

Paediatric haematology

# Before your child has a stem cell transplant

## A guide for families

### Introduction

This information sheet explains the investigations your child will need to have to prepare for a bone marrow transplant (BMT). It also explains a little about what to expect when your child is admitted to St Mary's Hospital for their transplant.

Your child will need to be fully investigated before being admitted for their transplant; outpatient appointments with your child's consultant will be necessary, and various investigations including blood tests, scans and a bone marrow harvest will be carried out. It is very important that all the required tests are completed. Wherever possible, investigations will be scheduled at convenient times for you to ensure minimal disruption to your family life. Play specialists and psychologists are available to help your child understand the procedures using age-appropriate explanations and hospital play. If your child is receiving a matched family donor they will also need to be fully investigated before donating their stem cells.

### What tests will my child need?

On the following page is a list of the investigations that need to be carried out before your child is admitted for transplant. If you have any questions about any of the tests you should contact your named BMT coordinator to discuss this with them (please see page 6 for contact details).

Many tests will need to be carried out and, depending on your child's size and weight, this may take more than three visits. Blood tests will also need to be taken so, where possible, these will be coordinated with the other investigations to avoid multiple attempts at taking blood. Blood tests will take place either in the paediatric outpatients department (sixth floor, the Queen Elizabeth the Queen Mother (QEQM) building) or in the paediatric haematology day care unit (sixth floor, QEQM Building).

<b>Requested blood test</b>	<b>Reason for test</b>
Human leukocyte antigen (HLA) typing (tissue typing)	This is a very important test to confirm that your child has a matched donor, and is repeated on a separate occasion to confirm previous results.
Molecular diagnosis	These tests look at your child's DNA to confirm their haematology diagnosis.
Clotting	Your child's clotting will be investigated; it may sometimes need further investigation if the clotting is prolonged. This is carried out to ensure that your child will be safe during any operations that are scheduled.
Blood group	It is important to check your child's blood groups as they will change to their donor's group, post-stem cell transplant (SCT). Precautions will also need to be taken while infusing the stem cells if blood groups are different. Different blood groups do not affect having a transplant.
HLA antibody screen	Your child may have developed antibodies if they have been on a regular transfusion programme, we need to screen for these to ensure there is no cross reaction with the donor's HLA typing.
Red cell phenotype	This is performed to assess if any antibodies are present in your child's red blood cells. This is to make sure that the safest blood product can be given to your child.
Chimerism	This is tested so that it can be stored and compared to chimerism samples following your child's transplant to see how many 'donor' cells are being produced. This test result is expressed as a percentage.
Hormone profiles	Baseline profiles are tested so that your child can be fully assessed post-BMT in the late effects clinic. Vitamin D supplements may be prescribed and are usually continued for three months before being retested.
Virology	Viral screening needs to be performed within 30 days of the bone marrow harvest. It is important that your child's viral status is determined as they can reactivate during transplant.

### **Chest x-ray**

All children undergo a chest x-ray, which gives a picture of the lungs using a low dose of radiation. This is checked for any signs of infection which will then need to be investigated and treated before transplant. X-rays are taken in the radiology department (third floor, QEQM building, St Mary's Hospital). If your child is having a bone marrow transplant for bone marrow failure this test will be replaced by MRI techniques to prevent radiation exposure.

### **ECG (electrocardiogram)**

All children need an ECG, which shows how often and how regularly the heart is beating. This is carried out at the Royal Brompton Hospital at the same time as the Echocardiogram (please see the next page) is completed. For donors this is done in the Waller Cardiovascular clinic, located on the ground floor of the Mary Stanford Building at St Mary's Hospital.

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### **ECHO (echocardiogram)**

All children need an ECHO, which is an ultrasound scan of the heart. It shows the structure, function and blood flow through the heart. This is carried out at the Royal Brompton Hospital.

### **Lung function**

Lung function tests are carried out to assess your child's lungs and airways. This is to determine a baseline, so that your child can be monitored if a complication like graft versus host disease (GvHD) develops. Depending on your child's age, this test can be performed by the allergy nurses in the paediatric outpatient department, or in the chest and allergy clinic, which is located in the mint wing (South Wharf road, towards Paddington station). Children under the age of seven are not routinely screened with this test, this is because they need to be able to follow instructions to coordinate their breathing, which is difficult in younger children.

### **Dental reviews**

All children will be referred to the dentist to check for any decay or infection that needs to be treated before their transplant. Treatment may be carried out under local or general anaesthetic. If dental treatment is carried out under local anaesthetic you will be seen in the dental department. If treatment is needed under general anaesthetic, your child will be admitted as a day case. All patients are referred to the dental service based at King's College Hospital.

### **Transcranial Doppler studies**

This test will only be performed if your child is receiving a BMT for sickle cell disease. The test will measure the pressure of blood flow in the vessels in your child's head and neck which supply blood to their brain. This test is used to determine if your child is at an increased risk of a stroke. This test is like an ultrasound and takes place in the Irvine vascular studies department, ground floor, Mary Stanford wing, St Mary's Hospital.

### **Head and brain MRI/MRA scan**

This test is routinely performed for all children having a BMT for sickle cell disease to identify if any vessels which supply blood to the brain are narrowed or blocked which may lead to a stroke. In some instances this test may be performed in children with bone marrow failure, if this is needed your child's named nurse will discuss this with you.

### **Heart and liver MRI scan**

This test will be performed on children aged seven and older who need a BMT and have been on a regular transfusion programme. Younger children may also be referred after an assessment with the play specialist, who may also accompany the child through the scan if this is thought to increase the chance of a successful scan.

### **FerriScan**

This is an in-depth MRI of your child's liver and is very accurate at measuring the amount of iron stored in the liver. It may be repeated on more than one occasion depending on the severity of iron overload. A FerriScan can be performed under oral sedation and therefore children as young as two years can have the test as long as the sedation is successful. If your child requires this procedure under oral sedation you will receive confirmation from your BMT nurse on how to prepare for the scan.

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### **Abdominal ultrasound**

All children will have a scan of their abdomen, this is to look at the following organs; spleen, liver, gallbladder, pancreas and kidneys. The scan will take place in the radiology department, located on the third floor of the QEQM building, St Mary's Hospital.

### **GFR (glomerular filtration rate)**

Children who have previously had kidney problems or who are having a BMT for a bone marrow failure syndrome will be referred for this test, which shows how well the kidneys are working. A dye is injected into a vein and a series of blood samples are taken over a few hours to see how well the kidney filters out the dye. Your child will need to be seen in the paediatric day care unit, Westway ward, seventh floor of the QEQM building, St Mary's Hospital) 30 minutes before their GFR appointment so that two cannulas can be inserted (one to give the dye through and the other for taking the blood samples). The dye will be given by staff in the clinical physics department, third floor, QEQM building, St Mary's Hospital.

### **Chest CT scan**

If your child has previously had chest problems or is neutropenic (a blood disorder characterised by a lack of neutrophils, a type of white blood cell), they will need a chest CT scan. If your child is having a BMT for a bone marrow failure syndrome this may be replaced by MRI techniques to reduce radiation exposure. A CT scan uses x-rays and a powerful computer to build up a picture of your child's chest and lungs. Your child may also need a cannula inserted, as contrast may be needed depending on the detail required for the scan pictures. The scan will take place in the radiology department, located on the third floor of the QEQM building, St Mary's Hospital. Your child can be accompanied by a play specialist if they are anxious about the scan.

### **Autologous bone marrow harvest and bone marrow aspirate**

An autologous bone marrow harvest (where their own bone marrow is harvested and stored) is performed if your child is having an alternative donor transplant (an unrelated donor or haploidentical donor – a donor with a 50 per cent match). This will happen under general anaesthetic and, at the same time, some bone marrow cells will be collected to be examined in the laboratory. Your child will be admitted to paediatric haematology day care and will stay overnight in hospital to be monitored.

### **Liver biopsy**

If your child has been on a regular transfusion programme, a liver biopsy will be carried out at the same time as the bone marrow harvest. Small pieces of liver tissue will be examined to determine if there is any fibrosis in the liver and the amount of iron which is present. Your child will be admitted to paediatric haematology day care and will stay overnight in hospital to be monitored. Children having a BMT for bone marrow failure may also need a liver biopsy to exclude fibrosis which, if present, can be a risk factor for complications during transplant.

### **Neuropsychometric testing**

This will only be undertaken if your child is receiving a transplant for sickle cell disease. It is a test designed to look at brain function through performing tasks designed to focus on information processing, attention, memory and language. The test will be completed by the clinical psychologist and an appointment will be made for your child. These tests are performed in the paediatric outpatient department.

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## **Psychology review**

All families are seen by the clinical psychologist so that they have the opportunity to express any concerns or worries, and help can be offered to develop coping strategies, if needed. It is helpful to meet the psychologist, even if you don't have any concerns, as you may want to meet them whilst your child is admitted for transplant.

## **Insertion of a central line**

All children will have a Hickman line inserted; this is usually inserted at the same time that your child undergoes the procedure for preserving fertility. This is completed at the John Radcliffe Hospital in Oxford.

## **Fertility preservation**

In children who have not yet reached puberty, fertility can be preserved by undergoing cryopreservation of either ovarian tissue (girls) or testicular tissue (boys). Girls who are having regular periods and are not compromised by cerebrovascular disease caused by an underlying disease process (sickle cell disease) can have oocyte vitrification (a technique to stimulate the ovaries and collect eggs which can be used in an IVF pregnancy at a later date). Boys who have reached puberty can have semen stored and cryopreserved for use at a later date. This will be discussed with you in clinic by your child's consultant. The decision to proceed is made in agreement with the patient (age dependent) and parents.

All of your child's preparation tests are organised by your named BMT coordinator. The progress towards transplant and your child's condition will be discussed frequently by your child's consultant and the BMT coordinators.

During this time you should contact your named BMT coordinator if you have any queries about tests or investigations that have been arranged.

## **Test for donors**

### **Sibling donor aged less than 16 years**

If your child is having a BMT from their sibling, their sibling will also undergo many of the blood tests (explained above) and will also need to have a chest x-ray and an ECG.

A donor medical examination will be carried out by the recipient child's consultant, then the bone marrow harvest is explained to the child and support can be given from the play specialist to help them understand the process in an age-appropriate way. They should also be involved in the psychology review so that they understand that if an unsuccessful outcome occurs, it is not their fault.

Any sibling under 16-years-old will need a Human Tissue Authority assessment (HTA).

This is a legal requirement which is designed to ensure that children are not being coerced into acting as donors.

The bone marrow donation will take place on the same day the bone marrow is scheduled to be infused for the recipient. The donor is admitted to paediatric haematology day care and will need to stay overnight in hospital. They will be discharged the following day by the medical staff and will be given a prescription for iron supplements, which will need to be taken for six weeks following the harvest. At that point, they will be seen in the paediatric outpatient department, where they will be reviewed and have a blood test to see if their iron stores have been replenished. The donor will then either continue taking iron supplements or be discharged from clinic.

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### Adult-related donors

Adult donors are seen in clinic by your child's BMT consultant and they are also reviewed by the adult haematologist to confirm that they are medically fit to donate bone marrow.

Adult donors undergo the same investigations as those for sibling donors and the bone marrow is taken under general anaesthetic. If peripheral stem cells are required, these are taken at a different unit, usually at the Hammersmith Hospital.

### Unrelated donors

If your child has an unrelated donor, their bone marrow registry will contact the donor to find out if they are available for the date(s) we have requested. This process can take several weeks and although we understand that this can be a very stressful time, we are not able to influence the donor's availability in any way. Donors have to have a full medical before their cells are collected to ensure they are fit to undergo the procedure.

### Who do I contact for more information?

**BMT coordinators:** 020 3312 5062 / 020 3312 3345 - 07766991070

**Paediatric haematology day care unit:** 020 3312 5096 + 0203 3125095

Additional patient information is available on our website:



### How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at **imperial.pals@nhs.net**. The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to express your concerns in **writing** to:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY.

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## Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille, or in alternative languages. Please email the communications team:  
**[imperial.patient.information@nhs.net](mailto:imperial.patient.information@nhs.net)**

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