Witness Name: John James
Statement No.: WITN5210001
Exhibits: WITN5210002 – 012
Dated: 18 May 2021

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF
JOHN JAMES

I, John James, of The Sickle Cell Society, WILL SAY as follows:

1. I provide this statement on behalf of the Sickle Cell Society ('the Society'), in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 August 2020, based on my own knowledge and experience and the information provided to me by other staff at the Society.

2. I am the Chief Executive Officer at the Society, and have worked in that role since 2013. I have a Masters in management and have previously worked in managerial/board level roles.

3. I have adopted the numbering of the questions from the Inquiry in the response below.

A. BACKGROUND

4. Sickle cell is one of the most common genetic inherited conditions in the UK (and the world). It is an inherited blood disorder, which affects the red blood cells. For an individual with a sickle cell disorder when the red blood cell gives up too much oxygen it loses its flexibility and uniform roundness adopting a sickle shape (sickling). This makes the cell difficult to pass through the blood vessels and creates blockages. When these blockages occur, they cause a great deal of pain, called a

sickle cell crisis, for the individual. Over time, people living with sickle cell can experience damage to organs, such as the liver, kidneys, lungs, heart and spleen.

5. The Society is a national charity, first founded in 1979, supporting persons with sickle cell disorders for over 40 years. The Society's focus is to support the Sickle Cell community in the UK, improve public information, assisting in research into the causes and treatment of the condition and work toward changes in national policy. The Society does this, working within tight financial constraints. It has worked closely with many public and industry partners over many years to help achieve those objectives.

6. The Society has, and continues to, work closely with the Inquiry team to provide information about the impact of infected blood on the Sickle Cell community, assist in identifying potentially affected persons from within the community and inform those within the community about the Inquiry and its work.

B. RESPONSE TO QUESTIONS FROM THE INQUIRY ARISING FROM DOCUMENTS REVIEWED AT THE SOCIETY OFFICE

Q1. A publication titled 'Proceedings of a Patients & Carers Education Seminar on Adequacy & Safety of Blood Supply' by C. Olason and Nkohkwo (2012)' includes a PowerPoint presentation on the current practice of blood transfusion, safety and calls for donors amongst the sickle cell community WITN5210002 ***The PowerPoint presentation at page 14 was led by Dr Shubha Allard, Consultant Haematologist at Barts and the London NHS Trust & NHS Blood and Transplant. The questions that arise include the following:***

- ***(a) How was this information on "current practice of blood transfusion and safety... amongst the sickle cell community" relayed to the SC community? How did this information impact the practice that the SCS adopted for "calls for donors amongst the sickle cell community"?***
- ***(b) Who were the recipients of this publication?***
- ***(c) What communications have you received from recipients of this publication regarding the safety of blood they had received?***
- ***(d) On page 5 it is stated that "Patients with sickle cell disease need information on blood transfusion specific to their clinical needs" including the "risks and benefits". What were the risks communicated to the SC community?***
- ***(e) Please describe the relationship and communications between the SCS***

and Dr Shubha Allard?

7. I was not the CEO in 2012 and so my first-hand knowledge about the publication and PowerPoint presentation is limited. None of the employees with first-hand knowledge of this publication remains working at the Society. Philip Nortey, former Chief Executive Officer of the Society led on this publication, but is no longer with the Society. Carlotta Olason, Information Officer, Asaah Nkohkwo may be better able to assist with the Inquiry's questions. The Society would be happy to provide contact details to the Inquiry for Asaah, if that would be of assistance. Unfortunately, we are unable to assist with contact details for Carlotta Olason.

8. If it is of assistance, we can provide the Inquiry with a copy of the Society newsletter which gave information about the Seminar and may provide some further context. Unfortunately, we do not have any further records or knowledge relevant to the Inquiry's questions Q1(a) – (e).

Q2. The SCS Newsletter: June 2011 contained " GRO-A ***story" (*** WITN5210003 ***). This is about a person in the 1980s who had sickle cell disease and stopped receiving blood transfusions after hearing of the HIV scandal. Questions arising from this are:***

(a) This article suggests that a SC patient was aware, in the 1980s, that there was a risk of HIV infection by blood transfusions. When did the SCS become aware of this risk?
(b) After becoming aware of the risk, what information did the SCS provide to their members about the risk?
(c) What platforms did the SCS use to make the SC community aware of this risk?

9. Again, this newsletter was published before my appointment as CEO at the Society. None of the employees with first-hand knowledge of this publication remain working at the Society. I am therefore unfortunately unable to assist the Inquiry with its questions.

Q3. The SCS Newsletter: Issue 8, Winter 2011, on page 16 titled 'Your blood is special and will help save lives', states that "During a blood transfusion, a person receives healthy blood from a donor which is carefully screened for diseases before it is used" (WITN5210004 ***). From this section, the following questions arise:***

(a) What prompted the SCS to use the term "carefully screened for diseases before it is used"?

10. Neither myself, nor anyone currently employed by the Society were involved in the publication of this newsletter. However, the Society has had a close relationship with the NHSBT over the years and so it is possible that the phrase was taken from literature from NHSBT, though I cannot say this with any certainty.

(b) Blood is described as "carefully screened for diseases". When did the SCS become aware of the screening of blood donations for diseases?

11. I cannot say when the Society became aware of the screening of blood donations for diseases. However, it is likely that the Society learned about screening processes through liaison, information sharing or meetings with NHSBT. Given the close working relationship between the Society and NHSBT that would likely have been soon after the NHSBT became aware of screening of blood donations for diseases. The NHSBT may be able to assist better with a timeframe for that.

(c) What was the earliest newsletter in which the SCS acknowledges "screening" and "diseases" when campaigning for blood donors?

12. I am unable to advise on the date of the earliest newsletter in which the Society acknowledges "screening" or "diseases" when campaigning for blood donors. Unfortunately, the Society doesn't have the resources to undertake such a search. However, the Inquiry is welcome to re-inspect the Society's records.

(d) What was the relationship between the SCS and the author of this post, Theo Clarke, Lead Donor Relations Manager - BME & Special Projects, NHSBT?

13. The Society is mainly a BAME organisation. Theo Clarke had a focus for BAME and special projects in NHSBT and was one of the key individuals working with staff at the Society prior to my arrival. Theo would attend Society meetings and education days (where he would arrange for there to be an NHSBT stand). This would allow people with Sickle Cell and others to get more information about blood donation.

(e) Mentioned at page 14 in the contents of this newsletter, is the Scottish Sickle Cell and Thalassaemia Support Group. What is the SCS's link to this Support Group?

14. The Scottish Sickle Cell and Thalassaemia Support Group is one of the support groups with whom we work.

(f) At page 15, it is stated that the SCS, UK Thalassaemia Society and the All-Party Parliamentary Group on Sickle Cell and Thalassaemia had been working collaboratively. What records do you have of any meetings with these organisations? What is the connection between the SCS and these organisations?

15. At the time the parliamentary group was supporting policy work on blood matters for both Sickle Cell and Thalassaemia. The UK Thalassaemia Society has now set out its own parliamentary group on Thalassaemia.

16. I am not aware of any records of the meetings held by the Society. The Inquiry is welcome to inspect the Society's records, if that would be of assistance. There may also be parliamentary records of the meeting which the Inquiry could access.

(g) The recent publications of the SCS Annual Report and the second edition of the SCS programme standards is announced on page 15 of this newsletter. Prior to the "programme standards", how was the screening framework and services monitored, particularly when the SCS was first established?

17. The NHS Screening Programme was not established as a national programme when the Society was formed as a charity in 1979. The Society was involved in campaigning for improvement in the way persons with Sickle Cell were cared for. Prior to the screening programme Sickle Cell was rarely diagnosed. It would be picked up through haematologists or through emergency admissions because of lack of care.

18. Once a screening programme was established, the Society developed a close working relationship with the screening programme and through that process information about monitoring and data collection was developed. The Society

had someone on our staff who was dedicated to working with the programme.

19. The programme standards would have been created by Public Health England, who run the SCT Screening Programme. I cannot comment specifically on how the framework was monitored but would expect that was through joint working arrangements agreed between the parties.

Q4. Page 11 of the SCS Newsletter: Issue 7, Summer 2011 refers to the sub-Committee under the care of Professor Dame Deirdre Kelly on SabTO which had been "reviewing the criteria for deferring people from donating blood to the National Blood Services (NHSBT)" and the "current life-time donation ban will be revised for any man who has recently had sex with a man at the considered donation date" (WITN5210005).

(a) What is your knowledge of the "criteria for deferring people from donating blood to the National Blood Services"?

20. Neither myself nor any other staff member at the Society has any knowledge of the "criteria for deferring people from deferring people from donating blood to the Nation Blood Services" at the time. The NHSBT may be able to assist, as they set the criteria.

(b) When did the SCS become aware of the "criteria for deferring people from donating blood to the National Blood Services"? How was this communicated to the SC community?

21. Again, unfortunately neither myself nor the staff currently working at the Society have direct knowledge the criteria at the time.

22. The Society had a bilateral and close working relationship with NHSBT and so it is likely that was communicated to the Society quickly, but I cannot provide any certainty on that point.

(c) What is the SCS's links with the Croydon Sickle Cell & Thalassemia Support Group mentioned at page 16 in the contents of this newsletter?

23. The Society has always had a good relationship with Croydon Sickle support Group. A current staff member of the Society was appointed as Regional Care Advisor for South London for the Society. She attended Croydon Sickle Cell

support group meetings regularly. Croydon Sickle Cell are one of the support groups that participated in almost all our Society events, e.g. AGM, Patient Education Days and remains an active participant collaborating with the Society.

Q5. In the Fair Shares for London Report, on Sickle Cell Disorders in Greater London: January 1997, page 73 states that "Blood transfusion has been used over the past year, by majority of centres, for patients with sickle cell disorders (WITN5210006). While indications remain contentious, 'top up transfusions appeared to have been used not only when the patients have had a significant fall in haemoglobin'." Further the report states that some centres are "probably transfusing more patients than really need it, with the associated risks of alloimmunisation, iron overload, and potential viral transmission." The further questions that arise from this report include;

(a) What actions did the SCS take to "study the role of transfusion in SCD"?
(b) What steps did the SCS take to reduce the risk of unnecessary transfusions?
(c) How were these risks communicated to clinicians and the wider SC Community?
(d) Why was the Fair Shares for London Report commissioned and to what extent was the SCS involved in the research?
(e) How was this report received by the SCS and its medical advisors?
(f) What further actions did the SCS take as a result of the publication of this report?

24. I was not the CEO in 1997 and so my first-hand knowledge about report is limited. None of the employees with first-hand knowledge of this publication remains working at the Society. I therefore cannot provide answers to the Inquiry's questions with any certainty. However, I expect communication of risks to clinicians were through the NHSBT and NHS.

25. The Fair Shares report was authored by Dr Alison Streetley, Public Health England specialist. She may be able to assist with your questions. Dr Streetley is a patron of the Society. The Society would be happy to facilitate communications between the Inquiry and Dr Streetley, if it would be of assistance. I can say that the Society campaigned for better services in the 1970's and 80's evidencing and identifying the health inequalities in terms of resources etc. for Sickle Cell patients. I'm unable to confirm the extent to which the Society contributed to the report itself.

Q6. The SCS Annual Report of 1995 to 1996 states that the SCS has "teamed up with the South West Thames Regional Blood Transfusion Centre to produce a leaflet emphasising and encouraging the need for greater participation from all Afro Caribbean residents in the UK." WITN5210007)

- ***(a) How long did this campaign last and are there copies of the leaflets available to view?***
- ***(b) What information did the leaflets contain about donating blood, in particular did they inform potential about the risks associated with donating blood?***
- ***(c) What other centres did the SCS roll out these leaflets to?***

26. Neither myself nor staff currently employed at the Society have direct knowledge of this report. Unfortunately, I am unable to provide further information to assist the Inquiry with its questions.

27. The Inquiry has reviewed our records. The Inquiry is welcome to view our records again to identify copies of the leaflets, if they are available.

28. I otherwise note that staff from the South West Thames Regional Blood Transfusion Centre were transferred to NHSBT and so NHSBT may be able to assist further.

Q7. In reference to the screening of blood donations in the Sickle Cell News Review (1995) 'Black Blood Donation Debate Update' WITN5210008 ***), please can you answer the following:***

- ***(a) It is stated that several meetings took place including one on 6 April 1995 between Dr Elizabeth Anionwu, representatives from OSCAR, Commission for Racial Equality, SCARF, Public Health Laboratory Services and the National Blood Services. What was the purpose of this meeting? What records does the SCS have of this meeting?***

29. Dame Professor Anionwu remains a patron of the Society but is now retired. I am not aware of any records of the meeting. However, the Inquiry is welcome to inspect the Society's records. The Society would also be happy to facilitate communication between the Inquiry and Dame Professor Anionwu, if that would be of assistance.

(b) It is stated that "Dr Virge James of the Standing Advisory Committee on Donor Selection gave background information on the treatment of blood. Once it has been collected, blood is tested mandatorily for HIV 1, HIV 2, Syphilis, Hepatitis B and C" How did the SCS inform its members of the screening of blood for HIV, Hepatitis B or Hepatitis C?

30. Neither myself nor current staff of the Society are aware of how the Society informed members of the screening of blood for HIV, Hepatitis B or Hepatitis C in 1995.

31. I can advise that the Society now runs specific programmes of work which seek to increase number of black blood donors and do that in collaboration with NHSBT. These include running meetings with NHSBT staff specialists for patient and clinicians. We also inform patients and clinicians through distribution of publications and leaflets at universities, local authorities, NHS Trusts, Churches and public events. Since the global pandemic the Society has been using social media to distribute similar publications and information.

Q8. In the SCS Annual Report of 1986 to 1987, it is stated that at a session on pain in SCD, chaired by Dr Baughan, the Deputy Mayor and Mayoress "wanted more information on blood transfusions" (WITN5210009).

(a) What knowledge does the SCS have about the information requested by the mayoress?
(b) What records or notes did the SCS retain from this session, if so is this available to view?

32. The Society has a good relationship with previous and the current mayor of Brent (where our office is located). The Mayor has run a number of sessions about the Society and blood donation.

33. Unfortunately, neither myself nor current staff at the Society have any direct knowledge of the report and session referred to. The Inquiry is welcome to review the Society's records again to identify whether there are any records or notes from the session.

Q9. The SCS Newsletter: No. 21, February 1985, 'Black on Black Sickle Cell Society Blood Donor Campaign' refers to a four week campaign launched by Channel 4 (WITN5210010). The SCS received 800 calls and correspondence from the public wishing to donate. It is stated that many did not know where to attend

and donate blood, some "became frustrated or were turned down either because they thought the blood they give will only be used for sickle cell patients or because their blood was not acceptable".

(a) During that campaign, what information did the SCS provide to individuals wishing to donate blood? In particular what was communicated about the risks of donating blood?
(b) Why were individuals "turned down"?

34. I was not the CEO in 1985 and so my first-hand knowledge about the campaign is limited. None of the employees with first-hand knowledge of this campaign remain working at the Society. Philip Nortey, former Chief Executive Officer of the Society led on this publication, but is no longer with the Society. As mentioned above Carlotta Olason, Information Officer and, Asaah Nkohkwo may be better able to assist with the Inquiry's questions. The Society would be happy to provide contact details to the Inquiry for Assah, if that would be of assistance. Unfortunately, we are unable to assist with contact details for Carlotta.

(c) What was the criteria for assessing unacceptable blood?

35. Neither myself nor staff currently employed by the Society have information about what checks were done historically and how they compare to today's regulations. While the Society are consulted on the criteria, these are set by NHSBT and so may be that NHSBT better place to assist with this question.

36. Current criteria can be accessed online: https://www.blood.co.uk/who-can-give-blood/.

Q10. In the SCS Annual Report of 1983 to 1984 and 1984 to 1985, it is stated that the SCS has started a blood donor campaign spearheaded by Black on Black, to encourage people to get information, get tested and to donate blood **WITN5210011** ***).***
Further questions from the section include:

(a) What are the SCS's links to the Black on Black organisation and were there other campaigns of this nature rolled out? Don't know.
(b) Are there any copies or transcripts available of the campaign?
(c) In the campaign to donate blood, what information about the risks of contracting Hepatitis B or C or HIV was communicated to the SC

community?

37. Unfortunately, neither myself nor staff at the Society have direct knowledge of the report or the campaign with Black on Black. I am not aware of any records relating to the campaign. I am therefore unable to assist with the Inquiry with their question. However, the Inquiry are welcome to review the Society's records to identify whether there are any records available, which may assist the Inquiry.

Q11. In the SCS Newsletter: No. 9, November 1982, there is a plea for blood donors and a blood donor session of 8 September 1982 is mentioned as having "an embarrassingly low turnout" (WITN5210012).

(a) Why was there a "low turnout" at that blood donor session?
(b) What information was provided to potential blood donors at these sessions? In particular, what was communicated about the risks of donating blood?

38. Unfortunately, neither myself nor the staff at the Society have direct knowledge of the blood donor session of 8 September 1982. NHSBT may be able to assist the Inquiry with this information as it would have been NHSBT that would have run the session, even if it was jointly organised.

(c) What procedures and processes were adopted to reduce the risk of receiving infected blood at these blood sessions?

39. Unfortunately, neither myself nor current staff at the Society have direct knowledge of the newsletter or the session. I am therefore unable to assist with the Inquiry with their question with any certainty.

40. However, I can advise in relation to 11(a) that blood from BAME donors is important for persons with Sickle Cell because there are different blood types and donors are low in numbers. There are not enough BAME people giving blood now. Recording that there was a "low turnout" indicates this was also an issue in 1980. It is known there is a need for more black blood donors. That is an issue that the Society is currently trying to raise awareness and increase the number of black people donating blood.

C. RESPONSE TO QUESTIONS FROM THE INQUIRY ABOUT THE SOCIETY

HELPLINE

Q12. Thank you for the information about the SCS helpline which we have received. On review of that information, we have identified further questions which are as follows:

(a) ***We understand that the helpline has been running since 2015. Prior to 2015 what was the process for helping members of the sickle cell community with their queries?***

41. As happens now, an Information Officer was employed to take calls. Other staff also answered queries and referred the more complicated queries to either the Information Officer or the CEO.

(b) ***What statistics does the SCS have on infections due to blood transfusions from the helpline?***

42. The only statistic we have is the email enquiry received in March 2020, which the Inquiry has already reviewed (and referred to in Q13 below).

Q13. ***Thank you for the information confirming that the helpline received an email query in March 2020 from a parent whose daughter died in 2004 from hepatitis as a result of a blood transfusion.***

(a) ***Please can we have this person's name and we shall check our records and confirm whether they have made contact with us.***

(b) ***Alternatively, can we please have that person's email address?***

43. The name of the mother who sent the email is GRO-A.

D. RESPONSE TO QUESTIONS FROM THE INQUIRY SEEKING FURTHER INFORMATION ABOUT THE SOCIETY MEDICAL ADVISORS

Q14. The Inquiry is aware that the following doctors are medical advisors to the SCS:

Dr Nellie Adjaye
Professor Dame Sally Davies
Dr Mark Layton
Professor David Rees

Dr Allison Streetley
Professor Bernadette Modell
Dr Eugene Oteng-Ntim

(a) Please can you confirm which of these doctors were assisting the SCS in the 1970s and 1980s?

(b) Are there any other clinicians associated with the SCS during the 1970s and 1980s not already listed above? If so, can the SCS provide details for these clinicians (such as: names, addresses, emails or telephone numbers)?

44. I believe that Professor Modell advised the 1970s and 1980s. However, neither myself nor staff currently employed at the Society have direct knowledge of which other doctors acted as medical advisors to the Society in the 1970's and 1980's. I am therefore unable to assist with the Inquiry with their question with any certainty.

45. However, if it would assist the Inquiry, the Society would be happy to facilitate communication between the Inquiry and those doctors who remain medical advisors and patrons to the Society. Further information about this is provided in response to Q15 below.

Q15. The Inquiry has been in contact with Dr Moira Dick who has stated that in her 35 years of experience with the SCS, she did not receive any queries or see any cases of HIV, Hepatitis B or Hepatitis C related to blood transfusions.

Further, Dr Dick stated that blood transfusions were not regular or standard practice for sickle cell patients and would have only been done in acute cases, so one-off transfusions. The Inquiry intends to compare the calculations Dr Dick has provided with the calculations other doctors at the SCS may have made in respect of the rate of infection from blood transfusions during the 1970s and 1980s for sickle cell patients. In order to do so, we would need these doctors to provide the information below:

(a) Can all of the doctors above (apart from Doctor Dick) confirm whether they ever received any queries relating to the risk of contracting HIV, Hepatitis B or C, through blood transfusions in the 1970s and 1980s?
(b) If they received such queries, can they confirm what information or advice was provided in response?
(c) *Beyond the 1970s and 1980s, can all of the doctors confirm whether they have received any queries relating* to contracting HIV, Hepatitis B or C through blood transfusions?

46. Not all of the doctors listed remain as medical advisors for the Society. Dame Sally Davies and Dr Alison Streetley are patrons of the society, but no longer medical advisors.

47. Whilst the Society has working relationships with the remaining doctors, they are not employees or under the direct control of the Society and so the Society has no power to direct them to provide the above information. The Society is, however, happy to assist the Inquiry by facilitating communication between the Inquiry and those professionals that remain medical advisors to the Society.

If you are aware of any other societies similar to yourselves that may be of assistance to the Inquiry, can we please have contact details for an individual or the organisation, so that we can make contact with them.

48. The Inquiry is already aware of the Croydon Sickle Cell & Thalassemia Support Group. However, if it would be of assistance the Society can provide contact details for their secretary and chair.

STATEMENT OF TRUTH

I believe that the facts stated in the witness statement are true.

Signed: **GRO-C**

Date: 18 May 2021