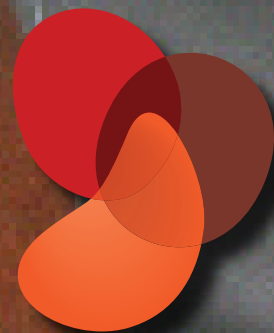


Croydon
Sickle Cell & Thalassemia
Support Group



ANNUAL REPORT 2019

A helping hand is sometimes all that is needed

My thanks to the management committee and volunteers who have worked tirelessly to ensure that the group continues to fulfil its obligations and objectives as a charity.

Sonia Meikle
Chair

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CONTENT

4. Testimonial
5. Team
7. Chairs Report
8. Secretary's Report
9. Assistant Secretary
10. Nurse Report
11. Sickle Cell Stats
12. Data Stats
14. Events
16. Workshops
18. Treasurers Report
23. 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 can not 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



Jackie Simpson



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

CHAIR'S REPORT

2018/2019 has been an exceptionally busy year for the support group. My thanks to the management committee and volunteers who have worked tirelessly to ensure that the group continues to fulfil its obligations and objectives as a charity. We host monthly support group meetings, with invited speakers, coffee mornings where members and their carer's can pop in to get advice or reduce their isolation and mother and toddler groups. Finding out your child has sickle cell or thalassaemia can be daunting and we are there to help navigate through this time. The support we provide is varied and our membership spans across all demographics.

This year our events included:

1. moving our annual sponsored walk back to Crystal Palace and welcoming new walkers to join us on what was an absolutely wonderful day
2. having an information stand at Thornton Heath Festival
3. raising awareness presentations to Home Office staff BAME meetings
4. contributing to clinical research trials with IMARA and Professor Simon Dyson of DeMont Forte University
5. attending All Party Parliamentary Group on Personal Independence Payment (PIP)
6. Members outings to see Nine Nights a new West End play in the Theatre
7. British Museum exhibitions
8. organising An audience with our elders for our black history month event and
9. our annual childrens Christmas Party, just to name a few.

We are particularly proud of our continuing partnership with the Specialist nurses at the Centre and welcomed Carol Edwards and Paula Lindo on to their team. The nurses assist with referring their patients to us for support and advice, which allows us to provide a seamless wrap around service with the nurses providing clinical support and the support group providing community support.

Towards the end of the year we invested in upgrading our IT equipment to provide the structure to support our plans for the coming year. We started with rebranding and our new website is under construction. We will be focussing on improving our data collection so that we can use it to inform the campaigns that we plan to launch and to improve the ways in which communicate with our members and stakeholders.

Management committee members attended digital support and safeguarding training courses to update and refresh their skills. Our report clearly outlines an increase in our membership, attendance at meetings and outreach support which includes home visits. We have maintained steady fundraising and our accounts demonstrate that we continue to attract funding consistently across the year from various benefactors.

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

SECRETARY'S REPORT

Even though I live with Sickle Cell disease, this has not stopped my passion, dedicated commitment and love for the support group. The office has become so busy that for the past year I have had help from Mary Clarke. My duties can be split into two areas: -
Clerical support for the group meetings which includes invites via post email and texts for:

1. Support group meetings
 2. Coffee mornings
 3. Men's support group
 4. Management meetings
 5. Mother and Toddlers Group
- Keeping records & minutes of meetings
 - Managing and monitoring or membership and stakeholder databases.
 - Inviting guest speakers
 - Organising refreshments
 - Booking venues for events
 - Planning outings
 - Co-ordinating volunteers
 - Keeping records of important donors, and organisations

Supporting Sickle Cell Patients
Co-ordinating Support group inpatients packs delivered to Croydon University and Kings College Hospitals. New baby packs – given to parents of new- with sickle cell by the specialist nurses
Providing a drop in mentoring support service to members and their carers.

I am living with sickle cell and this is often a good starting point, as I have a greater understanding of the challenges that sicklers face and can empathise
Meeting student nurses from the Royal College of Nursing University of London who shadow the specialist nurses. I share my experience as a service user and inform them of the support the group provides.

Annie McDonald
Secretary

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

ASSISTANT SECRETARY

I have been working in the support group office for the past two years. It has been a busy and a very enjoyable time .

The team in the office plan and organise the regular meetings, such as the coffee mornings and support group meetings, which take place each month. We also visit people in hospital to give some support, at what is often a difficult time.

In the office we also work closely with other members of the group, the Sickle specialist nursing staff, our chair Sonia Meikle and the clerical staff.

We raise funds for the group, and last summer we held a very successful sponsored walk in Crystal Palace.

I am so fortunate to be part of a team which want to extent a 'helping hand' to those living with Sickle Cell and Thalassaemia and their families.

I am also delighted, and honoured, to be a patron for the group.

Before joining the group I worked in the NHS, as a Haematology consultant , with a special interest in Sickle Cell disease. This was clinical work, but also involved teaching medical students and doctors about Sickle cell. I am still part of a network of people supporting those living with sickle cell disease.

Dr. Mary Clarke
Assistant Secretary

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

NURSES REPORT

There are between 12,500 and 16,000 people with Sickle Cell Disease according to NICE.

I came to work in Croydon in 2017 with a team whom I believe have the patients wellbeing at the forefront always. As I established myself as being a member of the team, I was introduced to the Croydon Support Group and their members.

I attended one of their coffee mornings, and was intrigued by the conversations and discussions had by all, very interesting and funny. Over time I have become more aware of the importance of the support group and how they help other individuals who have Sickle Cell. Once they are updated as to who is in hospital, hospital visits begin and not empty handed because they come armed with fruit and snacks for the patients. From my observations and feedback from patients, these visits are welcomed along with the conversations. Hospital packs are also given for those who come into hospital unprepared.

This support group is original in all that they do, and the hard work I have seen behind the scene putting together and organizing trips, coffee mornings, sponsored walks and Christmas parties for the children. If you are not a member already, I urge you to come and join the team for they are valuable.

Paula Lindo

Clinical Nurse Specialist

The Clinical Nurse Specialists and the administrative team continue to work collaboratively with CSC&TSG providing a unique service for the patient caseload of patients and their families living in Croydon and also patients who access care from outside the borough. CSC&TSG also continues to be a valuable resource within the community through various activities. The CNS's have attended the monthly meetings which have provided lively discussion with opportunity to conduct talks, network and to be update on topics relevant to patient health and wellbeing.

There is a good level communication where we are able to discuss and make referrals or signpost to CSC&TSG for patients requiring additional support which fall outside our remit. An example of this includes up to date benefits information and funding for individual needs.

Participation in the Educational Toddlers Group is an ongoing successful event. Parents attending the group find it beneficial to meet and discuss the support offered by CSC&TSG. It provides a valuable opportunity for parent to meet face to face with and adult on who is also affected with SCD as it provides insight of living with a long-term condition with positive aspects and some of the challenges they may experience living with SCD.

Also advantageous that a representative from CSC&TSG as also patient utilising the local services for this unique patient group. Also it provides an opportunity for patient to meet with someone when their child is well who may visit when they are ill to provide additional support. The CNS's have enjoyed engaging with

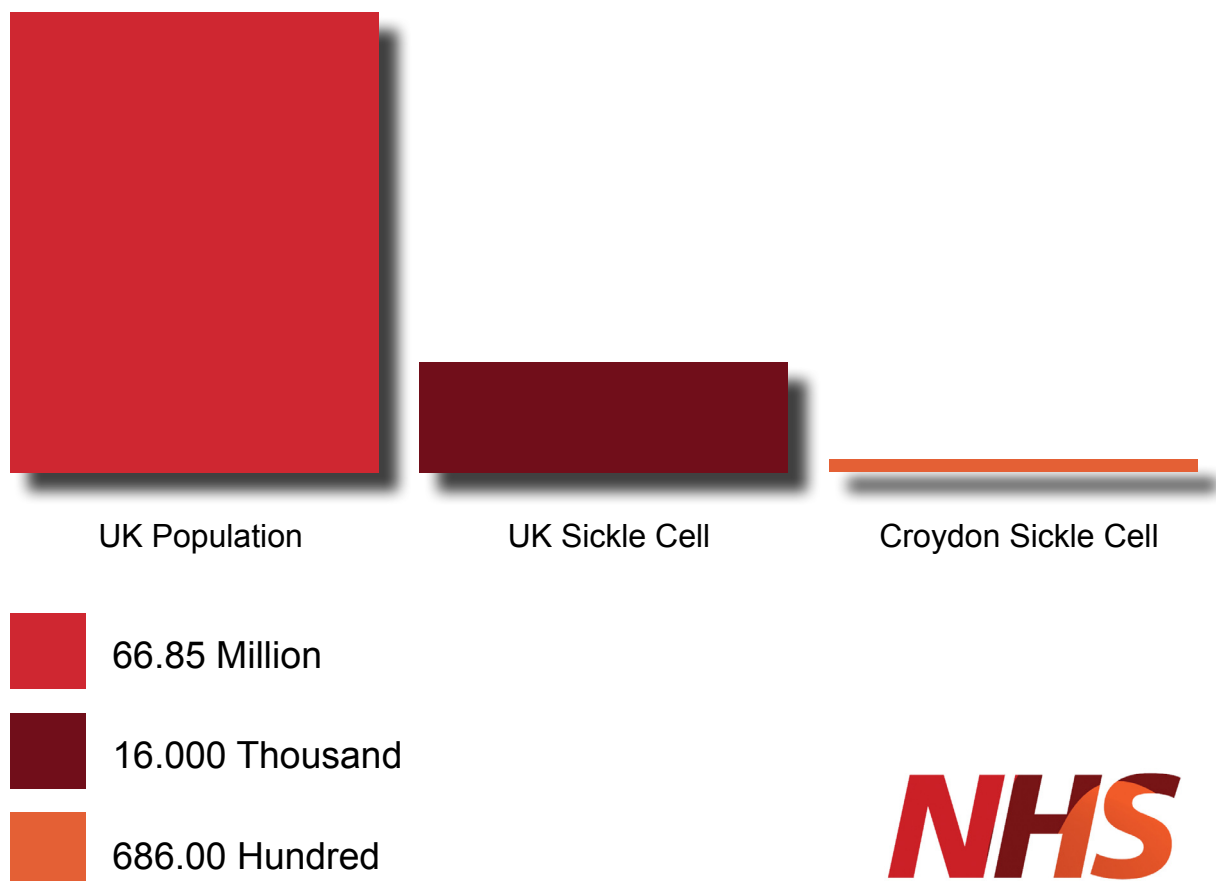
Cont.

SICKLE CELL STATS

fundraising activities such as the annual sponsored walks. The Educational Toddlers Group have also benefited from donation for refreshments. The provision of the 'Baby Packs' are a welcoming gesture from the charity which is warmly received by the parents embarking on the journey caring for a child with sickle cell disease or thalassaemia. The team value the work CS&TSG do and look forward to continue to work in partnership.

Carol Edwards

Clinical Nurse Specialist



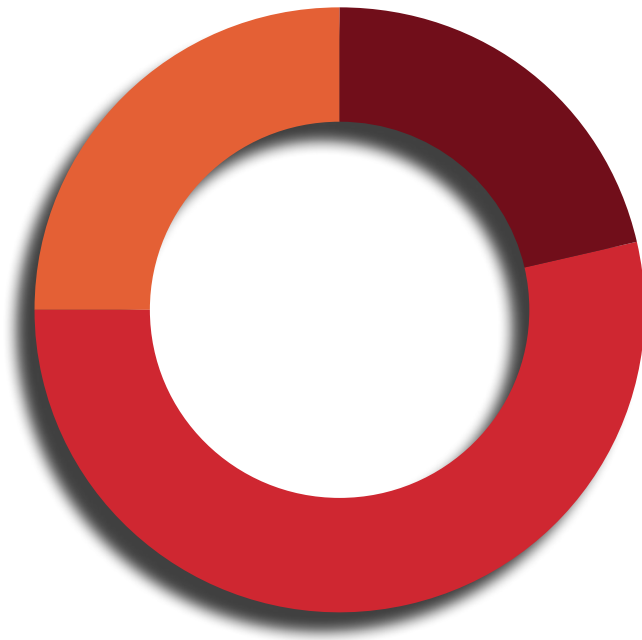
Hospital Packets: 15

Hospital visits: 15

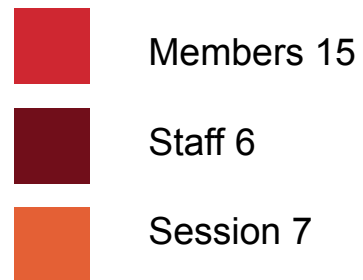
Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

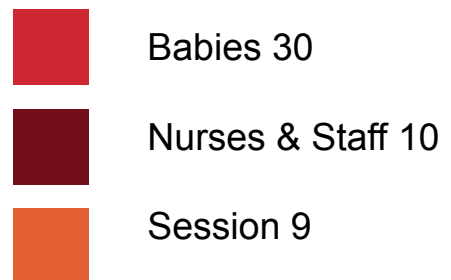
DATA & STATS



Support Group Meeting



Mother & Baby Group

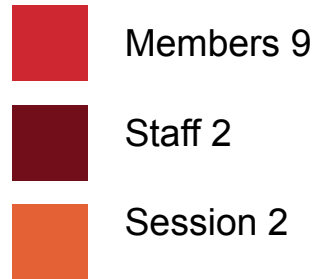


Croydon
Sickle Cell & Thalassaemia
Support Group

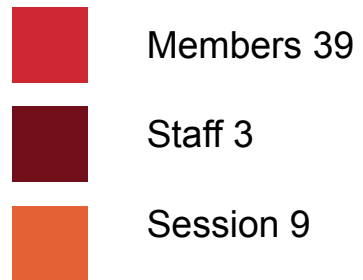
Annual General Meeting

DATA & STATS

Mens Group



Coffee Morning



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

EVENTS

Nine Nights

8th February 2019

Venue: Tratalgar Studios

Annual Children's Christmas Party

9th December 2018

Venue: Croydon BME

An Audience with Our Elders

13th October 2018

Venue: Parchmore Community Centre

BAME: Home Office BHM

31st October 2018

Venue: Home Office

Kew Gardens

15 August 2018

Venue: Kew Gardens

The British Museum | Community Preview

Munch

I Object Ian Hislop's Search for Dissent

I am Ashurbanipal: King of the World, King of Syria

Rodin and the Art of ancient Greece

Charmed lives in Greece Ghika, Craxton Leigh Fermor

Living with Gods

Opening of the Albukhary Foundation Gallery of the Islamic world

Scythians Warrior of Ancient Siberia

American Dream



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

WORKSHOPS

Safeguarding Adults

24th January 2019

Venue BAME

World is your Oyster

28th March 2019

Venue BAME

Healthy Homes

Malcolm Bell

09th February 2019

Venue: CSC&TSG Office

Universal Credit

Sonia Meilke

10th November 2018

Venue: CSC&TSG Office

Mental Health Awareness Session

18th February 2019

Venue: BME

Transition Workshop for Young Adults with SCD

26th October 2018

Venue: CSC&TSG Office

Digital PR & Marketing Workshop

4th March 2019

Venue: BAME.

Film & Photography Sessions

Solomon Popola

March/October 2018

Venue: CSC&TSG Office

Microsoft Office Training

Junior Nathaniel Small

4th March 2019

Venue: CSC&TSG Office

Student Nurse Education

Paula Lindo CNS

Visits to Support Centre

Unleash Your Talent at Work

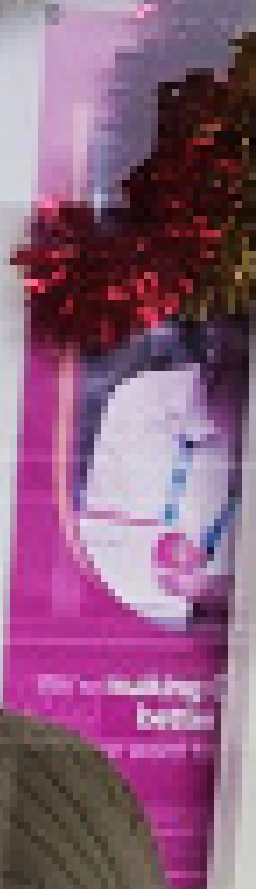
21st March 201

Venue: BAME



Today, one in ten people in the U.S. are of African American origin call Sickle Cell Disease.

Do YOU know where your GRANDPARENTS Come From?



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 2017**

| | Unrestricted £ | Restricted £ | Total 2017 £ | Total 2016 £ |
|---------------------------------|-------------------|-----------------|--------------------|--------------------|
| <u>Receipts</u> | | | | |
| Donations | 3103.35 | - | 3103.35 | 3323.35 |
| Grants | | - | 0.00 | 0.00 |
| Membership Subscriptions | 5.00 | - | 5.00 | 0.00 |
| Income from Events | 909.00 | - | 909.00 | 124.46 |
| Interest | 4.44 | - | 4.44 | 5.19 |
| Other Income | 719.45 | - | 719.45 | 0.00 |
| Total Receipts | 4741.24 | 0.00 | 4741.24 | 3453.00 |
| <u>Payments</u> | | | | |
| Donations | 461.17 | - | 461.17 | 495.95 |
| Danique Dawkins - Funding Grant | 0.00 | - | 0.00 | 1000.00 |
| Expenditure: | | | | |
| Arts Project Costs | | - | 0.00 | |
| Events Costs | 595.72 | - | 595.72 | 1107.80 |
| Volunteers Expenses | 1037.27 | - | 1037.27 | 656.20 |
| Refreshment | 19.64 | - | 19.64 | 92.52 |
| Support Cost: | | | | |
| Professional fees | | - | 0.00 | 277.81 |
| Postage | 33.00 | - | 33.00 | 57.60 |
| Management & | | - | | |

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

REPORT 2017

Administration:

| | | | | |
|-----------------------|--------|---|--------|--------|
| Travelling Expenses | 11.00 | - | 11.00 | 239.00 |
| Insurance | 536.40 | - | 536.40 | 519.01 |
| Telephone | 379.46 | - | 379.46 | 366.93 |
| Printing & Stationery | 58.98 | - | 58.98 | 186.43 |
| AGM Costs | 0.00 | - | 0.00 | 0.00 |
| Bank charges | | - | 0.00 | 124.33 |
| Sundries | 106.77 | - | 106.77 | 159.11 |

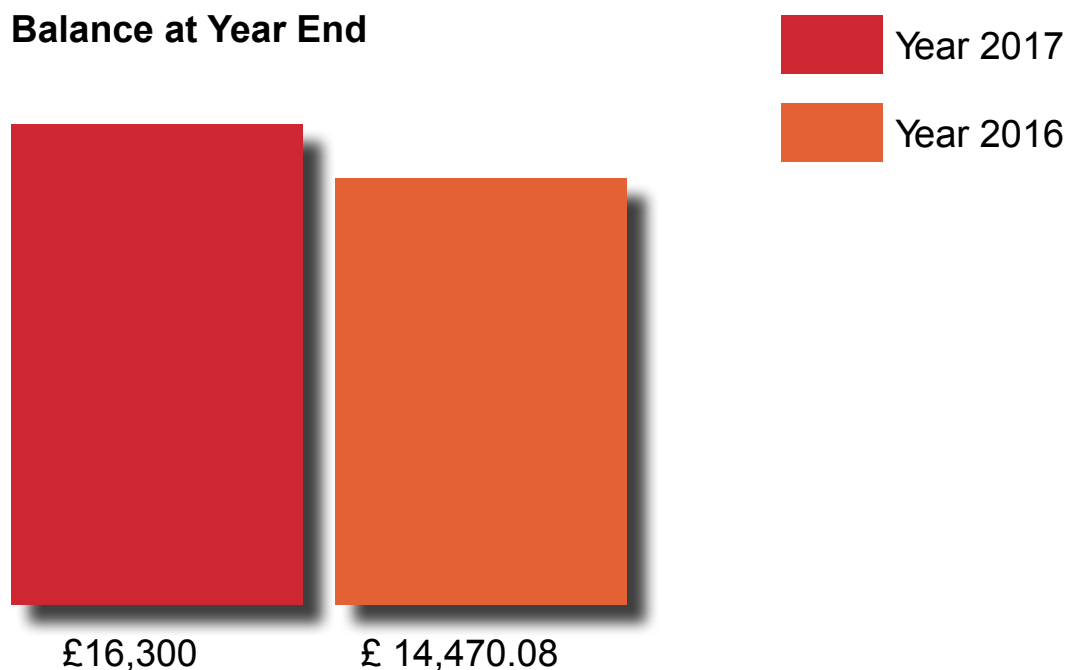
| | | | | |
|-----------------------|---------|---|---------|---------|
| Total Payments | 3239.41 | 0 | 3239.41 | 5282.69 |
|-----------------------|---------|---|---------|---------|

| | | | | |
|-----------------------------------|---------|---|---------|----------|
| Surplus (Deficit) for year | 1501.83 | 0 | 1501.83 | -1829.69 |
|-----------------------------------|---------|---|---------|----------|

Movement in Funds

| | | | |
|--------------------------------|-----------|--|-----------|
| Funds at 1 April 2016 | 14,470.08 | | 16,299.77 |
| Surplus (Deficit) for the year | 1501.83 | | -1829.69 |

Balance at Year End



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 2018**

| | Unrestricted | Restricted | Total 2018 | Total 2017 |
|---------------------------------|----------------|-------------|----------------|----------------|
| | £ | | £ | £ |
| <u>Receipts</u> | | | | |
| Donations | £285.58 | - | £285.58 | 3103.35 |
| Grants | | - | 0.00 | |
| Membership Subscriptions | 32.00 | - | 32.00 | 5.00 |
| Income from Events | | - | 0.00 | 809.00 |
| Interest | 3.32 | - | 3.32 | 4.44 |
| Other Income | | - | 0.00 | 719.45 |
| Total Receipts | £300.90 | 0.00 | £300.90 | 4741.24 |
| <u>Payments</u> | | | | |
| Donations | £03.22 | - | £03.22 | 481.17 |
| Danique Dawkins - Funding Grant | | | 0.00 | 0.00 |
| Expenditure: | | | | |
| Arts Project Costs | | - | 0.00 | |
| Events Costs | 848.84 | - | 848.84 | 585.72 |
| Volunteers Expenses | 402.37 | - | 402.37 | 1037.27 |
| Refreshment | 67.35 | - | 67.35 | 19.84 |
| Support Cost: | | | | |
| Professional fees | 100.00 | - | 100.00 | |
| Postage | 28.40 | - | 28.40 | 33.00 |
| Administration: | | | | |
| Travelling Expenses | 24.87 | - | 24.87 | 11.00 |
| Insurance | 578.13 | - | 578.13 | 536.40 |
| Telephone | 413.38 | - | 413.38 | 378.46 |
| Printing & Stationery | 161.13 | - | 161.13 | 58.98 |
| AGM Costs | 4.98 | - | 4.98 | 0.00 |
| Bank charges | | - | 0.00 | |
| Sundries | 821.83 | - | 821.83 | 108.77 |

Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

REPORT 2018

| | | | | |
|-----------------------|----------------|----------|----------------|----------------|
| Total Payments | 4057.51 | 0 | 4057.51 | 3239.41 |
|-----------------------|----------------|----------|----------------|----------------|

| | | | | |
|-----------------------------------|----------------|----------|----------------|----------------|
| Surplus (Deficit) for year | 5243.38 | 0 | 5243.38 | 1501.83 |
|-----------------------------------|----------------|----------|----------------|----------------|

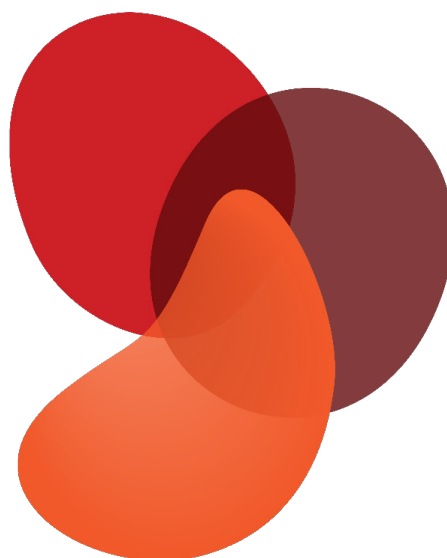
Movement in Funds

| | | |
|--------------------------------|------------------|------------------|
| Funds at 1 April 2017 | 15,971.91 | 14,470.08 |
| Surplus (Deficit) for the year | 5243.38 | 1501.83 |
| Funds at 31 March 2018 | 21,215.30 | 15,971.91 |

Statement of Assets & Liabilities as at 31 March 2018

| | | |
|---|------------------|------------------|
| Cash at Bank (Current & Reserve Accounts) | 21104.18 | 15881.28 |
| Cash in hand | 111.11 | 10.83 |
| Funds at 31 March 2018 | 21,215.30 | 15,971.91 |

Approved by the Trustees on



Croydon
Sickle Cell & Thalassaemia
Support Group



Croydon
Sickle Cell & Thalassaemia
Support Group

Annual General Meeting

THANK YOU

Project Linus
Natasha & Dwayne Smith
Christine Williams
Sherril Gregory
Reta Watson
Rhonda Skeete
Rowland Brothers
Parchmore Community Centre
Mrs E Banks
Len Carr
Solomon Popoola
Junior Nathaniel Small
Natwest Bank
Home Office BAME Team
British Museum Community Team
Jo Negrini - Chief Executive Croydon Council
CACFO
Dr Mary and Hugh Clarke
Croydon BME
Cornfield Bakery
Cherril Print - Brett Tomlinson

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

Donations

Linus Project Quilts and Knitted blankets Elizabeth Powderham
Team Asprey London Toiletries- Large Box

In memory of

Alice Allison

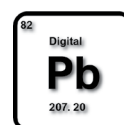
12th January 1946 - 18th June 2016



**Croydon
Sickle Cell & Thalassemia
Support Group**

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

Charity Number 1100120



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