The children’s sickle cell and thalassaemia clinic

This leaflet offers further information about the children’s sickle cell and thalassaemia clinic, including what it is and what you can expect when you bring your child to clinic. If you have any further questions or concerns, please contact us using the details given at the end of this leaflet.

What is the children’s sickle cell and thalassaemia clinic?
The children’s sickle cell and thalassaemia clinic (also known as the haemoglobinopathy clinic) is open to all children with sickle cell anaemia, thalassaemia major and other haemoglobinopathies. The purpose of the clinic is to provide regular care for these children and to provide counselling and support for them and their families. The clinic is open to children from the time they are born until they are about 18 years old. When the children become teenagers, we will prepare them to move to the appropriate adult clinic.

We are dedicated to providing the best care for your child and believe that your family benefits from having a whole team of experts involved in your child’s care. The clinic is therefore run by a multidisciplinary team, which includes:

- consultant paediatric haematologists
- consultant paediatricians
- a haematology registrar
- a specialist nurse in paediatric haematology
- a community sickle cell counsellor
- paediatric nurses
- a clinic receptionist
- medical students
- nursing students.

The clinic is run on Wednesday mornings between 9.30am and 12.30pm.

What can I expect from the clinic?
Upon arrival to the clinic you and your child should register at the reception desk. The reception staff will check your address, contact details and the name of your GP.

A staff member will measure your child’s weight and height, as well as his/her blood pressure and oxygen saturation level. After this, your child will be seen by a doctor.

During the very first visit, the doctors will gather a lot of information about your child and your family. It is an opportunity for the doctor to get to know your child and to understand your concerns. In addition to examining your child, the doctor will give you information about your child’s condition and answer any questions you may have.
During follow-up appointments the doctors will:
- examine your child
- find out how your child has been doing since their last clinic appointment
- monitor any changes in weight and height
- answer any new questions that you may have about your child’s health
- review information about sickle cell disease
- ensure that your child is taking the right medications and receiving his/her vaccinations.

At some clinic appointments your child will need to have a blood test. This will usually happen on the same day as the clinic appointment and will take place in the blood drawing room, on the ground floor of Lanesborough Wing (opposite the reception desk). While you and your child are waiting for the blood to be taken, the nurse will apply a numbing cream to your child’s skin. This will decrease the pain of the blood test.

Occasionally your child may require other tests such as x-rays, ultrasounds, doppler scans, hearing tests or eye tests. The doctor will arrange these for you and will explain why these are necessary. These tests will sometimes take place on a different day.

After each clinic appointment your child’s doctor will write a letter to your GP and your community counsellor about your child’s visit. You will also receive a copy of the letter.

The doctor may also give you a prescription at the end of your visit. Please go to the outpatient pharmacy on the ground floor of Lanesborough Wing to collect your child’s medication.

At the end of the visit your doctor will ask to see your child again in a couple of months’ time. It is important to make a follow-up appointment for your child before you leave the clinic. This can be done at the clinic reception desk. As your child gets older they will only have to come to the clinic once or twice a year.

Please remember to bring your child’s red book to each of these clinic visits.

**What if I need to cancel an appointment?**

It is very important to attend all of your child’s clinic appointments. Even if your child is doing well it is important to meet with the doctor to review his/her progress. If you cannot attend an appointment, please call the clinic reception as soon as possible on **020 8725 1741** – this may allow another child to use your original appointment slot. During this phone call, please make another appointment for your child at a time that is more convenient.

Also, if you cannot attend an appointment for a doppler scan, eye test, hearing test or heart test, please call the specific departments to cancel. Again, you should make another appointment that is more convenient for you.

**Should I bring my child to clinic if he/she is sick?**

If your child is unwell, do not bring him/her to the sickle cell and thalassaemia clinic – we do not have antibiotics or pain medicines readily available. Children with sickle cell disease have direct access to Frederick Hewitt Ward (5th floor, Lanesborough Wing) and may be assessed there for fevers and pain.

Call Frederick Hewitt Ward **020 8725 2081** if your child has any of the following symptoms:

- fever greater than 38.5 degrees Celsius
- severe chest pain or difficulty breathing
• severe abdominal (tummy) pain or swelling
• severe headaches/dizziness
• problems with seeing
• painful erection (priapism)
• paleness
• inability to move arm(s) or leg(s)
• seizures
• vomiting or diarrhoea
• severe pain that is not responding to painkillers

It is important to call the ward in advance to notify them of your child’s illness.

If your child is very unwell (unresponsive, lethargic, has difficulty breathing) please take them directly to your nearest accident and emergency (A&E) department or call 999.

**Is there any support available for children with SCD and their families?**
Sickle cell disease and thalassaemia may affect some children and their families more than others, and you may want to meet with the specialist counsellor for haemoglobinopathies. The specialist counsellors are attached to the clinic and work closely with the hospital team and community services. They are usually available in the clinic and can offer affected children and their families:

• support and genetic counselling
• information and advice regarding sickle cell disease and thalassaemia
• social support, such as liaising with support groups, nurseries, schools, and colleges, or providing supporting letters to your local housing department.

**Further support**
**The Sickle Cell Society**
Provides advice, information and support to people with SCD and their families, and raises funds for the education of carers and health professionals.
Tel: 020 8961 7795 Web: www.sicklecellsociety.org

**UK Thalassaemia Society**
Raises awareness in health education and provides counselling services to children with thalassaemia and their parents/families.
Web: www.ukts.org

**Wandsworth Sickle Cell and Thalassaemia Support Group**
Provide services and programmes to provide social welfare and recreational and other leisure facilities to improve the lives of those living with and affected by SCD and thalassaemia who are receiving treatment in the Borough of Wandsworth.
Tel: 020 8682 9489 Web: www.wsctsg.org.uk Email: wsctsg@btinternet.com
Contact us

<table>
<thead>
<tr>
<th>Department</th>
<th>Telephone number</th>
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<tbody>
<tr>
<td>Childrens outpatient department (Dragon)</td>
<td>020 8725 5292</td>
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<tr>
<td>Haemoglobinopathy counsellor</td>
<td>020 8812 0636</td>
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<tr>
<td>Paediatric haematology secretary</td>
<td>020 8725 3921</td>
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<tr>
<td>Freddie Hewitt Ward</td>
<td>020 8725 2081</td>
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If you wish to contact the paediatric haematology consultant please contact the paediatric haematology secretary.

Additional services

Patient Advice and Liaison Service (PALS)
PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9am and 5pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer). **Tel:** 020 8725 2453  **Email:** pals@stgeorges.nhs.uk

NHS Choices
NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.
Web: www.nhs.uk

NHS 111
You can call 111 when you need medical help fast but it’s not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. **Tel:** 111