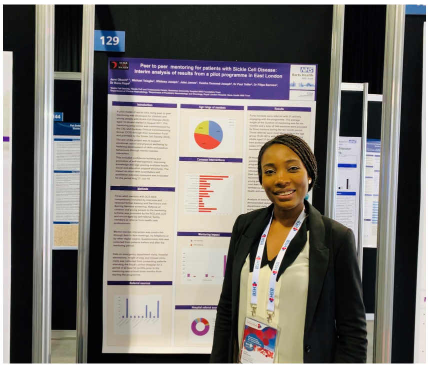
SICKLE
CELL
SOCIETY

2018/19 IMPACT REPORT



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The Sickle Cell Society exists to assist and empower people with sickle cell disorder to achieve their full economic and social potential.

We provide recreational activities for affected individuals and their families.

We work towards the improvement of public information, assisting in research into the causes, treatment of the condition and dissemination of such information.

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Celebrating
40
YEARS
1979 - 2019

Summary Statement

This report showcases the many positive ways in which we support people living with sickle cell at a national level and increasingly with a global perspective. It also shows our stewardship of the kind donations we receive and the grants we secure. Working closely with a range of partners and service users we have worked really hard to translate our aims and objectives into visible improvements and impact for people living with sickle cell and their families.

Last year we alerted you to the continuing complex and challenging environment that charities of our size have to navigate. We also signalled turbulence during 2018/2019 because of funding constraints, political uncertainty, and high expectations of the sickle cell community and other partners. That has proven to be exactly the case. It was therefore a tough but productive year. We have ended the year with a deficit of just over £37,000

Despite these circumstances, we have achieved a great number of things this year, including:

- Publishing the 2nd Edition of the Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK in partnership with the UK Forum on Haemoglobin Disorders.
- Publishing two reports as part of our role as joint secretariat for the All-Party Parliamentary Group for Sickle Cell and Thalassaemia.
- Winning the tender to continue the delivery of a programme of work in collaboration with UK Thalassaemia Society for the NHS Sickle Cell and Thalassaemia Screening Programme.
- Winning the tender for South London Community Organising in collaboration with NHS Blood and Transplant (South London Gives).
- Our continued work with NHS England ensuring a patient perspective on a major service review of haemoglobinopathy services in England.
- Our Chief Executive being awarded an OBE for services to sickle cell disorder and health in the Queen's Birthday Honours.

Looking forward, we know that the turbulence will continue and it will be another challenging year. Nevertheless, we remain committed to continuing the positive work we do for the sickle cell community and doing so with good governance, transparency and accountability.

We hope you enjoy reading this account of our 2018/2019 activities and achievements and that it will provide new insights in to our work.

Kye Gbangbola	**John James OBE**
Chair	Chief Executive

Membership

The Sickle Cell Society has maintained its free membership policy and the current membership stands at almost 3,000. Members receive two print or PDF newsletters a year as well as a monthly e-newsletter and other emails about various projects and events.

Almost
3,000
Members

The Sickle Cell Society is the national umbrella for over 40 independent support groups and voluntary organisations across the UK.

Media and Communication

The Sickle Cell Society Twitter page has gained almost 900 new followers

The Sickle Cell Society Facebook page has gained over 600 new likes

The Sickle Cell Society Instagram account has gained almost 800 followers

The Sickle Cell Society website receives, on average, 19,000 views per month

Helpline and Information

The Society received 898 requests for information by telephone from April 2018 to March 2019.

In more than half the cases, we have been able to provide information immediately.

10,484

Minutes spent on the phone

The most common topics of calls were fundraising, benefits and the South London Project.

56% of callers were new callers. The team spent a total of 10,484 minutes (approx. 174 hours) on the phone.

63%

of emails were responded to with information immediately

As part of the helpline service we also responded to emails. The Society received a total of 1,066 emails during April 2018 to March 2019.

63% of emails were responded to with information immediately.

Mentoring Scheme

The Hackney and City Mentoring Scheme is for people living with sickle cell aged 10-25 in Hackney and City.

31 **New referrals (11-24 years old)**

Mentoring sessions (approx) **150**
including virtual contacts

Session topics include:

- Education
- Career Advice
- Work Experience
- Public Speaking
- Treatment Plans
- Self-Management
- Fitness
- Stress Management
- Transitions
- Wellbeing
- Maturity
- And More

"The programme has put forward genuine and relatable role models who our young people can look to for support, encouragement and to build aspirations." Community Response

Breaking Down Barriers

The Breaking Down Barriers project expanded this year by working closely with a range of local organisations in order to enable service users with fast track access to employability services and wellbeing services locally. They also worked with the South London Link designing a ‘Sickle Cell Journal’.

The project ended in March 2018 but the resources designed will remain available for online for free at www.sicklecellsociety.org

Education Days

The Society ran two education days, one in Cardiff with Friends of Cardiff Sickle Cell and Thalassaemia Support Group and one as part of our 39th AGM in July which focused on the NHS England Sickle Cell Service Review and the Hackney and City Mentoring Scheme.

The Screening Programme

In June 2018, the Sickle Cell Society in collaboration with the UK Thalassaemia Society successfully won a 3-5 year tender to improve service provision with the NHS Sickle Cell and Thalassaemia Screening Programme.

Key Project Achievements

- Draft edition of *"Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care"*
- Recruiting a Medical Writer /Editor
- Collaborative talks with the Writing Group of the *"Parents' Guide to Managing Sickle Cell Disease"*
- Raising awareness of *"Parents' Stories"* and the Screening Programme's Newborn Outcomes System
- Producing user-friendly leaflets to promote the National Heamoglobinopathy Registry.

Children's Activities

The Children’s Activities project aimed to deliver a programme of regular activities to children and young people with sickle cell. This was to enable them to reduce their isolation, increase their confidence and improve their wellbeing.

30 **Activities, workshops and events provided for children with sickle cell**

Different children benefited from the children's activities **94**

"Great session. My first. Activities for kids was amazing. My little warrior (5) had a great time. Thank you" A parent

Children's Holiday

30 Children with sickle cell attended our adventure holiday

From the 18th to 22nd August we took 30 children with sickle cell on an adventure holiday to the Pioneer Centre. Alongside learning about their sickle cell, the children experienced activities such as climbing, zipline, caving and archery, as well as evening activities such as a talent show and disco.

"I am grateful to see my daughter go on a trip with others who share the same situation as she and I am grateful that I have got to know some parents as well" A parent

South London Link

We are now in the third year of the Big Lottery funded Sickle Cell South London Link project.

The project has engaged with adults, young people and children living with SCD as well as parents, carers, and support groups.

14 **Children's Activities (approx)**

Total number of children who attended activities (approx) **57**

10 **Information Workshops**

Total number who attended the information workshops **84**

30 **Total volunteers with 3 new volunteers this year**

Groups who attended the Collaborative Working Support Group Building Capabilities Workshop **7**

Hackney Engagement Project

The Hackney Engagement project started delivery in April 2017 and completed work in June 2018.

3 **Events focused on health and well-being delivered between April and June 2018**

Total project beneficiaries from April 2017 to June 2018 **171**

"This relaxation session has shown me how I can help my child when he is having a crisis and how to calm him down using breathing techniques"

South London Gives

In January 2019 we won a tender from NHS Blood and Transplant to deliver South London Gives, a project which aims to increase the numbers of people of black African and black Caribbean origin donating blood. The project will be working in:

Greenwich - Lambeth - Lewisham - Southwark

Sickle Cell Service Review

Between May and December 2018 the Sickle Cell Society carried out an extensive consultation project with sickle cell patients, carers and supporters in response to NHS England's (NHSE) planned changes to sickle cell services.

86 **Survey Responses**

Facebook Live Comments **189**

140 **People at our 2018 AGM**

People at our Birmingham Event **22**

Parliamentary Work

The Sickle Cell and Thalassaemia All Party Parliamentary Group (SCTAPPG) secretariat service under the auspices of the Sickle Cell Society and UK Thalassaemia Society has been operational since the 4th December 2017.

Key Achievements:

- Publishing the 2nd edition of the *Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK*
- Publishing *How Did You Contract That?* a report into the institutional failures of Personal Independence Payment (PIP)
- Publishing *I'm In Crisis* a report into the lack of representation the sickle cell and thalassaemia has in pre-registration nurse and midwife education

appg All-Party Parliamentary Group Sickle Cell and Thalassaemia

SICKLE CELL SOCIETY

UNITED KINGDOM THALASSAEMIA SOCIETY

Self Over Sickle

The Self Over Sickle programme promotes improved physical, psychological, social and emotional wellbeing, primarily for young people aged 16-25.

Following its birth in January 2018, a number of developments have taken place to ensure the reach of this project is relevant and enjoyable.

The project has moved away from committing itself to 30 face-to-face workshops. Instead, the project is focusing on offering young people the ability to participate in the project from the comfort of their own home, tuning in to podcast episodes.

40 **Young people and their families at the launch event**

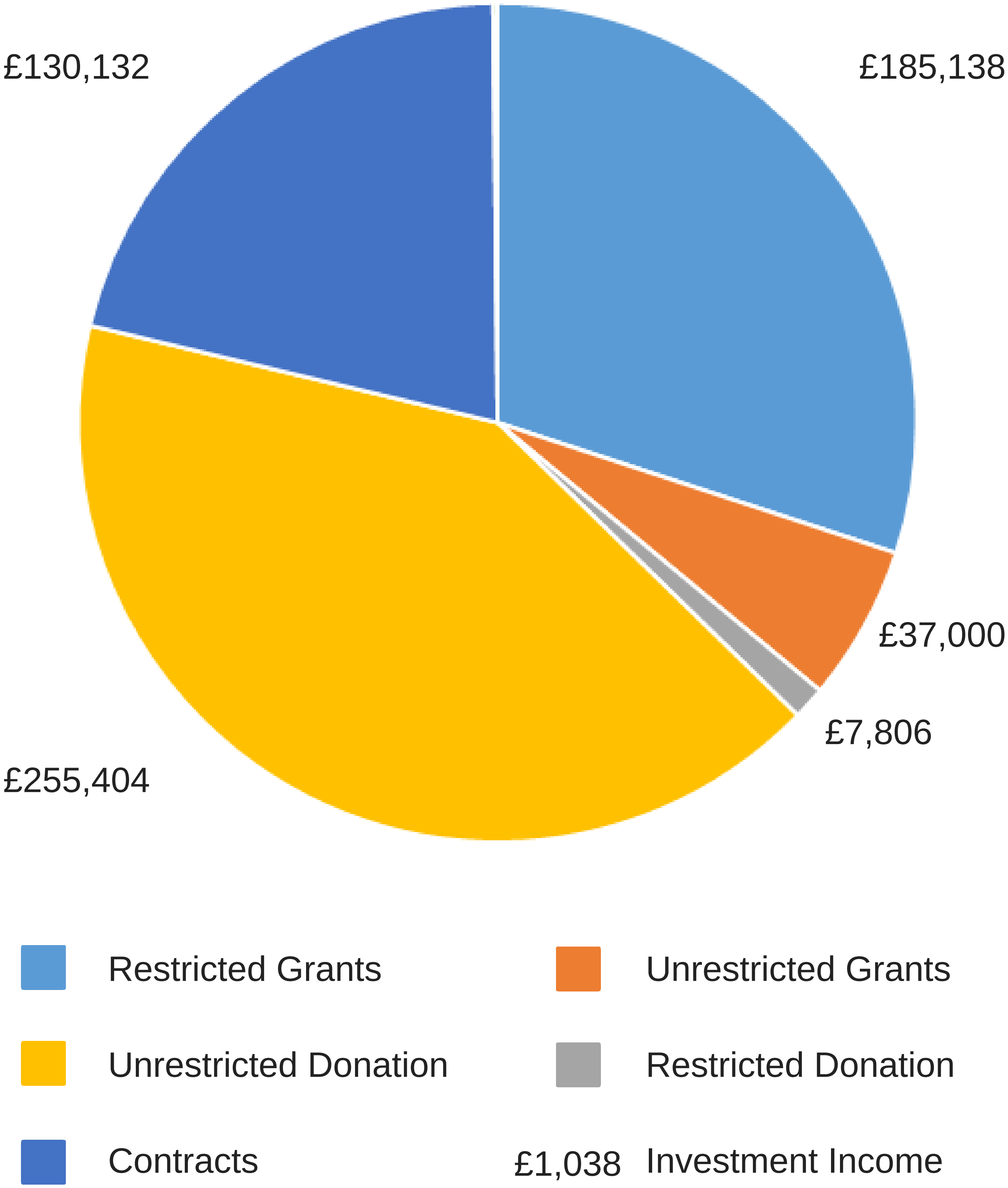
Podcast plays on the three published episodes **300**

The podcast covers topics including: relationships, mental health and wellbeing, entrepreneurship, employment, and support services available.

It is hoped that the podcast continues to unite young people with sickle cell cross-regionally and show them that support is not just in their local area or hospital but nationwide with the Sickle Cell Society as a central hub.

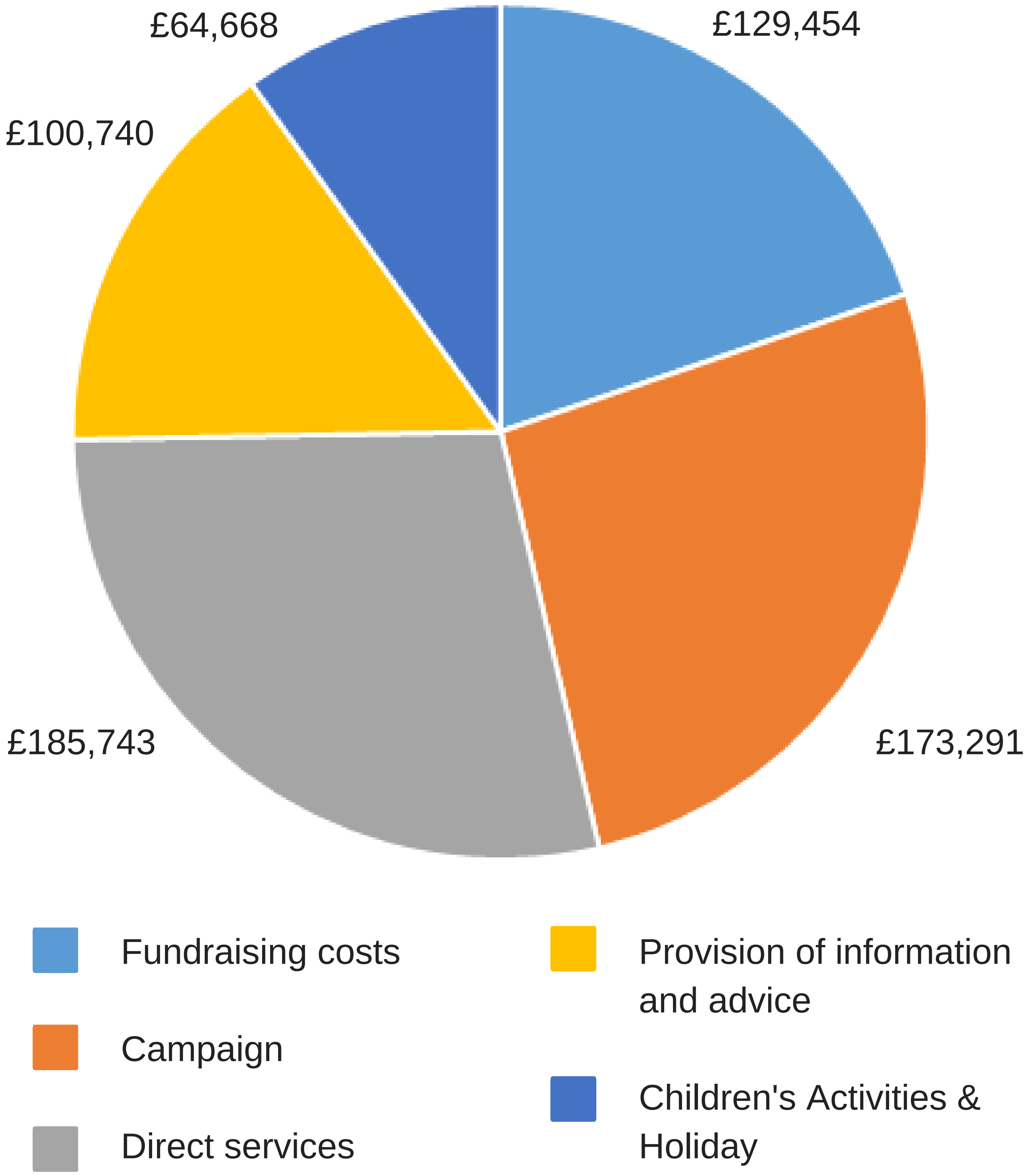
Financial Summary

Total Income: £616,519



Financial Summary

Total Expenditure: £653,896



The Future

Our strategy for 2018-20 is built upon the following 6 priorities

1) **Engagement**
Growing our membership and reach alongside building and strengthening Support Groups

2) **Financially sound**
Developing and diversifying our income base whilst continuing strong financial discipline of our financial resources

3) **Well Led**
Covers governance, including the role and well being of trustees, staff and volunteers

4) **Influence and Impact**

Having an ongoing dialogue with policy makers and funders which advocates for the needs of people with Sickle Cell and their families

5) **Making a difference for Children and Young People with Sickle Cell**

Building on the work done with the Picker Institute and the feedback from the Society's membership on next steps

6) **Supporting and engaging with Industry and the NHS on appropriate research and development on Sickle Cell**

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For more information visit:
www.sicklecellsociety.org

INVESTORS
IN PEOPLE
Accredited
Until 2020

2018
Winner
GSK IMPACT Awards
In partnership with
The King's Fund