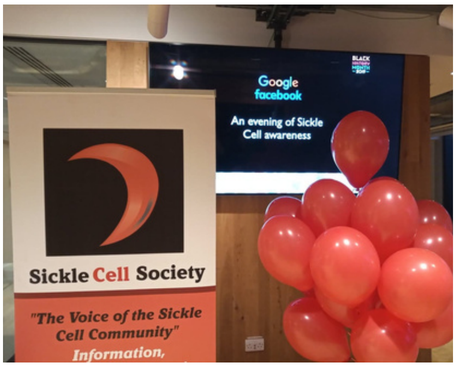
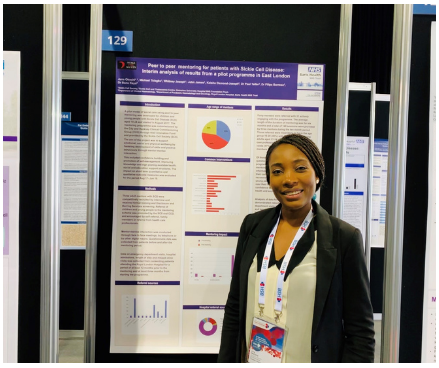
SICKLE
CELL
SOCIETY

2019/20
IMPACT REPORT





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Sickle Cell Society

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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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.

This year we have continued to see turbulence because of funding constraints, political uncertainty, and high expectations of the sickle cell community and other partners. Despite these circumstances, we have achieved a great number of things this year, including:

- Publishing the Hackney and City Mentoring Scheme in the British Journal of Haematology and presenting at the British Society of Haematology Conference in Glasgow in April 2019;
- Hosting several education days, focusing on key issues including employment, the Infected Blood Enquiry and clinical trials;
- Established a Sickle Cell Society archive as part of the Our Journey, Our Story heritage project;
- Published the third edition of Sickle Cell Disease in Childhood: Standards and Recommendations for Clinical Care;
- Saw the successful completion of the South London Link and Self Over Sickle projects;
- Continued working with NHS England on the Sickle Cell Service Review, seeing the establishment of Haemoglobinopathies Coordinating Centres (HCCs) as well as the National Haemoglobinopathy Panel (NHP) across the country;
- Celebrated our 40th Anniversary with a celebratory Gala Ball hosted at the Royal National Hotel and with guests including service users, politicians, celebrities, healthcare professionals and other key Sickle Cell Society supporters;
- Continued our partnership with NHS Blood and Transplant to promote the recruitment of black heritage blood donors through the South London Gives project;
- Published End the Blood Tax: An investigation into the impact of prescription charges for those living with sickle cell and thalassaemia through our role as secretariat of the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG);
- Continuing to work with pharmaceutical companies on clinical trials for potentially new sickle cell modifying drugs;
- Continuing collaborations with the Kings Fund and GSK through their leadership development programme, learning and sharing learning alongside other diverse charity leaders across the UK.

The Coronavirus (COVID-19) pandemic has had a massive impact on those living with sickle cell and their families and carers. We have worked hard to ensure sickle cell was included on shielding list and have worked with our medical advisers to keep our website up to date with the latest Coronavirus related guidance.

We know that the next year we will continue to see significant COVID-19 related turbulence and challenges. Despite this, we remain committed to supporting the sickle cell community, our staff and volunteers and continuing the positive work we have done, doing so with good governance, transparency and accountability.

We hope you enjoy reading this account of our activities and achievements in 2019/20 and that it will provide you with a deeper insight into 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 around 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.

Around
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 over 1000 new followers

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

The Sickle Cell Society Instagram account has gained over 800 followers

The Sickle Cell Society LinkedIn account has gained almost 200 followers

The Sickle Cell Society website receives, on average, 24,000 views per month

Helpline and Information

The Society received 628 telephone calls from April 2019 to March 2020.

The Society provided information and support for 70% of all calls - with 77% receiving information, support or being signposted to relevant places.

7385

Minutes spent on the phone

The most common topics of calls were fundraising, managing sickle cell, benefits and awareness.

70% of callers were new callers. The team spent a total of 7385 minutes (approx. 123 hours) on the phone.

65%

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 1070 emails during April 2019 to March 2020.

65% of emails were responded to with information immediately - with 76% receiving information, support or being signposted to relevant places.

Mentoring Scheme

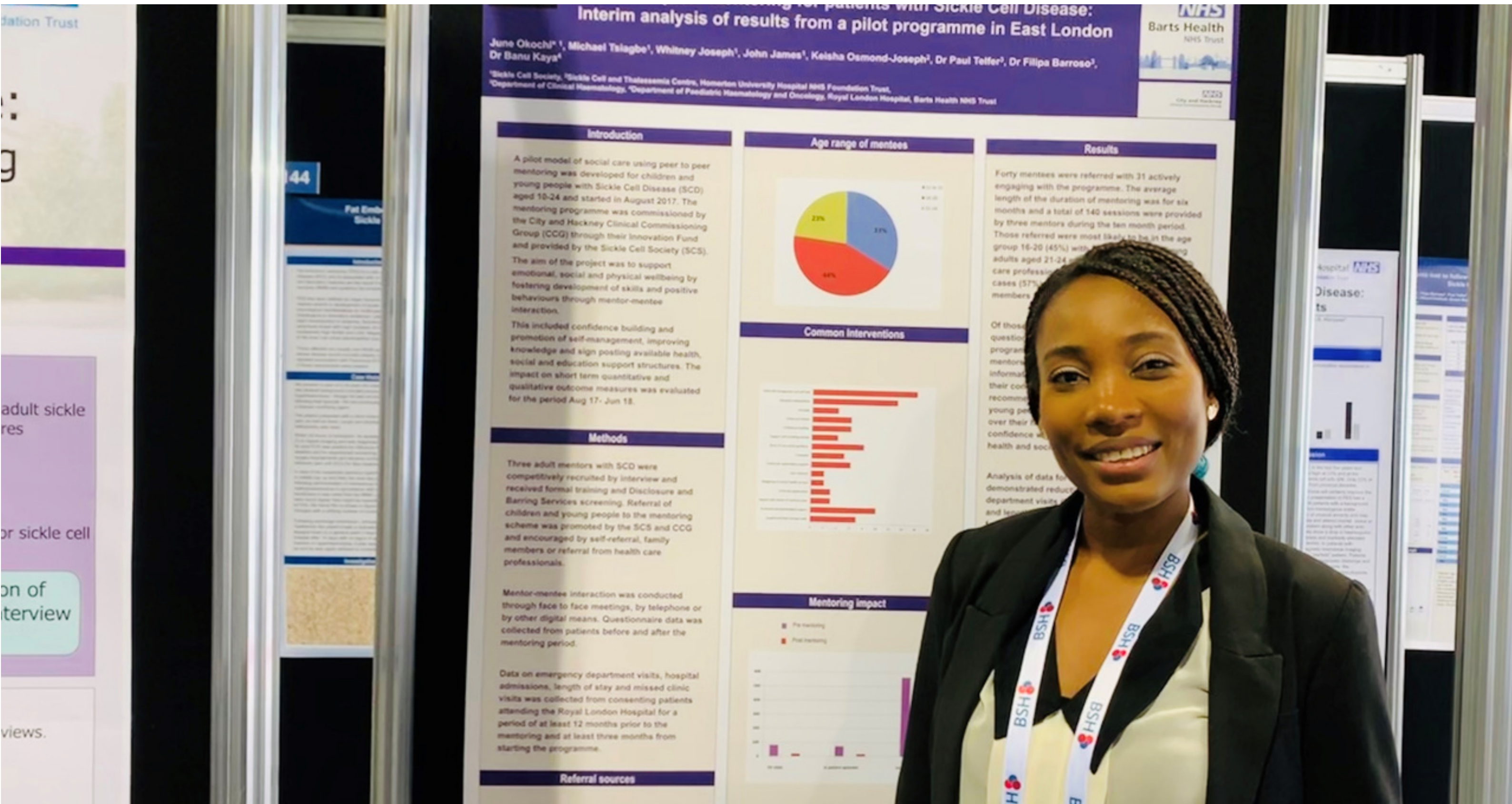
The Hackney and City Mentoring Scheme is for people living with sickle cell aged 10-25 in Hackney and City.

This year the mentors were fortunate to have had the opportunity for the mentoring programme to be published in the **British Journal of Haematology** in Spring of 2019 outlining the outcomes of the model on children and young people.

Our mentors were then at the British Society of Haematology Conference in Glasgow in April 2019 to present their work.

The Society is in early conversations with all of the East London Clinical Commissioning Groups (CCGs) across the 7 boroughs about the potential expansion of the City and Hackney Sickle Cell Peer Mentoring Programme which has successfully piloted over the last 2 years.

We hope the programme will resume and re-launch in late 2020.



Education Days

The Society continues to honour the United Nations declaration of World Sickle Cell Day on 19th June each year by celebrating the day and raising awareness. This year we celebrated with an online awareness campaign, sharing through our membership, website and social media information and graphics.

The Society ran two education days, one in London which focused on men living with sickle cell and one as part of our 40th AGM in July which focused on the Infected Blood Enquiry, clinical trials and the Sickle Cell Work and Employment guide.

Staff, Trustees and Volunteers continued to provide talks and presentations within local and national businesses, schools, universities, churches, government and corporate organisations in order to raise awareness of sickle cell disorder and the important work of the Society.

Our Journey, Our Story

Our Journey, Our Story is collecting oral history as part of the Sickle Cell Society's Heritage Project funded by the Heritage Lottery Fund. The project will chart a history of sickle cell disorders in the UK since the Windrush generation's arrival.

Objectives

- Create a film
- Establish a Sickle Cell Society archive
- Developing Heritage workshops engaging young people and the over 50s affected by SCD
- Oral histories obtained from campaigners, pioneers, patients, and other prominent individuals
- An exhibition accompanied by public events

Key Achievements

- Recruited 8 volunteers to assist with interviewing
- Collected archives from other researchers and established an agreement with the Wellcome Collection
- Organised heritage workshops across the country (delayed due to COVID-19)
- Met with the BCA and confirmed exhibition (end of 2020)
- Met with filmmakers and Hat Trick production
- Created an Instagram page and started raising awareness

The Screening Programme

From 1 April 2019–31 March 2020 the Sickle Cell Society and UK Thalassaemia Society worked on the 2nd year of a collaborative tender with the NHS Sickle Cell and Thalassaemia Screening Programme which officially commenced on 15 August 2018.

Key Project Achievements

- Successful consultation (32 parents and 25 health professionals) leading to production of a new edition of the publication ‘Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care’
- Successful online and face-to-face consultation with a total of 60 parents of children with sickle cell, for an updated version of the ‘Parents’ Guide to Managing Sickle Cell Disease’ due to be launched in 2021.
- Participation in a working group providing service user perspective for updating the sickle cell and thalassaemia counselling competencies.
- Raising awareness (6 public talks, 2 newsletter articles, 2 TV appearances, 2 stalls, and 3 roundtables/conferences).
- Produced 4 user-friendly information posters to raise awareness of sickle cell, thalassaemia and screening

> "The book is like the sickle cell bible, very useful."
>
> "I personally have learnt so much from this book. It has been like our second doctor in my house."
>
> - Quotes from parents from the handbook consultation

Children's Holiday

30 Children with sickle cell attended our adventure holiday

From the 10th to 14th August we took 30 children with sickle cell on an adventure holiday to Condover Hall. Alongside learning about their sickle cell, the children experienced activities such as lazer conquest, high ropes, caving and archery, as well as evening activities such as a talent show and disco.

"I learnt that we are not alone with our condition and it is really easy to meet people who have sickle cell" - Camper

Self Over Sickle

The Self Over Sickle project was designed to support young adults in the transition to independence with advice, information, practical training, signposting and opportunities to meet others with sickle cell. The project came to an end in July 2019.

This year, the Self Over Sickle project produced 4 podcasts (two live episodes and two pre-recorded episodes) covering topics ranging from relationships, careers and support services.

As well as the live recordings, the project ran in-person events to raise awareness and build community.

The project also ran a 40 day social media challenge which focused on raising awareness, improving wellness and getting to know the sickle cell warriors and extended advocate family.

South London Link

April 2019 to September 2019 was the final 6 months of the South London Link project. Over the last 6 months the project has run a range of workshops and activities including: 4 information workshops, a family day, a activity day, a volunteer gathering and a sickle cell play for the local community in Brixton.

31 **Children who attended the South London Link Children's Activities**

Adults who attended the South London Link information workshops **59**

Sickle Cell Service Review

Over 2018 and 2019 the Society worked on the Sickle Cell Service Review (Haemoglobinopathy Service Review) by an extensive consultation project with sickle cell patients, carers and supporters in response to NHS England's (NHSE) planned changes to sickle cell services.

This year, after this extensive consultation, NHSE have introduced Haemoglobinopathies Coordinating Centres (HCCs). HCCs are responsible for coordinating, supporting and promoting a system-wide networked approach to the delivery of haemoglobinopathy services.

You can see the full list of HCCs including sickle cell and thalassaemia, the National Haemoglobinopathy Panel (NHP), and Specialist Haemoglobinopathies Teams (SHTs) at our website: www.sicklecellsociety.org/servicereview/

40th Anniversary Gala Ball

On Saturday 14th September we joined with supporters, service users, patrons and celebrity guests at a glamorous dinner and dance to celebrate the last 40 years.

Hosted in the Royal National Hotel, the evening opened with a red carpet drinks reception before guests then enjoyed a delicious three course meal at tables hosted by celebrities.

The evening was hosted by Chizzy Akudolu (Actress: Holby City, Dead Set, Jinx) and saw performances from:

- A Star (London rapper, and sickle cell advocate)
- Shaila Prospere (Soul/R&B singer and songwriter)
- Victoria Ekanoye (Coronation Street and The Royals actress)
- B Positive (Official NHS Blood and Transplant Choir and Britain's Got Talent finalists)

The evening also saw a fundraising raffle and auction, a presentation from The Voice newspaper and talks from John James OBE and Kye Gbangbola.

Thanksgiving Service

On Sunday 23rd June, the Sickle Cell Society held a Thanksgiving and Celebration Service at the beautiful St Marks Church in Kennington.

The theme for this years' service was '40 Years of Caring' and was a time to reflect on the progress made so far, remember those who have passed away and look forward to the future.

Rev Canon Stephen Coulson gave the welcome and the address was delivered by Rev. Rose Hudson-Wilkin, Chaplain to the Speaker of the House of Commons.

There were also talks from Cllr Ibrahim Dogus (Mayor of Lambeth), John James OBE and Michele Salter.

To set the celebratory tone the service also included musical performances from soloist Savannah Hall and Classic Brit Award nominees, Classical Reflection.

Hackney Engagement Project

The 2019/20 project has focused on addressing a number of key issues which had been highlighted by previous years' feedback and information. These areas were: community support for people with sickle cell, awareness and screening, improving the sickle cell experience in education, managing health and wellbeing.

Events organised to focus on these issues included a:

- forum event
- men's discussion
- children's activity day & party

20

Care packages sent to women who are parents/carers or have sickle cell

The project's efforts to raise awareness were demonstrated through:

- drop-in clinics at local community spaces
- outreach at a range of community events such as university open days and local community events
- forum meetings
- connecting with local and government organisations.

Collaboration

Two exciting project collaborations which have come from the projects network building efforts are:

- A 'sickle cell in education project" in partnership with New City College Hackney and Clapton Girls school.
- A monthly health and wellbeing workshop and drop-in service run in partnership with the leisure and physical activity team at Hackney council

South London Gives

South London Gives (SLG) planned and delivered a range of awareness raising, engagement and blood donor recruitment activities designed to increase the numbers of people of black heritage who regularly donate blood.

SLG has been funded by NHS Blood and Transplant and started delivery in January 2019. The project involves a team of trained volunteers (Community Advocates) who promote the need for more ethnically matched blood to treat those most severely affected by sickle cell disorder.

Key achievements:

- Development of a 3-stage training programme for project volunteers
- Secured strong partnerships with a range of organisations who have supported the project to engage with their audiences

16 **Community Advocates recruited and trained**

Blood donation recruitment events attended **30**

499 **New people of African and Caribbean heritage signed up to the blood donation register**

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.

Publications

- *‘End the Blood Tax’* an investigation into the impact of prescription charges for those living with sickle cell and thalassaemia
- *'A Guide to Sickle Cell and Employment'* authored by Barriers and Enablers to Employment: Black Disabled Peoples Living with Sickle Cell Disorder Project.

Key Meetings

- With Chief Executive and Registrar, Andrea Sutcliffe and Director of Education and Standards, Dr Geraldine Walters from Nursing and Midwifery Council
- with Liz Fenton RN, Queen's Nurse, Deputy Chief Nurse at Health Education England

New Officers

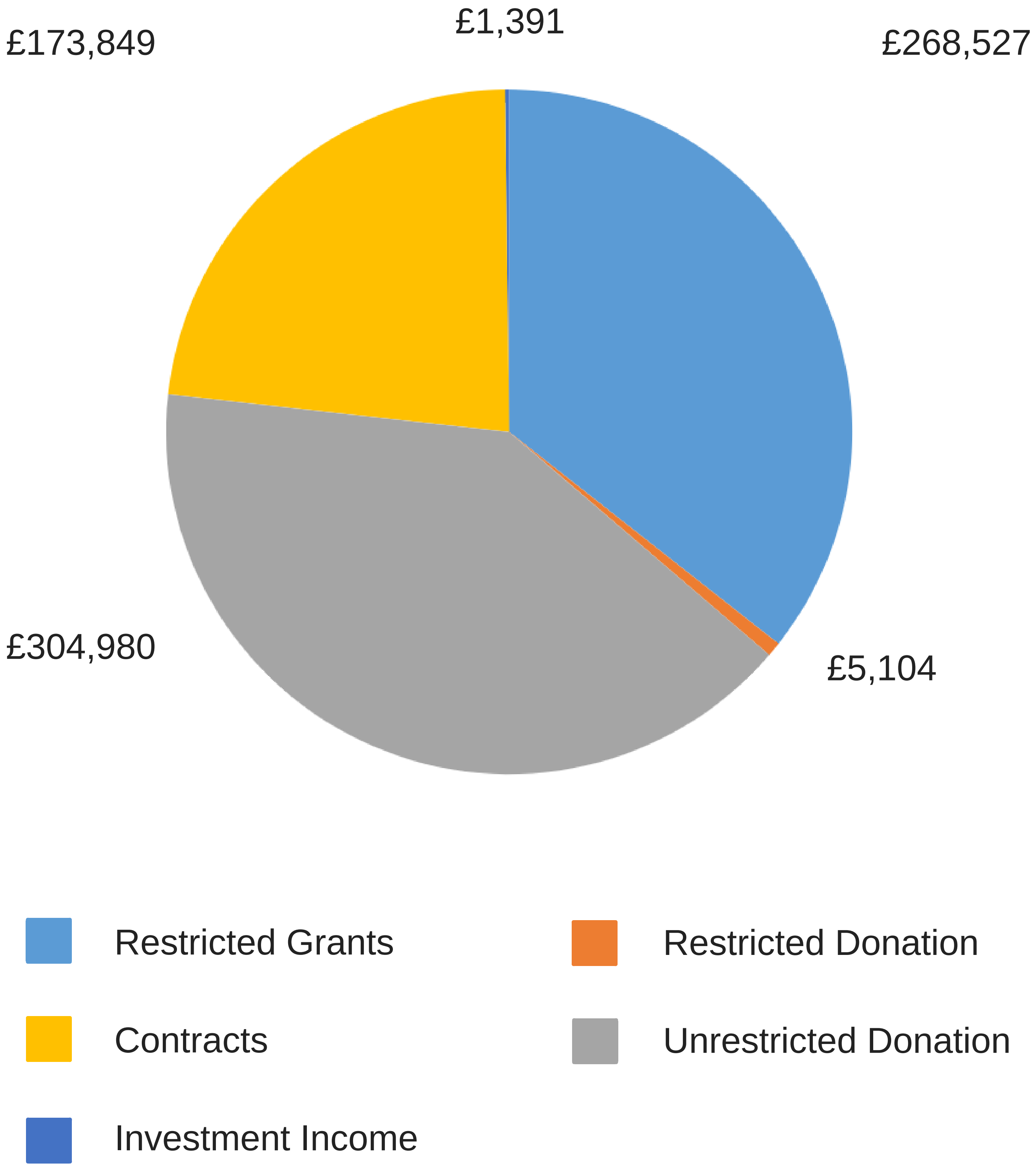
- Chair & Registered Contact: Rt Hon Pat McFadden MP
- Vice-Chair: Janet Daby MP
- Officer: Jess Phillips MP
- Officer: Baroness Benjamin
- Officer: Dawn Butler MP
- Officer: Kate Osamor MP
- Officer: Bell Addy-Riberio MP
- Officer: Sir David Amess MP
- Officer: Helen Grant MP

appg
All-Party Parliamentary Group
Sickle Cell and Thalassaemia

SICKLE CELL SOCIETY

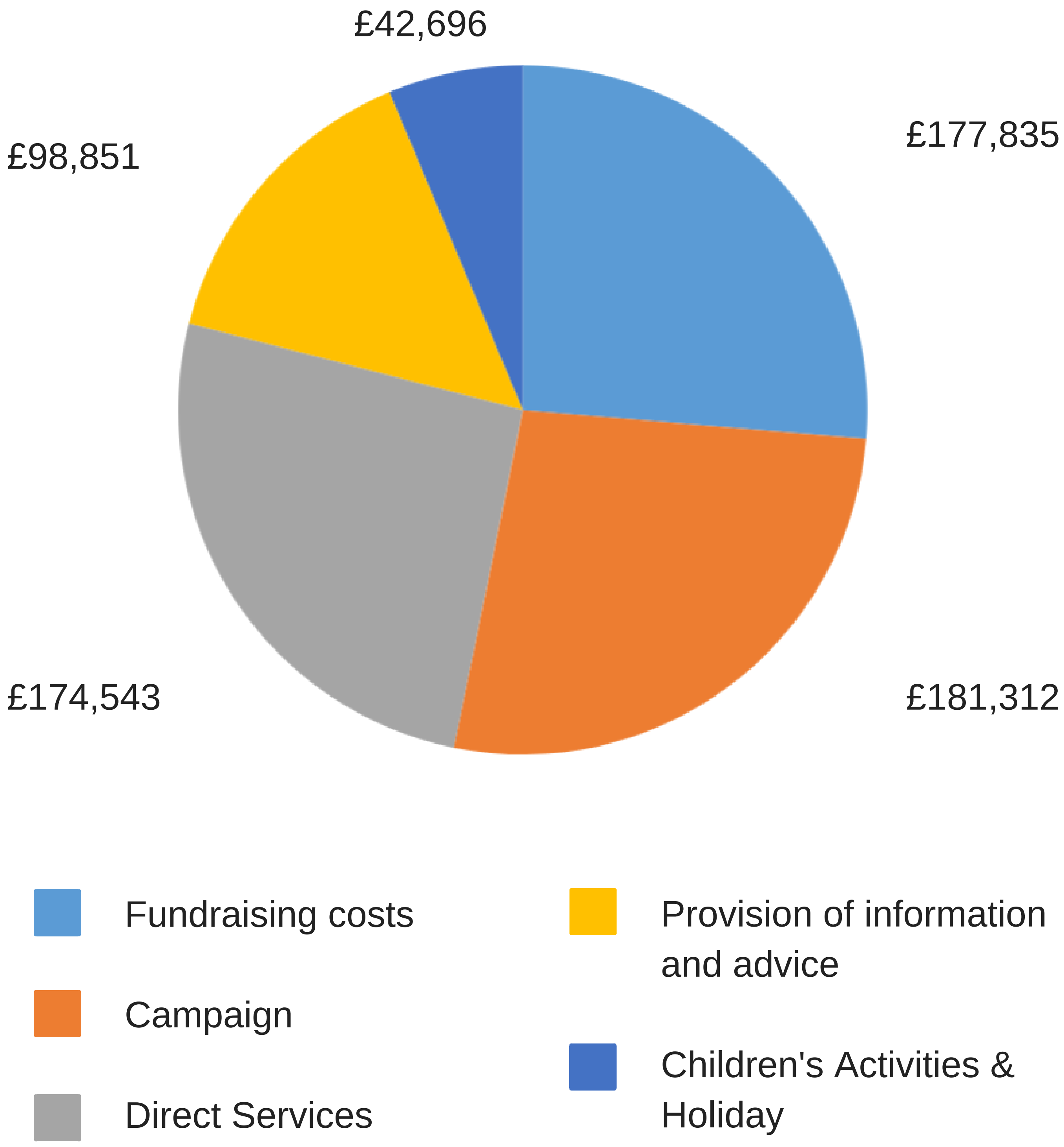
Financial Summary

Total Income: £753,851



Financial Summary

Total Expenditure: £675,237



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