



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families **Welcome to the Immunology/Bone Marrow Transplant long-term follow-up clinic: information for families**

This leaflet explains about long-term follow up after your child has had a bone marrow transplant at Great Ormond Street Hospital (GOSH). It explains about the need for follow up and what will happen at clinic appointments.

Who is the clinic for?

This clinic is for children who have had a bone marrow transplant for an immune disorder. Your child's follow-up will be transferred to this clinic when he or she has reached a certain stage in their progress after transplant. The timing varies but is generally around six months to a year after transplant. Your child's new immune system will need to be developing well, which means he or she will be off most medicines. Initially your child may be seen every three to six months in this clinic, gradually reducing to yearly visits as appropriate.

Before your child moves to the long-term follow-up clinic his or her routine care will have transferred from the BMT team back to the care of the immunology medical and specialist nursing team. The lead nurse for children, who have had a transplant, will aim to meet with you before transfer, and answer any questions you may have. If you have any queries about your child's care or about transferring to the follow-up clinic, please contact us (details at the end of this leaflet).

Transferring to the follow-up clinic may feel a little daunting. However, most of the people running the clinic will be familiar to you from before transplant, and the transfer is a sign that your child's new immune system is developing as it should and that all is well. So it is a very positive step.

Where and when is the clinic held?

The clinic is held in the Medical Outpatients Department, Royal London Homeopathic Hospital (2nd floor), on the first Friday morning of each month.

Which professionals come to the clinic?

The clinic is run by a team of immunology doctors, a clinical nurse specialist and a clinical psychologist. It is likely that you will already know most of the doctors from immunology clinics before BMT or from the BMT clinic. The team meets before clinic to review the children coming to clinic on that day. This helps us to offer advice and care which is based on the combined expertise of all the team. Because several doctors take part in this clinic it is unlikely that you will see the same doctor each time you come to clinic, but all the team members work closely, so will be familiar with your child's care.

This document must be read in conjunction with all Great Ormond Street Hospital NHS Foundation Trust Policies and Procedures.



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

If you have a preference to see a particular doctor please discuss this with the nurses when you come to clinic or beforehand with the immunology nurses (see contact details), although we cannot make any guarantees.

The team at this clinic works closely with other specialist departments in the hospital, specifically including growth clinic, dental, and hearing departments. We will liaise with other departments where necessary.

What happens at the clinic?

Your child will be weighed and have his or her height measured before seeing the doctor. There will be plenty of time for you to ask questions. Your child will usually need to have some blood tests done to continue to monitor their new immune system. The doctor will write a letter to your family doctor (GP) and local consultant to inform them about your clinic visit and give details of the blood tests results. A copy of this letter will be sent to you.

The clinical nurse specialist may join the doctor for your child's consultation. She will be available throughout the clinic if you have any questions or worries or need help with any aspect of your child's care. If necessary, she will also be able to liaise with your local healthcare team, such as GP and community nurses. Psychologists are also available for discussions where necessary.

Other aspects of follow-up

As well as monitoring your child's developing immune system, there are a number of other areas of general health that will need to be monitored because of possible effects of your child's original disorder, or of some of the medications they had around the time of BMT.

Immunisations

The immune system your child has developed since BMT is a new, immature immune system – in terms of their immunity it is a bit like being a baby again. The new immune system will not 'remember' any of the immunisations your child may have had before, so he or she will need to have all their immunisations again. The doctors will discuss with you when immunisations should be started (usually when your child has been off replacement immunoglobulin for at least three months) and ask your GP to arrange these with you. Blood tests will be performed at the next clinic visit to check that the new immune system is making antibodies in response to immunisations.

Growth and development each time you come to clinic the doctor will plot your child's growth on a chart to make sure he or she is growing appropriately for their age. If a child appears to be a bit behind growth-wise, the doctor will recommend a visit to the specialist growth clinic at GOSH. An appointment at this clinic is also offered as a routine to all children who have had BMT when they are approaching puberty.

This is because puberty is such an important time for growth and development and it is important to find out if things are going well from the start. At this time the doctors will request a blood test to



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families
check whether your child is making the right hormones to help their body develop towards adulthood.

Fertility

You will have been told before your child underwent BMT that some of the medicines needed to prepare the body to accept the new immune system can affect future fertility. These medicines are chosen carefully to maximise the chances of a successful transplant while minimising the risk of future infertility, but we cannot accurately predict those risks at this stage. The specialists in growth and development will monitor hormones and development during puberty and may be able to tell you whether your child's fertility is likely to have been reduced.

Hearing

Hearing can in some cases be affected by the original immune disorder, or by infections, and in a few cases by the medicines needed during transplant. If there are concerns about hearing an assessment will be arranged immediately, but in all children a routine hearing assessment will be requested about a year after transplant. This is often carried out at GOSH but can also be done locally. If your child does need further assessment or help with hearing then this can be set up in your local area.

Dental health

All children should see a family dentist on a regular basis (usually every six months) to ensure their teeth and gums stay healthy (and they get used to going to the dentist!). If your family dentist has any concerns we will arrange referral to a specialist dentist.

Psychology

Adapting back to normal family life after having a transplant can be difficult for your child and the whole family, and it takes time to adjust. Some children who have had transplants do have some psychological difficulties as they get older, and this may be due to their original condition and/or the actual transplant process itself. These difficulties can include learning difficulties and/or emotional or behavioural difficulties.

In order to identify any difficulties as early as possible, all children are offered a developmental assessment between the ages of three to four before starting at school, and again prior to starting secondary school at about age ten. The aim of these assessments is to identify any difficulties at an early stage in order to ensure the child receives any additional support they require, for example from speech and language therapy or additional support within school. If necessary, psychological treatment for a child or family can be arranged with the clinical psychologist attached to the clinic or with a local service.

Genetics

All of the disorders of the immune system that are treated by BMT have a genetic basis, and you may already have had some genetic counselling before or around the time of BMT. However, there may be issues that were not completely clear, and these can be re-visited in the long-term follow-up clinic, either by the doctors in the clinic, or by referral back to the Genetics department. As your child grows older, he or she is likely to want to understand the genetics, and it will be important that



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families
your child understands any possible risks that his or her own children could be affected by the same disorder.

What arrangements are made for follow up services when my child is reaching adulthood?

There is a follow-up clinic for adults held at the Royal Free Hospital, which is only a short distance away in Hampstead, north London. We aim to ensure that there is a smooth transition of care from GOSH to the adult clinic at the Royal Free Hospital. In order to do this, the GOSH team will discuss with you and your child the transition arrangements and will make sure you have the information you need prior to transferring. In addition, some of the clinic staff from the Royal Free Hospital may come to the clinics at GOSH, and there are always one or more members of the GOSH team at the Royal Free clinics.

Useful numbers

GOSH switchboard – 020 7405 9200

Clinical Nurse Specialist – ext. 5024

Doctors – 020 7829 8834 or 020 7813 8121

Clinical Psychologist – 020 7829 8679