

Croydon
Sickle Cell & Thalassaemia
Support Group



25

Anniversary

ANNUAL
REPORT 2022/23

Our mission is constant. To ensure that service providers are aware of and respond to the needs of people living with sickle cell and thalassemia, whether that been in an educational environment or at work.

Sonia Meikle
Chair

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CONTENT

- 02. Excerpt
- 03. Content
- 05. [Team](#)
- 07. [Chairs Report](#)
- 09. [Secretary's Report](#)
- 13. [Events](#)
- 16. [Nurses Report](#)
- 19. [Web Services & Communications](#)
- 23. [Treasurer's Report](#)
- 26. [Member's Statement](#)
- 27. [Thank You](#)

NB: This is a interactive PDF, all underlined text are active links,



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

TEAM

Sonia Meikle . Chair
Annie McDonald . Secretary
Jacqueline Simpson . Treasurer
Junior Nathaniel Small . Web Services
Dr. Mary Clarke . Assistant Secretary
Janine Perry . Young People Group Lead
Chidi Umezurike . Member
Colin Sandiford . Mens Group Lead Lead



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CHAIR'S REPORT

Looking back at 2022/23, I have to begin by acknowledging and saluting the resilience of the management committee in responding to the new demands, driven by coming out from under the cloud of Covid and into the cost of living crisis.

During this time we were fortunate to welcome three new members on to our management committee, each supporting and leading on different areas that we want to progress on.

Janine Perry joins us to support the secretary with facilitating the parent and toddler group and will be leading on reviving our young peoples group. The sickle cell warrior movement across the UK is gathering momentum and we intend to be a part of it. Colin Sandiford joins us to support the treasurer and also to lead on facilitating the mens group. He has a great vision for the direction of the mens group and we will report on that later in the year.

We were extremely honoured to have been selected as one of the Civic Mayor Cllr Alisa Fleming's charities of the year. This meant that we would be recipients from fundraising events that she and her team organised. This set our year off with an inspiring start.

We continue to support our members, their families and carers both remotely and in person through these challenging times. I believe we have successfully moved into the new normal in our service provision.

Our membership has increased steadily through the year to over 300 members aided by a greater presence through our social media interaction, enquiries and requests for support. We took part in an awareness day hosted by Croydon University Hospital and contributed to an awareness session hosted by Croydon BME. Our team carried out presentations to several schools around the borough, talking to students about sickle cell and thalassaemia and how they can help fellow students. The teachers provided feedback and found the information very useful. We have since received a number of direct referrals from teachers and parents asking for assistance and information.

Our mission is constant. To ensure that service providers are aware of and respond to the needs of people living with sickle cell and thalassaemia, whether that be in an educational environment or at work.

Sonia Meikle
Chair

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CHAIR'S REPORT

Summary of work completed

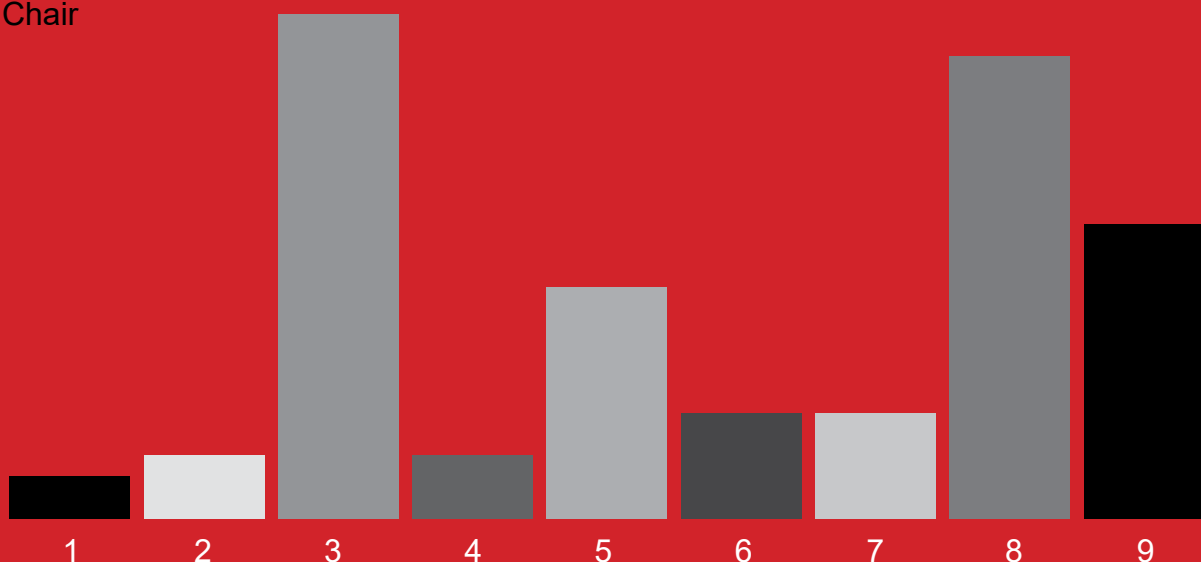
1. Assisted 2 households to move home
2. Supported 3 households to challenge housing decisions
3. Supported 24 members with welfare benefits advice to maximise their income
4. Supported 3 members to successfully challenge/appeal benefit decisions
5. Facilitated 11 support group meetings
6. Facilitated 5 men's group meetings
7. 5 sickle cell/thalassaemia awareness presentations
8. 22 Christmas hampers prepared and hand delivered
9. 14 members provided with thermal winter clothing

As we move into the next financial year, we are seeking to build on the amazing foundations set up by the founder members of this support group. This year's World Sickle Cell Day will coincide with our celebrating 25 years of the opening of the Croydon Sickle Cell and Thalassaemia Centre on Whitehorse Road.

The space has undergone some transformation to ensure that it continued to be fit for purpose and supported our co-location with the Clinical Nurse Specialists (CNS). Our continued partnership with the CNS is mutually beneficial for both teams but more importantly to the patients and members that we serve. We would like to thank the CNS and business support officers that manage the smooth running of the centre so seamlessly.

Sonia Meikle

Chair



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

SECRETARY'S REPORT

We were delighted that Annie and Mary were able to work together as Secretaries of the Croydon Sickle & Thalassaemia Support Group during a challenging few years of restrictions, imposed during the COVID-19 pandemic. These restrictions required us to change the way we worked, with most meetings held on line to protect us all. However, these online meetings did enable us to keep in contact with many of our members during the monthly support group meetings.

We heard from guest speakers and also had regular updates on the welfare benefits system and health issues, as well as helpful insights from the Sickle cell Clinical nurse specialists. Sonia Meikle our Chair, continued to work tirelessly on behalf of the group and even succeeded in delivering food parcels and Christmas hampers during the winter period.

Now that the office is open, we can again be the visible face of the group and provide the personalised help and advice that we love, front of house.

The Support Group has continued to work closely with the Clinical Nurse Specialists. There is real benefit to the Support group that we are co-located with the nurses', as this facilitates a good working relationship and communication between the Nurses and the Support Group, for the benefit of our members.

We would like to warmly welcome two new members of the Management Team, Janine Perry and Chidi Umezurike. They bring with them knowledge and a desire to help those living with sickle cell and thalassaemia. Janine will help to re-establish the group for young people living with sickle cell and thalassaemia and also to support the Parent and Toddlers Group. Chidi brings a wealth of corporate knowledge which is so important in the charity sector.

The Group have had the great honour of being chosen as one of the Civic Mayor, Rt. Honorable Cllr Alisa Fleming's three charities for the year 2022-2023.



F A V O R I T



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

SECRETARY'S REPORT

Christmas Hampers

These continue to be made up by the group and in December 2022 Sonia delivered twenty hampers to families

School Visits

The group is keen to continue providing support for school children with sickle cell and thalassaemia and their parents. We have been invited to schools to give talks about living with sickle cell and thalassaemia at The Norwood School and St Cyprian School.

Website

Our website underwent an overhaul and is expertly designed and maintained by Junior Small. Here you can find useful Information about events within the group and topical related updates.

CSCATSG merchandise including mugs and sweat shirts are available to purchase and all funds raised go towards funding the services we provide. You can also complete your membership of the group and donate to the group securely on line using PayPal and JustGiving.

Finally, we would like to thank Lynette Heywood who has helped prepare the much needed hospital packs to be delivered to members admitted to hospital. Lynette has also contributed to the conversations with people with sickle cell who drop into the office to see us. We would also like to thank Tina Reeve who knitted hats and clothes for babies to add to the parent and Baby Packs provided by the group to mothers with a new-born baby with sickle cell or thalassaemia.

Thank you to the British Museum who continue to invite the Group to community pre-views of its new exhibitions

Annie and Mary wish to thank our Support Group Management team and The Specialist clinical nurses for their continued support working with us.

Annie McDonald

Secretary

Dr. Mary Clake

Assistant Secretary



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

EVENTS

Patient Public Voice Group - Monthly

This group is part of West London Haemoglobinopathy co-ordinating Centre (HCC) and is chaired by Patrick Ojeer. At present it is attended by Sonia Meikle and Mary Clarke from the support group but the HCC warmly welcomes any members who would like to have the opportunity to influence the delivery of sickle cell care in West London NHS to participate.

St Georges Red Cell Awareness day 10 June 2022

The Phoenix Centre St Georges Hospital

This meeting was hosted by the St Georges pain team and psychology team. It included medical talks, relaxing massages were on offer from Full Circle and also demonstrations of making easy healthy salads.

Performing Arts BRIT School 05 July 2022

Teachers and students from the BRIT school. The meeting was held to discuss refreshing the art work on the Centre's windows, which was originally carried out by students from the Brit School.

The Association of Guyanese Nurses 27 August 2022

St Stephens Church Thornton Heath

The Support Group was invited to have a stand at a fair held at St Stephens Church to support fundraising by the Association of Guyanese nurses. Lynette Heywood, Annie McDonald, Jackie Simpson and Mary Clarke.

Crystal Palace Charity Football Match 17 September 2022

John Fisher Sports and Social Club

Sonia & Junior attended a fundraising event for the group arranged by YABAC

House of Commons All Party Parliamentary Group

(APPG) SC 17th October 2022

Portcullis House

The APPG meeting was held to discuss the findings of their report with the Sickle Cell Society entitled 'No one is listening'. This report followed the investigations into the Preventable death of Evan Nathan Smith in 2019

Also discussed was the provision of the Red Cell exchange transfusion Apheresis service for sickle cell. The emphasis was on staffing levels and the importance of the lack of availability of suitable blood from donations, limiting the availability of the service. Representatives of The NHS Race & Health Observatory also attended. Their aim is to tackle ethnic health inequalities.

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

EVENTS

They reported to the group about looking at the management of acute Sickle cell in the accident and emergency department. The observatory has also appointed a clinical advisor for Sickle Cell, Dr Carl Reynolds who is a respiratory physician at Imperial College.

Meeting with Croydon Councillors 25 October 2022

Civic Centre Mayors Parlour

Members of the management committee met with councillors to discuss the aims and objectives of the support group.

The Mayors Valentine's Reception 14th February 2023

Braithwaite Hall, Croydon Town Hall

The first of three fundraising events organised by the Civic Mayor to raise funds for three charities for the year in term.

Dinner and Dance Fundraiser 24th February 2023

The Grand Sapphire Hosted by Civic Mayor Alisa Flemming

Digital Skill Workshop 11th - 14th April 2023

Facilitated by AMITY Youth Group Sponsored by Croydon Council

The Association of Guyanese Nurses 27 August 2022

St Stephens Church Thornton Heath

The Support Group was invited to have a stand at a fair held at St Stephens Church to support fundraising by the Association of Guyanese nurses. Lynette Heywood, Annie McDonald, Jackie Simpson and Mary Clarke.

Guyana Lodge – Ladies Night 15th April 2023

Holiday Inn Regents Park

The Worshipful Master Oswald Dickens and his wife hosted a wonderful fund raising dinner and dance with invited guest Sonia Meikle, Junior Small, Annie McDonald and Jackie Simpson

Support Group Hosted Events

Film screening 'His Sickled Journey' 19 June 2022 CACFO

This film was a warm-hearted romantic comedy, exploring some of the more serious issues around living with sickle cell in a relationship. It was produced in collaboration with the NHS Blood and Transplant service. The director, Phil Ossai along with some of the actors and crew, took part in Q & A after the show given some insight into why the film was produced.

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

EVENTS

Sponsored Walk 9th July 2022

Crystal Palace Park This enjoyable annual event continues to raise money for the group and raise awareness about these diseases for members of the public also using the Park

Sickle Awareness and Information Event 11 October 2022 Croydon University Hospital (CUH)

The group was invited to hold an information stand about sickle cell disease and thalassaemia. This was situated in the main entrance hall of the Croydon University Hospital. Many members of the public stopped to ask about the conditions including doctors, nurses and other health care workers as well as Dr Stella Kotsiopoulou consultant haematologist and Deputy Chief Executive Dr Subhro Banerjee.

Restart Scheme Office 17 October 2022

Norfolk House

The group was asked to provide information about Sickle Cell for a table top display for the staff in the restart scheme office in Croydon. The aim was to increase staff awareness

Audience with our Elders Black History Month held at CACFO 22 October 2022

An informative and powerful evening with a panel of speakers sharing their experiences on coming to live in England. The Civic Mayor Alisa Flemming attended. The panel members were Pastor Oliver, Shirley Martin, Ade Sawyerr and Cynthia Antoine.

The Croydon CANCER Conference 2022 Wednesday 30th November

CAN YOU C ME? Saint Mary's Conference Centre Croydon

Hosted by Croydon BME Forum Attended by Annie McDonald and Lynette Heywood

Christmas Party for Children 17 December 2022

St Albans Church Thornton Heath a rather cold day there was a cheerful welcome with games and toys for children

Wellness Event 28 March 2023

Whitgift Centre

The group was invited by Croydon BME to give a talk about the health impact of living with sickle cell. The presentation was provided by Sonia Meikle and we had an information stand about the group and the services we provide.



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

NURSES REPORT

The Clinical Nurse Specialists (CNS) and the administrative team continue to work collaboratively with the Croydon Sickle Cell & Thalassaemia Support Group (CSCATSG) providing a unique service for the caseload of 750 patients and their families who reside in Croydon. Patients and families who reside outside the borough also access the service. This is beneficial for these patients and families who live in areas where a specialist service for sickle cell and thalassaemia is not available.

CSCATSG continues to be a valuable resource within the community through other various activities. Therefore, focus is not solely on the condition the patient suffers from but with access to other activities that provide an outlet for enjoyment such as the annual Children's Party and excursions.

The CNS's have attended the monthly meetings, which have provided lively discussions with opportunity to conduct talks, network and signpost. There is also the opportunity to update on topics relevant to the patients' health and wellbeing. An example of this is the new drug, Crizalizumab, which has recently been given to patients at CUH. Our intention is to give some feedback on the patient experience with the intention to support informed choices for other patients who are eligible to have this drug. Covid has changed some of the ways in which care is delivered. However the onset of Covid means we have become more 'tech savvy' with the zoom meetings which have served to reach a wider audience and as a result at times more than 1 CNS's is able more able to attend.

Educational Toddlers Group, which CSCATSG also support, will be relaunched with primarily starting the newer parent having access. The initial links continued with the parents following receipt of the welcome 'Baby Pack' from CSCATSG. Parent enjoy having direct access to CSCATSG to explore wishes and feeling around sickle cell disease. CSCATSG members Annie and Jackie provide information on the lived experience with sickle cell disease and being a parent for a child with sickle cell disease. Practical advice from the group such as links/signposting to others whilst providing opportunities for befriending. Our intention for this year will involve inviting other speakers e.g. a representative from the Sickle cell society to give a national perspective of sickle cell disease.

Welfare right advice support through benefits system are an integral part of care for some patients to help them achieve their full potential therefore improving their quality of life. Patients tend to find it extremely difficult to navigate the various benefit forms. Positively referrals made by our service to the support group has been beneficial for patients. This allows for the delivery of a systematic approach to deciding which benefits they are eligible for; completing the relevant applications and where necessary support any appeals. Where necessary there is also sign posting to other relevant sources such as food banks and funding for e.g. tuition

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

NURSES REPORT

The adult patients welcome the hospital visit from the support group. The patients appreciate and the CNS's have enjoyed participating with fundraising activities such as the annual sponsored walks. Ensuring accurate and up to date information through awareness events are also an essential part of the service. These help to dispel myths and provide information about sickle cell disease and thalassaemia. There will be a joint awareness at Croydon University Hospital on World Sickle Cell day 19th June.

The team value the work CSCATSG do, it is a pleasure to continue to work collaboratively with the group.

Carol Edwards
Clinical Nurse

A L I S

FIELD NOTES

48-Page Memo Book
Durable Materials / Made in the U.S.A.



SALISBURY DISTRI

WEB SERVICES & COMMUNICATIONS

I joined the team officially over seven years ago. As a small self-contained group, ambidexterity comes with our roles. Initially I was helping out where I was needed setting up for events and creating poster/flyer artwork designs for events which was rewarding for me, as I had a background in interior design and digital media design.

Two years later I spoke with the team about the benefits of having a website and it was agreed that I would create and build a company website in addition to branding the organisation. Your website and your social media platforms are your organisations first point of contact, I would state the website is the most important. This is where a more detailed account of the organisations ethos, mission and vision are outlined, for this reason it is important the website looks professional and your brand is identifiable. This is extremely impactful when executed properly.

Several years on, the website remains a valuable asset as a portal in providing information about sickle cell disease and thalassaemia. The useful links tab, provides information on [FACTSHEETS](#), [Government support](#), [PiP](#), [DWP](#), [NHS](#), [Welfare Rights and Pharmacies locations](#). In addition this is where we sell our [merchandise](#) and list our events. Our supporter and sponsors can donate freely and importantly securely. The website is user friendly in design and easy to navigate.

This year's web stats are refreshing! From the data capture it is clear that traffic to the website is from a number of sources globally. We have had website visits from numerous locations, ranging from some of the most unlikely locations in the world, with the average page duration of 6 - 8 minutes. Here in the United Kingdom across London we had captured website visits from over 104 towns and cities, demonstrating the groups appeal reaches much further than its local boundaries of Croydon. ([Please refer to the list on the other page](#))

Moving forward

- Website new automations forms to help with workflow
- New business telephone service to manage calls, messages and transcripts
- Updated members form for added security complying with GDPR regulations

Junior Nathaniel Small

Digital Media Design & Web Services

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CITIES & GLOBAL LOCATIONS

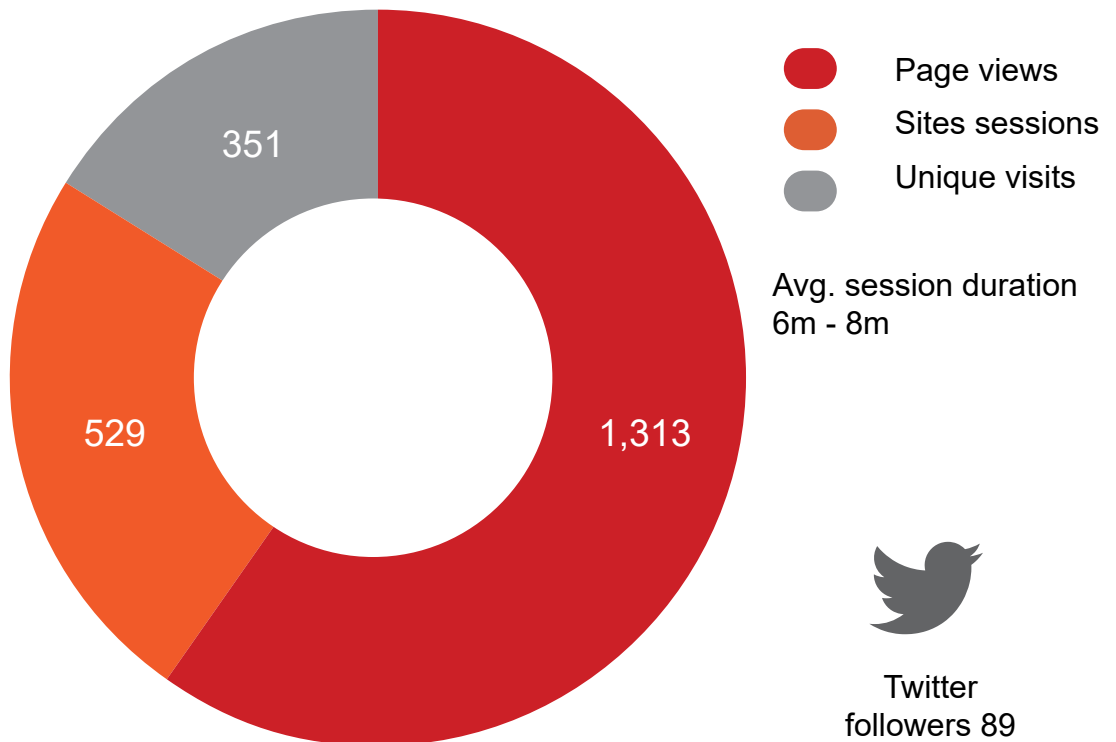
City

Aberdeen	Dulwich	Las Vegas	Este
Abuja	Durham	Leeds	South Norwood
Accra	Ealing	Leicester	Southwark
Acton	Edmonton	Lewisham	Stoke-on-Trent
Ahmedabad	Enfield	Lisbon	Streatham
Amersham	Erith	Liverpool	Surbiton
Anerley	Ernakulam	London	Sutton
Antalya	Ferndown	Los Angeles	Telford
Balham	Finchley	Lusaka	The Villages
Banbury	Glasgow	Luton	Thornton Heath
Bardsley	Grays	Manchester	Tonbridge
Barnet	Greenford	Miami	Toronto
Beacon	Greenwich	Middlesex	Twickenham
Beckenham	Hackbridge	Middletown	Utrecht
Belvedere	Hackney	Mitcham	Wakefield
Berlin	Hammersmith	Morden	Wallington
Bexleyheath	Harlow	Nairobi	Walsall
Birmingham	Harrogate	New Cross	Walthamstow
Bolton	Harrow	New Malden	Warlingham
Bordon	Hatfield	Newbury	Watford
Bridgend	Haywards Heath	Northolt	West Bromwich
Brierley Hill	High Wycombe	Oldbury	West Ealing
Bristol	Horley	Oxford	Wimbledon
Bromley	Hounslow	Plainfield	Windsor
Calgary	Hyderabad	Pleasanton	Wolverhampton
Carshalton	Ilford	Purfleet-on-Thames	Worcester
Catford	Iligan City	Purley	
Charlotte	Isleworth	Rainham	
Chesterfield	Islington	Raynes Park	
Chippenham	Kempston	Reading	
Cippenham	Kensington	Richmond	
Clapham	Kidbrooke	Rio de Janeiro	
Crawley	Kingston	Rochester	
Croydon	Kingston upon	Roseau	
Dagenham	Thames	Royal Leamington	
Dammam	Lagos	Spa	
Dublin	Lambeth	Santo Domingo	

WEB SERVICES & COMMUNICATIONS

Country

- Brazil
- Canada
- Country
- Dominica
- Dominican Republic
- Germany
- Ghana
- India
- Ireland
- Jamaica
- Kenya
- Netherlands
- Nigeria
- Philippines
- Portugal
- Saudi Arabia
- Turkey
- United Kingdom
- United States Zambia





Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

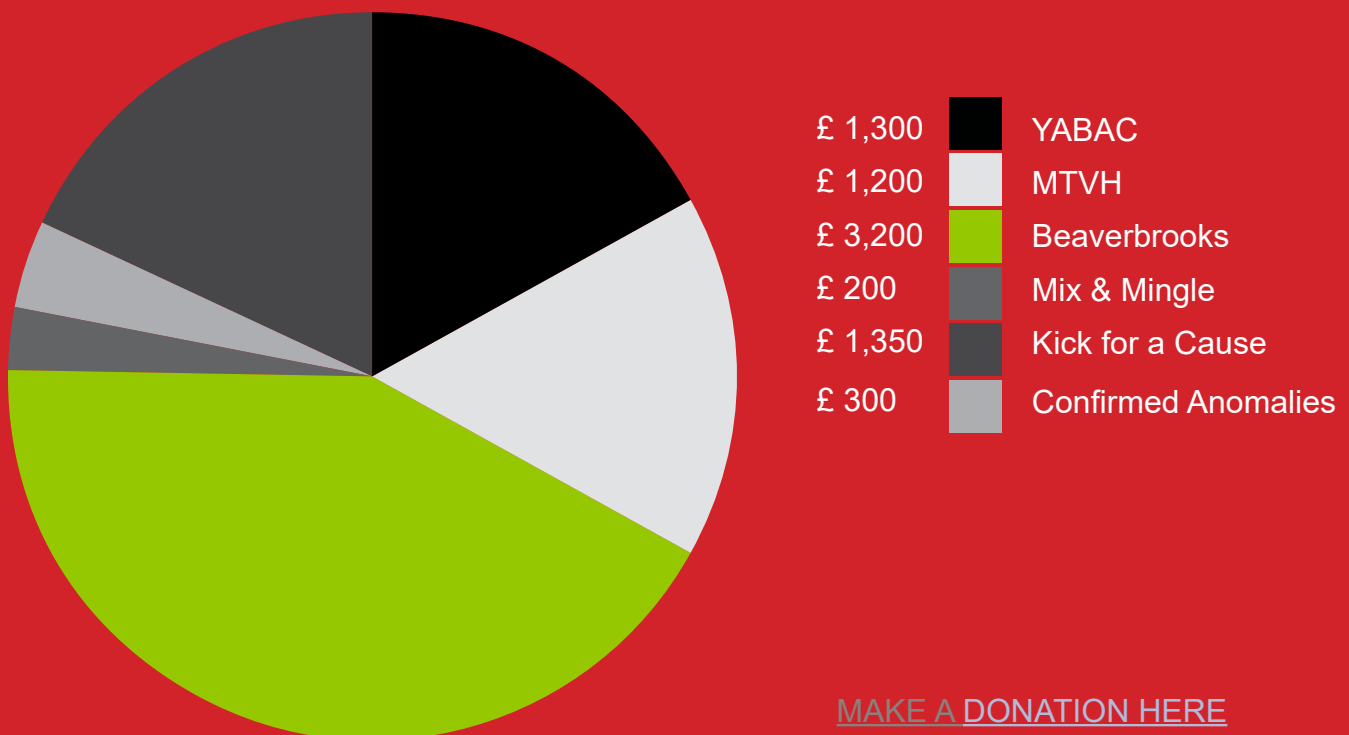
TREASURER'S REPORT

We are really pleased to be able to report that despite the cost of living crisis unfolding around us this year, members of the public have continued to support us with donations and organising fund raiser events. This has allowed us to continue providing all the services we offer.

Many thanks to all our regular donors through PayPal and JustGiving

Jacqueline Simpson
Treasurer

We are still winding down accounts for 2022/23. Here is a summary of our accounts which will be published in full by 31.5.2023

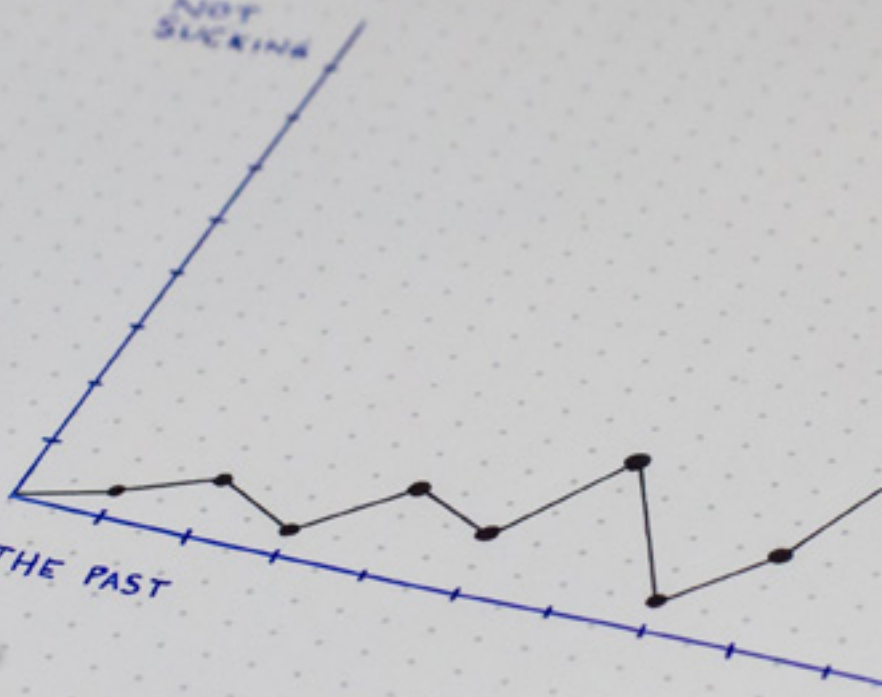


[MAKE A DONATION HERE](#)

NOT
SUCKING

SUCKING

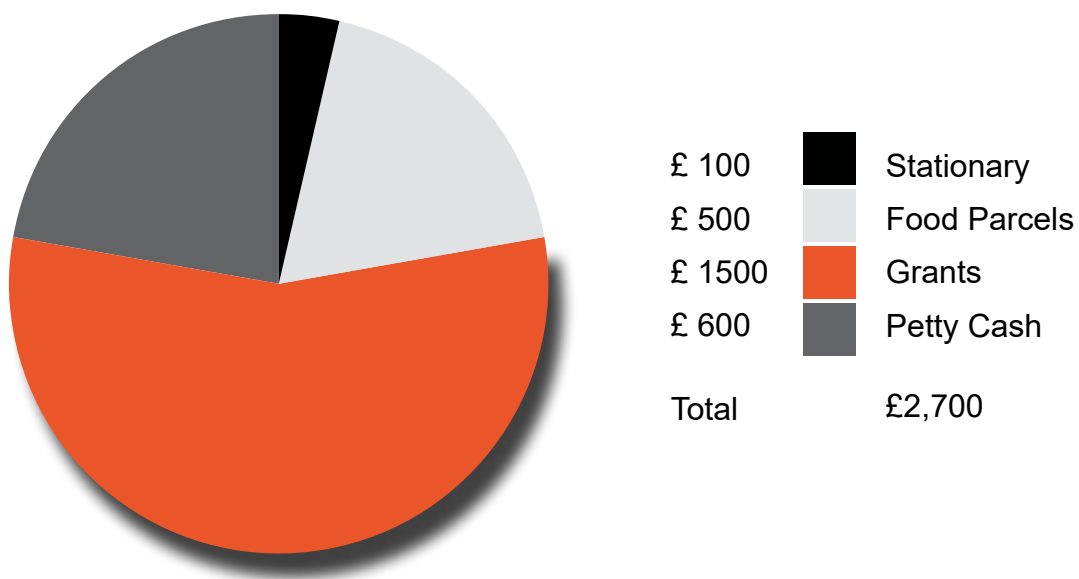
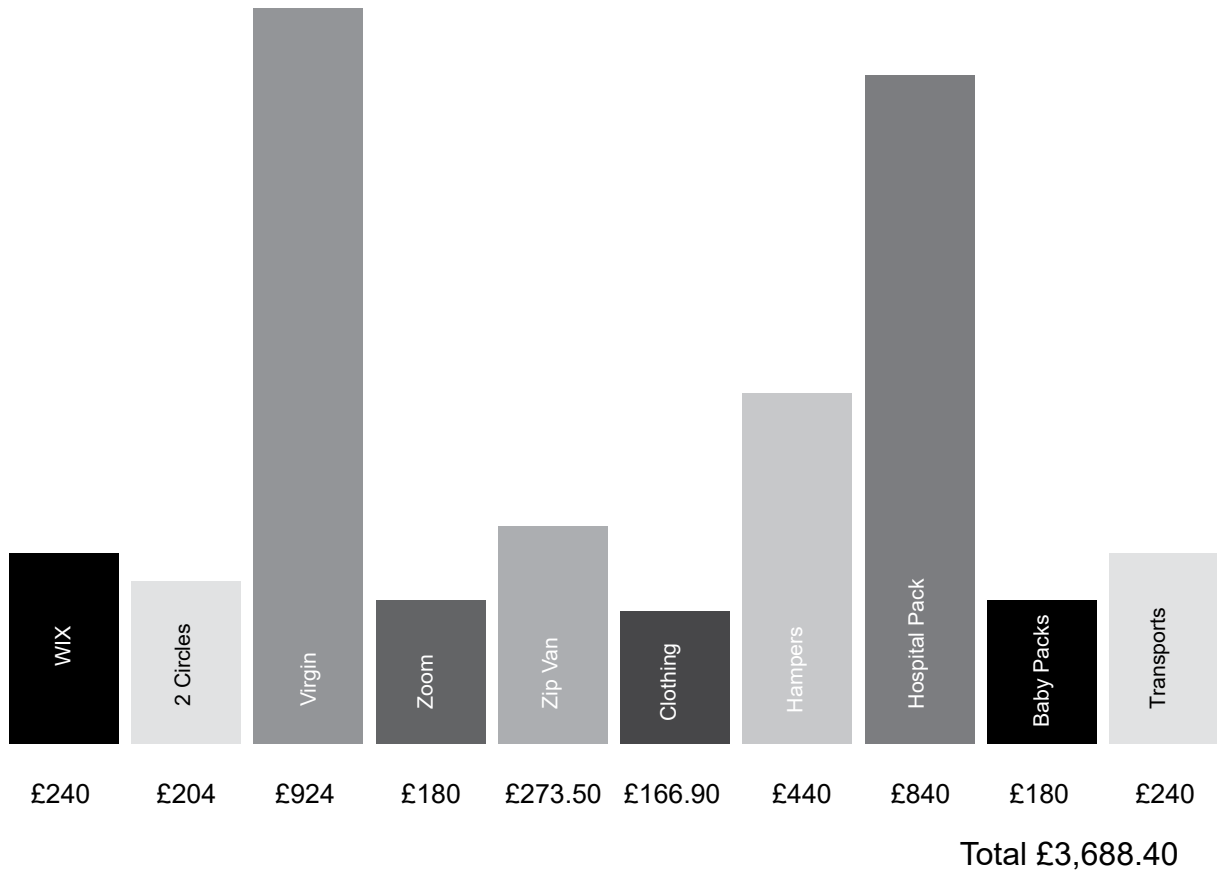
THE PAST



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

TREASURER'S REPORT



[MAKE A DONATION HERE](#)

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

MEMBER'S STATEMENT

Hello everyone and hello support group. I just want to use this medium to say thank you for the wonderful work the support group are doing. I am a mother with a sickle cell child. For me, I bear the burden as much as my child does. The group has lightened that burden. The burden of mental torture, the burden of not knowing what to do and also teaching me to act at the right time in order to alleviate the problem. It cannot be eradicated completely but, at least it goes a long way to do justice to this disease called sickle cell.

The people in the support group are wonderful, they are wonderful ladies and gentlemen. Some of them do not have sickle cell but still they take time to support and help those who are living with the disease. People like Annie and Jackie, even with the pain they are going through, they still go out of their own way to help the little children living with this disease.

I remember one day, I dashed out of my house, rushing my child to the hospital. At that time it never occurred to me that he might be admitted. All I wanted was to get my child to the hospital to get the medical care needed. I went with nothing. Not even a bank card because the ambulance came for us. I wasn't thinking how I am going to get back. Sometimes you rush out without even a toothbrush or a little token on you. But the support group will always come to my assistance and to the assistance of others that call on them. In this kind of situation, Jackie and Annie are wonderful. They will ring you, ask you if you need anything and if its within their limit, they will do it and get it across to you. They need to be appreciated and that is why God is keeping them and giving them long life and I believe that the young children they are taking care of will pray for them and will bless them.

Thank you sickle cell group. Keep up the good work. And for those who are not nurses like Dr Mary, a wonderful lady. These people contribute to our well-being without monetary value. Therefore, they need an applause. They need to be appreciated. They need kisses and hugs because they are wonderful.

With all these people around, I feel I can help my child. I am happy because I am within this environment where I can reach them. At one point I wanted to live outside London and I checked and this help was not there. I decided I had stay in London because I do not wish to miss this wonderful community. Thank you support group and God bless you all.

Emily Ezeh
Member

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

THANK YOU

Unite the Union
Home Office BAME Team
British Museum Community Team
Hugh Clarke
LA Carr
Beaverbrooks
YABAC

Croydon Health Services NHS Trust
Charlotte Palmer, Lauren Devaney
Dr. Stella Kotsiopoulos

Mix and Mingle
MTVH
Guyana Lodge
Consolidate Anomalies
Cllr Alisa Fleming
Cllr Carlton Young - CACFO
Croydon BME
Brett Tomlinson - Cherril Print
Professional Ladies

Specialist Clinical Nurses
Linda Sawyerr, Paula Lindo, Carol Edwards
Thank you to all our fundraisers and donors

JOIN OUR COMMUNITY

Special Acknowledgements

Lynette Heywood - Oldest resident of Croydon living with Sickle Cell

Founder Members/Supporters

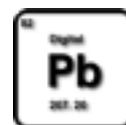
Nancy Banton - Health Visitor, Christine Williams - Nurse specialist, Alberta Salmon Health Visitor, Maggie Mansell MP, Malcolm Wickes MP, Beulah Skeete - Health Visitor, James Cummings, Bishop Wilfred Woods of Croydon 1999

Photo by: Kier in Sight (1) Nathan Dumla (4) Ignacio R (6) Florian Klauer(10) Nicole Fahey (12) Mat Napo (16) Annie Spratt (18) Micheile Henderson (22) Isaac Smith (24)



**Croydon
Sickle Cell & Thalassemia
Support Group**

316 Whitehorse Road
Croydon CR0 2LE
t: 020 3859 5441
m: + 44 (0) 7305 953 422
Charity Number 1100120



Design by
Junior Nathaniel Small/
Digital Pb.
www.juniornathanielsmall.com