Witness Name: Oleander Agbetu
Statement No.: WITN4729001
Exhibits: **WITN4729002 - WITN4729005**
Dated: 5 January 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF OLEANDER AGBETU

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 16 November 2020.

I, Oleander Agbetu, will say as follows: -

Section 1. Introduction

1. My name is Oleander Agbetu. My date of birth is GRO-C 1963 and my address is known to the Inquiry. Prior to the covid 19 pandemic I ran my own social enterprise, delivering creative workshops in the community for people with mental health issues. This included sewing, baking and upcycling. Due to the pandemic, I was no longer able to carry out face to face work as all of the community centres remained closed for long periods of lockdown. I am now working for a charity, helping patients start up their own self-help groups.

2. I live with my husband and our two children, our daughter who is 20 and our son who is 17. My husband has a child from a previous relationship. I am of African-Caribbean heritage, which has relevance to this statement.

3. I am a carer for my son GRO-A and I simultaneously cared for my late mother who also suffered with the illness. My daughter has normal blood and is not affected.

1. I intend to speak about my late mother Agatha William-Brown, who was born on GRO-C 1937 and sadly passed away on GRO-C 2013, at the age of 76. Mum was infected with Hepatitis B (HBV), as a result of receiving a number of blood transfusions to treat her sickle cell anaemia.

4. In particular, I intend to discuss the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

5. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

6. Sickle cell disease is caused by a gene that affects how red blood cells develop. If both parents have the gene, there's a 1 in 4 chance that each child will be born with sickle cell disease. The child's parents often will not have sickle cell disease themselves and they're only carriers of the sickle cell trait.

7. In dehydrated, cold, damp or stressful situations the cells get caught and block the capillaries, causing a sickle cell crisis that renders the person incapacitated because of the pain. Mum would say that the pain was comparable to a hot knife being stabbed into her as well as being hit by a hammer in the same place at the same time. Morphine is the only thing that can relieve the pain.

8. The worst sickle cell crises, as they are called, are those that occur in the chest and in between the ribs. The person cannot take deep breaths and shallow breathing makes the lungs start to fill with fluid. This causes a lot of damage to the organs including but not limited to liver damage, kidney failure, heart failure and strokes. It also affects the bones and those affected suffer with necrosis (death of the bone). Even children can require hip replacements, as a result.

9. It is a very life limiting disease and sufferers have a very low life expectancy. The disease was not well understood in the UK during the 1970s and 80s but there have been advancements in treatment.

10. My Mum came to the UK from St Lucia in the late 1950s when she was 18 years old. She was unaware that she was pregnant at the time with my twin sisters. She moved over here to join her cousin in GRO-C and had planned to train as a nurse, but the hospital let her go because she kept being sick and was always in pain. She was told that she was not suitable for nursing.

11. My father (and the father of my twin sisters) eventually came over to be with my mother. They did not get married straight away, I believe they did after I was born. When I came into the picture, our family had settled in GRO-C. I am the youngest of 7 children.

12. Throughout her life she experienced pain, but did not know the cause and was later told by the doctors that she had arthritis. I am not sure how much of an issue the pain was in St Lucia because it has a warmer climate.

13. When I was at college aged about 24, my family was involved in a car accident. My parents were divorced at the time of the accident, but Dad came to pick us up from a family function. He was diabetic and had not eaten enough, so his blood sugar levels were affected, which I believe was the cause of the accident. It was not a severe accident because my father was only driving at 20mph when we mounted the pavement. I cut the inside of my mouth and my baby nephew (who I had been holding in the car) had a hairline fracture of the skull. Mum had some Pyrex dishes by her feet and all of the glass went into her lower legs. We were all taken to Kings College Hospital to be checked over.

14. Mum was still in so much pain, so she was transferred to another hospital. I think this may have been Croydon Mayday Hospital. My mother was hospitalised so much that I find it difficult to remember precisely when and where she went at any particular time.

15. At some point around this time, Mum was moved to St Thomas' Hospital. A doctor who was a pioneer in Sickle Cell Disease was over from America. I recall visiting Mum and this consultant telling me that she had Sickle Cell Disease. I asked what that meant and it was explained to me. It was also suggested that I was tested myself and I eventually was and was found not to have the disease but I was a carrier. Mum would have been 50 when she was diagnosed, I was still living with her in GRO-C at the time.

16. Mum started having regular blood transfusions (on average 3-4 times a year), but they did not seem to make her better because she remained in continuous pain. I remember on one occasion, she was told that her blood was so bad that it had to be administered via her neck. It was very traumatic – Mum was swung around on some apparatus, so that she was almost upside down. I was there and witnessed this. I was about 32 at the time, so this would have occurred in the mid 1990s.

17. After this quite traumatic blood transfusion, the hospital started to give her Hydroxyurea – a drug also used to treat people with cancer. It has the same effects as chemotherapy and can make men infertile.

18. Mum had to have a shoulder replacement because she could not lift up her arm beyond a certain point. During the procedure she received a couple of bags of blood.

19. In the year that my mother passed away (2013), she was taken into St Thomas' Hospital in a confused state with a marked deterioration in her memory. She was treated for an infection with antibiotics, but remained confused and it was clear that she had some a kidney infection due to dehydration, diabetes and her sickle cell condition. It was during this time that we were told a liver function test had been carried out and had returned abnormal results. This prompted the doctors to screen her for hepatitis, which came back positive for HBV.

20. I went to visit Mum at St Thomas' and the registrar was talking to me about how she was doing and what care was being given. During the conversation she just threw in the comment '"....and with your Mum's Hepatitis B, which has affected her liver"..... I did not know what HBV was at the time and I thought it was

something to do with people who inject drugs. I immediately knew that it was something dangerous, but did not know it was linked to the liver.

21. We were informed at the time that my mother could have been infected from any one of the 8 blood transfusions she received from St Thomas, or the one from Croydon University Hospital and that an investigation was underway to trace the donor. My memory is that Mum had far more blood transfusions than that, though this comment may refer to the blood transfusions she had before blood supplies were routinely screened. We never received a satisfactory response to this.

22. I wrote to the Chief Executive of St Thomas Hospital, Sir Ron Kerr on the 7 February 2013 because my family and I considered this to be a matter of clinical negligence. The specific issue of my mother's HBV is among other aspects within the letter that are mostly not directly relevant to infected blood. I exhibit this letter as **WITN4729002**.

23. I did not receive a response to this letter, so on 17 April 2013, I sent another letter Sir Ron Kerr, by email and by hand. I exhibit this letter as **WITN4729003.**

24. In response to the second letter, I received what looked like a generic initial letter (apart from names and dates) from a Guy's & St Thomas' complaints officer, merely explaining that my concerns would be investigated and that I should receive a response within 25 days. I exhibit this letter as **WITN4729004.**

25. On 21 May 2013 I received another letter from the same department, explaining that the investigation in to my mother's case was taking longer than anticipated and that it may take a further 4 weeks. I exhibit this letter as **WITN4729005**

26. I never received another response beyond that, as far as I can be aware

27. The numerous blood transfusions Mum received for the treatment of sickle cell disease, can be the only way she contracted HBV.

28. Mum was kept in hospital for the most part of 2013. She could not be on her own and so we had to make a lot of adjustments in my house so that she could come and stay. The social services arranged for a bed and commode to be put in the

living room and carers were allocated. However, there was a problem which meant that GRO-C Council (where she lived) and GRO-C Council (where I lived) argued over who would pay for the care. This meant that Mum had to stay in hospital for a further 6 months when she was clinically well enough to go home.

29. Mum sadly passed away on GRO-C 2013. I remember adema (swelling and inflammation) and liver disease were mentioned on her death certificate.

Section 3. Other Infections

30. As far as I am aware, my mother did not contract any other infections other than HBV as a result of being given infected blood.

Section 4. Consent

31. I have been asked by the Infected Blood Inquiry whether my mother would have consented to any treatment or tests. It is very likely that Mum was treated without her explicit, informed consent because of her character – she would have said yes to everything because she had complete faith in the medical profession. However, it would be impossible for me to provide specific instances.

Section 5. Impact

32. Mum's extensive medical problems impacted her whole life and it is very difficult to distinguish the impact of HBV from the impact of sickle cell disease.

33. Mum had a lot of medical issues that arose from her sickle cell anaemia. Whilst most of her health problems did not come from being given infected blood, this was another issue that she should not have had to deal with, compounding that which she was born with. By having faith in the NHS, she was inflicted with another infection that must have had an impact on the rest of her health. Over the years she unknowingly had HBV, this would have had an even greater impact on her organs because of the sickle cell disease. People with sickle cell have a weakened

immune system and cannot fight infections well because the spleen is compromised. They have to take penicillin every day.

34. Mum also suffered with arthritis and whilst this was independent from sickle cell disease, it would trigger a sickle cell crisis. Likewise, a sickle cell crisis would trigger an arthritis flare up. Sometimes the doctors would be confused over what occurred first. Sickle cell disease caused the primary pain and the arthritis was secondary.

35. My mother's abdomen grew in size over the years and I was told that her organs were swollen. I looked at photographs of her and when she was my age we were the same size, but as time went on her middle expanded. I recall having a conversation with a doctor who told me that her spleen was enlarged, but it was too dangerous for them to do anything. This conversation was before I met my husband and had my children, so would have been in the mid 1990s. Her abdomen further expanded after this point, which made me think it was not just an enlarged spleen that caused increase in size. It was never explained to me that the cause of the problem could be ascites and I do not remember any fluid being drained from her stomach.

36. I was a mother of young children at the time of Mum's HBV diagnosis and I was scared if my mother had given it to my children – I was particularly worried about my son, GRO-A.

37. I had to think really hard about whether Mum should come to live with us when she was unwell or whether she should go to a home. I had a conversation with my husband about this and we decided that she would stay with us. Mum was physically in my home for approximately 3 months during 2013, as she spent most of that year in hospital.

38. I have never been tested for HBV and neither have my children.

Section 6. Treatment/Care/Support

39. No one ever offered any counselling or psychological support to my Mum or any of her family.

40. I feel that psychological support should have been offered because we were only told of the infection in passing and were not sat down properly to be told the news. It was all very matter of fact. I was very disappointed and upset because no real care was ever given to Mum.

41. My Mum was very old school and did not want to be any trouble or create a fuss to any medical professional. No matter what they said to her, she would have accepted it. In Mum's generation, doctors were put on a pedestal and were believed to be individuals to have faith in – Mum would have put her life in the hands of the professionals and would never question anything.

Section 7. Financial Assistance

42. My mother and I were never made aware of any funds or government schemes that were set up for the victims of those that were given infected blood.

Section 8. Other Issues

43. I first heard about the Infected Blood Inquiry when I attended the Sickle Cell Society's AGM in summer 2019. A representative from the Inquiry spoke about it's work and objectives and I thought it was of relevance to Mum. I spoke to them in the lunch break and mentioned that my mother had passed away. I was assured that Mum's story was still important.

44. The same representative spoke at the online Sickle Cell AGM in 2020 and said that she would pass my details onto the relevant person.

45. I wanted to be able to tell my Mum's story and even though it cannot help her now, I hope that it will help someone else.

46. I feel that the NHS needs to learn from the contaminated blood scandal and make amends where they can. In providing this statement, I feel that I have had the opportunity to provide some input into that.

47. The Inquiry Investigator has explained the type of places where the infected blood was sourced from. I therefore believe the governments of the time did not care how they came by the blood and made efforts to cover up this scandal.

48. People who suffer with sickle cell disease tend to be of African heritage and I believe that 'we' have been side-lined by the NHS and made to feel as though we are not important. The way the disease was dealt with by the health profession was I believe, racist and it is not treated in the same way as other life limiting health conditions are. The fact that sufferers were also given infected blood is another thing on top of this and checks should have been made to ensure the blood was safe.

49. I would also like to add that the trust within that African & Caribbean community is very low generally. This I believe stems from stories that I recall from my childhood about experimentation around the world. It was also a long time before sickle cell disease was recognised let alone understood here and I believe that this mistrust in the medical and governing authorities extends to this day. You only have to look at the lower take up of the covid vaccines among this community to see that this is the case. It would also not surprise me at all to hear that people from the African & Caribbean community were reluctant to become witnesses to this inquiry.

Statement of Truth

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

Signed GRO-C

Dated 5th JANUARY 2022