



2017/18 IMPACT REPORT



Sickle Cell Society
54 Station Road
London
NW10 4UA

info@sicklecellsociety.org
020 8961 7795
www.sicklecellsociety.org
 @SickleCellUK



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.



Summary Statement

Over the last 4 years the Sickle Cell Society has been operating in a changing environment, particularly NHS and Local Authority austerity, NHS commissioning reconfiguration of Clinical Commissioning Groups, Charity Commission regulation to name a few.

The Sickle Cell Community nationally is also consistently evolving, raising its voice and supporting our work in raising the profile of Sickle Cell Disorder (SCD).

We are therefore very pleased to report that despite the ever changing environment in which we operate, the financial year 2017/18 has been one of continued growth and solid service performance, building on the improvements made over the last 4 years.

We have now ended the financial year with a small surplus. This is the fourth consecutive year this has been achieved and is testimony to the hard work of our staff, volunteers, donors, friends and supporters from across the country. We thank you.

The 2017/18 financial year has been a continuation of the journey we set 4 years ago. The course of that journey was about, amongst other things, leadership, accountability and transparency, financial sustainability and improvements in the range and quality of services for people who live with SCD and their families. We are confident that we are navigating that journey well, which in part is evidenced by the external assessment to secure the GSK/Kings Fund Impact Award and the Investors in People external accreditation.

Looking forward, we already know that there will be turbulence during 2018/19 year because of funding constraints, political uncertainty, high expectations from our sickle cell community and other partners. We will therefore continue to work hard to continue the course of improvement we have set and look forward to your continued support in doing so.

We hope you will enjoy reading this Impact Report which gives a brief overview of our work over the last year. Our full Annual Report is available on request.

Kye Gbangbola
Chair

John James
Chief Executive

Membership

The Sickle Cell Society has maintained its free membership policy and the current membership stands at almost 2500. Sickle Cell Society members receive two print or PDF newsletters a year as well as emails about various projects and events.

Almost
2500
Members

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

Media and Communication



The Sickle Cell Society Twitter page has gained over 1000 new followers



The Sickle Cell Society Facebook page has gained over 500 new likes



The Sickle Cell Society Instagram account has gained over 500 followers

The Sickle Cell Society website receives, on average, 20,000 views per month

Helpline and Information

The Society received 879 requests for information by telephone from April 2017 to March 2018.

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

9126
Minutes
spent on the
phone

The most common topics of calls were fundraising, benefits and general information.

66% of callers were new callers. The team spent a total of 9,126 minutes (approx. 152 hours) on the phone.

78%
of emails were
responded to
with
information
imeadiatly

As part of the helpline service we also responded to emails. The Society received a total of 390 emails during April 2017 to March 2018.

78% of emails were responded to with information immediately.

Hackney and City Mentoring Scheme

The Hackney and City Mentor Scheme was launched in August 2017 and has three mentors.

30 Referrals ranging from 11 to 24
years old

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

125

The young people were referred by a range of different people and places. The mentors have also delivered talks and presentations to raise awareness of both sickle cell and the new mentoring programme.



Breaking Down Barriers

In September 2016, the Sickle Cell Society partnered with the Breaking Down Barriers project which is funded by the Sylvia Adams Trust. After a successful first year, the Sylvia Adams Trust agreed to renew funding for the second consecutive year.

The Breaking Down Barriers project provides French and Portuguese resources as well as support with:

- Managing Sickle Cell & Sickle Cell Trait
- Benefits
- Housing
- Awareness
- School and Education Information
- General Information through the helpline services



Understanding genetics together

Education Days

The Society ran two education days, one in Manchester and one in London in collaboration with the Royal Society of Medicine's Medicine and Me programme.

The Society also held a patient and carer education event in London at our 38th AGM in July which featured talks on opioids and complementary treatment from Dr Paul Telfer, Dr Kofi Anie, and Dr Jeremy Anderson.

The Screening Programme

From 1st April 2017 - 31st March 2018, the Sickle Cell Society worked collaboratively with the UK Thalassaemia Society and NHS Sickle Cell and Thalassaemia Screening Programme on the second year of a two year Screening Programme tender.

Key Project Achievements

- **Parents' Stories Booklet**
- **Screening Programme Handbook**
- **Screening Programme Leaflets**

A link to these resources can be found at www.sicklecellsociety.org/resources/



Parents' Stories



65

health professionals, service users and other stakeholders attended a conference to discuss the results of the two-year collaboration.

"I hope to use this learning to make a difference"

"The parents' stories will stick in my mind"

"Very informative and enjoyable"

Quotes from the conference: *'Parents' Stories and Service Evaluation: investigating the causes of late offers of antenatal screening and prenatal diagnosis'* - Birmingham 21/03/18



Children's Activities

The Children in Need funded project aims to provide a programme of activities for children and young people with sickle cell to enable them to reduce their isolation, increase their confidence and improve their wellbeing.

50

Activities, workshops and events provided for children with sickle cell

Children's Holiday

30 Children with sickle cell attended our adventure holiday

From the 19th to 26th August 2017, the Society took 30 children with sickle cell on an adventure holiday to PGL Liddington. Alongside learning about their sickle cell, the children experienced activities such as climbing, zipline, quad biking and mountain biking, as well as evening activities such as a talent show and disco.

"I have learnt that I can do anything even with my sickle cell and I am very blessed"



South London Link

We are now in the second 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.



56 Children's Activities (approx)

Total number of children who attended activities (approx)

120

9

Information Workshops

Total number who attended the information workshops

50

9

New volunteers - building on the 20 previously recruited

Support groups who attended the 1st Support Group Building Capabilities workshop

8

Hackney Engagement Project

The project started delivery in July 2017 and is funded by London Borough of Hackney. It follows on from significant previous engagement work in the borough which has the highest levels of sickle cell in London.

11 Events delivered - from play and holistic health activities to conferences attended by Professor Simon Dyson and Dianne Abbott MP

Beneficiaries reached through events and community outreach days

100

"This has made my weekend; this is exactly what I have been looking for"



Awards and Accreditation



The Society is very proud to have beaten more than 350 organisations from all over the UK to be one of the eight winners of the 2018 GSK IMPACT Awards, a national award that recognises charities that are doing excellent work to improve people's health and wellbeing.



**INVESTORS
IN PEOPLE**

Accredited
Until 2020

The Society was proud to be accredited against the Investors in People standard this year. Investors in People is the international standard for people management, defining what it takes to lead, support and manage people effectively to achieve sustainable results.

The Information Standard

The Society maintained its Information Standard Certification. The scheme was developed by the Department of Health to help the public identify high quality, evidence-based health and social care information.



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.



A programme of party business topics that affect people with sickle cell and thalassaemia has been acquired for the financial year 2018/2019.

Research

A research report is being authored on the perceived institutional failures regarding the Personal Independence Payment (PIP) process.

Patient Education and Information Project

January 2018 saw the birth of a new project, specifically designed to target 18-25 year olds within:

- South London
- The Midlands
- Manchester
- Yorkshire
- Merton (16+)

The programme is led by the Patient Training and Education Lead with the support of **4** **Regional Representatives** and a number of support groups.

162 young adults

are set to be engaged by the project.



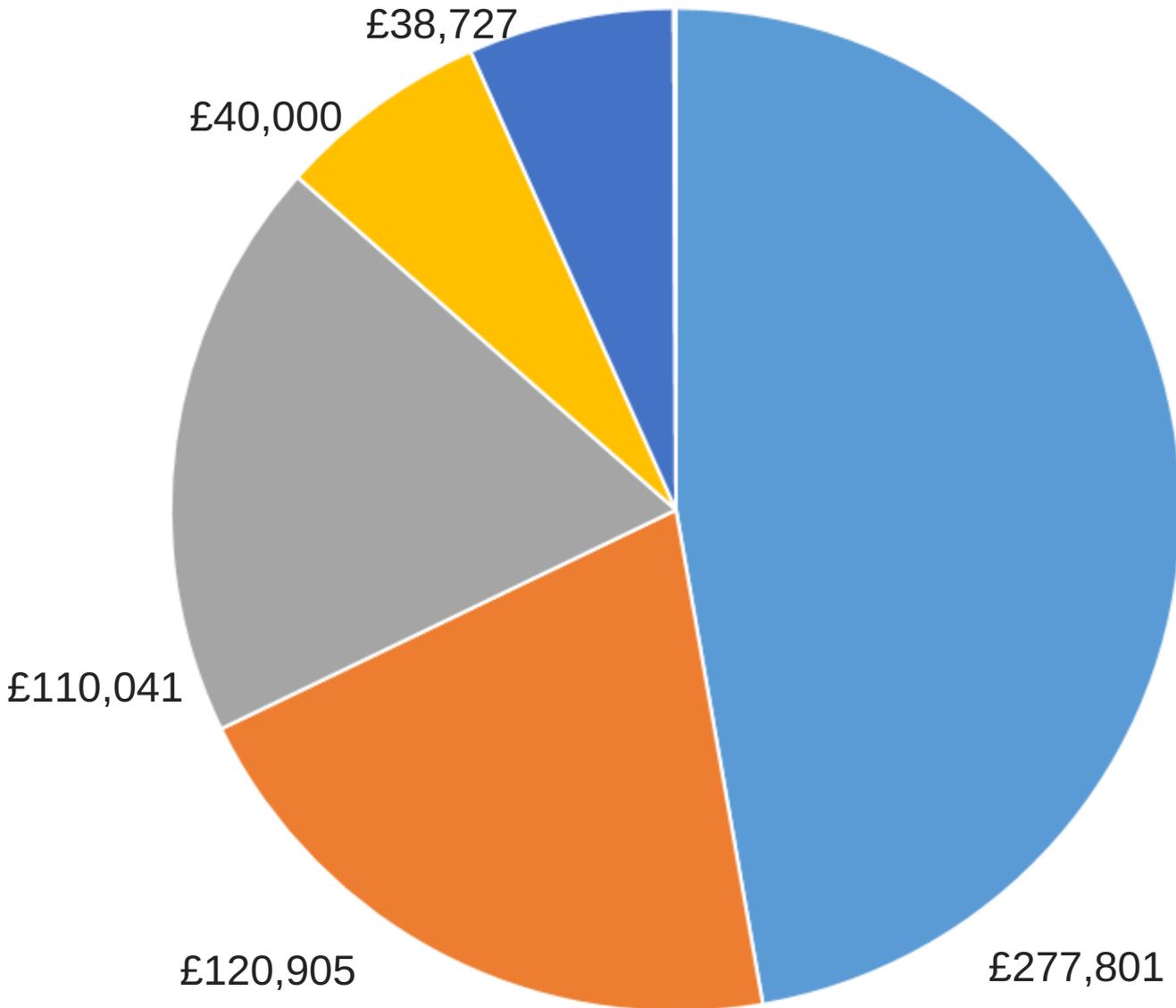
Annual Thanksgiving Service

The annual Thanksgiving Service was held in July 2017, hosted for the third time by Reverend Canon Stephen Coulson of St Mark's Church Kennington in Lambeth, South London.

The service was also a memorial gathering for the Society's dear colleague Comfort Ndivve who passed away on 27th October 2016.

Financial Summary

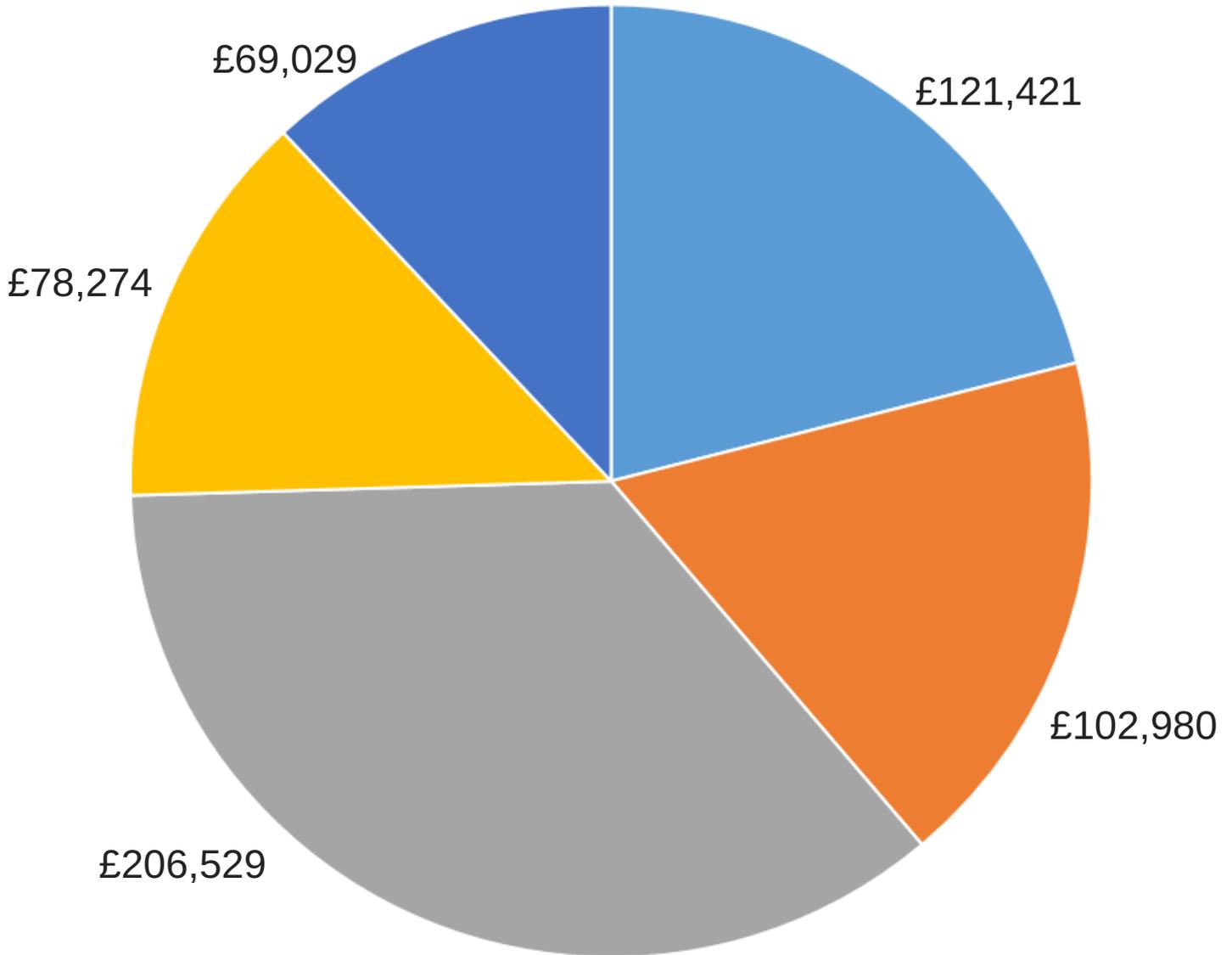
Total Income: £587,905



- Restricted Grants
- Unrestricted Grant
- General Donation
- Restricted Donation
- Donation from Fundraising
- Investment Income

Financial Summary

Total Expenditure: £578,233



 Fundraising costs

 Provision of information and advice

 Campaign

 Children's Activities & Holiday

 Direct services

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





**For more information visit:
www.sicklecellsociety.org**



**INVESTORS
IN PEOPLE**

Accredited
Until 2020

