

The Sickle Cell Society (SCS)

The Sickle Cell Society supports and represents people affected by sickle cell disorder to improve their overall quality of life.

The Sickle Cell Society believes that individuals with sickle cell have the right to quality care. This can only be achieved if funding is made available to educate health carers and other professionals about the condition. The Society aims to provide this.

First set up as a registered charity in 1979, the Sickle Cell Society has been working alongside health care professionals, parents, and people living with sickle cell to raise awareness of the disorder. The Society's aim is to support those living with sickle cell, empowering them to achieve their full potential.

The Society does not discriminate between the types of sickle cell disorders or the ethnic groups concerned. Both sexes are equally affected, and should have equal access to support and services within a confidential and sensitive environment. SCS respect the views of every patient.

SCS has a network of committed volunteers, who play an important part in running the charity, providing administrative backup, and helping with fund-raising activities.

Activities include support to those with Sickle Cell Trait (SCT), and health, education and social care professionals through:

- National Helpline and Online Service (Information Standard certified) provides the latest clinically informed guidance and practical advice.
- Children's activities and annual holiday reaching children and young people who benefit from educational and social support and peer mentoring.
- Geographically focused outreach and awareness raising to areas of high Sickle Cell Disease prevalence and isolated communities where the condition is less understood.
- Engaged members 'online' this year at their AGM.
- Assisting with medical or social research regarding Sickle Cell Disease globally.
- Campaigning and lobbying for policy to reduce health inequalities through their work as part of the Sickle Cell and Thalassaemia All-Part Parliamentary Group, via seminars and social media.
- Advocating for rights to health, education, welfare, housing and employment for people affected by Sickle Cell Disease; eg: via Sickle Cell & Thalassaemia All-Part Parliamentary Group.
- Public Health England funded Screening Programme; enabling prospective parents to make well informed choices regarding this inherited condition.

Contact information:

Website: www.sicklecellsociety.org Phone: 02089617795 Email: info@sicklecellsociety.org

For help, advice, and information or to share your story

Healthwatch is your health and social care champion.

If you use GPs and hospitals, dentists, pharmacies, care homes or other support services, we want to hear about your experiences. We have the power to make sure NHS leaders and other decision makers listen to your feedback and improve standards of care. We also help people to find reliable and trustworthy information and advice



Last year, we helped nearly a million people like you to have your say and get the support you need.



If you are setting up or would like to share news of a similar project we would be interested to hear from you. Please contact Cheryl Berry, Community Partnership Lead: cheryl.berry@healthwatchwestsussex.co.uk

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