



## **Sickle Cell Society**

### **Role Description - Sickle Cell Society Trustees**

#### **About Us**

We are the UK's patient charity for people living with sickle cell disorder. We believe that people living with the condition have the right to quality care.

We support and represent people, patients and families affected by sickle cell disorder to improve their overall quality of life.

Our aim is to support those living with sickle cell, empowering them to achieve their full potential.

#### **About Sickle Cell Disorder**

Sickle cell disorder affects over 18,500 people in the UK, and is the nation's fastest growing genetic condition. The condition affects millions of people globally.

Sickle cell affects the red blood cells, which carry oxygen throughout the body. In people with the condition, these cells are mis-shapen into sickles or crescent moons, rather than the usual round and flexible shape. They can get stuck in small blood vessels, blocking blood flow and leading to excruciating pain which requires hospitalisation and can lead to organ damage.

Complications include infections, delayed growth in children, stroke and acute chest syndrome. Mental health can also be impacted. Chronic anaemia causes severe tiredness, and with frequent medical visits; daily activities, work, relationships and education are all disrupted, which can take a huge toll on quality of life.

The condition comes with a history of chronic underfunding of treatments and care, evidence of failures in care, and attitudes in the care system underpinned by racism.

#### **We offer :**

- **Information and advice.** We run a telephone and email advice line.
- **Mentoring for young people.** We run programmes in London, Sheffield, and the North West.
- **Advice about sickle cell testing.**
- **Family Retreat.** We run a retreat each summer for families of children with sickle cell disorder.
- Our campaigns include encouraging people from black heritage communities to **give blood**. To help those affected by Sickle Cell, 250 blood donations are needed each day.

- We also engage with parliament through our secretariat of **the Sickle Cell and Thalassaemia All Party Parliamentary Group (SCT APPG)** to advocate for change in the NHS so that people living with sickle cell can have the quality care they deserve.
- We work with partners across the NHS, DHSC and Industry to **advocate for improvements in care** and more **safe and effective treatment options** for people living with the condition.

## **The Role of the Board of Trustees**

The role of the Trustee Board is to receive assets from donors, safeguard them and apply them for the charitable purposes as declared in the objects of the Society. The Trustee Board must always act in the interests of the Society exercising the same duty of care that a prudent person of business would in looking after the affairs of someone for whom he/she had responsibility. The Trustee Board must act as a group and not as individuals.

## **Role and responsibilities for Board Trustees**

As a Trustee you will work alongside our other Trustees and staff. You will share responsibility with other Trustees for the decisions made by the Board and for the success of the organisation.

Each Trustee should use specific skills, knowledge and experience to help the Board reach sound decisions.

You will be expected to demonstrate high standards of corporate and personal conduct.

## **Main Tasks**

- To work with other Trustees to ensure that the Society functions within the legal and financial requirements of a charitable organisation and strives to achieve best practice
- To work with other Trustees to ensure that the policy and practices of the Society are in keeping with our charitable aims
- To work with Trustees and staff in formulating and reviewing the strategic aims of the Society

## **Main duties**

- To safeguard the good name and values of the Society
- To ensure the financial stability of the Society
- To ensure that financial controls and systems of governance and risk management are robust and in place and reviewed
- To contribute to the strategic direction of the Society, setting overall policy, defining goals, setting targets and evaluating performance
- To be accountable for the Society's objectives and ensure you act in the best interests of people with sickle cell and their families
- To attend meetings of the Board of Trustees and other events and meetings as appropriate
- To take part in training sessions provided for the benefit of the Trustees

- Maintain good relations with fellow Trustees and with staff

### **Person Specification**

- A good understanding and commitment to the aims and mission of the Society
- A background in business, the public sector including charities and/or other experience relevant to the Society's development
- Experience of a senior Trustee role or similar governance or Board experience
- A willingness to devote the necessary time and effort to the work of the Society
- A good understanding of and acceptance of the legal duties, responsibilities and liabilities of Trusteeship
- Integrity
- Strategic vision
- Good interpersonal skills
- Sound judgement and maturity
- Ability to think creatively
- An ability to work as a member of a team

At this time we would particularly welcome applications from people living with sickle cell disorder, or with wider lived experience of the condition. We are also keen to strengthen the Board's expertise in charity fundraising, and would ideally appoint at least one trustee with this experience.

### **Time Commitment**

Trustees are expected to attend an induction session at our offices prior to attending their first Board meeting. Board meetings are currently held on the last Monday of each month in the early evening, sometimes online and sometimes in person at the Society offices in London.

Trustees are also expected to attend the in-person AGM and patient education day, which is usually held in London on a Saturday in early September.

### **Period of Appointment**

Successful Trustees will be appointed for a three-year term from the date of commencement.

### **How to apply**

To apply, complete our Application Form and the Equal Opportunities Form and return the completed forms along with your CV to [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org) The subject line of your email should be 'Board Trustee Application'.

Closing date : **6pm on Friday 24<sup>th</sup> April 2025.**