



Sickle Cell Society **IMPACT REPORT** 2022/2023



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GIVE BLOOD, SPREAD LOVE

Our *Give Blood, Spread Love (GBSL)* project works with Black African and Caribbean heritage communities to raise awareness of sickle cell disorder; we explain why people living with sickle cell need ethnically matched blood and encourage people from these backgrounds to become regular, lifesaving blood donors.

Now in its fourth year of delivery, GBSL continues to engage with our target communities through events with corporate organisations, community associations, sport and leisure agencies and faith groups, enabling us to speak face to face with hundreds of people and share our important messages and calls to action.

Social media and online engagement remains a significant part of GBSL, supporting us to reach younger audiences and connect to many thousands of people with our easily accessible information on sickle cell, blood donation and related topics. Our volunteer team, the 'Give Blood Squad', is comprised of blood donors and blood recipients, and those with a personal connection to sickle cell, and are essential to this work, bringing the authenticity of lived experience to our campaigns.

**GIVE
BLOOD
SPREAD
LOVE**



THIS YEAR WE:

Attended **29** 'face-to-face' events



spoke to

2640 people



453

people took part in online events

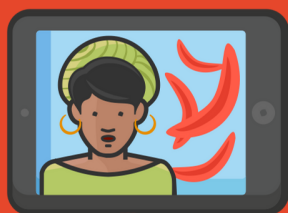
Developed **231** online engagement resources



Recruited **340** new Blood Donors



Delivered **7** blood donation awareness sessions to organisations across England



Held **9** expert-led online workshops, including, 'Boosting Iron Levels', 'Managing Sickle Cell in the Workplace', 'Men's Mental Health' and 'What Happens at a Blood Donation Session.'



Ran **6** group blood donation sessions

Produced



8 promotional films

Featured in:



3

Online Media Articles



1

Radio Interviews



1

Podcast



Held **4** volunteer support sessions



Reached over **50,000** people via our events and social media

Received **311** Hours of Volunteer Support

WHAT PEOPLE ARE SAYING ABOUT US

“With huge thanks to you and your fantastic team! People found it incredibly informative – we already have people who have registered to become blood donors!”

CORPORATE ORGANISATION



"Fantastic combination of information, personal lived experiences, and ACTION!! Thanks so much!"

EVENT ATTENDEE



“I’ve just signed up to be a blood donor and booked into a session near my home. Thank you for such an informative and touching session.”

EVENT ATTENDEE



“Thanks for attending and supporting our events; your volunteer team were excellent and very well prepared.

Your campaigning is invaluable to the community, and we're keen to keep working with you.”

PROJECT PARTNER

THE SCREENING PROGRAMME

Throughout the year, we continued our work with the UK Thalassaemia Society (UKTS) on the NHS Sickle Cell and Thalassaemia Screening Programme (NHS SCT Screening Programme), which was commissioned in August 2018. The current commission runs until July 2023 and the Society has submitted a tender application to continue this work.

In the wake of the COVID-19 pandemic, the project team continued to deliver the revised project objectives for antenatal and new-born screening in England virtually and later commenced in-person outreach.

KEY PROJECT ACHIEVEMENTS:

- Organised national screening conference to launch a new report.
- Input feedback from our 'No One's Listening' report to the current revision of the NHS SCT Screening Programme e-learning resource for health professionals.
- Member of NHS England and NHS Improvement (NHSEI) task and finish workstream for 'Preconception, Antenatal, Newborn and Maternity'.
- Represented on a King's College research project investigating stakeholder views on prenatal therapy for sickle cell.
- Recorded a comprehensive sickle cell podcast for the Department For Environment, Food and Rural Affairs (DEFRA) which was shared with its 30,000 staff.

RAISED AWARENESS OF SICKLE CELL AND SCREENING:



6

Online Talks & Conferences

5

Newsletters, Articles and Interviews



3

Workshops

PARLIAMENTARY & POLICY WORK

THE SICKLE CELL & THALASSEMIA APPG

The year 2022/23 has been a notable year for the work of the Sickle Cell & Thalassaemia APPG (SCTAPPG). This stems directly from the launch of the 'No One's Listening' APPG report in November 2021. We have continued working closely with the SCTAPPG through our work as secretariat and with our Parliamentary & Policy Officer. The SCTAPPG aims to raise awareness and promote sickle cell disorder and other haemoglobin disorders on the political agenda. Accountability is achieved through the SCTAPPG's Chair, Janet Daby MP.

Interest in the work of the SCTAPPG continues to grow with the Secretariat tracking noticeable increases in those who have signed up to attend meetings. Meeting discussions remain constructive and the SCT APPG continues to provide an invaluable platform for patients, clinicians, MP's and other stakeholders to communicate. Patients, stakeholders, parliamentarians and other stakeholders have provided positive feedback on the continued work and management of the SCTAPPG.



PARLIAMENTARY & POLICY WORK

THE SICKLE CELL & THALASSaEMIA

APPG

A key shift in the funding for the project has been the announcement by Global Blood Therapeutics that they will be merging with Pfizer. We will continue to work closely with representatives of GBT throughout the merger and endeavour to make the relevant links with new staff members if necessary.

The key functions of the SCTAPPG parliamentary work:

- Organise and execute four SCTAPPG meetings a year, plus one Annual General Meeting.
- Organise any relevant Emergency General meetings
- Manage SCTAPPG secretariat services
- Communicate SCTAPPG secretariat activity to politicians, stakeholders, Sickle Cell Society (SCS) and other interested parties
- Influence, build and manage effective relationships
- Maintain records of meetings and communications
- Pursue the implementation of the recommendations of the 'No One's Listening' report
- Provide awareness raising sessions on Sickle Cell and the work of the SCTAPPG to various stakeholders and groups
- Direct patient support



PARLIAMENTARY & POLICY WORK

SCT APPG AGM

The SCT APPG held its Annual General Meeting in Parliament on Wednesday 22nd July 2022. After many dedicated years as the Chair of the APPG, Pat McFadden MP stood down due to the pressures of his Shadow Cabinet role. Janet Daby MP was successfully elected as the new Chair. New officers were elected to the APPG, the full current list of SCT APPG officers is as follows;

- Janet Daby MP - Chair
- Pat Mc Fadden MP
- Paulette Hamilton MP
- Baroness Thornton
- Baroness Ludford
- Marsha DeCordova MP
- Greg Clark MP
- Florence Eshalomi MP
- Bell Ribeiro-Addy MP
- Bambos Charalambous MP

The meeting covered updates on progress since the launch of the 'No One's Listening Report'. The new Chair, Janet Daby MP also shared the forward look of the work of the APPG which will focus on following up the implementation of the report's recommendations alongside a wider area of work to improve sickle cell care in the UK.

APPG Meetings 22/23

- Mon 7th March 2022
- Wed 22nd June 2022 – AGM
- Mon 17th October 2022
- Mon 19th Dec 2022
- Mon 20th Mar 2023
- Mon 12th June 2023 - AGM



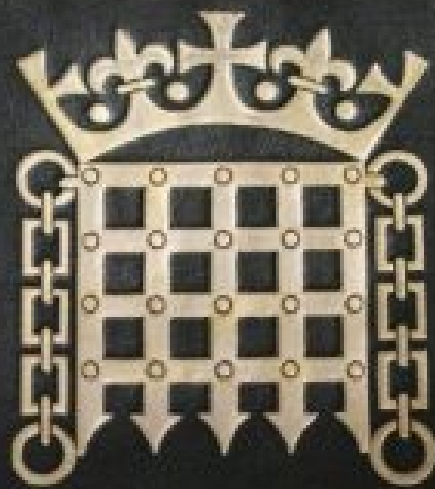
PARLIAMENTARY & POLICY WORK

SCT APPG AGM

Since going hybrid with SCT APPG meetings in December 2022 we average 20 - 25 people attending physically and 30 - 40 people joining online for meetings. This continues to be an excellent mix of patients, carers, community organisations, healthcare professionals and MP's/Peers.

Sickle Cell has continued to be raised in Parliament through oral and written questions. These are often made by the Chair of the SCT APPG, Janet Daby MP. However, Janet is supported in this by other MP's who raise questions. A total of 54 Sickie Cell and related questions have been asked since January 2022.

The Chair of the APPG, Janet Daby MP has continued to push the government on their plans to improve healthcare inequalities for Sickie Cell patients. Janet met with Health Minister Neil O'Brian on Tuesday 14th March 2023 to discuss the 'No One's Listening' report and it's according recommendations. The SCT APPG also received a letter from the Minister and the Department for Health on 25th January 2023 which detailed the governments programmes to support improving care for those who live with Sickie Cell.

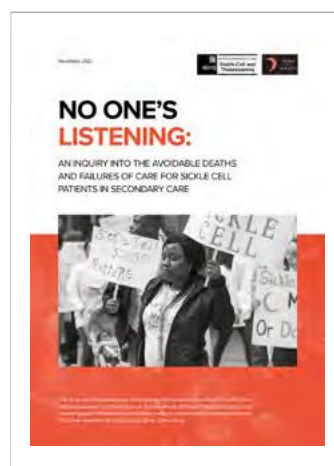


NO ONE'S LISTENING REPORT

Since the launch of the report in November 2021 there have been notable milestones achieved as the SCTAPPG continues to follow up the implementation of the report's recommendations. We were pleased with the substantial national media coverage which the report received when it was published. Similarly, the Westminster Hall Debate held in Parliament on sickle cell healthcare was a welcome milestone after the launch of the report.

November 2022 marked the one year anniversary of the report and some of the key achievements can be summarised as follows;

- A commitment from the Nursing and Midwifery Council to review the teaching and training of nurses in Sickle Cell.
- Dr Bola Owolabi, Director for National Healthcare Inequalities Improvement Programme, will be leading on the NHS review of the entire Sickle Cell pathway.
- The launch of the NHS campaign, 'Can you tell it's Sickle Cell?' The campaign was aimed at clinicians and healthcare workers alongside the general public.



THE 'NO ONE'S LISTENING' REPORT HAD A TOTAL REACH OF OVER 61.5 MILLION.

The NHS Race and Health Observatory research project compiled their initial report. Highlights include looking at digital transformations to improve sickle cell care, recommendations to redesign Sickle Cell services, creation of standardised care guidelines for clinicians and healthcare workers and development of wearable technology for Sickle Cell patients.

The launch of the Spectra Optia patient survey project seeking to improve access to automated red blood cell exchange.



NO ONE'S LISTENING REPORT CONT.

It is important to note that improvements to Sickle Cell healthcare have never been more important due to the cost of energy crisis, costs of living crisis, NHS blood shortages and NHS strikes. All factors impact directly on the lives of those who live with Sickle Cell.

Over a year on from the launch of the report, the Society continues to learn of failures in the healthcare of Sickle Cell patients. Changes to improve Sickle Cell services within many Trusts remains slow, with very little change in others.

There remains much work to be done to realise the report recommendations throughout Trusts in England. It is for these reasons that the work of the SCTAPPG continues and the implementation of the report's recommendations will remain the focal area of work for 2023 and onwards.



CHILDREN'S ACTIVITIES

We have continued to successfully deliver virtual children's activities for young people with Sickle Cell. We were also able to extend our activities a few more months due to an underspend. From January - March 2023 we ran teenage transition workshops for teenagers with Sickle Cell. We commissioned professional guest speakers to lead the workshops.

The activities we ran last year included:

- Zumba Class
- African-Caribbean cooking class
- Quiz and creative writing workshop
- Black History Month events
- Storytelling
- Cloth Making
- Drama
- Arts and crafts

FEEDBACK FROM FAMILIES:

"Thank you for these great opportunities."

"He was very happy and smiling. He was very excited and was happy for the rest of the day."

"The guest speakers were amazing. They shared useful information. The Q&A was very informative too. I like the fact that they had prepared a resource pack for us to have."

"It was very good to hear about other people's experiences and also how to advocate for yourself."



VIRTUAL HOLIDAY

The Virtual Children's Holiday in 2022 took place from the evening of Friday 5th August to Sunday 7th August. 45 families took part, including 54 children with sickle cell, 44 siblings and 59 parents, with families joining us from all around the UK. We had 20 volunteers helping us make the magic happen, as well as 21 workshop practitioners and 1 BSL interpreter. It was a unique and joyful weekend of education, conversation, excitement and fun!

This year, like last year, the Children's Holiday was delivered virtually via zoom, with an accompanying activity box full of self-led activities. The children were split into 5 'cabins' so that they had ample time for small group chats: Bears (4-6yrs), Zebras (7-9yrs), Tigers (10yrs), Giraffes (11yrs), Lions (12-15yrs). Alongside the children's programme we ran a programme for parents and a special session for siblings.

Activities during the busy weekend included:

Getting To Know You Games, Sickle Cell Education, A Theatre Workshop and Performance, Indoor Gardening, Juggling, Yoga, Relaxation/Meditation, Singing, Biscuit Decorating, LEGO Building, Arts and Crafts, Parent Mindfulness and a Sibling Wellbeing Session.

The families had a marvellous time and 93% are interested in attending another children's holiday in the future, with particular interest in an in-person offering. We found it was particularly valuable to involve the parents and siblings in the programme this year and this is something we will aim to continue.

The highlight of the holiday, reported across the board, was the positive community that we created and the families knowing that they are not alone.



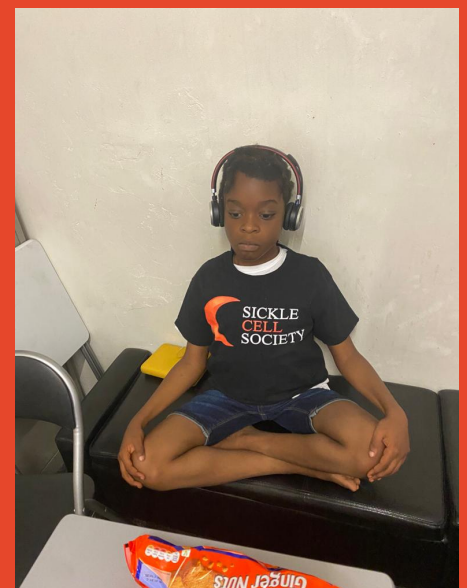
FEEDBACK FROM FAMILIES:

"It honestly has been life changing for my daughter and as a mother I feel supported and cared about. It's difficult having a child with sickle cell and all of these things ease the pain" - **Parent**

"Thank you all so much for allowing my family to be part of a community. A community that I can relate to and grow from. A community that lets me know that me and my family are not alone. A community that is doing their very best to improve the quality of life that children with sickle and their family experience. Keep up the great and important work because it is totally needed." - **Parent**

"I can wholeheartedly say that the children's holiday has been a huge catalyst for my 7 year old sickle cell warrior not feeling so isolated by having the condition, and also getting a better understanding of how to best live a wholesome life. Seeing other warriors gave her a sense of belonging and not feeling like she's the only person to be affected. Thank you SO much for all the hard work. It blew us both away and we can't wait to be able to join one again in future." - **Parent**

"These holiday clubs make having sickle cell less of an issue and more of a superpower." – **Parent**



KIDS ACTIVITIES IN NUMBERS



80

Children with Sickle Cell were impacted by our work

88

Parents attended Monthly Talks



6

Transitions Educational Workshops



34

Teenagers signed up to our Transitions Workshops



185

Families benefitted from our family workshops (this included siblings and parents).

48

Families watched our festive performance over the last 3 years, this included siblings, parents and wider family members.



CHILDREN AND YOUNG PEOPLE'S MENTORING SCHEME

In April 2022, we began the process of re-launching our peer mentoring programme in East London so that we can continue to help and support children and young people between the ages of 10-24 who are living with Sickle Cell.

In this time, we have been able to recruit, onboard and train mentors living with Sickle Cell to work with us on this programme. It was and still is important for us to secure recurrent funding for our programme and over the past year, we have been working hard to obtain funding to secure the future of our Sickle Cell Peer Mentoring Programme.

After many months and years of meeting and speaking with commissioners, North East London Integrated Care Board have agreed to fund the programme for a further 12-months (April 2023-April 2024). The next year will be dedicated to onboarding children and young people living in East London to our caseloads and getting them engaged in mentoring. We strongly believe that every child and young person living with Sickle Cell can reach their full economic and social potential with the right support and guidance from mentors on our programme.

Over the next 12-months, we will be working hard to achieve our key performance indicators and show our funders that once again, our programme is proven and successful. By the beginning of April 2024, we are aiming to get the Sickle Cell Society permanent recurrent funding for the programme and hopefully be able to take this innovative programme London wide.

We mostly receive referrals to our service from medical staff, nurses including specialist Sickle Cell nurses and allied health professionals. However, we also take self-referrals parents, carers and wider community workers. Contact mentors@sicklecellsociety.org for referral to the service.



There are currently 51 referrals on our caseload



This year we have attended 12 Engagements



SCS IN NUMBERS



2932

Members of the Sickle Cell Society, including

413 new members.



National Umbrella for over **40**

independent support groups, & voluntary organisations



20

Speaking Engagements during Black History Month 2022 from a variety of organisations nation-wide including churches, museums, prisons, and corporates.



£20,000

Raised during Black History Month 2022



98

young people attended our Children's Activity Holiday.



8

Trustees governing the charity

WE HAVE CONTINUED WITH OUR MONTHLY PARENT TALKS, WHICH ATTENDEES HAVE FOUND VERY BENEFICIAL.

FEEDBACK FROM FAMILIES:

"He was very happy and smiling. He was very excited and was happy for the rest of the day."

"The guest speakers were amazing. They shared useful information. The Q&A was very informative too. I like the fact that they had prepared a resource pack for us to have."

"The event was well organised and speakers were great."

"Great idea to have these workshops. I am really enjoying them. Thank you, I feel like it's very helpful and informative and I only wish I'd had this experience sooner!"

"It was very good to hear about other people's experiences and also how to advocate for yourself."

MEDIA & COMMUNICATION

We continued to work on growing our presence on Facebook, Twitter, Instagram, and LinkedIn. As a result, we have seen a significant increase in social media followers, allowing us to reach out to more people and communities with support and advice, and extend the reach of our fundraising efforts.



The Society's LinkedIn (Sickle Cell Society) gained over

1496
followers



The Society's Twitter (@SickleCellUK) gained over

584
followers



The Society's Facebook (Sickle Cell Society UK) gained over

260
followers



The Society's Instagram (@sicklecelluk) gained over

413
followers



The Sickle Cell Society website received, on average,

17,500 views per month.

www.sicklecellsociety.org

HELPLINE ACTIVITY

TELEPHONE CALL



Total calls for year
**April 2022 –
March 2023:**

452 calls

EMAILS RECEIVED

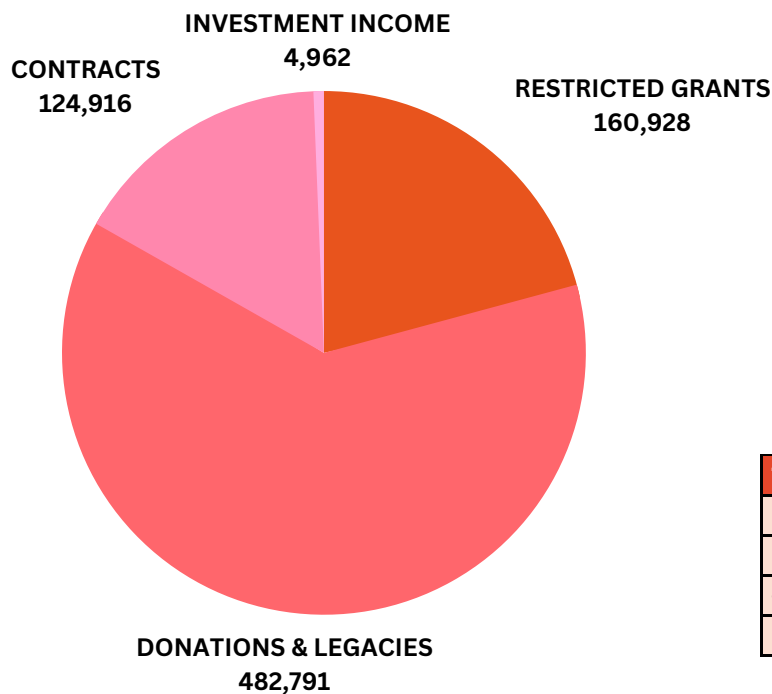


Total emails for year
**April 2022 –
March 2023:**

701 emails

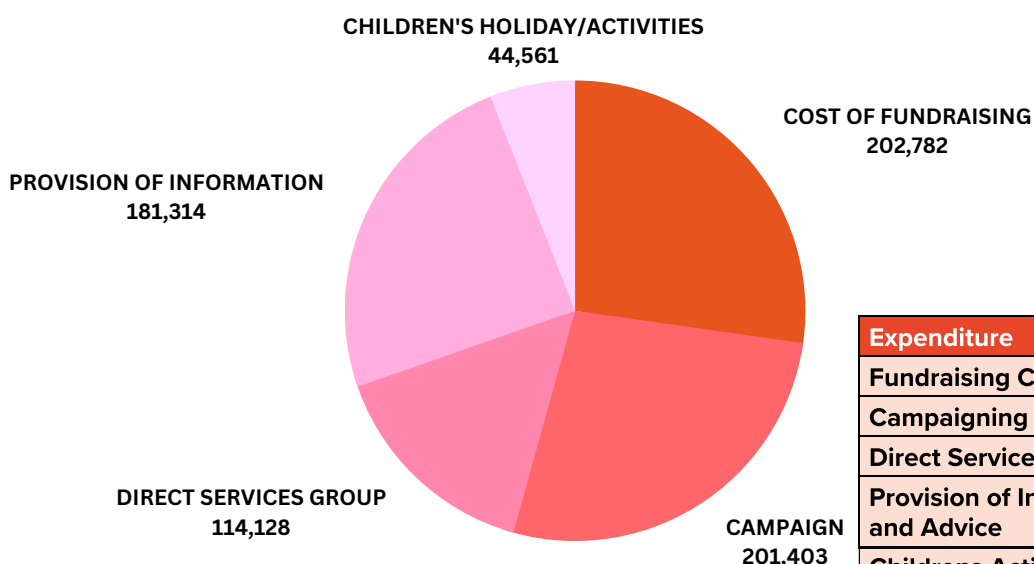
FINANCIAL SUMMARY

TOTAL INCOME



Total Income	£773,597
Restricted	£160,928
Unrestricted	£482,791
Contracts	£124,916
Investment Income	£4,962

EXPENDITURE



Expenditure	£644,188
Fundraising Cost	£202,782
Campaigning	£201,403
Direct Services	£114,128
Provision of Information and Advice	£181,314
Childrens Activities	£44,561



CONTACT US

Sickle Cell Society

54 Station Road
London
NW10 4UA

T: 020 8961 7795

E: info@sicklecellsociety.org

www.sicklecellsociety.org

Registered charity no.
1046631

Sickle Cell Society **Impact Report** 2022/23

@SickleCellSociety



@givebloodspreadlove

#givebloodspreadlove

