NHS
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Children's Sickle Cell Disease and Thalassaemia Clinic

Information for parents

This information leaflet explains the services provided by the Children's Sickle Cell Disease and Thalassaemia Clinic. If you have any questions or concerns, please do not hesitate to speak to any member of the team caring for your child.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

Welcome to the Children's Sickle Cell Disease and Thalassaemia Clinic

At our specialist clinic, you and your child will see specialist haematology doctors and nurses who will check your child's health. You can find out more about sickle cell disease and thalassaemia and how we treat it.

Clinic appointments are also a chance for you to discuss issues such as school, your child's transition from paediatric to adult services, travel, and medication and research opportunities.

It is very important that your child comes to all their clinic appointments, and that you and they are also available for telephone appointments.

These appointments allow us to get to know you and your child and understand their individual needs. They are also a chance for you and your child to get to know the team who will be caring for them. Please take this opportunity to ask as many questions as possible so you can get as much information as you need to care for your child at home.

When will you first see my child?

If you have a newly diagnosed baby, their first clinic appointment will usually be when they are three months old.

How often will they have appointments?

We usually aim to see your child or telephone you three or four times in the first two years.

Who works in the haematology team?

- Consultant paediatric haematologists
- Haematology registrar
- Clinical nurse specialists (CNSs)
- Community sickle cell nurse specialist
- Specialist psychologist
- Transition (young adult) nurse specialist
- Research nurses and doctors

What happens at clinic appointments?

When you bring your child in for their appointment, please check in at reception. One of our nurses will then take their height and weight and measure their blood pressure, heart rate and oxygen levels.

Blood tests

Your child may need a blood test when they come in. If so, please to take a ticket from reception and wait for your number to be called for the phlebotomy room.

Your child may need to have blood tests at another time. The doctor or nurse specialist will call to let you know when to take your child to the phlebotomy department.

The phlebotomy department is located in the Children's outpatients Department, 3rd Floor Hambledon Wing, open 9am to 5pm, Monday – Friday.

Vaccinations

Your child may need extra vaccinations. They will usually have these at their clinic appointment.

Prescriptions

Please collect any medication prescriptions from King's Outpatient Pharmacy on Denmark Hill (between King's Dental Institute and the Faraday Building).

Stroke screening

Children with sickle cell disease are more likely to have a stroke than other children, so we offer transcranial doppler scans (TCD) from 2 years of age. These help us to check your child for the signs that show they are at risk of having a stroke and discuss treatment options at an early stage.

Please ask us for more information about this test.

Other services

While you are at the clinic you will usually be able to speak with other members of our team such as the CNSs, the transition (young adult) nurse, the community nurse specialist and the specialist psychologist. If you would like more information about our psychology service, please ask one of our team.

GP letter

After each clinic appointment, we will write to your GP (home doctor) to let them know the treatment your child is having. We usually send you a copy as well.

Telephone consultations

Your child will have some of their consultations with us by phone. Their appointment letter will tell you which type of appointment they have. Please make sure that you are available to speak on the telephone at the time of the appointment.

How do I cancel or change an appointment?

Phone the children's outpatients department as soon as possible on **020 3299 3560** to make another appointment.

If you and your child are running late for their appointment, contact the children's outpatient department on 020 3299 3560 and let them know.

Community services

The community specialist nurses and welfare officer work closely with the hospital team, the clinic and community services. They can help you with:

- genetic counselling
- information and advice on sickle cell disease and thalassaemia
- liaising with support groups, nurseries, schools, colleges and universities
- providing supporting letters
- applying for benefits
- housing advice
- immigration advice.

They are based at the South East London Sickle Cell and Thalassaemia Centre, Wooden spoon house, 5 Dugard Way, Renfrew Road, London SE11 4TH
Tel: **020 3049 5993**

What should I do in an emergency?

If your child is unwell, first contact your GP.

If they are very unwell, take then straight to your nearest Emergency Department (ED/A&E). Do not wait until your next clinic appointment and do not take them to the Children's Sickle Cell and Thalassaemia Clinic.

Who can I contact with queries and concerns?

Please contact the CNSs or the paediatric haematology secretary, who will be able to pass your message on to the team.

Children's outpatients department
Tel: **020 3299 3560**

Paediatric haematology secretary
Tel: **020 3299 3773**

Clinical nurse specialists
Tel: **020 3299 4752** or **020 3299 1916**
Email: **kch.tr-paedhaematologycns@nhs.net**

Community sickle cell nurse specialists and welfare officer
Tel: **020 3049 5993**

Toni & Guy Ward
Tel: **020 3299 4400**

Philip Isaacs Ward
Tel: **020 3299 4200**

More information

The Sickle Cell Society
www.sicklecellsociety.org

UK Thalassaemia Society
ukts.org
020 8882 0011

PALS

The Patient Advice and Liaison Service (PALS) offers support, information and assistance to patients, relatives and visitors. The PALS office is on the ground floor of the Hambleden Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS
Tel: **020 3299 3601**
Email: **kch-tr.palsdh@nhs.net**

You can also contact us by using our online form at
www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.

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