

Myths and truth about Sickle Cell

Myth 1:

Only Black people of African/Caribbean decent get sickle cell disorder.

Truth:

Sickle cell is a disorder that affects people of all different racial and ethnic backgrounds, including African, Arabian, Israeli, Greek, Italian, Hispanic, Turkish, and Pakistani. For this reason, all races must be screened at birth for the type of haemoglobin responsible for causing sickle cell disorder. i.e. Genotype testing

Myth 2:

Stroke only happens to older people.

Truth:

Children between the ages of 2 to 16 are at high risk of having a stroke. Most kids will have a 'Silent stroke' which is much subtle but may affect a child's - behaviour, handwriting, memory. It is important that parent/carers and Teachers know the warning signs of an 'major stroke'. All children with Sickle cell need to have yearly TCD scans.

Myth 3:

Not all sickle cell patients need blood transfusion

Truth:

Majority of children that are identified as high risk of stroke or have had at least one stroke are put on an indefinite blood transfusion program. It is important that you donate blood regularly, giving these children a chance of a healthier life. Blood transfusions reduces pain, prevents stroke and reoccurring strokes.



Join us

If you have Sickle Cell Anaemia or have a child that has suffered a stroke from it you are very much welcome to join. Siblings, relatives, friends and Health professionals are all welcome.

To join today please contact us on

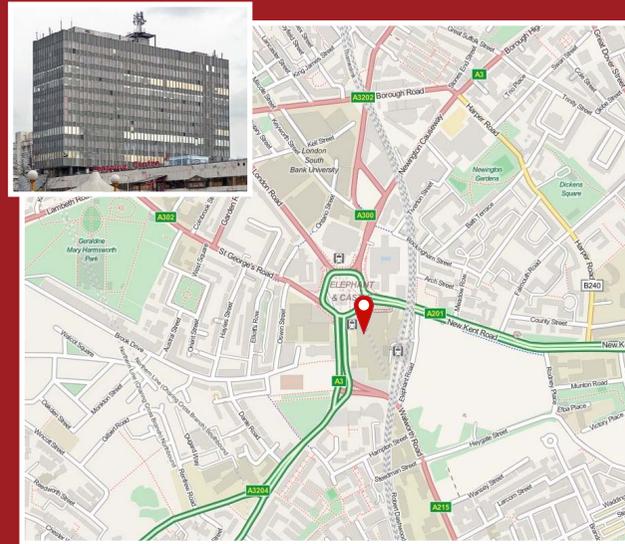
08000 842 809

info@scyss.org

Contact Us

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Our office is located in Hannibal House which is next to the shopping centre.



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(Lines open from 10-4pm)

Tel: 08442 092 922

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www.facebook.com/scyss



[@SCYSS](https://twitter.com/SCYSS)

Registered as a charity in England & Wales.

Reg Number: 1120902



Sickle Cell & Young Stroke Survivors



Building Bridges, Breaking Stigma

Supporting and educating young people and their families with Sickle cell and Childhood Stroke

Freephone: 08000 842 809

www.scyss.org

Who we are...

Sickle Cell & Young Stroke Survivors (SCYSS) is a registered charity that holistically supports children, young people and their families affected by sickle cell anaemia and childhood stroke.

It started as a support group in June 2005 by a parent who had to manoeuvre the lonely Stroke maze when her 6-year-old child had a stroke as a result of Sickle cell anaemia. As the need grew, in September 2007 it became a registered charity.

Our mission...

The aim of the charity is to holistically support and educate children, young people and their families affected by sickle cell disorders and childhood stroke.

Our vision is for all children and young people with sickle cell anaemia to have access to adequate care and management of their condition. It is for sickle cell induced strokes to be recognised immediately, treated appropriately and for care, support and information to be given to both children and their families.

Our Values are based on our own experiences of sickle cell, our passion to make the lives of children more comfortable and our commitment to end any stigma surrounding sickle cell disorders.



What we do...

Every month we have exciting activities for children, young people and their families living with sickle cell. Come and meet other children, share ideas and just have fun. Siblings are included.

You can find a registration form for the SCYSS club on our website, all siblings and young carers will need to fill in this form.

SCYSS Club which includes:

- Saturday Cub
- Summer Play scheme
- Youth club
- Free Tutorial classes

Family Service and Drop in

- Advice & Advocacy
- Young carer support
- Respite for Parents/carers
- Counselling
- Support Group
- Hospital Visits

Lobbying and Outreach Work

- Creating awareness on Sickle Cell & childhood Stroke
- Lobbying for change of policy at local, national government levels and Parliament.
- Outreach in the community

Long term Condition Training Courses

- Sickle Cell - Know the basics Training
- Parent Empowerment training

Sickle Cell in Africa project

- Partner with other NGO'S around the world to form a unified voice.



Volunteering

As we have no paid staff, we rely on the expertise of volunteers to carry out our work. We welcome volunteers from all walks of life. You can download a volunteering application form our website www.scyss.org

We are also looking for **Trustees** to help us plan the cause of the charity and welcome new ideas to help our service users. If you feel that this is a more suitable role for you please do not hesitate to give Carol a call on **07854827600**.

Fundraising & Donations

We really need your help in raising funds for our charity, we have been finding it difficult to raise funds because Sickle cell is a stigmatised condition and most people living with it keep silent.

Its a vicious cycle because it affects children and young people and they grow up repeating the same cycle of keeping quiet. Most people do not know that Children who live with sickle cell are at high risk of stroke. Sickle cell and Young Stroke Survivors is here to speak up for our children and young people.

If you would like to make a donation, please visit our website www.scyss.org

Please support us today

