SICKLE
CELL
SOCIETY

IMPACT
REPORT
2023 - 2024

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THE SICKLE CELL SOCIETY

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.

We work with health care professionals, pharmaceutical companies, researchers, parliamentarians, parents, and people living with sickle cell to support and advise, raise awareness of the disorder and campaign for improvements in treatments and care.

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 17,500 people, and is the UK's fastest growing genetic condition.

Sickle cell affects the red blood cells, which carry oxygen throughout the body. In people with the condition, these blood cells are shaped like sickles or crescent moons, rather than the usual round and flexible shape. They are sticky and don't last as long as normal round red blood cells, leading to chronic anaemia.

The abnormal shape of the red blood cells can cause them to get stuck in small blood vessels, blocking blood flow and leading to pain and potential organ damage. The painful episodes are known as a 'crisis' and the pain can be severe and result in hospitalisation.

Over time, the disorder can lead to complications such as infections, delayed growth in children, and damage to organs like the spleen, heart, liver, kidneys and eyes.

Other complications include stroke, acute chest syndrome and priapism – a serious condition where there is a prolonged and often painful erection of the penis that lasts for hours beyond or without sexual stimulation. Mental health can also be impacted.

Children with sickle cell disorder are also at increased risk for stroke. The risk is highest between the ages of 2 and 16.

Sickle Cell and Thalassaemia All Party Parliamentary Group meeting, including our staff, volunteers, parliamentarians and representatives from the sickle cell community

WHERE WE MAKE AN IMPACT

We aim to make a significant difference in the lives of people affected by sickle cell disorder. These are the areas we're working in to make that happen :

CAMPAIGNING FOR NEW TREATMENTS

When it comes to the healthcare of people living with sickle cell, significant gaps remain in the research and development of new treatments.

For decades, only one drug was available; now, there is promising activity with new treatments going through the approval process, including a ground breaking gene therapy.

We campaign at the highest levels for more research and faster approval of new treatments, ensuring that the voices of the sickle cell community are included in the process.

BLOOD DONATION

Regular blood transfusions are a key part of treatment for many with sickle cell. Most people have heard of the main blood groups (A, B, AB, and O). However, beyond this there are more specific blood matching requirements for these patients to achieve the best health outcomes.

Given that most people with sickle cell in the UK are of black heritage, we focus on encouraging blood donations from black communities through our '**Give Blood, Spread Love**' campaign to ensure the best possible match for transfusions.

This year we have seen a World's first blood genotyping test being put into use by the NHS, for people with sickle cell. The test makes a DNA analysis of a patient's blood and may allow for more accurate matching for people who need transfusions and help find the best compatible blood for people with sickle cell.

This new service adds to the many improvements we've seen in the NHS sickle cell care pathway since we released the No-One's Listening report in 2021, which highlighted devastating care failings, and was a huge catalyst for change.

Last year we spoke to
1,120
people about blood donation at events

176
people registered to give a blood donation

photo credit : all 3 images Simon Roberts Photography

WHERE WE MAKE AN IMPACT

INFORMATION AND HELPLINE

Our Helpline Service plays a vital role in offering confidential information, guidance, and emotional support to individuals and families affected by sickle cell disorder across the UK.

The helpline team not only support people diagnosed with sickle cell, but also their wider support network, including family members, friends, teachers, employers, and healthcare professionals. We ensure that all aspects of living with sickle cell are addressed, recognising that the wide ranging impacts of the disorder extend far beyond physical health.

By providing access to accurate, up-to-date information and tailored advice, across a wide range of topics, we empower people to make informed decisions about their care and wellbeing. Additionally, the service offers advocacy and signposting to external agencies and support groups, ensuring that users receive the appropriate help and resources beyond our core areas of operation and expertise.

RAISING AWARENESS

Part of our mission is to deepen public understanding of sickle cell disorder and the challenges faced by those living with the condition. By increasing awareness, we help create safer environments for individuals with sickle cell.

We use our social media platforms, our website, newsletters and e news, and work with journalists and with a wide range of valued stakeholders to get key messages about sickle cell out to the sickle cell community, and the general public.

We provide online resources and attend face to face events, talks and conferences all over the country.

Interest in our work extends far beyond British borders, and with the help of overseas conferences and online webinars and podcasts, we attract interest and website visitors from across the globe.

208
countries and territories visited our website for information

photo credit : Simon Roberts Photography

Photo credit : Peter Young

Our Help Line handled
406 calls, and 775 emails

RAISING AWARENESS - PRIAPISM

We launched a campaign on World Sickle Cell Day 2023, to raise awareness of a serious condition which can affect up to 50% of young men with sickle cell. Priapism is a painful erection of the penis, which requires urgent medical attention.

The film, developed in collaboration with Guy's and St Thomas' Hospital, and with the support of Boston Scientific, aimed to raise awareness of the condition, and the need for prompt care when it occurs.

Not only has the film so far resulted in over 368 hours of watch time on YouTube, it also won three prestigious awards at the Association of Medical Illustrators Conference in Nevada in 2023.

42,550,000

Prime Time listeners reached in a radio campaign about Priapism

Award winning animated film about Priapism viewed almost

10,000

times...

...which resulted in

368.5

hours of watch time on YouTube

> As a Sickle Cell Warrior, I know how extremely serious sickle cell disease is and i think this animated short can be very helpful for adolescents who may not fully understand what's happening with their anatomy yet.
>
> Priapism is a very serious matter and any relatable and reliable, awareness brought to that, and of course sickle cell in general, is a good thing.

YouTube visitor comment

RAISING AWARENESS

PRESCRIPTION SAVING CAMPAIGN

In November 2023 we worked with NHS England on a campaign to raise awareness of savings that can be made on prescription charges. People living with sickle cell disorder require regular medication, and those costs can sometimes result in under-use of treatments that are designed to support people's health.

The campaign focussed on making it simple for people to check their entitlements and get helpful information about what they can save and how to access the savings.

MEMBERSHIP AND ONLINE COMMUNITY

We have grown our membership through the year to over 3,000 members, and we aim to return to a regular schedule of newsletter mailings. In the mean time, we have been maintaining updates through our e-newsletters, and enjoying the engagement and direct feedback that has allowed us to have with members.

We grew to

3,005

members in our free membership scheme

We are the umbrella organisation for over

40

independent support groups and voluntary organisations

NHS

If you live with Sickle Cell, you could save money on your prescriptions

Find out if you can get free prescriptions by using the eligibility checker at **www.nhsbsa.nhs.uk/check.**

Sickle Cell Society and NHS prescription saving campaign social media post

WHERE WE MAKE AN IMPACT

CHILDREN AND YOUNG PERSON'S PEER MENTORING PROGRAMME

Young people with sickle cell face unique challenges as they transition from paediatric to adult healthcare services, often taking on greater responsibility for their own health management.

At this critical time, many feel disconnected from their condition and care. Our Children and Young Person's Peer Mentoring Programme offers one-to-one support during this crucial period, starting at age 10 and going into young adulthood. Through this programme we provide advice and guidance as youngsters navigate their health, future plans, and independence.

In previous years, the Peer Mentoring programme only covered London City & Hackney. In the spring of 2023 we received confirmation of 2 years of funding to roll the programme out across London, and further news that we are able to extend the programme to Liverpool, Manchester and Sheffield. During 2024 we will make more progress on these programme developments.

OUR PEER MENTORING PROGRAMME

“Emotionally it has helped me gain confidence in myself-which in turn has helped me put myself out there.”

“The programme has inspired me to learn more about SCD to create awareness in my university and hopefully the world soon.”

“My mentor has been so helpful to me, through working together and talking regularly with my mentor I have gained a better understanding of my condition. Working with my mentor has enabled me to ask questions about my condition and question how to deal with the impact on my life.”

Last year we spoke about mentoring at

16

events across London

110

young people were referred for mentoring across London

WHERE WE MAKE AN IMPACT

FAMILY RETREAT

As well as young people needing one to one support, there is a need for support for the family unit, particularly for the families of younger children living with sickle cell. We provide an annual family holiday to provide advice, support and connection in a fun setting.

Last year we took 29 families from across the UK (everywhere from Newcastle to Bristol) who had one or more children with Sickle Cell, for a Family Retreat at the Pioneer Centre in Shropshire for a busy summer weekend of sickle cell education, adventure activities, networking and fun.

Overall, the families had a fantastic time, and the feedback was overwhelmingly positive. Many told us that the highlight was seeing the children meet and play together, with no one feeling like their family was different. Some families shared that, for the first time, they felt they had a real support network to rely on. Others mentioned that this experience marked a significant turning point for their child. Perhaps most importantly, many families reported that they no longer feel alone.

During the retreat, the families took part in the following activities:
Activity Blitz: Inflatable Challenge, Abseiling, Zip Trek, Archery, Challenge Course
Campfire
Yoga
Mindful Doodling
Fencing
Caving
Hand Massage and Relaxation
Sickle Cell Education
Mindfulness
Sickle Cell Q&A
Arts and Crafts
Team Challenge
Drama
Healthy Living
Sibling Mental Health and Wellbeing
Disco
Family Mental Wellbeing
Parent Session with a Nurse Counsellor
Under 8’s Play Sessions
Board Games

The 2023 Family Retreat :

29
families

37
young people

19
siblings

48
parents

Photo credit : Peter Young

2023 FAMILY RETREAT

“It was a beautiful moment for my family, the teachings, the people, the activities everything was beautiful”

Parent

“The sickle cell holiday helped us get a holiday,....this was my 12 year old son's first holiday get away ever. Thank you so much, the funders and Sickle Cell Society, for making it possible. Thanks to the volunteers who made us feel so comfortable”

Parent

“The best bit was meeting other families just like us. It can often feel isolating as a parent but the retreat showed us we are not alone. We live in an area where we rarely meet other people with sickle cell.”

Parent

“This retreat.....was a marvellous and unforgettable experience.... it was amazing to see my children playing, talking and mingling with other children. The kids were so free because they knew no one would judge or make fun of them....it has boosted their self-confidence...and broadened their horizons. Thank you is not enough for your support, bringing happiness to my family, and providing us with the strength to continue life with the challenges of illness.”

Parent

Photo credit : Peter Young

> **Part of our mission is to deepen public understanding of sickle cell disorder and the challenges faced by those living with the condition....**
>
> **.... through our helpline, online resources, face to face events, talks and conferences.**
>
> *Sickle Cell Society*

photo credit : Dean and Chapter of Westminster Picture Partnership

Our Patron, Dame Elizabeth Anionwu, speaking at Westminster Abbey during the NHS's 75th anniversary celebration, August 2023

WHERE WE MAKE AN IMPACT

SCREENING PROGRAMME

Do you know your sickle cell status?

Part of making sure everyone with the condition has access to the healthcare and support they need, is ensuring that there is equitable access to testing so people know if they are a carrier.

Our advocacy efforts have already led to the successful implementation of antenatal and newborn screening for sickle cell on the NHS in England.

We continue to work collaboratively with the UK Thalassaemia Society, to ensure that families receive test results with sensitivity, and can access the necessary follow-up support. We also raise awareness about how sickle cell disorder is inherited, the importance of testing and how to access it.

Last year we completed a consultation with users of the screening pathway which culminated in the launch of a report; ‘It’s in Our Genes: Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia,’ at a national conference attended by 168 stakeholders.

We also presented the report at the London Maternity and Midwifery Festival 2024 and Brighton and Sussex Medical School’s Anti-racism in Healthcare Conference.

We contributed service user feedback and experiences to the NHS SCT Screening Programme review of their ‘Protocol for Reporting newborn screening results for sickle cell disease and thalassaemia major to parents,’ targeted at health professionals.

We regularly raised awareness of sickle cell and screening in the media, online, in video, at public talks and stalls, webinars and conferences.

Sickle Cell inheritance information accessed

91,109

times on our website

Report launched to an audience of

168

stakeholders

"It's in our genes"

Service User Experiences and Feedback on the Communication of Screening Results for Sickle Cell and Thalassaemia

APRIL 2023
CONFERENCE EDITION

Sickle Cell testing information accessed

38,897

times on our website

WHERE WE MAKE AN IMPACT

CAMPAIGNING, PARLIAMENTARY & POLICY WORK

The Sickle Cell & Thalassemia All-Party Parliamentary Group (SCTAPPG) aims to raise awareness and promote sickle cell disorder and other haemoglobin disorders on the political agenda.

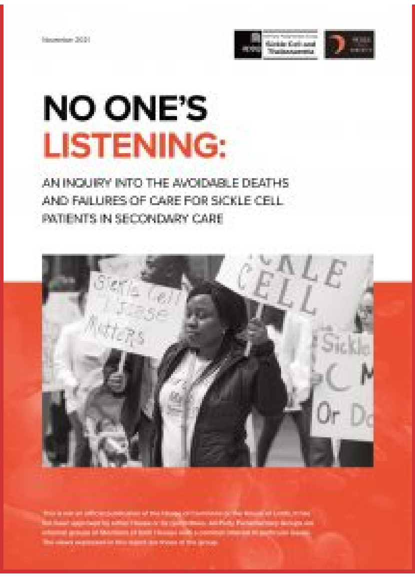
Accountability was achieved through the Group's Chair, Janet Daby MP. We worked closely with the SCTAPPG through our work as secretariat, and with our Parliamentary & Policy Officer.

The Group met regularly through the year, at the Houses of Parliament, and focussed on ensuring that the 'No One's Listening' report recommendations were progressed. The NHS responded to the release of the report with a review of the sickle cell care pathway, and have been working, with our input and support, on the development and delivery of a range of initiatives, with a focus on prioritising emergency care - including :

- Pre-payment prescription certificate campaign, and a review of medication and prescription charges
- Digital Care Plans for people with sickle cell disorder – allowing online access to health records across NHS England, and meaning people can have care tailored to their needs at any location
- Emergency Bypass Units (also known as 'hyper acute units') – allowing people to by pass A&E during a crisis, and go straight to a unit containing sickle cell specialists, available 24/7
- Sickle Cell Acronym – helping A&E staff to have quick access to information and instruction about care for people arriving in a sickle cell crisis
- Patient Cards – to present to ambulance staff and/or A&E staff to show sickle cell patient status, and with guidelines for urgent administration of pain relief on the reverse
- Blood group genotyping test – to improve blood matching for people with sickle cell and thalassaemia

No-One's Listening Report total reach of over

61.5M



November 2021

NO ONE'S LISTENING:

AN INQUIRY INTO THE AVOIDABLE DEATHS AND FAILURES OF CARE FOR SICKLE CELL PATIENTS IN SECONDARY CARE

YouTube video which explains the report has over

73 hrs

of watchtime

CAMPAIGNS - SPECIALIST SICKLE CELL NURSING REPORT

Two years after the release of the No-One's Listening report, in November 2023, we released 'The Difference Between Life and Death' – a new report which highlighted dangerous shortages in the sickle cell nursing workforce in England.

The report presented research which found a disproportionate shortage of sickle cell nurses in the NHS workforce due to decades of underfunding and under-prioritisation.

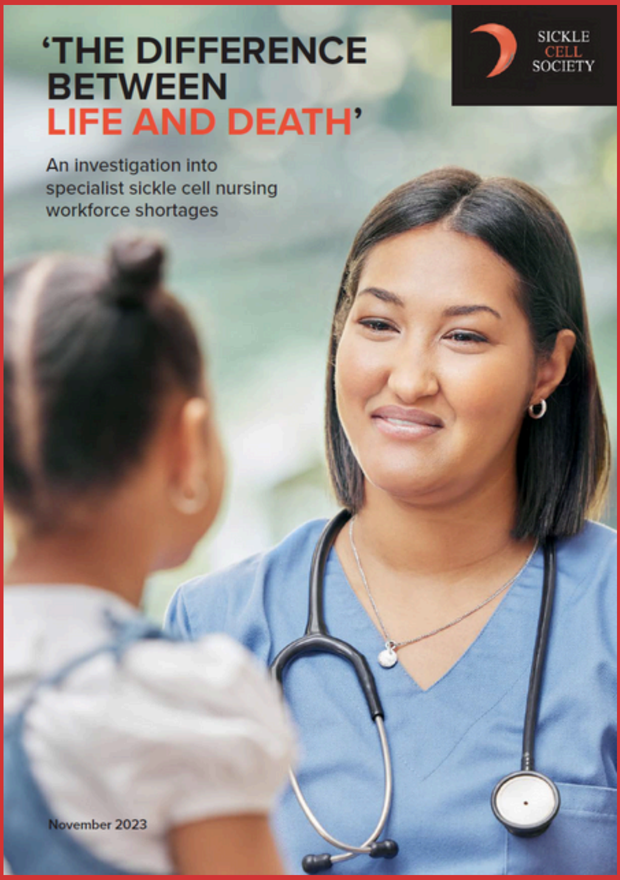
Specialist Sickle Cell and Thalassaemia nurses undertake a wide range of vital roles for sickle cell patients including running and assisting with patient clinics, supporting people presenting at Emergency Departments in sickle crisis and educating and advising colleagues who may not have experience of treating the condition.

The report found an overwhelming consensus among sickle cell healthcare professionals, patients, patient carers, relatives and relevant organisations that there is an insufficient number of specialist sickle cell nurses to deliver a good standard of care to patients. This was supported by our analysis of workforce data which found that, in many parts of the country, there is a lower number of specialist sickle cell nurses than required to enable routine delivery of good care.

The Difference Between Life and Death report highlights that this shortage of specialist sickle cell nurses has a profound impact on patients and their carers, but also on the specialist nurses and their clinical colleagues. In some instances the consequences of the shortage of specialist staff are deadly. Care failings have led to patient deaths, and 'near misses' are not uncommon.

The report found that there are a range of factors which have caused the workforce shortfall including an under-prioritisation of sickle cell among healthcare leaders and, consequently, a lack of funding for specialist sickle cell nurse posts.

We called for the sickle cell workforce to be an urgent priority and given particular attention as part of the implementation of the NHS Long Term Workforce Plan.



'THE DIFFERENCE BETWEEN LIFE AND DEATH'

An investigation into specialist sickle cell nursing workforce shortages

SICKLE CELL SOCIETY

November 2023

Specialist Sickle Cell Nursing Report launch media coverage - total reach of over

9.3M

WHERE WE MAKE AN IMPACT

VOLUNTEERING

We made significant progress with our volunteer programme, particularly after recruiting a Volunteer Coordinator in June 2023.

Key advancements were achieved in areas such as helpline and information support, volunteer engagement, recruitment strategies, social media initiatives, and partnerships with educational institutions and other charities.

While there were some challenges, the overall trajectory is positive. We received 30 new applications, and nearly half of these candidates were successfully onboarded and inducted as SCS volunteers. We are immensely thankful and grateful for all the work our volunteers do for the sickle cell community.

30

new volunteers recruited

357

hours of volunteer support

Volunteer, Brenda, pictured with our Patron, Sir Lenny Henry

OUR IMPACT

INNOVATIVE SOLUTIONS FOR SICKLE CELL AIMED AT ADDRESSING HEALTHCARE INEQUALITIES.

At this year’s Royal Society of Medicine Conference, "Tackling Inequalities: Through Innovation and Entrepreneurship," we were announced as one of only two winners of the Health Inequalities Targeted Call, a competitive initiative by NHS England, the NHS Race and Health Observatory, and supported by the NHS Innovation Accelerator.

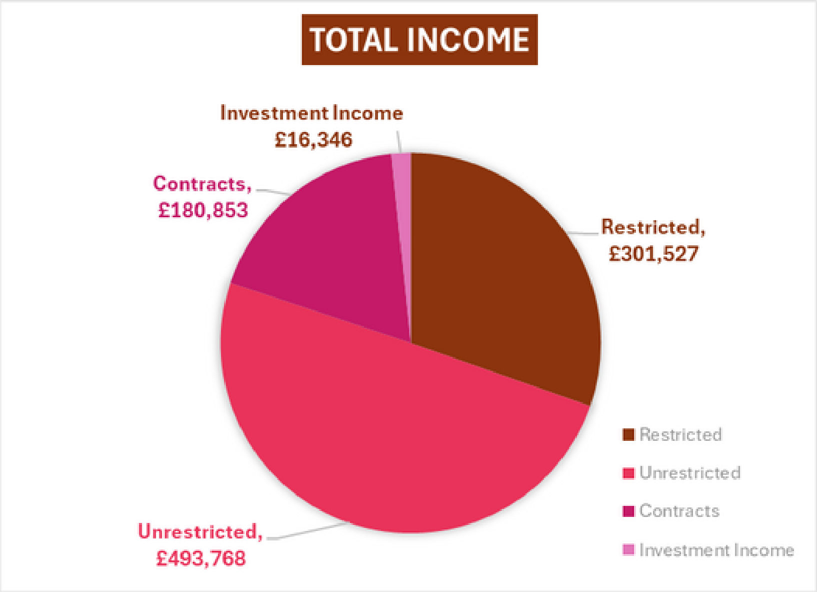
The programme seeks innovative solutions to address healthcare inequalities, and we were recognised for our role as catalysts for transformative change. Our innovative work in tackling health inequalities, particularly through the Children and Young People’s Peer Mentoring Programme, was highlighted as a key example. The programme empowers young people to manage their condition independently, reducing reliance on hospital care and contributing to the broader effort to address healthcare inequalities.

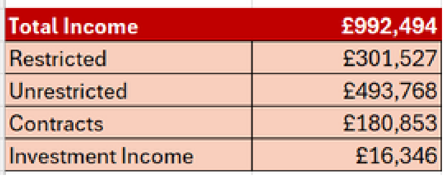
This accolade comes with a support package and funding, allowing us to expand the Peer Mentoring Scheme to support children and young people in South Yorkshire and the North West.


photo credit : NHS England

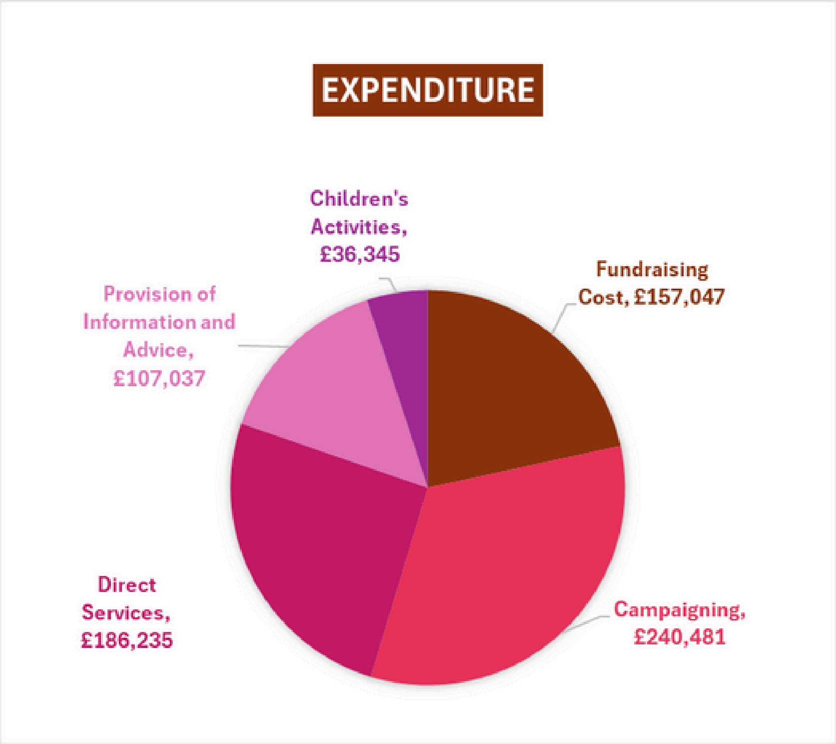
Sickle Cell Society Chief Executive, John James OBE, with Professor Bola Owolabi; NHS England, Konrad Dobschuetz; NHS Innovation Accelerator and Steve Barnett, C2-Ai who were also winners.

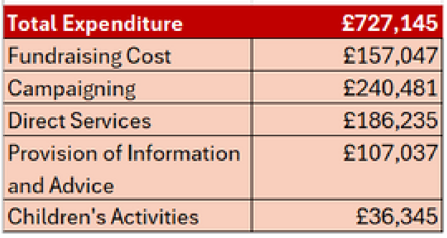
FINANCIAL SUMMARY





Total Income	£992,494
Restricted	£301,527
Unrestricted	£493,768
Contracts	£180,853
Investment Income	£16,346





Total Expenditure	£727,145
Fundraising Cost	£157,047
Campaigning	£240,481
Direct Services	£186,235
Provision of Information and Advice	£107,037
Children's Activities	£36,345

photo credit : Arteh Odjidja

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