Who are the Sickle Cell & Thalassaemia Support Project (SCTSP)?

The Sickle Cell & Thalassaemia Support Project (SCTSP) was founded in 1990 with the aim of addressing health disparities in service provision for families impacted by sickle cell disease or thalassaemia within the community. Presently, we extend our support to affected families residing in Wolverhampton, Walsall, Dudley and the surrounding areas.

What we aim to do:

- Collaborates closely with the NHS and other partners to facilitate the screening and counselling of individuals at risk of, or affected by, sickle cell or thalassaemia. To learn more about this process, please visit <u>https://www.nhs.uk/pregnancy</u> and search for screening for sickle.
- Dedicated to increasing awareness of these conditions through the development of comprehensive education and training programs designed for community groups, caregivers, and healthcare professionals.
- We also offer support, advice, and care coordination services to individuals and families living with major haemoglobin disorders.
- Serve as a specialised resource for other professionals and communities at risk, working in close collaboration with the statutory, voluntary, and community sectors to develop a coordinated service.
- Our team further partners with consultants in Birmingham, Wolverhampton, Walsall and Dudley to enhance client care.

Community Haemoglobinopathy services

Care Plans and Assessments

All affected children attending a childcare or educational facility, are offered a personalised healthcare plan. These plans are developed collaboratively with parents, caregivers, and educational providers, and are reviewed annually or whenever changes arise.

Similarly, we conduct annual assessments for adults, which involve ensuring that their condition is well-managed and clearly communicated to both the individual and relevant agencies.

Visits

This project carries out visits to clients as part of our commitment to support service users and families in the management of their condition. These visits can be done in hospitals, at home or in the community.

Referrals to other agencies

Referrals and signposts can be made to relevant agencies regarding welfare benefits, such as housing, disability living allowance and social services.

Support

Supporting service users to become experts in managing their own care. The project also supports the planning and coordination of care.

Counselling services linked to screening programmes

Genetic Counselling

Our organisation has established a close working relationship with the NHS to provide the Sickle Cell and Thalassaemia Screening Programme. In the event of unusual results from antenatal and neonatal screenings, we offer individuals counselling appointments.

- Individuals who are at risk of haemoglobinopathies are provided with complete access to information regarding their condition.
- Our services include one-to-one counselling sessions, which utilise appropriate and easy-to-understand techniques.
- We liaise with other professionals to ensure that counselling issues are addressed effectively. Our counselling services are tailored to respect the cultural backgrounds and ethnic customs of families.
- We cover a broad range of topics, including genetics (diagnosis and risk factors), health and social factors (effective care and management), and psychological matters (coping strategies).

Training, Education and Awareness

Training

The project actively supports health professionals within the primary care setting as well as allied health professionals working in the wider community with regular training programmes.

Education

The project also works closely with both primary and secondary schools to raise awareness of both sickle cell and thalassemia with staff and pupils alike.

Awareness

Community awareness is a vital component of the organisation. Preventative work within the community enhances knowledge and understanding of the conditions and how they can be managed.



Sickle Cell & Thalassaemia Support Project



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Service Information Leaflet