

Croydon
Sickle Cell & Thalassemia
Support Group



**ANNUAL
REPORT 2019/20**

We remain particularly proud of our continuing partnership with the Specialist clinical nurses at the Centre, who refer members to us for support. This has helped us to work towards preventing homelessness, financial distress and allows us to provide timely advice and **advocacy to our community.**

Sonia Meikle
Chair

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CONTENT

- 04. Testimonial
- 05. Team
- 07. Chairs Report
- 11. Secretary's Report
- 13. Assistant Secretary Report
- 16. Nurses Report Data
- 17. Branding & Communications
- 20. Treasurers Report
- 25. Thank You

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

TESTIMONIAL

When I moved to South Norwood, a friend recommended I visit Croydon Sickle Cell and Thalassaemia Support Group as he had heard good reviews about them.

My intention was to volunteer my time to assist where I can. However, from the first introduction with tea and biscuits, I was made to feel like family. I was introduced to other staff and was made aware of the outstanding work and support offered. I remember being told that the next group meeting is the Coffee Mornings and it was a few days away. I attended and here I met some of the other members and staff. A few weeks later when the weather changed to winter, I was invited to another meeting where I was given a winter kit - which included some thick winter sweaters and blankets plus other useful materials. A while later when I was feeling unwell,

Annie and Mary went through a lot of effort to get a care pack to me - this included things such as toothbrush, toothpaste, face wash and everything to keep fresh whilst in pain. It's the little things like these that allow for good recovery. When the group has not heard from me in a while, I can expect a phone call to check on my wellbeing.

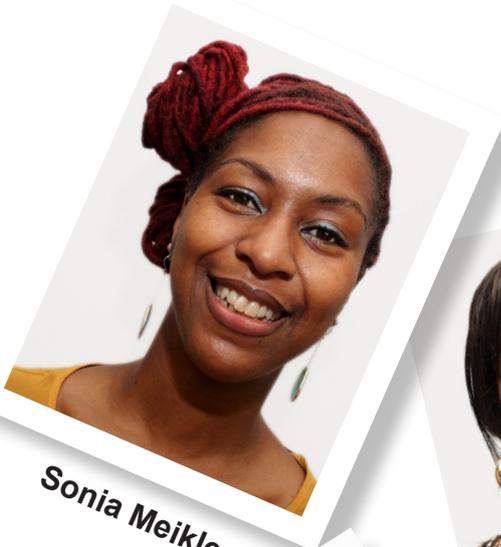
If I had not made contact with Croydon support group when I moved in to the area, settling here would have been more difficult. I cannot begin to count or mention the many ways this group has been of value to me and I am forever grateful

Solomon Popoola

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

TEAM



Sonia Meikle



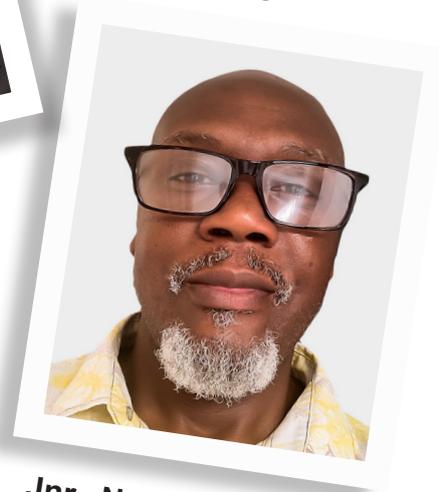
Annie McDonald



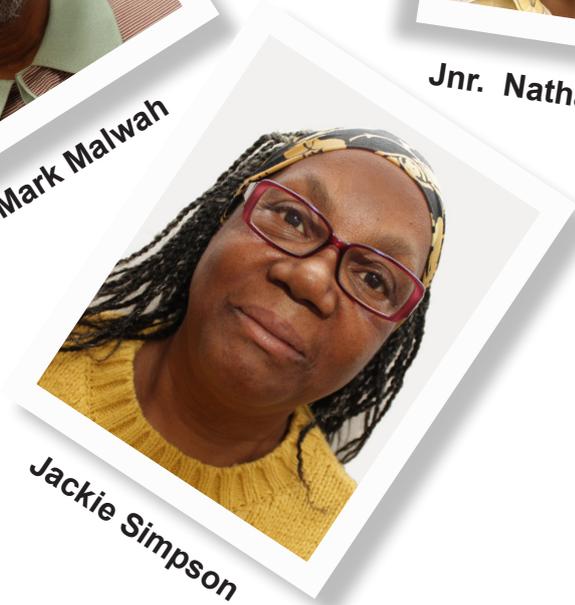
Dr. Mary Clarke



Mark Malwah



Jnr. Nathaniel Small



Jackie Simpson



COVID-19
Coronavirus
Vaccine
08/15-2020-290v217

Coronavirus
Vaccine
08/15-2020-290v217

Co
V
08/15-2020-290v217

19
s

SARS-CoV-2
COVID-19
Coronavirus
Vaccine
08/15-2020-290v217

SARS-CoV-2
COVID-19
Coronavirus
Vaccine
08/15-2020-290v217

SARS-
C
08/15-2020-290v217

19
s

SARS-CoV-2
COVID-19
Coronavirus
Vaccine
08/15-2020-290v217

SARS-CoV-2
COVID-19
Coronavirus
Vaccine
08/15-2020-290v217

SARS-
C
08/15-2020-290v217

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CHAIR'S REPORT

2019/2020 has been an exceptionally extraordinary year for the support group. COVID-19 put the UK into lockdown restrictions that were unprecedented. My thanks to the management committee and volunteers who rose to the occasion and have worked tirelessly to ensure that the group continued to fulfil its obligations and objectives as a charity.

We had to suspend all activity at the centre. However, despite this, we worked hard to respond to the needs of our members, moved the majority of our services and access online and our membership has continued to grow throughout the year.

Our membership is varied and broad. Hosting online meetings meant that we had to take some time to ensure that our members were comfortable with using digital platforms. We conducted a survey and established that if we provided clear instructions and took the time to walk beginners through the process, we could all connect effectively. We have now held four successful group meetings through zoom.

Summary of the topics and presentations

Dec 2020 COVID-19 This was to update the group about the effect of COVID infections, especially for those living with sickle. The importance of the coronavirus spreading by droplets from coughing and sneezing was highlighted. The data about the number of people with sickle getting COVID was being collected in centres in the US UK and France. Some early data showed that there was an increase in the death rate in those getting COVID but not perhaps as much as had been initially feared.

Feb 21 Oxybrya (voxeletor) This was the first in a planned series on treatment of sickle 'old and new' ! Oxybryta is a new tablet treatment for sickle cell. This is one of several exciting new treatments becoming available which actually tackles the sickle process itself and not just the symptoms. It does this by interrupting the process of haemoglobin becoming 'sticky' and making polymers and so damaging the red cells.

Mar 21 Hydroxycarbamide This looked at an old and trusted drug which works well for sickle . However there is sometimes reluctance to use it. After looking at what hydroxycarbamide does, this reluctance was explored with an illustration case of a young woman with sickle. She valued natural methods such as diet and healthy lifestyle but on becoming a mother reappraised her views. She restarted hydroxycarbamide not just to reduce the pain episode and acute chest syndrome, but to reduce organ damage from sickle cell and so help to prolong her life and remain fit for any future treatment breakthroughs

CHAIR'S REPORT

Apr 21 Infection in Sickle Cell This looked at the high risk of infection in people living with sickle cell. The risk of infection was increased by the loss of the spleen as seen in most people with sickle from an early age was explored. The danger of infections was highlighted as contributing to the sad death of Evan Smith in 2019. He had sickle cell and developed an infection after surgery on his bile duct. He rapidly went on to develop widespread organ failure due to sickling triggered by infection. His case was highlighted as he resorted to calling 999 for oxygen from his hospital bed as the people looking after him did not understand sickle or how to look after sickle cell patients

The support we have provided has also evolved to meet the new demands of this time and this includes:

- delivering food hampers to members who were shielding
- delivering prescriptions
- partnered with education providers to provide additional tuition and accessed devices for students to study from home
- regulars calls to our members to reduce the impact of isolation
- contributed to All Party Parliamentary Group on sickle cell
- provided welfare rights advice for our members and advocacy
- distributed Christmas hampers

This year regrettably, all our events including our fundraisers were suspended due to lockdown restrictions. We launched our virtual coffee mornings which have been well attended and prizes given to the person with the best mug.

Our communications lead, Junior Nathaniel Small, designed our branding and we expanded to deliver new merchandise including hoodies, t-shirts, mugs and mouse pads. These are now available from our online shop. We are working on promoting sales through our social media networks.

We were able to do this through the continued support and generosity of our supporters and donators. We remain particularly proud of our continuing partnership with the Specialist clinical nurses at the Centre, who refer members to us for support. This has helped us to work towards preventing homelessness, financial distress and allows us to provide timely advice and advocacy to our community.

Many schools and colleges reached out to us this year as a result of our raising awareness campaigns and we supported many of them with advice and guidance for how to support children and young people living with sickle cell and thalassaemia.

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CHAIR'S REPORT

Corona Virus and its impact

Our members are classified as clinically extremely vulnerable and had to shield during each of the Coronavirus lockdowns. From November 2020 to February 2021, we provided food parcels to 36 households. The average cost for each food parcel was £50.

During the Christmas period we delivered 24 specially made up hampers to those families in need and those who would have to spend Christmas alone due to the pandemic restrictions. The hampers estimated cost was £30 each.

Many of our members with children have been concerned about the interruption to their childrens education and some of this was in part because they did not have devices for their children to adequately take part in online learning. We provided 4 households with laptops and supported the enrolment on extra tuition classes for 10 children.

Looking forward we will need to plan carefully, bearing in mind reduced funds and increased needs, whilst people are still on furlough and the potential increase in redundancies. One step that we have taken is to register for Smile Amazon, which allows for 0.5% of a buyers purchase cost to be donated to our charity and we encourage people to donate through Gift Aid. We will continue to seek out further opportunities like this to secure the future finances for the group.

Our objectives through the year remain:

- roll out of our raising awareness campaign, approaching human resources services across the local authority in order to provide training on the impact of living with sickle cell and thalassaemia and the services we provide
- fundraising for a new apheresis machine for Croydon University Hospital to facilitate blood exchange,
- work with the blood transfusion service to increase blood donation in the borough
- the further development of our mens group and young peoples groups, to ensure everyone has a voice and a channel to communicate with us through

I cannot conclude this report without mentioning some of the members who we have lost this year:-

Reta Watson
Mr Sandiford
Natalie Edwards
Albertha Salmon

Our thoughts are still with their families.

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CHAIR'S REPORT



Special thanks to:

Clevedon Deroche /Laptops
Sybil Banks /Fundraising
Peter Brown /Fundraising
Junior Nathaniel Small /IT and Web Service
Michelle Marshall /Santander Bank
Natalie Mcneish /Fundraising
Lloyds Charitable Trust
Sickle Cell Young Stroke Survivors
Beaverbrooks Charitable Trust
Nurses Association of Jamaica (UK)
Robert Mills /Member
Carlton Young (CACFO)
Marie Seacole Association
Roxanne Gleave (NEU)
Jacinth Martin (CSEP)

Sonia Meikle
Chair

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

SECRETARY'S REPORT

The work of the Support Group work has been very challenging over the last year but our Group still grows from strength to strength. As joint secretaries, we work tirelessly and take our duties very seriously. We were in the office on Mondays and Thursdays but our work is often seven days a week behind the scenes!

January 2019 saw our Support Group wall planner fill with dates for our regular planned events which include:

- Coffee Mornings
- Mother and Toddlers Group (second Wednesday each month led by clinical nurse specialist Carol Edwards)
- Men's Group (last Thursday of each month)
- Management meeting (monthly)
- Welfare Benefit Advice drop in session (monthly) Saturday morning (Led by Sonia Meikle)
- Support Group Meeting (monthly)
- Annual Sponsored Walk Crystal Palace Park 13 July 2019
- Summer outing to Longleat Sari Park 22 August 2019
- Black History month celebration hosting "An Audience With Our Elders" 19 October 2019
- Children's Christmas Party 14 December 2019
- Transition workshop for young people with Sickle Cell in preparation for change to adult care (led by clinical nurse specialist Linda Sawyerr) 31 May 2019
- Table Top Sale 21 September 2019

Other Activities over the past year have included:

Attending the following events

- Croydon Town Hall Mayors Parlour celebration of the festival of Diwali, Festival of Lights 30 October 2019
- Councillor Patsy Cummings party at Selsdon Park Hotel to mark and celebrate the Windrush Generation 21 June 2019
- CAFCO Windrush Celebrations 22 July 2019
- Thornton Heath Festival 7th September 2019 date
- Red Cell Celebration Day Haematology St Georges University Hospital featuring music by Rebecca Sewell ensemble 14 October 2019
- All Parliamentary Party Group on Sickle Cell (APPG SC) Portcullis House 30 October 2019
- Official Opening of the new Welcome Galleries at the Science Museum 20 November 2019

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

SECRETARY'S REPORT

Providing Social security support and advice

The Government changes through welfare reforms to Disability living allowance, Universal Credit and Personal Independence payment benefits, often left sickle cell sufferers and other people who were in receipt of disability benefits having their benefits withdrawn or experiencing delays in payments. Many people with Sickle Cell turned to the group for advice. Mary and I were first port of call, where we would listen, give support and forward information to our Chair. Monthly advice clinics were set up in 2019 and run by Sonia Meikle who has also held information sharing teaching sessions at the centre.

Making Packs and Hampers

- Baby packs for mothers of newborn babies with Sickle Cell
- Preparing and distributing Christmas hampers
- Hospital packs for people with Sickle cell admitted to hospital
- Food Hampers delivered (by Sonia Meikle) during COVID-19 lock down 2020

Hospital visits

To support people with Sickle Cell admitted to hospital and taking fruits, snacks and a hospital pack

Research Collaboration

Meetings have continued with Professor Simon Dyson of De Montfort University concerning his recently published research study on the effects of Sickle Cell in Education and in the work place. Annie and Jackie Simpson have collaborated with this research over several years and attended meetings at Friends House 13 April 2019, and a meeting on 14 October at the Olympic park with funders of the research and stake holders

Celebrating the appointment of two new Professorial Chairs in Haematology

We Attended Kings College Hospital for the Inauguration of Dr Jo Howard Dr Baba Inusa as Professors on 25 09 2019. Both have a special interest in Sickle Cell disorders.

Teaching and Awareness Sessions provided about Sickle Cell

We were Invited speakers at

- St Albans Church 10 October 2019
- Anointed Apostolic Church Women's Conference 15 February 2020
- Museum of London Docklands as guests of Iyamide Thomas organiser of the Krios of Sierra Leone exhibition 3 March 2020

Educational and Cultural events attended

- British Museum (as part of scheme to support community groups) Edvard Munch exhibition 7 April 2019

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

ASSISTANT REPORT

Office redecoration and upgrade

Space is always a premium and with the increased demand for support, resources and services, we recognised the need to redecorate and upgrade the office to better accommodate our needs. This was welcomed and made possible by the hard work of Sonia Meikle and Junior Small in September 2019

Meeting with Management Team Croydon University Hospital

The groups committee attended a meeting with Dr Nnenna Osuji Deputy Chief Executive and Medical Director, Dr Stella Katsiopoulou Consultant haematologist, Jackie Green Nurse consultant Linda Sawyerr Clinical Nurse Specialist and a lead consultant from Accident and emergency. The meeting was held to discuss the management of sickle cell in A/E.

Organising a surprise Party:

A Surprise 80th Birthday party for Lynette Heyward an active member of the group and one of the most senior people living with Sickle Cell in the Borough

COVID-19 Pandemic

In accordance with government advice and particularly in the light of the vulnerability of many of the members of the group, on March 23 2020 face to face meetings at the centre were stopped. However thanks to the hard work of our chair Sonia Meikle food boxes were delivered to some of our members in need. Digital platforms were developed and used in the following months to help support the work of the Group and allowed us to resume our monthly support group meetings.

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

ASSISTANT REPORT

Big Thank you!

Mary and I wish to thank Jackie Simpson and Mark Malwah and
And all our volunteers:

Christine Williams
Rhonda Skeete
Patrick Ojeer
Lynette Heywood
Cynthia Phillips
Junior Nathaniel Small
Hugh Boardman

And also the following

The Nurses and Secretarial staff at the Croydon Sickle Cell and thalassemia centre
for their continued and unfailing support of the group

Sonia Meikle our Chair for all her hard work

The Unite Union and Unison for their continued support

Liz Powderham and the team at Linus Project for their donations of hand made quilts
for babies and children with Sickle Cell Local shopkeepers for having Collection Tins
for the Support Group and Bonnel for supervising them.

Annie McDonald

Secretary

Dr. Mary Clake

Assitant Secretary



MANNEX

SURGICEL® SNOW™
Absorbable Hemostat

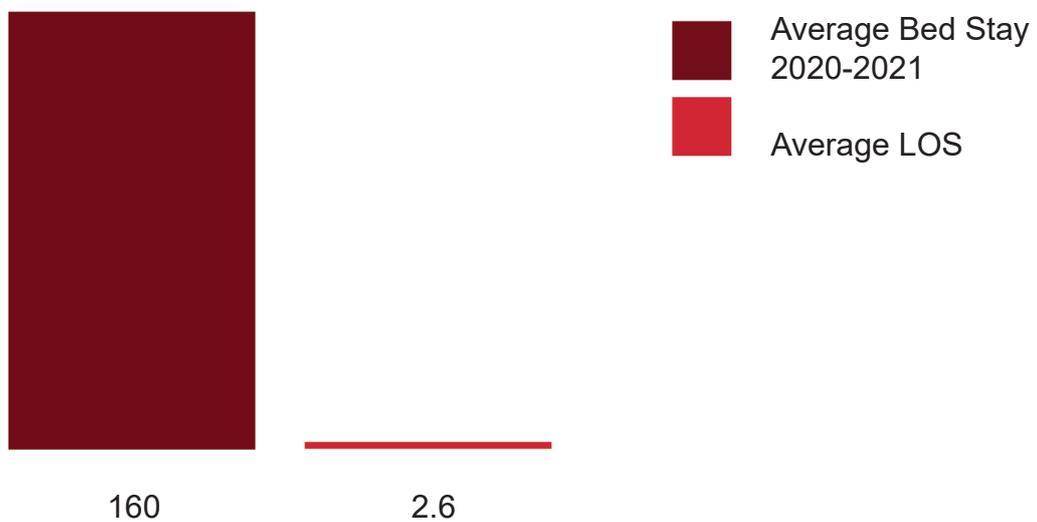
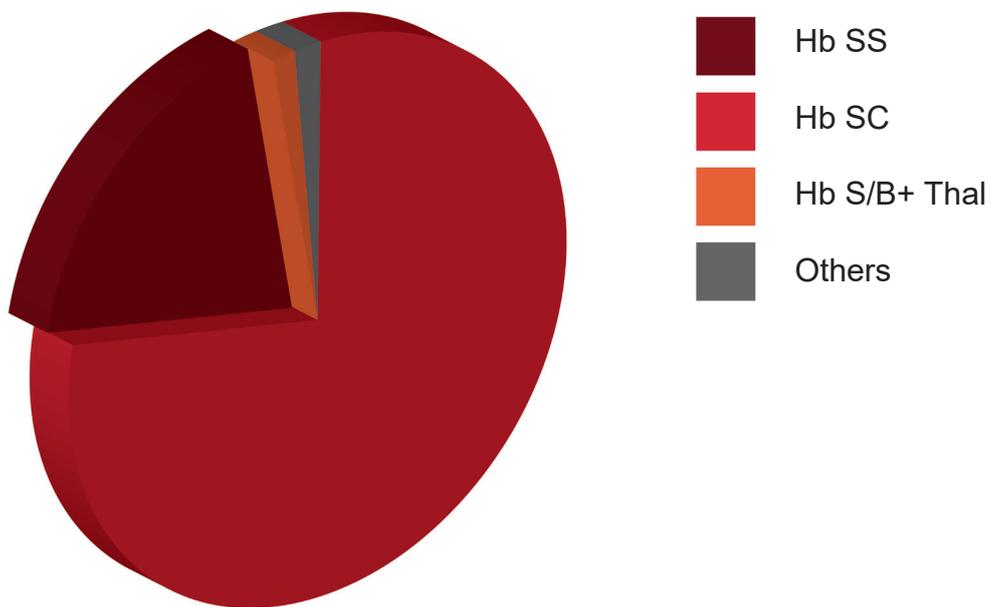
Surgicel

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

NURSES REPORT DATA

Genotype Admission/A&E 2020-2021



BRANDING & COMMUNICATIONS

I have been a Sickle Cell member officially since 2015 in a supportive role, helping where I could at events. Prior to that I had no real knowledge about sickle cell & thalassaemia disease and the impact it has on the individuals and their families. But once armed with the correct knowledge I began to have a sense of wanting to do more for the group. In 2019, a year on since the passing of our chair Alice Allison 12th Jan 1946 – 18 June 2016, the group invited me to join the management committee in the capacity of Branding, Web Development & Communications.

I have a degree in Digital Media Design, so this suited my skillset perfectly. It was agreed I would rebrand the group's logo. This I thought was a necessary step to give the organisation a professional appearance and bring awareness to this disease. We are competing with organisations like Cancer Research, Macmillan, The British Heart Foundation. All of which have a strong media presence, and the awareness around these diseases is substantial.

Having researched the sickle cell logo's iconology, it was apparent to me that everyone was using the same imagery to convey their message about sickle cell.

I felt that the group needed to stand out, So I went about deconstructing this imagery. The new logo has the use of colour, and these colours are symbolic with its visuals. Red is depicting a healthy Blood Cell, Dark Red deoxygenated blood and lastly Orange representing the sickle cell that is damaged. I did not use the colour red as the damaged cell as I want

to convey a positive message. Orange has many traits but is representative of optimism, boldness and joy. Once the logo was in place I moved on to the website. The branding has now been rolled out across all of our social media platforms. In addition all publicity material has been updated along with new photo ID cards, sickle cell banners, Information pamphlets and personalised stationary.

Website

Last year we had 927 visits to our site with an average browsing time of 7 minutes and 23 seconds. This year we have had 318 visits whilst still being impacted by the Covid pandemic as many companies have been.

Campaign

In 2020 we were approached by Santander Bank as a charity they would like to support for Black History Month. I thought we could use this opportunity to run a campaign. The campaign was called Robert's Story: Good Day, Bad Day. This was an insightful snapshot into the life of a person living with sickle cell and their daily challenges.

Merchandise & Shop

At the end of last year, we moved into merchandising this was an initiative to promote awareness around sickle cell. The shop took 3 months to develop, was launched in April and we are already trading.

BRANDING & COMMUNICATIONS

World Sickle Cell Day

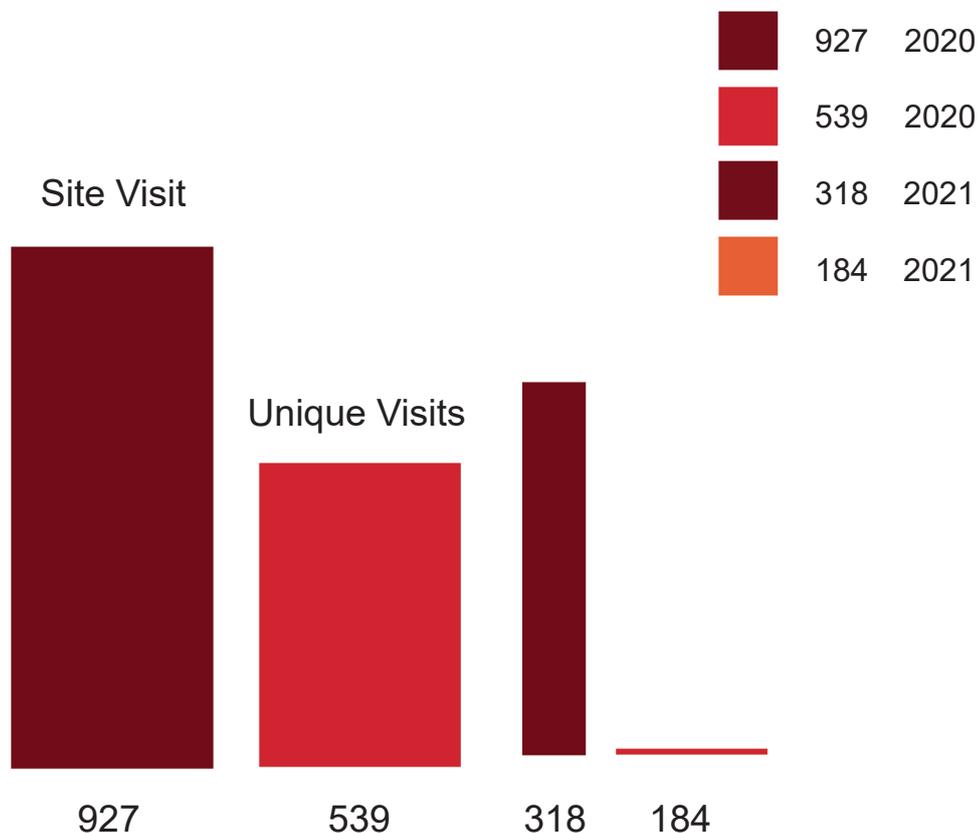
World Sickle Cell Day 2021 was another opportunity to push awareness about the disease, with our “I pledge” campaign. We created a pledge for visitors to sign and promise to take part in an activity for WCSC2021. This could range from:

- Wearing something red
- Promoting awareness
- Organising talks
- Attending online events
- Donations

To close I am incredibly pleased to announce that the group now has a fully functioning website with a blog, useful information link, events calendar, and online shop. I am committed in my continuing support of the group.

Junior Nathaniel Small

Digital Media Design & Web Services





Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

TREASURER'S REPORT

Hi everyone, I am Jacqueline Simpson,

I am the treasurer for the support group. I have sickle cell and I have a daughter with sickle cell. I must say, the group has come through a very trying and disturbing time, both personally and as a charity. Yet as before, the group has stayed strong due to the dedication of those involved in the group. Donations and fundraising has kept the group going financially. We also have donations through Paypal and Justgiving going directly to the charities current account, which allows for transparent accounting to the Charities Commission. This generous giving has been very welcoming. Michelle Mathews from Santander in Norbury is one of many supporters who has continued to carryout fundraising in the bank for the group.

Towards the end of 2019 and throughout 2020, the impact of COVID-19 began to manifest through greater demand being made on the support group to assist people who were having to shield, being furloughed and seeing a reduction in income. We were able to provide food hampers over the Christmas period and throughout the school holidays. We used our funds to support adults, children and families who were struggling with staying connected and engaged with education by providing laptops and additional tuition. Looking forward with pandemic restrictions being gradually lifted, we hope to resume fundraising activity and continue to deliver the support and services that our members need.

Jacqueline Simpson
Assistant Secretary

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

TREASURER'S REPORT

**Croydon Sickle Cell & Thalassaemia Support Group
Receipts and Payments Accounts
for the year ending 31 March 2020**

	Unrestricted	Res'	Total 2020	Total 2019
Receipts				
Donations	5566.17	-	5566.17	5108.74
Grants		-	0	0
Membership Subscriptions		-	0	0
Income from Events	974.26	-	974.26	2200.47
Interest	26.23	-	26.23	16.03
Other Income		-	0	
Total Receipts	6566.66	0	6566.66	7325.24
Payments				
Donations	1615	-	1615	536
Danique Dawkins - Funding Grant			0	
Expenditure:				
Arts Project Costs	45	-	45	
Events Costs	3463.41	-	3463.41	3078.17
Volunteers Expenses	748.35	-	748.35	322.21
Refreshment 203.12		-	203.12	206.49
Support Cost:				
Professional fees		-	0	0
Postage	173.88	-	173.88	407.45
Management & Administration		0		
Travelling Expenses	89.25	-	89.25	27.85
Insurance	185.69	-	185.69	99.31
Telephone	607.42	-	607.42	523.32
Printing & Stationery	20.96	-	20.96	1447.14
AGM Costs		-	0	91.8
Bank charges		-	0	

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

REPORT 2019/20

			Total	Total
	Unrestricted	Res'	2020	2019
Receipts				
		-	0	0
Sundries	617.81	-	617.81	658.58
Total Payments	7769.89	0	7769.89	7398.32
Surplus (Deficit) for year	-1203.23	0	-1203.23	-73.08
Movement in Funds				
Funds at 1 April 2019			21,142.22	21,215.30
Surplus (Deficit) for the year			-1203.23	-73.08
Funds at 31 March 2020			19,938.99	21,142.22
Statement of Assets & Liabilities as at 31 March 2020				
Cash at Bank (Current & Reserve Accounts)			19730.42	21063.39
Cash in hand			208.57	78.83
Funds at 31 March 2020			19,938.99	21,142.22

Approved by the Trustees on...

Sonia Meikle (Chair)

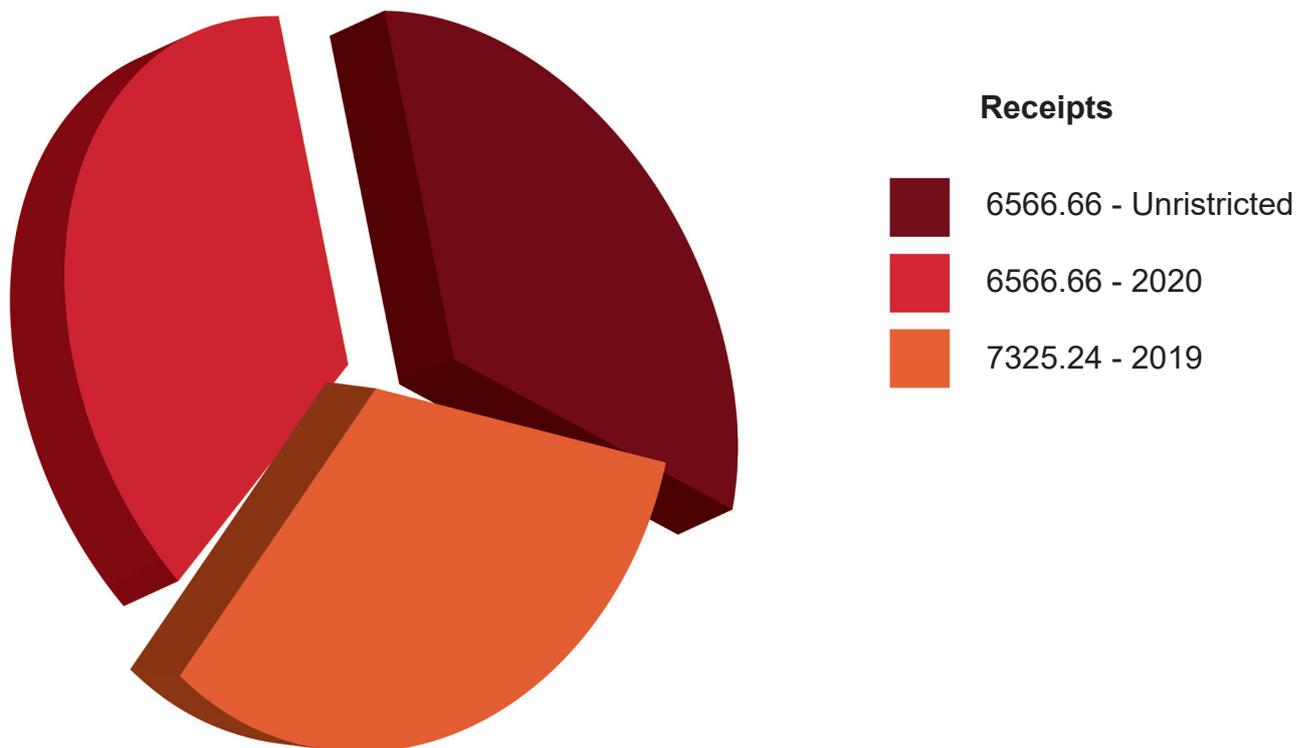
Signed on behalf of all the Trustees



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

REPORT 2019/20



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

THANK YOU

Project Linus
Natasha & Dwayne Smith
Christine Williams
Sherril Gregory
Rhonda Skeete
Rowland Brothers
Parchmore Community Centre
Len Carr - L.A. Carr
Solomon Popoola
Junior Nathaniel Small
Natwest Bank
Home Office BAME Team
British Museum Community Team
Carlton Young - CACFO
Dr Mary and Hugh Clarke
Croydon BME
Cornfield Bakery
Brett Tomlinson - Cherrill Print

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 Junior Nathaniel Small (1,5) Daniel Schludi (6) Sj Objio (15) Charles Etoroma (19)
Luke Jones (23)

In memory of

Alice Allison

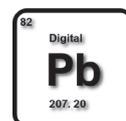
12th January 1946 - 18th June 2016



**Croydon
Sickle Cell & Thalassemia
Support Group**

316 Whitehorse Road,
Croydon CR0 2LE
t: 020 8251 7259

Charity Number 1100120



Design by
Junior Nathaniel Small/
Digital Pb.

www.juniornathanielsmall.com