



NATL 007 03
(Relates to NATS CLS 026)
HPC-A COLLECTION (OR "PBSC" COLLECTION):
RELATED ALLOGENEIC DONOR INFORMATION LEAFLET
FOR RELATED DONORS



INFORMATION LEAFLET FOR RELATED DONORS

This leaflet has been especially written for people who may be about to undergo a PBSC collection as a donor for one of their relatives. (PBSC collection is sometimes also known as "HPC-A" collection, which means the same thing.) We hope the leaflet and a discussion with the nursing and medical staff of the Clinical Apheresis Unit (CAU) will help you understand this procedure and what it involves.

What are stem cells?

The phrase 'stem cells' is used in several different ways by doctors, the television and the newspapers. In this leaflet, 'Peripheral Blood Stem Cells' refers to the immature cells in the bone marrow that grow and divide into mature red blood cells, white blood cells, or platelets.

The bone marrow can be stimulated by injections of a drug called G-CSF, so that some of these stem cells spill over into the peripheral blood that circulates in the veins, from where they can be collected.

What is a PBSC collection?

A PBSC collection is a procedure involving the separation and collection of stem cells from the circulating blood. PBSC collection has now largely replaced the older method of getting stem cells from the bone marrow via a surgical bone marrow harvest. However, sometimes a bone marrow harvest is used instead. This could be because of the specific blood disorder that your relative has, when stem cells collected from the bone marrow are thought to be best for them. It could also be because the donor prefers this method of collection, or occasionally because not enough stem cells can be collected from the blood.

Why is a PBSC collection necessary?

Your relative's doctor has recommended a stem cell transplant as an appropriate treatment for them. This involves giving them a high dose of chemotherapy.

The use of high dose chemotherapy dampens down the bone marrow's normal function of making stem cells for many weeks, during which time your relative would be prone to infection and bleeding, and need blood transfusions. To help to reduce this unwanted side effect of the high dose chemotherapy, PBSC can be given to restore bone marrow function. This means that your relative gets the benefits of the high dose chemotherapy while reducing this unwanted side effect.



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A specific minimum number of PBSC will be collected from you as a healthy donor and either given to your relative within a few days of collection, or frozen for storage and given at a later date.

Either way, the PBSC are transfused to your relative. They migrate to the bone marrow and once there, begin the process of creating new blood cells by growing and dividing into mature red blood cells, white cells and platelets.

Do I need any tests before having a PBSC collection?

Yes. You will need some blood tests to make sure that you are fit to go ahead with the collection. We also need to assess whether you have been exposed to infectious agents such as HIV, hepatitis, HTLV and syphilis before we are able to collect stem cells from you. This is also done by a blood test. The implications of any abnormal test results will be discussed with you before the tests are done, and you will be told the results of all of these tests. If any of the tests are abnormal, we will arrange for you to be seen by an appropriate hospital specialist, who will then arrange any other tests or investigations that are needed.

What actually happens during a PBSC collection?

The collection is done using a piece of medical equipment called a blood cell separator machine. It uses a centrifuge to separate PBSC from the other blood cells and plasma. The PBSC are then collected into a bag and the other cells and plasma are returned to you. Qualified medical and nursing staff will operate the blood cell separator and will monitor you and your medical status at all times.

Before having a PBSC collection, you will receive a prescribed dose of a drug called granulocyte colony stimulating factor (G-CSF). G-CSF is a growth factor for white blood cells. This drug causes some of the stem cells in the marrow to be released into the bloodstream, so that they can be collected.

G-CSF is given as an injection just under the skin, usually in the tummy region, once a day for a period of 4 to 5 days with the PBSC collection usually happening on the fifth day. If we do not collect the minimum safe amount of PBSC needed by your relative on this day, then you will be asked to have one more G-CSF injection and come back for a further PBSC collection the next day. Very occasionally, if we still do not have enough cells, you may be asked to come back for a third PBSC collection the next day again.



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So that your blood can be processed by the cell separator machine, two lines, or cannulas, need to be placed in the arm veins, usually at the elbows. This allows blood to flow from you through one line and into the machine where it is processed, and then returned to you through the other line.

If the veins in your arms are small or difficult to use, you will need to have a thin plastic tube called a central venous catheter placed in a large vein by a doctor in advance of the HPC-A collection. This will allow blood to be removed and returned easily during the HPC-A collection, and the line will only be needed for the collection(s). Your CAU doctor will discuss this with you further if you require to have a central venous catheter inserted.

The cell separator machine has to add a drug called "citrate" to the donor's blood as it draws it out, to prevent the blood from clotting. Some citrate remains with the collected PBSC, but some stays with the fluid that is returned to you. This will not cause you any harm but may cause a temporary lowering of one of the blood salts, the blood calcium. A feeling of numbness or tingling around the lips and fingers, shivering, cramp or a strange taste may be symptoms of a low calcium level. If you get any of these symptoms, you should tell the staff looking after you who can easily treat you with a small amount of calcium in the form of a milky drink or a tablet.

The cell separator machine carries out the collection in an automated, continuous, and safe manner. The sterile tubing sets and needles are used one time only and then discarded.

Some points which may arise:

1. Sometimes to achieve adequate blood flow from the lines, the staff may ask you to change your position in the bed or donor chair.
2. Although the cell separator machine removes and replaces just over a teacupful of blood at any one time, this small change in blood volume can make some donors feel dizzy or light-headed. You should tell the staff immediately if you begin to feel uncomfortable.
3. The anticoagulant used to keep the blood from clotting might cause a sour taste in the mouth, tingling around the lips, or in the fingers or toes. You should tell the staff immediately if you feel any of these symptoms.
4. If several PBSC collections are required, the number of clotting cells called platelets in your blood can occasionally be reduced. Low numbers of platelets can increase your tendency to bruise or bleed. This will be monitored by the staff and is unlikely to cause a significant problem.



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Other questions frequently asked

Q *What are the possible risks of G-CSF?*

- A** G-CSF has been used in healthy individuals to date in the following circumstances:
1. Healthy donors who are donating PBSC for a relative, as an alternative to bone marrow.
 2. A number of donor registries worldwide, including the Anthony Nolan Trust in the UK, have introduced the use of G-CSF to collect PBSC from unrelated donors.
 3. When a potential bone marrow donor is unsuitable for a general anaesthetic.
 4. In the USA, when donors have been asked to donate white cells for patients with severe infections.
 5. In several countries G-CSF has been given to allow collection of PBSC from the bloodstream after a bone marrow transplant has not "taken" or engrafted properly.

It is believed that there have been more than 100,000 healthy **donors** who have received G-CSF worldwide to date. It has also been administered to many hundreds of thousands of **patients**. The course of G-CSF you are being asked to consider would be classed as a "short course" and would usually not extend for longer than 4-6 days. No long-term side effects following "short courses" of G-CSF have been reported either in patients or in normal donors. However, in most published studies, donors have only been followed for 5 years so far. The largest study so far is a study of 12,500 volunteer donors from the German volunteer registry published in late 2010, which showed no increase in long-term health problems in either HPC-A donors or bone marrow (HPC-M) donors compared to the general population after an average of 3 years of follow-up, with some donors having been followed up for 10 years or more.

Bone and/or muscle pain is the commonest significant short-term side effect caused by G-CSF. This is usually mild, affects between 50 to 90% of people taking G-CSF and can be controlled by paracetamol. There have been some rare reports (less than one in a thousand patients) of allergic reactions that have occurred usually when the drug has been injected directly into the blood for other uses, rather than just under the skin. Finally, there have been 5 reports since 1999 of healthy donors who suffered rupture of the spleen requiring surgery after receiving G-CSF. In most of these cases, the donor took part in contact sport during or shortly after PBSC collection, and so you will be advised to avoid contact sports and other strenuous activities while you are receiving G-CSF and for 2 weeks afterwards to minimise the chances of this extremely rare complication occurring.

G-CSF is licensed for the mobilisation of stem cells in healthy donors.



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WARNING: GCSF should **not** be used during pregnancy or whilst breast-feeding. If you are female and of child bearing age, you will be asked to take a pregnancy test before receiving G-CSF. You should use reliable contraception until the G-CSF course is finished and for at least one month after.

Q *Will there be any pain?*

A Insertion of needles may cause some discomfort. Staying still for the time required for the procedure may be uncomfortable.

Q *Is PBSC collection a safe medical procedure?*

A Greater than 25,000 PBSC collections are performed worldwide each year with few problems. Another one million procedures, which are very similar to PBSC collections, are performed each year on volunteer donors for plasma and platelets, again with few problems.

Q *Are there any reactions or lasting side effects from the PBSC collection procedure?*

A You may feel tired after a PBSC collection and require rest.

Side effects during the procedure might include feeling dizzy, light-headed, nauseated, and cold. Some donors may feel tingling in the fingers and around the mouth. These side effects can be quickly and easily treated by the staff.

Any questions you may have about these side effects should be directed to the CAU staff.

Q *How long does a PBSC collection take?*

A This varies from donor to donor. The current cell separator machines used by SNBTS usually perform a PBSC collection in around four hours.

Q *Will I be left on my own?*

A No. The nursing staff will be there all the time. A doctor will be available nearby throughout the procedure.

Q *How often will PBSC collections need to be performed?*

A The number of PBSC collections varies from donor to donor, and depends upon your marrow's response to the growth factor. Most donors have either one or two collections, but occasionally 3 are needed. The collection staff will make sure that the required number of stem cells are collected, and in as few collections as possible.



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Q *Can I catch a disease from the supplies being used?*

A No. The blood tubing set and needles are sterile, used one time only, and discarded.

Q *What can I do during a procedure?*

A You will be advised to have a milky drink and will be given the chance to use the bathroom before the collection starts. You'll be able to read a book or magazine, watch TV or a DVD, or listen to the radio during the procedure. If need be, you'll be able to use a bedpan or bottle.

Q *Can I have visitors?*

A Yes. There's room for someone to come with you and keep you company during the collection. It's also advisable that there's someone to take you home afterwards.

Q *What if I change my mind, and decide I don't want to go ahead with the collection after all?*

A You **always** have the right to change your mind and decide not to donate your stem cells, right up to the time when your relative is admitted to hospital to start the transplant process. Your participation is voluntary and you are free to withdraw at any time, and without giving any reason. However, there are significant consequences to your relative if you should change your mind in the two week period prior to the planned harvest date, which will be explained to you by the CAU staff. In particular, these consequences may include a longer hospital stay for your relative, a greater risk of infection and bleeding, which may be life-threatening, and possibly death before a suitable non-related donor can be found. Therefore, it is important that you agree that you will not unreasonably withdraw your consent in this period, except where proceeding could endanger your health.

Q *Who can I contact if I have more questions?*

A You'll be given contact phone numbers when you visit the CAU so that you can phone the unit afterwards if you have any questions after your visit.