Witness Name: Trevor Clarke

Statement No: WITN5416001

Exhibits: WITN5416002

Dated: 04 March 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF TREVOR CLARKE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 December 2021.

I, Trevor Clarke, will say as follows: -

Section 1. Introduction

1. My name is Trevor Clarke and my date of birth is GRO-C 1956. I live in South East London and I am a retired civil servant.

2. This statement is written with regards to my late partner, Enid St Cyr, who was infected with Hepatitis C through blood transfusions and passed away in 1999.

3. I am not legally represented, and I am happy for the Inquiry team investigators to assist me with my statement.

Section 2. How Infected

4. Enid was born in GRO-C on GRO-C 1954. She came to the UK sometime in the 60's, as a teenager.

5. Enid's mother would be considered part of the currently used term, the Windrush generation. Her mother, along with thousands of others, left the West Indies for the UK in the 1950s and 60s. Like many other children, Enid was initially left behind. Her mother established other relationships here, and had other children; they were a bit younger than Enid when she arrived in the late 1960s.

6. She grew up in GRO-C, where there's a close-knit community of St Lucians and other West Indians. There were always events going on; Enid was very sociable, popular, and got herself involved in all manner of activities. She worked at Lambeth Town Hall.

7. Enid was born with Sickle Cell Anaemia, the most extreme form of Sickle Cell Disease, suffering with pains almost daily. She was hospitalised often, and took various tablets. She was also seen by her GP regularly.

8. I met Enid in 1981. I'm more the quiet type, while she was always outgoing. There wasn't a time when she didn't want to be socialising: visiting or meeting up with friends and family; concert going; partying etc. She would go on day trips, or venture abroad to Spain, Portugal, France etc..

9. To enjoy life, such activities would always be a gamble on whether she remained relatively healthy or suffer the effects of a tiring body. There was a need to act and be perceived as normal.

10. When she first explained Sickle Cell Disease to me I didn't really comprehend the day to day physical and mental impact. When we started seeing each other on a regular basis, I had myself examined for Sickle Cell. It was a relief I didn't have any form of it.

11. There were a few days when there were no adverse effects on Enid's body, but these were rare. Still, she would always make sure she remained active . Most of her friends and family were aware of her Sickle Cell, but they weren't completely aware of the efforts she made to have as normal a life as possible.

12. Most of the time she would have either headaches, stomach aches, joint pain, or breathlessness. Sometimes it was a combination of these various aches and pains. After any weekend of entertainment and/or activities, she would be extra tired and needed time to recover. I can't remember the various tablets she was on; folic acid was one of them.

13. One of her biggest fears was having to go into hospital – it usually meant a few weeks in that environment. She may be suffering quite a lot, but she would always try to go to work whatever the pain.

14. Everyone is different suffering in contrasting ways, with various parts of the body affecting them. Enid was particularly worried about her leg; the area just above the inside ankle; she was always careful to avoid the slightest knock in case it triggered the development of an ulcer – one of the consequences of Sickle Cell.

15. A comment I heard was that, before I met her, her leg had reached such a state that her consultant recommended skin grafts to lessen the chance of ulcers occurring; apparently, her mother did not submit to this request.

16. When we began seeing each other, we maintained most of our separate interests but made sure we would meet up to spend time together. When I detected she was suffering more than usual, I would stay at her flat until she felt able to cope on her own . There were a few sleepless nights. Occasionally, I would need to phone an ambulance to take her to hospital; quite often, it would be early morning before I left the hospital after she was designated an hospital ward.

17. My description of her sickle cell crises would consist of her whole body burning up internally; everything in pain. When in crisis, sometimes she felt unable either to lie down, or sit down at the same time; there was nothing one can do about it but tough it out until treated in hospital. No tablets could provide relief – the only option was hospital for administered pain relief.

18. At that time, when admitted into A&E, the hope was to be quickly identified as someone having a crisis. The main course of action was receiving diamorphine and blood transfusions; the diamorphine to relieve the pain, and the transfusions to help with the sickling in the blood.

19. Enid had many blood transfusions; at first, I think she received them about three times a year when admitted to hospital. About 95% of these were administered at St Mary's Hospital, Paddington and on a few occasions at Kings College Hospital, London.

20. When I met her, she was living in GRO-C , not far from Kings College Hospital, but she preferred to go to St Mary's Hospital (as from the time she arrived in the UK) where she was well-known and had well-established relationships with doctors and nurses.

21. At St Mary's she was given care more swiftly and effectively. At that time, she was less willing to go to King's as it usually took hours to be properly identified, examined, diagnosed, and treated by medical staff in A&E. Invariably there was less urgency, and on average seemingly less awareness of the pain and effects of Sickle Cell Disease. The extra hour of excruciating crisis pain of waiting, then getting to St Mary's Hospital more than compensated for the hours on a trolley in another hospital without attention or pain relief.

22. In those days, I don't know whether it was the norm, but when the ambulance service was contacted and she asked to be taken to St Mary's, they would normally oblige. There were rare occasions where she was so delirious with pain she was undecided where to go; or the ambulance crew were adamant in taking her to the nearest hospital, which inevitably was King's. But usually, when insisting on going to St Mary's, the ambulance service agreed.

23. Occasionally, a family member or friend would be on hand to take her there by car. On those occasions, she was aware there would be a build-up to a crisis and able to plan ahead.

24. In those earlier days, when she was admitted, she would be in hospital for four or five weeks; sometimes a bit shorter. During those periods of hospitalisation, she would be given numerous blood transfusions.

25. Her treatment changed in the mid-1980s, whereby blood transfusions were given on a regular basis as a preventative measure, at least every one to two months up to the time of her death in January 1999. The transfusions were given to her outside of the crisis mode, to keep the blood from sickling.

26. Enid was extremely fortunate with the medical staff who looked after her, compared to others with Sickle Cell Disease.

27. Enid and I were engaged but not married. In 1988, we bought a house and moved in together. We had Wills drawn up; also, we later certified joint parental responsibility documents regarding our daughter. We knew it was more likely Enid would go before me; we made plans in case that eventuality occurred.

28. On GRO-C 1989, our daughter was born. As well as her sickle cell anaemia, Enid had gynaecological complications and told she would never have children; that however, turned out to be possible!

29. Our daughter was born at St Mary's Hospital and both received the highest level of care under the best consultants, professors, nurses and gynaecologists available.

30. I was with her when she had the baby. Enid stayed weeks in hospital after the birth. This wasn't totally unexpected as it was made clear given birth would be risky and it was uncertain how healthy the baby would at the time of birth. However, I hadn't comprehended how dangerous the birth was until I overheard doctors concurring sometime after, with one saying "Yes, we nearly lost her."

31. Enid was in intensive care for some time, and the baby specially monitored for a while. I don't think she held the baby for about two weeks after the initial contact at birth. She was isolated in a room where a nurse was designated to monitor her constantly.

32. I believe Enid found out that she had been infected with Hepatitis C (HCV) as early as 1987/88. I have in my mind that she told me about the diagnoses when she was still living in her flat, which would have been 1988 or earlier .

33. Since Enid was given blood transfusions frequently, I am unable to indicate when Enid was given infected blood or showed any resultant effects. Until she was informed about the HCV, I/we would have assumed any symptoms would have been part and parcel of the on-going effects of Sickle Cell Anaemia .

34. The numerous blood transfusions were the only way that she could have been infected. She didn't have tattoos. She never touched alcohol or drugs. She had her ears pierced at a reputable place.

35. As for the "general" risks of frequent blood transfusions, she was aware of the long-term effects but she needed them to either maintain recovery from, or stave off recurring Sickle Cell crises.

36. It was difficult, especially knowing the more blood transfusions given, the more the iron levels would have an effect on liver, heart, kidneys etc. You're between a rock and a hard place; needing transfusions, knowing they could eventually have a bad effect on the organs.

37. I can't remember how she was told about the HCV. The diagnosis must have been at least recorded in some form of documentary evidence, such as hospital notes and letters to her GP.

38. I think with the kind of relationship she had with her doctors, they would not have fudged the issue at all. But I'm not sure when, how or what precisely she was told; I did not attend with her, what became the numerous routine medical appointments within which some tests were conducted.

Section 3. Other Infections

39. I do not recall any other infections, sickness or complaints that would not have been considered part of the Sickle Cell Anaemia regime.

Section 4. Consent

40. Regular blood transfusions were the norm for dealing with Sickle Cell Anaemia, therefore consent was not sought.

41. Enid was not tested on without consent – at least not to my knowledge. All I can remember is that from around the mid 90's, Enid had a series of blood tests. I cannot recall any precise outcome from these. During that time, she was regularly going for appointments at St Mary's to see various consultants, including scheduled appointments to receive blood. She was also seeing her GP on a regular basis.

Section 5. Impact

42. Being told that she had HCV would have devastated Enid with extreme worry, but in the context of a lifetime of suffering, albeit with a few good days from time to time, she was attuned to taking each day as it comes, trying to make the best of it, especially for her daughter born against the odds.

43. Up to the point where the physical effects of HCV was also known to be having an effect, it would have been experienced as part of suffering i.e. regularly feeling sick, tiredness, frequent joint and muscular pains, abdominal pains etc.

44. Therefore, for quite a while, without taking account of the effects of HCV on its own, any intensified occurrences or frequency of pain would have just been assumed to be the continued effects of Sickle Cell Anaemia . There was no specific HCV support offered at the time. There was disability related support offered from the mid-1990s onwards which came in the form of e.g. the Motability Scheme.

45. Being proud, private, and determined; Enid hid her daily struggles and participated in any and every event where possible. She attended functions, dances, holidays, knowing she would suffer the effects either during and/or after.

46. Most of her friends and family were obviously aware of her health problems since she was hospitalised on a frequent or lengthy basis. But they didn't necessarily comprehend how she suffered getting through each day outside of hospital.

47. Although it may be difficult to differentiate some of the effects between the Sickle Cell and HCV, I am sure that by 1998, at the latest, we were both increasingly concerned about how HCV was affecting her body. I do remember leading up to the last time she was hospitalised, it was at the forefront of her thinking.

48. I am certain Enid would have been told the ramifications of HCV, but at what stage I do not recollect. I do not recall any extra measures being provided; I assumed it would have been incorporated into her general health management.

49. Confirmation of HCV remained a strictly private matter, therefore stigma was not an issue. It's quite possible there may have been a few people she told; overall, it was not in her nature to do so, with this desire not to be side-lined as being different. Plus, in the community she circulated in, there are always the ignorant few who embellish or exaggerate stories beyond reality; to avoid this, she would not have wanted people to know her circumstances.

50. Although she didn't face stigma in general, at least on one hospital admission, as I recall, she was put in an HIV ward. I had to dress in protective gear on each occasion, in what would now be called PPE, before being allowed to see her. It was never explained why she was in there. Naively, any concerns about wearing protective gowns in an HIV ward was secondary. The fact that she was being treated as quickly as possible was the main concern. That was in the early 90's.

51. Back then there were scare stories about people having AIDS. I had no concerns about entering an HIV ward; I was more fascinated by the high security and the hush-hush secrecy associated with the ward.

52. One thing to note, despite decades of "concern" not enough is known still about Sickle Cell Disease and its effects. Enid was very, very lucky with the medical care she received. She witnessed other Sickle Cell patients who didn't receive the treatment or understanding she had. It probably comes down to the lottery of knowing the right people and fortunate to be in the right location to receive the expertise and care.

53. I can remember one example of this very young, demur and personable young man. Whilst he was hospitalised in the same ward as Enid, he needed desperately to go to an employment interview. Despite being in some discomfort he was very driven and determined not to miss his interview opportunity. He came to an understanding with the staff nurse he would be back. When he did return, they had given his bed to someone else; he left the hospital in mid-treatment.

54. As for the impact on Enid's work, her colleagues were generally very understanding. They were empathetic and would send her home if she was struggling due to the pain, despite her best efforts. Her bosses ensured her annual leave allowance wasn't affected, and made allowance for extended sick leave.

55. For a long time, she didn't have any major problems if she had to take days off due to crises. But in around 1995, there was a change in management personnel in her department; the new managers took a different stance where the work came a definite first and the welfare of staff became secondary. She was eventually manoeuvred into taking medical retirement.

56. Of course, the main impact is that Enid passed away. That was on 17 January 1999.

57. She had been in hospital for a couple of weeks at least. I was visiting her as often as possible, regularly picking up our daughter from After School Club during the week and taking her to see her mother.

58. Enid passed away on a Sunday. I had no inkling that anything was worse than usual. I arranged for my daughter to have her hair newly plaited by my cousin

so she would look her best for her mum. I was late getting to the hospital, feeling anxious for my daughter to spend the maximum time allowed with her mum.

59. Nevertheless, for me it was just one more hospital visit. When we arrived, I saw Enid's mother and two or three siblings around the bed, with the curtains drawn. That's when I was told she had died.

60. The hospital had always been given the impression Enid's mother was next of kin, no doubt dating back to Enid's teenage years; I hadn't been too bothered correcting this later. I'm certain the hospital telephoned her mother first when Enid passed away but no one bothered to contact me.

61. On the one day I was late, was the day Enid passed away. On reflection, it is possible that if my daughter and I had arrived earlier, she would have seen her mum pass away. In hindsight, perhaps being late was better for our daughter, given her tender age.

62. The next day, I returned to St. Mary's as arranged formally to see someone in their Administrative Office; to my surprise Enid's mum was already there, presumably on that assumption she was considered next of kin. I was presented with a prepared Death Certificate but was confused as to why HCV wasn't listed as one of the causes of death. The investigators have taken a copy of the Death Certificate **(WITN5416002)**.

63. I think I'm good at discerning non-verbal behaviour and having asked a few questions, it seemed as though these were being deflected; the atmosphere seemed uncomfortable. Although dissatisfied with responses, I wasn't in the state of mind to pursue anything at length; I was more wrapped up in the loss of Enid and the effects of this on our daughter; I decided the discrepancy was relatively unimportant in the context of the moment.

64. Enid's mother was shrewd and canny but totally subservient to authority and avoided any perceived social stigma at all costs. Therefore, if indeed she was aware that HCV wasn't recorded on the Death Certificate, there is no doubt she would have complied with its omission. However, at that time, I felt there was a

willingness to avoid close questioning or complications from the hospital's point of view.

65. Needless to say, the other major impact would have been concern for our daughter's welfare having lost her mum.

Section 6. Treatment/Care/Support

66. Given that Enid was already receiving medical care for Sickle Cell, I think the HCV diagnosis was incorporated into that treatment. I do not remember any sudden or significant changes to indicate otherwise.

67. I can't remember being told specifically that there was a change in management of her condition, or any specific HCV medication.

68. She was given excellent care. At St Mary's the consultants, nurses and professors who provided her with care were very empathetic. A few names I recollect were Professor Loeffler, Professor Wickramasinghe, Professor Bellingham, Doctor Sheridan, Doctor Leonard, Doctor Abdullah and Nurse Wilson. Her local GP, Dr. Kakad, would also pay home visits.

69. Looking back, I can't remember when or what we were told about transmission of the HCV. I was aware of some of the "do's and don'ts" in terms of hygiene safety but that possibly wasn't until the late 1990s.

70. I think she was offered counselling but wouldn't have asked for it. She definitely did not take it. On the more practical side, after medical retirement, she was offered services like gardening through the various disability related support schemes available at the time.

Section 7. Financial Assistance

71. Approximately six or seven years after her death, I read about the Skipton Fund and applied.

72. The main purpose of applying to the Skipton Fund was for confirmation and recognition that Enid was infected with HCV.

73. Although submitting the application was not based on financial considerations, I was determined any amount awarded would be placed directly into my daughter's account, acting as a direct link/ gift between mother and daughter.

74. The award also signified, in my mind, righting the wrong of a cover-up at the time of her death i.e. the award from the Skipton Fund affirmed the belief that infected blood was not acknowledged, reported, recorded, or registered as one of the causes of death. It confirmed my long held view that I was deflected from questioning its absence on the Death Certificate.

75. In 2005, I received a payment; I was informed it was the one and only final payment; I am sure it was conveyed in writing that the one-off payment precluded any subsequent awards. I cannot now recall the amount I received.

Section 8. Other Issues

76. I came across the label Sickle Cell in the 70's; for me, this never-ending story has been rumbling on since then. I have a sense of frustration, questioning whether the subject will it ever lead to substantially noticeable concrete action and change.

77. From time to time, I read recurring articles about the difficulties, unbelievable mistreatment of individuals, and avoidable deaths faced by people affected by Sickle Cell. The impression is, despite isolated incidences of good practice, the numerous studies and statistical surveys producing undeniable facts, the so-called caring professions, still lack empathy, awareness and/or expertise on the effects of Sickle Cell.

78. Is it a blatant fact that, as in all other facets of society, ethnic minorities' welfare remain way down the pecking order?

Statement of Truth

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

Signed GRO-C

Dated 04/03/2022