


South Thames Sickle Cell and Thalassemia Network
 info@ststn.co.uk www.ststn.co.uk



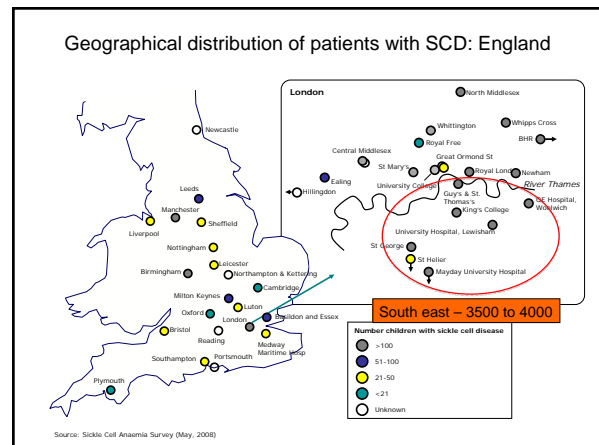
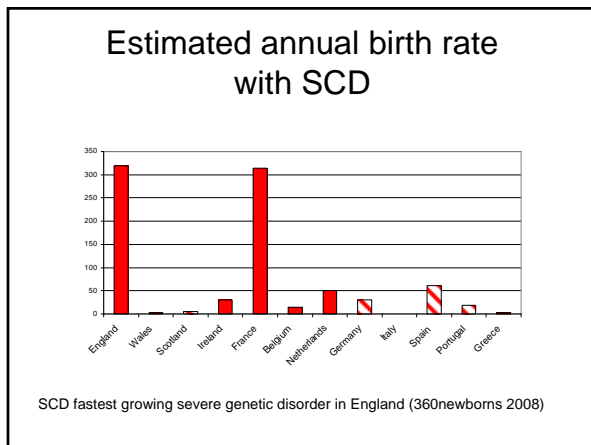

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Sickle Cell Disease in Western Europe



- Indigenous populations carrying HbS gene in Southern European countries
- Immigration of residents from former African and Caribbean colonies after their independence
- Recent increased immigration and migration from African and Caribbean countries across Western Europe



Developing a national service for SCD in England

- National linked antenatal and neonatal screening programme
- Newborn screening pathway
- Development of regional care networks
- Peer review of paediatric specialised centres
- National Haemoglobinopathy Register
- Guidelines for clinical care
- Quality assurance programmes: laboratory, TCD
- National Specialised Service Definition
- National commissioning project
- Education and training: PEGASUS, Nursing competencies



Practicalities for improving SCD services

- Better data- national registries, and national audits
- Advocacy (health)
- Use of existing models
- **Networks of care**

Network - Definition

'Linked groups of professionals and organisations form primary, secondary and tertiary care, working in a co-ordinated manner, unconstructed by existing and professional and (organisational) boundaries, to ensure equitable provision of high quality, clinically effective services'

Scottish Office DH 1999



Stepwise Development of STSTN

- Clinical association – sharing best practice
- Coordinated clinical forum – sharing audit and jointly agreed protocols
- No formal funding /management
- Good will



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Stepwise development of STSTN

- South Thames Sickle Cell and Thalassaemia Network (STSTN or the Network) was officially launched in October 2011
- STSTN is led by consultants from King's College Hospital (KCH), and Guy's and St. Thomas' (GSTT), both of which have about 1000-1200 patients with haemoglobinopathies
- Membership includes our sister hospitals, University Hospital Lewisham and the Queen Elizabeth Hospital Woolwich, with over 400 patients.
- The network also has strong links with centres across South London and beyond, including Epsom & St Helier Hospital, Medway Hospital and Brighton and Sussex University Hospital.
- The Network Support Manager is Annabelle Kelly based at King's College Hospital. This part-time position (3 days per week) has been initially funded by King's College Charity and Roald Dahl's Marvellous Children's Charity but is expected to be self-funding through event and conference income



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STSTN Terms of Reference

Mission Statement:

To improve treatment options and outcomes for patients with sickle cell disease and thalassaemia in the South Thames region through collaborative working



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STSTN Objectives

- To establish and maintain joint working methods throughout the network
- To collaborate in specialist clinics including renal, obstetrics, orthopaedics, cardiac, neurology, and urology
- To provide a peer-support network and educational programme for consultants, GPs, nurses, trainees and other healthcare professionals
- To publish guidelines on the care/treatment of sickle cell disease and thalassaemia
- To produce patient information sheets and a quarterly newsletter to highlight patient experiences and to update on the latest research and treatment news




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STSTN Objectives (2)

- To promote clinical excellence and improve clinical care
- To function as a forum and feed into the National Haemoglobinopathy Registry which will facilitate research into red blood cell disorders
- To disseminate information and raise awareness of ongoing research in the UK and internationally
- To function as a group and provide critical mass for collaborative research and evidence-based audits






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Network membership



- STSTN has been set up primarily for Consultants in the South Thames region, but those with an interest in sickle cell disease and thalassaemia are welcome to join and participate in meetings.
- Currently, membership is free but we envisage a paid membership service in future that will help facilitate the running of the network

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STSTN Meetings and Events

- Sickle Cell in Focus (an annual, intensive, international meeting by Professor Swee Lay Thein, KCH)
- South Thames Haemoglobinopathy course (a five-day course by Dr Baba Inusa, GSST)
- Peer-support meetings such as the Paediatric Sickle Cell and Thalassaemia Meeting and the Adult Sickle Cell and Thalassaemia Meeting
- In development: intensive exam focused revision for medical trainees
- Courses geared towards nurses, counsellors and GPs





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STSTN Contact

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Benefits of Networks

- Implementation of standards
- Commissioning whole patient pathways
- Service improvement – improving/monitoring quality (audit/research)
- Clinical leadership
- Public engagement in design




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Future directions:

Terms of Reference –

- Leadership
- Membership
- Aims and Objectives
 - Collaborative working to improve patient outcomes
 - Education – audits
 - research
 - workshops/updates

Future meetings and formats

