

# Sickle cell disease (SCD) and thalassaemia service for babies, children and young people

**This leaflet gives more information about what the SCD and thalassaemia service can do to help you and your child with their condition.**

## About our service

The paediatric (children's) sickle cell and thalassaemia team run a specialist and comprehensive care service for children and young people in south east London who are born with these inherited disorders.

The service we provide begins at birth and continues until patients are transferred to the adult team.

We are based at Evelina London Children's Hospital on the St Thomas' Hospital site (Westminster Bridge Road). If Evelina London is not your local hospital, we will work closely with your local NHS service to help you receive the specialised care that you need, both in hospital and in the community.

Within the service, our specialist adolescent team will make sure there is a smooth transfer from children's care to adult care when the time comes.

## Clinics

We hold regular clinics every Friday, 9am to 1:30pm at Evelina London on the ground floor (Ocean). Please arrive for your appointment on time to help us run the clinic smoothly and avoid delays.

## What happens in clinic

Please check in with the receptionist when you arrive and let them know if any of your contact or personal details have changed. Your child's weight and height will be taken by a nurse before you see the doctors. They will also note your child's blood pressure and oxygen saturation levels.

You will then be called to see one of the doctors who will talk to you and your child and examine them. You might not see your consultant, but a registrar doctor who works closely with the team. The doctor will discuss any concerns you have regarding managing your child's condition and making sure that they take their medications as prescribed.

If your child needs a blood test, they will be ordered on the computer system and we will ask you to go to the Blood Test Centre for this (in the main St Thomas' Hospital).

Any other tests that may be needed, such as urine, immunisations, X-rays, ultrasound or a Transcranial Doppler scan (TCD) will be explained and arranged by the doctor or specialist nurse you see in clinic.

## Who your child might see in clinic

Your child may also see one of the following members of our team:

- clinical nurse specialist
- research nurse
- community nurse specialist
- psychologist

## Therapy and psychology team

Our psychologists work in the children's psychological medicine and the child and adolescent mental health service (CAMHS) liaison teams. They are part of clinic consultation. A referral can be made to see them for assessment and treatment of emotional difficulties, including managing SCD, and their medications.

## Research

The hospital is also a major research centre. During your visit you may be asked if you are willing for your child to take part in a research study. You are under no obligation to do so. If you decide not to take part in research, it will not affect your child's treatment.

## Community services

We work closely with the community specialist sickle cell and thalassaemia nurses. Certain parts of your child's care are best provided by them rather than us. With your consent, we can refer you to them if you need support.

They can provide:

- home visits
- genetic counselling
- pre-conception screening
- support with housing and other social issues
- a care plan for schools
- help with benefits application
- access to the patient support group
- health promotion

## Joint specialist clinics

We work closely with other specialists to provide joint care for your child. If your child needs to be seen in one of these clinics, we will explain why.

In these clinics, your haematology consultant and a specialist consultant will see you together.

### **Joint respiratory clinic**

Once every two months on Wednesday, 2pm to 5pm.

### **Joint neurology clinic**

Once every two months, 9am to 12pm.

### **Joint nephrology clinic**

Once every two months on Friday, 9am to 12pm.

### **Joint endocrine clinic**

Once every four months, 1:30pm to 5pm

## Transition service

The transition service is involved in planning your child's care and supporting them to move from the children's to the adults' hospital. As your child has a chronic condition that will require ongoing treatment, it is important that you understand and prepare for the changes they will go through as they grow, and what this means to their care.

The transition team will discuss a number of issues with you. Their aim is to help you understand your child's condition better and to prepare you and your child for the transition to adult services.

### Transition clinic

Once monthly on Thursday, 1pm to 5pm at Guy's Hospital, Tabard Annexe Ground floor, Southwark Wing

## Cancelling appointments

If you cannot make an appointment, please contact the outpatient appointment department, **phone:** 020 7188 4000, as soon as possible and reschedule an appointment that is convenient.

## Admission to hospital

If your child is very unwell, they may be admitted onto one of the following wards.

**Mountain Ward:** Medical/Surgical, 5<sup>th</sup> Floor

**Forest Ward:** Paediatric intensive care unit (PICU), 2<sup>nd</sup> Floor.

If your child requires a blood transfusion, an MRI under general anaesthetic, or a day review, they will be admitted onto Snow Fox Ward, which is open from, Monday to Saturday, 7.30am to 8pm (excluding bank holidays), and is in St Thomas' Hospital, South Wing, Staircase D, First floor.

Your child may be seen by other doctors from other teams if they are admitted over the weekend or after hours, Monday to Friday. They will liaise closely with the haematology consultant.

## The spiritual care team

The members of the spiritual care team work together to give spiritual care to patients, families or friends of all faiths and beliefs, as well as people who do not have a particular faith. Please let the spiritual care team know if you would like any spiritual care resources such as a prayer mat, Bible, Qur'an, cross, rosary, prayer beads or any other appropriate resource. We will do our best to provide this for you. If you wish to continue receiving spiritual support after you leave hospital, please speak to us and we will try to put you in touch with the relevant group.

## Spiritual care at St Thomas' Hospital

### The Chapel

The chapel is on the First Floor of South Wing. It is open every day for quiet prayer and reflection, from 7am-8pm.

### Multi-faith prayer rooms

Multi-faith prayer, belief and reflection rooms are open daily. They are on the Ground Floor of South Wing. Washing facilities are next door.

For spiritual or religious resources, or more information, please contact, **phone:** 0207 188 5588, **email:** chaplains@gstt.nhs.uk

## Immigrations advice and support

**website: [www.Gov.uk](http://www.Gov.uk)** – This government website offers advice on all public services including immigrations, finance, benefits, housing, and employment. You can also contact your local Citizens Advice Bureau or your council to find out about more community services.

**Department for work and pensions** – for Disability Living Allowance (DLA) for children, Personal Independence Payment (PIP) from age 16-64 years and Universal Credit you will need to apply online, **w:** [www.gov.uk/government/organisations/department-for-work-pensions](http://www.gov.uk/government/organisations/department-for-work-pensions)



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## Further information

### **Sickle Cell and Thalassaemia Conference**

This annual international conference is held at Guy's and St Thomas', with world experts in haemoglobinopathies. For more information visit the websites below. If you are interested in attending, please email Dr Baba Inusa.

**website:** [www.scorecharity.com](http://www.scorecharity.com)

**website:** [www.ststn.co.uk](http://www.ststn.co.uk)

**email:** [baba.inusa@gstt.nhs.uk](mailto:baba.inusa@gstt.nhs.uk)

### **Sickle Cell Society**

Provides help and support for people affected by sickle cell disorders and their carers.

**phone:** 0800 001 5660

**website:** [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

### **The Sickle Cell & Thalassaemia Centre**

Provides information about sickle cell disease.

Thalassaemia counsellors can also offer support and information. The centre can also direct you to local services.

**phone:** 020 7414 1363

## Contact us

**Lead consultant for haemoglobin disorders, and consultant in haematology, phone:** 020 7188 6203 (secretary), **email:** [Dudhma.Banu@gstt.nhs.uk](mailto:Dudhma.Banu@gstt.nhs.uk)

**Lead nurse, phone:** 020 7188 9432 or 07918 338730  
**email:** [HaemoglobinopathyCNS@gstt.nhs.uk](mailto:HaemoglobinopathyCNS@gstt.nhs.uk)

**Nurse specialist, phone:** 07771 345847 or 07517 592436 **email:** [HaemoglobinopathyCNS@gstt.nhs.uk](mailto:HaemoglobinopathyCNS@gstt.nhs.uk)

**Research nurse, phone:** 020 7188 6637 or 07517 592436

**Specialist nurse – community, phone:** 020 3049 5993 or 07880 781545

**Therapy and psychology team, phone:** 020 7188 9125 or 07817 905844

Help and advice will always be available if you have any questions or concerns. Out of hours, please call the hospital switchboard, **phone:** 020 7188 7188 and ask them to bleep the haematology registrar.

If you need to come to emergency department (A&E) at St Thomas' Hospital, please telephone the department before you arrive, **phone:** 020 7188 2111 and let them know about your child's condition. This will help to improve your child's care when you arrive.

## **Evelina London Medicines Helpline**

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**phone:** 020 7188 3003, Monday to Friday, 10am to 5pm

**email:** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

## **Your comments and concerns**

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk). To make a complaint contact the resolution department **phone** 020 7188 3514 **email** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## **Language and accessible support services**

If you need an interpreter or information about your care in a different language or format, please contact the department your appointment is with.

## **NHS 111**

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111 **w:** [www.111.nhs.uk](http://www.111.nhs.uk)

## **NHS website**

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. **w:** [www.nhs.uk](http://www.nhs.uk)

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