient?
The majority of donors and recipients never meet as strict anonymity is maintained before and after transplant. This is to protect the right to privacy and prevent unrelated donors being coerced into donating for financial or other reward.

FACTS AND FIGURES
The Basics
Every year around 24,000 people are diagnosed with leukaemia or related cancers. At any one time there are approximately 7,000 people awaiting a bone marrow transplant in the UK. Anthony Nolan provides donors for three potentially lifesaving transplants every single day. But we can’t find a match for everyone who needs one. There are currently over 480,000 people on the Anthony Nolan register. Marrow recruit 28% of people who go on to donate. This is one of three registers in the UK and is accredited by the World Marrow Donor Association.

The Match
There is a 1 in 4 chance that a brother and sister will be the same tissue type. There is a 37% chance of finding a related tissue match. Currently the chances of finding a suitable match are:
• 90% for White Europeans
• 40% for people of Asian/Afro-Caribbean/Oriental/Jewish descent (Source: WMDA 2008)

In a 10-year period on the register, approximately:
• 10% of people will be asked to give a further blood sample
• 1% of people will be asked to donate marrow
• 0.96% of people will actually donate marrow.

On average, 90% of donations are by PBSC with 95% of transplant centres requesting this method.

The Recipient
For the recipient, transplant-related mortality is 15-30% (dependent on age, disease and many other factors). Overall disease-free survival following transplant is around 50-60% at five years following transplant.