

Witness Name: Jayne Elizabeth Kouadio

Statement No.: WITN0131001

Exhibits: **WITN0131002**

Dated: 15 January 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF JAYNE ELIZABETH KOUADIO

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2 January 2019.

I, JAYNE ELIZABETH KOUADIO, will say as follows: -

#### **Section 1. Introduction**

1. My name is Jayne Elizabeth Kouadio. My date of birth and address are known to the Inquiry. I am a healthcare support worker and have worked for the same company for 13 years. I am married and have three children; a daughter who is 31, and two sons who are 21 and 10. I intend to speak about my Hepatitis C (HCV) infection. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.
2. My infection and the memories I am recalling occurred some time ago, and as early as 1987. I have not had the benefit of my medical records, so the dates I have provided are approximate to the best of my knowledge.

## Section 2. How Infected

3. During the time before my infection, I was happy with my first love, my first real boyfriend and I was looking forward to giving birth. My daughter turned breach and I came into labour 3 weeks before my due date. During my labour I had Pre-eclampsia and so I had to have an emergency Caesarean. However, on GRO-C 1987 I had my daughter and I was in Fairfield General Hospital, in Bury. The baby was healthy but I felt very poorly. They took my bloods and they showed that my iron was low. A few days later, the Doctors decided they needed to give me a blood transfusion. It would have been in or about 17 April, but I cannot be sure of that date.
4. When the Doctor came in and told me about it, I immediately said I did not want it. I remember my exact words: "*I don't want someone else's dirty blood*". The doctor tried to reassure me by saying all the blood had been screened, because HIV was quite big back then. I still said I did not want it but, being only 17, I was quite young and I felt like I could not argue with a Doctor. They commenced a blood transfusion not long after.
5. I hated every minute of that blood transfusion. I had seen somebody else having one on the ward and it knocked me sick. I remember thinking, "*God, I hope I do not have to have one of those*", and then I ended up having one.
6. I cannot say it was an allergic reaction half way through the transfusion, but I did have a severe reaction to the blood. My mum and dad were there at the time. It was the second bag of blood and I suddenly just got boiling hot, turned this orange colour that I have never seen in my life and was itching like mad. The Doctors withdrew the blood straight away. I was scratching and I had rashes all over me. I also had a lot of abdominal pain.
7. After that, I was jaundice and they did not understand why. My liver function tests were all over the place. I was in hospital for about 3 ½

weeks, but eventually things must have calmed down for them to discharge me. I remained an outpatient at Bury General (now defunct). I was under the care of Dr Turck, Consultant Physician, and I had to go there often for blood tests.

8. In or around 1992, it was one of my friends' 21<sup>st</sup> birthdays and we had gone to Blackpool. We had gone away for the weekend and I had to come home before the first night was even over. I came out in this horrible rash and my joints were so sore. Thinking about it now it was probably the HCV having a bit of a flare up.
9. I went to the doctors and they just said it would be a virus and did not treat me for it. They gave me painkillers and told me to take bed rest. I just carried on with my tiredness and everything. But then I started to get high blood pressure. It is not hereditary because nobody in my family had it. It was ridiculous when I first went; it was something like 200/110.
10. My mum phoned me one night and just said that she had seen a preview for a programme on Panorama for anyone who had a blood transfusion before 1990. I think that was about 1993. It was going on about HCV, because apparently in 1990 HCV was not a recognised disease and they had come up with this new disease that had exactly the same symptoms as those I had been getting over the past 6 years. It sounded like they were talking about me. So I spoke to my GP, Dr GRO-D at GRO-D Medical Centre in Bury, who said he thought I was being silly but that he would give me a blood test anyway. He was then really apologetic a few days later when he had to tell me that I had tested positive for HCV.
11. I was not given any information about how to manage the HCV. I was devastated and it was the first time I have ever seen my dad cry. I think that information should have been provided to me; the doctor probably just did not want to scare me though with me being a bit vulnerable I suppose. I was 23 when I was diagnosed.

12. As to how it was communicated to me, I do not have any thoughts. I was not really told about the risk of infection to others until I was seeing Dr Dunbar. My GP did not say anything about that, but Dr Dunbar said that maybe my partner should be checked and also the baby. They were tested and both were fine. However, that was at the Consultant level and the GP should have said something before then.

### **Section 3. Other Infections**

13. I do not believe that I have received any infection other than HCV as a result of being given infected blood.

### **Section 4. Consent**

14. When the doctors advised that I needed a blood transfusion, I told them that I did not want it. However, I was poorly and so young that I do not remember all of the conversations. I know that in my medical notes one nurse, not the doctor, had written that I was not happy about the blood transfusion. I know this as the nurse recorded this fact in written evidence as part of litigation I have been involved in (case reference no: IJW.CM.12543).

15. There is now shown to me marked **Exhibit WITN0131002**, a witness statement of Ms Elizabeth Whitehead (Midwife Grade G of Fairfield General Hospital). In Ms Whitehead's statement, she refers to 'NM001A.' I understand NM001A as being me. **Exhibit WITN0131002** reads as follows:

*[...] [6] "The records show that on the 16 April 1987 I recorded: - "IBI drugs given by Dr Manns – 2400 hours. Seen by Dr Turck -0040 hours. Fluid balance charts maintained. Legs + ankles remain puffy. PT (patient) not happy re:- blood transfusion.*

*[7] I believe that the reference to the patient not being happy meant that she was unhappy about the fact that she was to have a blood transfusion. This may have been for a number of reasons. I am certain that had NM001A told me that she did not consent to or that she refused to have the transfusion, that I would have recorded in the notes that she did not consent to the transfusion I believe that I would also have discussed this refusal with her, to ascertain why she did not want the transfusion. I would have sought to reassure her and would have advised her to think about it and to discuss her concerns with the Doctors. In those days there were often Doctors available on the Unit throughout the day and night and it is likely that I would have asked a Doctor to speak to her that night, if she had said that she refused to consent to the transfusion and was very upset regarding the matter, unable to settle to sleep.*

*[8] I would also have informed the midwifery staff who were taking over her care in the morning about the refusal to consent to the transfusion and of the need for a member of the medical team responsible for her care to discuss the matter with her about it. It was not normal practice in 1987 or now, to obtain written consent from patients for blood transfusions. The reasons for procedures or for any treatment are explained to patients either by medical staff or midwifery staff, depending on the treatment required. The decision to advise a patient that a blood transfusion was necessary, such as in this case, would usually be made by the medical team who would discuss the reasons behind their recommendation with the patient.*

*[9] I cared for NM001A again on the nights of the 18 and 19 April. By the time I came back on duty on the evening of 17 April the blood transfusion had been completed. I recorded that NM001A was seen by Dr Woolfman at 2145 hours, and that the intravenous infusion was discontinued, but the cannula left in situ. I note that a colleague recorded that the cannula was resited during the day, because the previous line had tissue. The second unit of blood was subsequently recorded as transfusing well. There was no further reference to the blood transfusion in the patient's records [...]*

16. As far as I remember I never signed a consent form. I tried to take them to court for that non-consensual blood transfusion. All the way through they said I could have been treated with iron, until we went to court and an expert said I had to be treated with a transfusion.
17. My mum and dad came to visit me in the evening and were horrified to see that I was in the middle of a blood transfusion because nobody had signed for it and they knew how against blood transfusions I was. I remember my mum being really annoyed. I was under 18 and my mum and dad had not signed a consent form. My mum challenged the doctors and they just said they had no choice.
18. My objection to blood transfusions is just the fact of it being from somebody I do not know. They could be a drug user or anything. You just do not know. I have always viewed them as dirty.
19. I know I was given the transfusion against my will, but I have always thought that I am one of the lucky ones because it got found early. The HCV has gone and my children have still got me. My Consultant after testing positive was brilliant, but there was definitely a gap in information being given to me at the GP level.
20. I believe that all those people who were given that blood transfusion were guinea pigs for new drugs that were being made. I think it was all for the pharmaceutical companies. I may not have any evidence to support that, but it is how I feel.

### **Section 5. Impact**

21. Initially, I was back and forth to and from the doctors. It was only from the Panorama show that I got the blood tests and I had to push the doctor to do it. He did not want to. After I tested positive for HCV, I was referred to a Consultant at North Manchester General, Dr Dunbar. When I went to my

first appointment there I was horrified that I had to go into the Infectious Diseases Ward. I was so embarrassed because AIDS was a massive thing then. I just thought everyone would think I had HIV if they saw me going in there. My first appointment was a bit scary. They took my bloods again and explained they would have to do a liver biopsy. I had the liver biopsy on 8 March 1995. Just being on that ward was awful because it was full of drug users and alcoholics.

22. The liver biopsy itself was awful because they cannot anaesthetise the liver as it is in an encapsulated space. They came back to me with the results a couple of weeks later and my liver was already badly scarred. They brought me back in to tell me the results. They told me there was a drug to treat me called Interferon that had only a 25% chance of working, that it was all that was available at the time and that it was very expensive.

23. There were then difficulties around who was going to pay for it. I remember there being all this talk about £10,000 and this and that. That made me feel great, just great. My life expectancy had been shortened and they did not even want to pay for the drug to treat me. I had to think about fundraising at one point so I could pay for it myself.

24. I do not know whether my GP and Consultant got together. I do not know how the funding was agreed, but I got it in the end. They should not have discussed how much the medicine cost when they were the ones who gave me the disease in the first place. It is disgusting to discuss that in front of a patient. The cost of treatment was nothing to do with me and it should never have been an issue.

25. They explained that I could have headaches and flu symptoms and soreness in the legs. I commenced on the Interferon immediately after the liver biopsy results and was trained how to inject myself on the legs. It was over a period of a year. I have still got the diary upstairs of when I was doing it so I could record any side effects, if any.

26. The Interferon was awful. I had to inject myself in the leg every other day. I always hid myself away to do it because I did not want my daughter to see it. I used to go into my bedroom and do it. I just did not want her to be horrified by needles and by her mum injecting herself. I used to set aside that time to just be by myself. I did not want to have to explain it to a 6 year old. I would just disappear every other night into the bedroom.
27. Being honest, I did not have any side effects. However, I could not go on holiday, or even go away for the weekend, because I was too embarrassed about the needles. People might have thought I was a drug user or something.
28. I had 6 monthly blood tests after that for a year. I only had two checks on the liver function tests. I was told it could come back, but Dr Dunbar said if my levels had gone after two consecutive blood tests and it had not come back, the chances of getting it again are very low. After a year I went for another HCV test and luckily I was cleared. Dr Dunbar said out of all the patients he had, GRO-C I was the only patient who had not got it through self-infliction. This was in or about March 1996.
29. I was put on beta-blockers for my high blood pressure and have been on them ever since. That makes 27 years now. I am sure that is due to the after effects of the blood transfusion. I have always been breathless on my beta-blockers and they cause weight gain and tiredness. I cannot do vigorous exercise because they slow your heart rate down. So I just plod on. There have been no further complications other than high blood pressure and weight gain.
30. I have had a lot of gall bladder and bile duct problems. I have had my gall bladder removed. I am always in pain every day on my right hand side. I had stones in my bile duct removed but now the stones are back again. I do not necessarily attribute this to what has gone on with the HCV. I think that is just life. But you never know. I am waiting for an MRI to check my



bile duct stones have gone. The doctor will check my liver at the same time. I am on a lot of vitamin tablets for tiredness and things. But I feel absolutely fine other than my bile duct issues.

31. I never researched into other treatments and nobody ever made me aware of any. I believe there have been quite a few since. I was just reliant on the medical professionals steering me in the right direction.

32. When I had to tell the dentist that I had HCV he was off with me. He just went 'oh right, I'll write that down in your notes' and wore extra rubber gloves. I am not with him anymore. I have always been paranoid about the dentist now. I just think they are a bit off-handed. However, it has not stopped me from going.

33. At the age of 20 I felt like an old woman. I used to look after my baby nephew on a Saturday and I used to have to have a sleep halfway through the day. That is how tired I was. I was like that until I had the treatment for HCV. I was just tired all the time like an old woman. If I went out with friends, it used to take me 4 days to get over a night out not realising it was actually my liver. When feeding my baby, even when I got home I was just scratching and scratching; literally while I was feeding. My skin was bleeding because I was just scratching all the time. I would just sleep during the day but I could not explain why I was so tired. All while trying to see to a youngster, and my nephew at the weekend.

34. From the age of 11 I carried a donor card around with me. It is something I felt really strongly about because a friend had died of leukaemia. My mum was quite surprised when I applied for a donor card at that age. But now, because of the blood transfusion, I am not allowed to donate blood or organs. This has probably upset me more than anything else that that choice was taken away from me.

35. My youngest does not know anything about it. The middle child does not really know much about it either. I just do not want them to know. My

eldest daughter is obviously aware and she is so pleased that the Inquiry is coming. She keeps saying I need to get justice because it really affected her as well. I have sheltered the younger two from it.

36. As part of my original court case, I had to go to Nottingham to see somebody at this hospital for a private examination and blood tests. It is all a bit of a blur now, but this is something that my daughter remembers because I had to take her with me. The poor girl got dragged around with me. When we went to Nottingham we missed the last train back and she was hysterical that we were stranded at the station at night. We ended up getting a taxi back but she was absolutely terrified at the time.

37. I have got a good circle of friends that I can discuss anything with. I never have to feel ashamed. There are three of us. It took me a while to discuss things in detail, but at the beginning I used to say that I was poorly. I never wanted to discuss it in depth because it is upsetting and I just put it to the back of my mind.

38. My mum and dad were just devastated - it affected them really badly. My dad just kept saying he could not believe how unlucky we were and that we were always getting bad luck. The family were just going through uncertainty; because no one knew anything about HCV. I asked the GP once whether I was going to die. He said no and that he would make sure I was around to see my daughter get married.

39. It was only very close people who ever knew. I just never told anybody because I was so ashamed. There was such a stigma at the time. Nobody had any knowledge about it. I knew how everyone was about HIV so I did not want anybody to know. I felt like everybody knew, like everybody could see it. I was paranoid if I cut myself. It made me feel so dirty. When I was on my period I was scared in case my kids went to the toilet after me; that was probably one of the worst things. I was scared in case my daughter caught it. I used to scrub the toilet after I had been on it.

40. My daughter was too young at the time to understand what it was. It was only later on in life that she grew very angry about it. She is such a good girl. She is a beautiful young lady, so protective of me. But it was only in her 20s that we spoke about it. She keeps saying, 'Mum you need to go and get justice'. What she means is that I should go and get an apology; that I should fight for whatever I can get because we went through so much.

41. I have never felt isolated because I have always had very good friends. At 17 I had left school. I went to college later on so it did not affect my education at all. I would not let it affect personal goals. I was just working part time at a local pub. I was going to college to do my nursing at night school. I did only work part time. I could not work full time because of a combination of circumstances and the HCV.

42. Financially, I had to pay the outlay involved with the court case but I am sure I was reimbursed because I had legal aid. It cost me money in the forefront though. I tried to get life insurance for a mortgage and one of the questions was whether you have ever been diagnosed with HCV in the last 5 or 10 years. So I had to declare that I had and my premium went sky high. The mortgage was also affected. I could not get a mortgage and had to reapply at a later date. There was still a little bit of a thing about my HCV because they say your life expectancy is shorter. Even on beta-blockers it is shorter. It was turned down because of the life insurance aspect and I could not afford to pay the premium on it. My dad had to stand as guarantor for me in case anything happened to me in the meantime.

## **Section 6. Treatment/Care/Support**

43. My treatment was a bit of an obstacle because of the financial side of it. As for psychological support, nobody has ever asked me if I need support. I do not recall my doctor ever offering me support since day one.
44. When the Inquiry Team attended to take my statement, it was explained to me that the Inquiry is involved with the British Red Cross. I understand that emotional and psychological support is available to me through the British Red Cross should I wish to have it. The Inquiry Team gave me a number I can call.

### **Section 7. Financial Assistance**

45. I have received financial assistance from the Skipton Fund. I found out about it because I phoned a medical negligence company. It came up on the radio and I thought I would try it. The person at the office said he could not help me because I had been given the blood transfusion over 10 years ago at that point. However, he mentioned there was a nurse in the office and so he spoke to her about it.
46. When he came back to me he asked if I had ever heard of the Skipton Fund. The nurse had told him about it and said it was set up to pay people who were infected with contaminated blood. He gave me the website and I sent them an email.
47. Skipton got back to me and I had to fill in a load of forms and get a copy of my marriage certificate because my name had changed. I also had to send them copies of the blood results from my GP to prove that I had been infected. I had to pay the doctor £25 for those results. Luckily, they said I was eligible. This was in or about 2014-2015.
48. I got a payment of £20,000 and I get £330 a month. I also get a winter fuel payment of £500 and that is on the 1<sup>st</sup> December. I have a letter from the Skipton Fund dated 31 May 2016 which says it was an ex-gratia payment,

but I do not know what this means. I have registered with the EIBSS. They contacted me voluntarily and I have had some correspondence off them.

49. I know I am one of the lucky ones as I am not chronically poorly now or anything. But I was still infected, so why should I only get the basic amount when there are people getting much more? I could be spending my time now making up for the time that I lost if I got more. I feel that I am being penalised because I only had to suffer 6 or 7 years, as opposed to still having to suffer from it now. But the mental effects are still there. I was given that blood against my will. I did not want that transfusion. The physical effects have gone but the mental impact will always be there.

### **Section 8. Other Issues**

50. As explained in paragraph 14 above, I have been involved in litigation. I was talking to a friend whose husband was a solicitor and I was telling her about my HCV. She told me to try and do something about it because what they did to me was disgusting. My friend put me in touch with GRO-C a solicitor based in Altrincham. I have letters from them as early as 1995 and it ended around 2000.

51. GRO-C sent a lady to come and take a statement and she was concerned with the non-consensual blood transfusion. The case went on for so long. It was going really well and I even had to go and see a barrister at one stage to discuss whether he was going to represent me.

52. There was an expert who had said that I did not need the blood transfusion in 1987. However, he turned around and changed his mind and said that I did and that collapsed the whole case. It made me absolutely distraught.

53. I know from the litigation that there is paperwork tracing the blood I was given. However, all the main paperwork from the actual buying of the

blood itself went missing. That was another reason why they could not go forward.

**Statement of Truth**

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

Signed

GRO-C

Dated

13/01/2019