

## Patient information factsheet

# Southampton haemoglobinopathies service

We have given you this factsheet because you, or a member of your family, have been referred to the Southampton haemoglobinopathies service at University Hospital Southampton NHS Foundation Trust (UHS). It explains what the Southampton haemoglobinopathies service is and contains useful contact information for the team. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

### What is the Southampton haemoglobinopathies service?

The Southampton haemoglobinopathies service cares for people with inherited blood disorders, such as:

- sickle cell disease (a group of inherited conditions that affect the red blood cells)
- thalassaemia (a group of inherited conditions that affect a substance in the blood called haemoglobin)
- rare inherited anaemias (a group of genetic disorders affecting red blood cell production or function)

### Wessex and Thames Valley Haemoglobinopathy Network

UHS is one part of the Wessex and Thames Valley Haemoglobinopathy Network. The network is made up of:

- **Wessex and Thames Valley haemoglobinopathy coordinating centre (HCC)** - The HCC is based in Oxford and supports the Oxford and Southampton specialist haemoglobinopathy teams (SHTs) which, together with the local haemoglobinopathy teams (LHTs), cover the Wessex and Thames Valley Networks.
- **Specialist haemoglobinopathy team** – This is the Southampton haemoglobinopathies service. The team is responsible for providing specialist haemoglobinopathy care and supporting and advising your local haematology team.
- **Local haemoglobinopathy teams** – These teams are responsible for your day-to-day clinical care. Local haemoglobinopathy teams include:
  - Hampshire Hospitals NHS Foundation Trust
    - Basingstoke and North Hampshire Hospital
    - Royal Hampshire County Hospital, Winchester
  - Isle of Wight NHS Trust
  - Portsmouth Hospitals University NHS Trust
    - Queen Alexandra Hospital
  - University Hospitals Dorset NHS Foundation Trust
    - Royal Bournemouth Hospital
    - Poole Hospital
  - Dorset County Hospital NHS Foundation Trust
  - Salisbury NHS Foundation Trust
    - Salisbury District Hospital

# Patient information factsheet

- University Hospitals Sussex NHS Foundation Trust
  - St Richard's Hospital, Chichester
  - Worthing Hospital

For more information about the Wessex and Thames Valley Haemoglobinopathy Network, visit: [www.ouh.nhs.uk/services/departments/other/hcc](http://www.ouh.nhs.uk/services/departments/other/hcc)

## Our team

Our team at UHS is made up of several healthcare professionals, including:

- a consultant haematologist and adult haemoglobinopathy service lead
- a paediatric (children's) consultant with an interest in non-oncological haematology
- a paediatric (children's) haematology consultant
- haemoglobinopathy clinical nurse specialists (CNS)
- a clinical psychologist
- a paediatric (children's) clinical psychologist
- a specialist radiographer

## Clinics

We hold clinics for different inherited blood disorders throughout the month. Please see the table below for more information.

Clinics	Date
Adults	Tuesday afternoons
Children's sickle cell annual review	Second Monday of every month
Children's routine haemoglobinopathy clinics	Tuesday mornings and afternoons

Your appointment letter will contain specific details, including when and what type of appointment it will be (in person, or a telephone or video call).

## Contact us

If you have any questions or concerns, please contact us.

### Non-urgent care

Haemoglobinopathy clinical nurse specialist team

Telephone: **023 8120 4567** (Monday to Friday, 8am to 4pm)

Email: [haemoglobinopathiescns@uhs.nhs.uk](mailto:haemoglobinopathiescns@uhs.nhs.uk)

Outside of these hours, call NHS **111**.

### Urgent care

If you need urgent attention for your blood disorder or have a medical concern (for example, if you have sickle cell disease and think you might be developing a crisis), call **999** or go to your nearest emergency department (ED).

## Useful links

### NHS

[www.nhs.uk/conditions/sickle-cell-disease](http://www.nhs.uk/conditions/sickle-cell-disease)

[www.nhs.uk/conditions/thalassaemia](http://www.nhs.uk/conditions/thalassaemia)

# Patient information factsheet

## Anthony Nolan

[www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/understanding-blood-disorders/sickle-cell](http://www.anthonynolan.org/patients-and-families/blood-cancers-and-blood-disorders/understanding-blood-disorders/sickle-cell)

## UK Thalassaemia Society (UKTS)

[www.ukts.org](http://www.ukts.org)

## The UK's Diamond Blackfan Anaemia Syndrome Charity

[www.diamondblackfan.org.uk](http://www.diamondblackfan.org.uk)

## Congenital Anaemia Network (CAN)

[www.togetherwecan.uk](http://www.togetherwecan.uk)

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **PFSH@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **[www.uhs.nhs.uk/additionalsupport](http://www.uhs.nhs.uk/additionalsupport)**

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