



*Information, Counselling
and Caring for those with
Sickle Cell Disorders
and their families*
Charity Reg: 104 6631
Company No. 284 0865

SICKLE CELL SOCIETY

54 Station Road
London NW10 4UA
T 020 8961 7795/4006
F 020 8961 8346
E info@sicklecellsociety.org
www.sicklecellsociety.org

Ms Elizabeth Ogunoye
Associate Director
LAS Commissioning and NWL Provider Performance Management
1st Floor
Marylebone Road
London NW1 5JD

25 November 2015

Dear Ms Ogunoye,

Re- London Ambulance Service (LAS) and Sickle Cell Disorder (SCD)

PATRONS
Prof Elizabeth Anionwu CBE
Baroness Floella Benjamin OBE
The Rt Hon Lord Boateng
Sir William Doughty
Mr Derrick Evans
Mr Lenny Henry CBE
Dr Nola Ishmael OBE
Mr Clive Lloyd OBE
Mr Trevor Phillips OBE
Mrs Sherlene Rudder MBE
Mrs Millicent Simpson

MEDICAL ADVISERS
Dr Nellie Adjaye
Dr Phil Darbyshire
Dame Sally Davies
Dr Mark Layton
Prof Bernadette Modell
Dr Norman Parker
Dr David Rees
Dr Allison Streetly

SCIENTIFIC ADVISERS
Prof Simon Dyson
Dr Mary Petrou
Dr Kofi Anie

TRUSTEE DIRECTORS
Mr Babatunde Akintola BSc, MSc
Mrs Janet Baptiste-Grant
Ms Sally-Ann Ephson
Mr Joseph Ezeakunne
Mr Kye Gbangbola MBA
Ms Sheree Hall
Mr Kingsley Ibeke
Mr Mohammed Keubby
Mr Sanusie M Sesay
Ms Michele Salter
Mr Philip Udeh

I am sure you will by now, have heard about the very productive meeting held between representatives of the Sickle Cell Society, the UK Forum on Haemoglobin disorders, the LAS and the LAS Patient Forum on 11 November 2015. Unfortunately I could not be present because I was out of the country but the meeting was very well attended by people living with SCD. Our Chairman Kye Gbangbola was present and led for the Society.

During the meeting the LAS Medical Director Fenella Wrigley, expressed her strong support for a CQUIN that would promote a more focussed and effective service for people living with SCD who need an urgent response because of a crisis or severe complications from a crisis. Amongst the issues we would like to see developed through a CQUIN are as follows;

1. More effective and appropriate pain management control for people in crisis
2. Greater sensitivity to the needs of people in SCD crisis when they are transferred from their home to an ambulance and then to Accident and Emergency
3. An understanding of the intensity of pain that can be experienced during a SCD crisis
4. Greater understanding of the associated pathologies/complications that can be life threatening to people in crisis
5. The stigma that can affect the way people living with SCD and their families relate to care providers and ask for help from the emergency services
6. Attitudes amongst some clinical staff that can lead to people with SCD in crisis being labelled as 'drug users'

THE VOICE OF THE SICKLE CELL COMMUNITY

Officers:

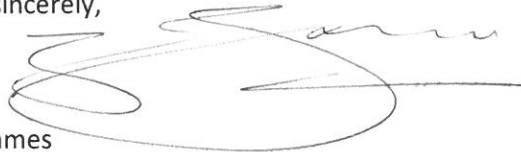
Chair: Mr Kye Gbangbola MBA; Secretary: Mr Mohammed Keubby; Treasurer: Ms Michele Salter, President: Mr Michael Parker FCCA, CBE
Chief Executive: Mr John James

7. The development of care plans by people living with SCD and their clinicians that can be linked to GPs and acute services and flagged with the LAS system to enable the patient to get the right care, first time.

It would be helpful if we could arrange a mutually convenient meeting, together with one of our Medical Advisers and the LAS, LAS Patients Forum Chairman, to discuss how we might move this agenda forward.

I look forward to hearing from you.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'John James', with a large, stylized flourish underneath.

John James
Chief Executive

cc- Kye Gbangbola-SCS Chairman, Fenella Wrigley- LAS Medical Director, Anne Yardumian- Chair UK Forum , Malcolm Alexander- Chair LAS Patients Forum