Sickle Cell & Thalassaemia Support Project

Annual Report

2025-2026



Empowering Families and Supporting Communities

sctsp.org.uk

Charity no. 1077687
Company no. 3575079

Chairmans Remark

My deepest gratitude and thanks go to everyone involved in supporting and maintaining our stability. Your contribution has helped us continue to achieve and develop our work.

We now provide Sickle Cell and Thalassaemia services across Wolverhampton, Walsall, Dudley and Sandwell, which has lead to additional staffing. We have also been delivering Family Support services in Staffordshire, resulting in a larger workforce than in the previous year. Although these services are delivered separately, we are all part of one team, working together to improve the life chances of individuals and families.

Despite these efforts, the more we do, the more we recognise there is still more to be done. We are listening to the people we serve and acting on what we hear, so that we can address gaps and continue making improvements.

This is all part of a journey. As we know, every journey brings obstables and challenges; however, through the continued hard work and committment of our staff, volunteers and leadership, we can be proud of the progress we are making. We look ahead with hope and confidence for an even stronger year to come.

Clarence Crosdale | Chair

About the Project

The Sickle Cell & Thalassaemia Support Project (SCTSP) is a community organisation that has been supporting individuals and families living with Sickle Cell and Thalassaemia for over 30 years. We are currently offering support to patients in Wolverhampton, Walsall, Dudley and surrounding areas.

We aim to:

- Provide specialist information, advice and practical support
- Deliver wellbeing and community activities that improve quality of life
- Raise awareness among health professionals and the wider public
- Empower families and young people to thrive despite the challenges of long-term conditions



Our work includes direct one-to-one counselling as part of the NHS Sickle Cell & Thalassaemia Screening Programme, group activities and wider health and wellbeing programmes.

Year in review

717
Unusual blood results received and processed

186
Adults living with sickle cell and thalassaemia receiving support

186
Children living with sickle cell and thalassaemia receiving support

Our team has supported service users with their health plans and worked with schools to provide a new or reviewed care plan for children. We have also supported many affected adults, children and their families with their wellbeing through multiple activities and events.

Pathway	Wolverhampton	Walsall	Dudley	Sandwell
Antenatal	246	179	137	168
Neonatal	136	79	33	—

Through the NHS Screening Programme, we've provided counselling for a total of 717 individuals and families. To learn more about this process, please visit https://nhs.uk/pregnancy and search for 'screening for sickle'.

Our finances

Annual income:
Contracts- **81.2%**
Donations- **16.3%**
Investments- **2.5.%**



Areas of support:
Net staff costs- **78.7%**
Other operating costs- **19.4%**
Rent and service charge- **1.9%**



Improving health & wellbeing

Supporting physical and emotional wellbeing remains central to our work. Free massage sessions were provided to adults affected by sickle cell disorder and thalassaemia. Participants reported positive experiences and welcomed the opportunity to access wellbeing support in a safe and supportive environment.

We also continued to provide advice, guidance and emotional support to individuals and families navigating the challenges associated with long-term health conditions.

Community Family Support Service

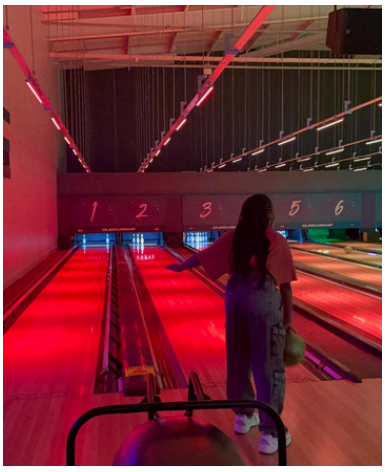
April 2025 also marked the re-start of our Community Family Support Service (CFSS) in Staffordshire and South Staffordshire. Through this service, our Family Support Workers have worked directly with children, young people and families experiencing a range of challenges, providing practical, emotional and early-help support and working alongside schools, local services and other professionals.

Alongside our commissioned services, we continued our wider community work, supporting families experiencing hardship, promoting health and wellbeing, providing information and advice, delivering community activities and developing opportunities to reach people who may otherwise experience barriers to accessing support.

Supporting families

Through funding received from the Peter Harrison Foundation, we delivered a range of activities designed to improve the wellbeing of young people and families. This included a day trip to Blackpool, exploring nature with Kingswood Trust, sports days and more.

These activities provided opportunities for families to spend time together, build confidence, strengthen relationships and improve emotional wellbeing.







Wolverhampton Grand Theatre generously donated tickets for families to attend the pantomime Sleeping Beauty. This provided a positive shared experience for children and parents, supporting wellbeing, reducing isolation, and creating opportunities for family enjoyment during the year.

Working in partnership with Wolverhampton Family Hubs, we supported parents and children through wellbeing-focused activities and engagement opportunities that aligned with the Government's Best Start for Life initiative.

We also provided practical support to families facing hardship, including food donations and emergency assistance where needed.

Education, research and advocacy

Comissioned by Black Country REN (Community Research for Health), our research explored the educational experiences of children and young people living with sickle cell disease. Through surveys, interviews and community engagement, 24 participants shared their experiences of school life. This highlighted the impact of pain, fatigue and hospital stays on attendance and learning, alongside challenges around awareness, emotional wellbeing and inclusion.

24
People shared their experiences

75%
Missed more than two weeks of school per term

56%
Felt teachers did not understand sickle cell

Importantly, the research also identified what makes a positive difference. Young people and families highlighted the value of understanding, flexibility, good communication and practical adjustments within schools.

The findings have informed recommendations around staff training, Individual Healthcare Plans, emotional wellbeing support and stronger collaboration between families, schools, health services and community organisations. By placing the voices of children, young people and families at the centre of the research, we have created an evidence base to help influence more informed, inclusive and responsive educational support for young people living with Sickle Cell across the Black Country.

To see the full feedback report titled 'Understanding the Educational Challenges and Coping Strategies of Children with Sickle Cell Disease in the Black Country' visit **https://sctsp.org.uk**

Promoting awareness

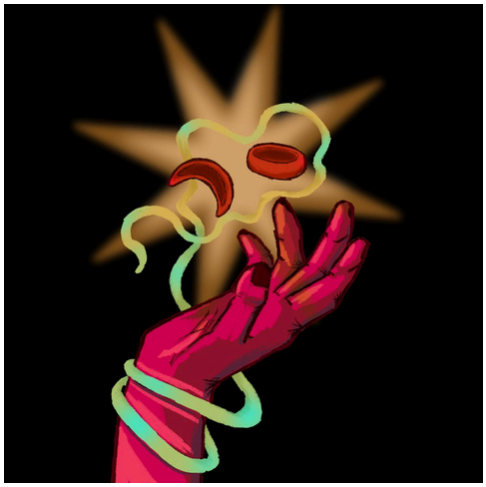
Alongside this work, we continued to advocate for greater awareness of sickle cell and thalassaemia across health, education and community settings.



One way we did this was through an interview on Radio WCR FM, where young people shared their experiences of living with sickle cell disease. We also highlighted the importance of knowing your carrier status and understanding what this can mean for you and your family.

Awareness through music

During the year, we developed a creative partnership with The New Black Film Collective and Beatsabar Music Project to produce a song raising awareness of sickle cell disorder. This project used music and video to amplify lived experience, challenge stigma, and engage wider audiences in understanding the condition. Ups n Downs is avaliable to view on Youtube (@sctspwolverhampton)





Health Equity Project

From September 2025 to February 2026, we contributed to the Health Equity Project (BAME Maternity Project) supporting women from Black and minority ethnic communities to access maternity services early and with greater confidence.

Weekly antenatal sessions provided a safe and culturally appropriate space for women, to ask questions, access interpreters and discuss maternity issues. The project also delivered preconception and community sessions, reaching more than 100 women. Community Champions were also trained to share information within their communities, helping to extend the project's impact.

One participant said: "If I knew previously what I have learnt now I beleive that I would not have had such a difficult labour experience previously."

NHS Primary Care Ambassador Project

We supported the NHS Primary Care Ambassador Project, helping local families understand and access digital primary care services, including the NHS App, GP website and Pharmacy First.

Through community engagement sessions, we worked with 40 people, providing practical, hands-on support to download and use the NHS App and understand its features. The sessions highlighted low awareness of digital services, with participants valuing simple explanations and face-to-face support.

Family Hubs Project

This year, our Family Hubs Project delivered 28 workshops supporting the emotional wellbeing of parents, children and young people. Sessions covered managing anxiety, parental wellbeing, confidence and behaviour, alongside innovative Virtual Reality sessions. The programme engaged 116 parents and reached approximately 360 junior school pupils across three schools, providing practical strategies that participants could use in their everyday lives.

The impact of the programme was extremely positive, with 100% of parents reporting that the sessions were beneficial, identifying strategies they could use and indicating that they intended to make a positive change. Young people also demonstrated that they were putting techniques into practice to manage emotions and strengthen relationships. To extend the benefits beyond the workshops, we developed Calm and Confidence Building Booklets, providing families with accessible tools to use at home. The project has helped turn learning into practical action, equipping families with strategies they can continue to use to support positive emotional wellbeing long after the sessions have ended.

Acknowledgements

We would like to thank the organisations, funders, volunteers and supporters who contributed to our work throughout the year. This includes the Peter Harrison Foundation, Wolverhampton Family Hubs, BAME Maternity Project partners, The New Black Film Collective, research partners, community organisations and volunteers.

Above all, we thank the individuals and families who have shared their experiences and placed their trust in our team.

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