Witness Name: GRO-B
Statement No.: WITN1823001
Exhibits: WITN1823002 - WITN1823012
Dated: 19 May 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1961 and my address is known to the Inquiry.

2. I am writing this statement on behalf of my late daughter GRO-B: D. Her name at birth was D and it was changed when she was six years old to D. Her date of birth is GRO-B 1985.

Section 2. How Affected

3. My daughter D was infected with hepatitis from a blood transfusion she received when she was five years old.

4. D passed away on GRO-B 2003, when she was 17, due to liver failure. **(WITN1823002).**

5. D had sickle cell anaemia ("sickle cell"). Sickle cell is a blood disorder that affects Afro-Caribbean people. It means that someone's red blood cells are shaped like a C, or a sickle, instead of being round. Because of this, sometimes the cells can get backed up in their bloodstream and have trouble travelling through it, which means that the person stops getting enough oxygen into their bloodstream. When this kind of blockage occurs it is called a sickle cell "crisis". This can happen anywhere in the body, and it causes the person to have pain in that part of the body. The person then has to be admitted into hospital and sometimes has to have a blood transfusion, depending on how serious the crisis is.

6. I was not aware that D had sickle cell until she had her first crisis, when she had just turned five years old in GRO-B 1990. She was in a lot of pain, and we took her to A&E at Charing Cross Hospital. When we arrived at hospital, D was initially placed in isolation because the doctors thought that she might have an infectious disease, but they soon realised that she had sickle cell anaemia, which is not infectious.

7. D was given oxygen and monitored for several days. After about three days, she began to get better. The doctors informed me that she could have a blood transfusion in order to speed up her recovery. I discussed this with my family, and my sister told me that I should not allow her to have a blood transfusion. My sister is a Jehovah's Witness and medical interventions like transfusions are against her religion, so she thought I should not allow D to have one if it was not medically necessary. I told the doctors that I did not want D to have a transfusion, and noted that it should not be necessary because she was getting better.

8. The following day when I was at work, D was given a blood transfusion without my consent. No one informed me that she would be having one, and it wasn't until I arrived at the hospital after work that I realised she was connected to a bag of blood. I asked to know what had

happened, as I was not happy about this. I asked the doctors why they had done this against my wishes when D s oxygen levels were much improved since her admission and her life was not in danger. I also did not understand why it had to be done while I was away, without any warning. The doctors laughed at me, and seemed to think I didn't know what I was talking about. They didn't seem bothered that I was upset. I don't remember the names of the doctors involved, just that it was a female doctor and a male doctor.

9. In D s hospital records from Charing Cross Hospital, there is an entry from 2 November 1990 which reads: "1 unit, 400ml packed cells". **(WITN1823003)**. I understand this to be referring to her blood transfusion.

10. There is also a discharge summary which notes that she was admitted to hospital on 28 October 1990 and discharged on 8 November 1990. The summary notes: "*Investigations – Hb. On admission 7.6 g/dl which later dropped to 5.6 g/dl and she was given top up transfusion. Post transfusion Hb 8.7 g/dl.*" **(WITN1823004).**

11. At no point was I ever informed of the potential risks of having a blood transfusion. It was mentioned to me as a possible treatment for D to help her improve faster, at which point I specifically told the doctors I did not consent to her having one, and then it was done behind my back.

12. On 23 January 1991, my mother (D s grandmother), who GRO-B GRO-B at Homerton Hospital, wrote a letter to Mr Jawad, D s paediatrician at Charing Cross Hospital. She wrote the following **(WITN1823005)**:

> *I am aware an appointment this month has been missed. Mrs GRO-B is reluctant to let her daughter attend hospital because of the blood transfusion her daughter was given without consent during her last admission. I note that a new appointment has been arranged for the 26th February for Dr Howarth's clinic and I shall*

> *take her then. In the meantime I shall appreciate it if you can sort out her antibiotic cover with Dr* GRO-B *so that there is no further need for blood transfusions.*

13. I do not recall D ever having another crisis after that first one. However, in her hospital records it states that did have another crisis on 18 June 1991. I believe she was being looked after by my mother at the time this happened, as I was working, although D's notes do mention that a discussion was held with me. Handwritten notes from the following days (19 and 20 June) state: "*long discussion with mother about blood transfusion. Explained to her in a lot of detail*".. and "*transfused yesterday*". **(WITN1823006).**

14. I do not remember discussing blood transfusions with D's doctor in June 1991, or D receiving any further transfusions. However, it has been hard for me to remember the details of this period due to the trauma of losing D and I accept that a discussion may have been held. If a discussion were held that day, I would certainly have expressed my wish for D not to have a transfusion.

15. A letter from Nicki Gilbertson, a Paediatric Registrar at Charing Cross Hospital to D's GP on 26 June 1991 states as follows **(WITN1823007)**:

> *In view of the severity of the anaemia, after discussion with Dr Haworth and Mrs* GRO-B D *received a blood transfusion after which she was very much better. A throat swab showed only normal flora and blood and urine cultures were also normal. Acute viral serology including parvovirus is awaited.*
> D *came to clinic for review today, a week following discharge. She is now looking very well. She has no cough or sore throat. Her grandmother remarked that she does sometimes seem quite hot at night but they have not actually taken her temperature. She continues her prophylactic dose of Penicillin 125mg b.d. and Folic Acid.*

> *On examination today she looked well and is thriving with height and weight around the 75th centile. There were no abnormal findings.*
> *Prior to discharge a repeat blood count following transfusion has shown a Hb of 7g/dl. And an elevated white cell count so that this has been checked again today with further viral serology and iron studies.*
> *I note that D has received Pneumorex in the past (December 1989).*
> *D's grandmother brought her to clinic today because mother was working. As you know, Mrs GRO-B has significant concerns about the management of GRO-B's problem and this has resulted in some reluctance to attend our joint paediatric haematology clinic although D's grandmother, who has care of her much of the time, would be quite happy to bring her to these appointments.*

16. I understand that D was taking Penicillin prophylactically at the time to prevent her from having a sickle cell crisis, and that this may have been what my mother was referring to when she mentioned "antibiotic cover" in the letter to Mr Jawad. I understand my mother to mean that if D had been taking antibiotics regularly at the time perhaps she would not have had a crisis and therefore not needed a transfusion. However, I also maintain that she did not need a transfusion either of the times she did receive one.

17. D did not have any further sickle cell crises after June 1991.

18. She was completely fine until she was about 14 years old. At this time, I began to notice that her eyes were turning yellow. They were so dark that they looked almost orange.

19. At this point her sickle cell care had been transferred to the paediatric department at Chelsea and Westminster Hospital, which had recently been built, and she attended appointments there every few months. I can remember at least three appointments when D was 14 to 16, at which I raised concerns with her doctors there about the colour of her eyes. I told her doctors that the whites of her eyes had turned dark yellow.

20. I remember saying to the doctor that I was concerned about the yellowness of her eyes because her eyes seemed to be getting progressively darker and I could not understand why. The doctor said something like “Most sicklers have that”. I remember debating the issue with him, telling him that I know three other people who have sickle cell and their eyes are not that colour, but he brushed it off. He didn’t do any liver test or blood test on D He just repeatedly said that it was common for people with sickle cell to have yellow eyes, and it was left at that. I felt like I was speaking, but nobody was taking any notice of what I was saying. The doctors seemed unconcerned about D because she hadn’t had a sickle cell crisis in many years; her only problem was her yellow eyes.

21. By 2002, when D was 16, she started to feel very tired and generally unwell. Her eyes were nearly orange, her stomach was distended and she was so exhausted she couldn’t do anything because she didn’t have the strength.

22. In June 2002, she collapsed, and I rushed her to Homerton Hospital because it was the hospital nearest to my mum’s house, where we were. She couldn’t walk, so I carried her to my car and drove to the hospital.

23. Because my mum GRO-B at Homerton, she knew the doctors that were treating my daughter, so they gave her more information than they were giving me about D s health, and my mum fed back some of that information to me.

24. I understand that after D was admitted to hospital, while I was away at work, doctors told my mother that D had tested positive for hepatitis. I do not know what the content of this conversation was; my mother simply told me later that this was D’s diagnosis.

25. When I arrived at the hospital after work that day, my daughter complained to me that the doctors were asking her strange personal questions. She

said, "*They keep asking me all these weird questions, like if I take drugs and if I have had sex, and I don't understand why they're asking me all these questions because I've not done any of those things.*" I went to the doctor and asked why he was asking her those questions. I remember having to explain to the doctor that D didn't go out, didn't drink or take drugs, she had never had a boyfriend, all she was interested in was being a fashion designer. I couldn't comprehend the logic in his questioning. I thought it was strange that he would be asking a 16-year-old those questions at all, let alone without me present, and without explaining the situation. The doctor said "*Because the illness she's got, she could only have caught it one of those ways.*" He then confirmed that she had hepatitis, and he asked, "Has she ever had a blood transfusion?" I said yes, that she had had one at Charing Cross Hospital when she was five years old.

26. There is no specific reference in the records my solicitors have received from Royal Free Hospital or Kings College Hospital which confirms which type of hepatitis D had, or that she was infected from the blood transfusion. My solicitors and I both requested records from Homerton Hospital, where the diagnosis was made, but they responded in both cases that no records existed for D However I understand from my conversation with D's doctor at Homerton that she did have hepatitis of some sort and this was why her liver function had deteriorated.

Section 3. Other Infections

27. As far as I am aware my daughter was infected with hepatitis only.

Section 4. Consent

28. I did not consent to D having a blood transfusion. Any transfusion she had was administered without my consent, against my wishes. I

understand that in some situations, transfusions have to be given without consent to save someone's life. However, D s life was not in danger and the transfusion was only given to speed up her recovery.

Section 5. Impact

29. D did not have physical symptoms of hepatitis until she became very ill, when she was 16. For a year or two before that her eyes started to turn yellow, but she was otherwise unaffected. When she was 16 she began to also feel very exhausted and lack energy, which worsened until her admission to hospital in June 2002.

30. After D was admitted to Homerton Hospital, the doctor told me over the next few days that he would need to obtain records from Charing Cross Hospital, where D had been treated for her sickle cell crisis and received her transfusion, and that he would attempt to find a possible treatment for her. I remember that she seemed to be in a sort of coma for a few days, and that when she came round she was moved to another wing and her behaviour became very strange. The doctors and nurses told me this was due to the medication in her system and that she would be okay after a few days. She did recover somewhat after a few days, and I assumed she would returning home.

31. However, instead of coming home D was referred to the Royal Free Hospital. I am not sure if the doctors at Homerton were ever able to obtain medical records from Charing Cross or her GP to determine the cause of her infection.

32. D was transferred to the Royal Free Hospital on 5 September 2002. The referral request reads:

> *"I would be grateful for your opinion on this 16 year old girl, who presented to us in June this year with jaundice. She had a previous history of sickle cell disease, but had rarely had crises requiring*

> *only three admissions to hospital with sickle pain all her life. She had noted jaundice for approximately 2 years but this had become deeper recently…During this admission she became septic and developed tense ascites. Ultrasound scanning of her liver showed a patent portal vein and hepatic veins but flattened Doppler signals in the hepatic veins consistent with chronic liver disease."* **(WITN1823008)**

33. Upon her arrival at Royal Free Hospital, D had a liver biopsy. It is clear from the biopsy record in her hospital notes that the treating doctors did not know what was causing D's liver damage. The "clinical details" section states: *"V. jaundiced. Known sickle disease (but not sickling now). Increasing wedge pressure +ve autoimmune profile. ? What is going on."* The "comment" section of the record states: "*A complex appearance comprising mildly active cirrhosis (with features suggestive of an alcoholic type aetiology) as well as ductular cholestasis indicating probable sepsis, together with intravascular sickled red blood cells*". **(WITN1823009).**

34. I did not see this record until my solicitors requested these records for the purpose of the Inquiry, so I was not aware the comment about alcoholic aetiology had been made. I am concerned that the biopsy note implies that D's liver damage could have been caused by alcoholism. She was a 16 year old child and did not drink alcohol. The doctors seemed to be going out of their way to explain her deterioration with any reason other than the transfusion(s) she had received, rather than reviewing her medical history and drawing conclusions from that.

35. D's doctors then began to assess her for a possible liver transplant, which involved performing several blood tests. There is a page of test results in her notes which lists her results as negative for a range of viruses, including Hepatitis B, Hepatitis C and HIV, and lists her diagnosis is listed as *"? Autoimmune hepatitis*". However, the test results pertaining to Hepatitis C are not clear. A test result from 16 September 2002 notes: "HCV PCR Comment: please refer to sample 02V59989 dated 13.09.02

for result." However, the only result with that sample number and printed on that date is a result for a HBV PCR test, which was negative. There is only one other test result correlating to that sample number, which refers to a negative HCV RNA test, but this was printed on the 17 February – the day after the result on the 16th. **(WITN1823010).** Unfortunately because D s diagnosis was never discussed with me directly by doctors, I am not sure what these tests mean, and if D did have Hepatitis C or some other form of hepatitis.

36. By October 2002, D s doctors said that her liver disease was so advanced that they could not do anything other than to make her comfortable. They said that she would not be able to receive a liver transplant because she was too ill. **(WITN1823011).** However, a nurse came to me afterward and said, "I think you should ask for a second opinion, you shouldn't just take their word for it." So I went back to the consultants and said that I wanted a second opinion. At that point, they contacted Kings College Hospital to see if there was anything they could do.

37. D was then taken from Royal Free to Kings College Hospital, as doctors there agreed they would give her a liver transplant. However, it took two months to find a suitable match for the transplant. By the time she received the transplant on 22 November 2002 **(WITN1823012)**, she was too ill for her body to accept it, and she kept going into sickle cell crisis. After that, she just went from bad to worse until she died in hospital on GRO-B 2003.

38. D s rapid deterioration was a shock to me. Throughout her illness, I remember my mum saying to me, "I don't think you realise how ill she is". I just always thought she was going to come home, I never imagined that she was going to die. I remember D asking me, "Mum, am I going to die?" to which I replied no. I am so upset that at the very end, at no time did I realise how gravely ill she was. It is a mother's worst nightmare.

39. I feel D 's doctors at Chelsea and Westminster didn't listen to my concerns about her signs of jaundice when I expressed them at routine appointments from 2000 to 2002 and instead tried to attribute her jaundice incorrectly to her sickle cell. As a result, her condition declined and she became critically ill very quickly.

40. Once it was discovered that D had hepatitis, I felt that a stigma was attached to her by doctors. Although she was only 16, doctors immediately assumed she had contracted it sexually or through drugs and began questioning her about this, without my consent and despite her medical history of transfusions. I felt this was shocking and inappropriate.

41. I also think the doctors at Royal Free Hospital should have been aware that she had had blood transfusions when she was younger, considered her medical history and tried to determine the source of her hepatitis. It seemed that the doctors had no idea what was wrong with D and felt that there was nothing they could do except make her comfortable. It was at the suggestion of a nurse that I should fight for my daughter's life and demand a second opinion that they sent for a consultant from Kings College Hospital. If I had not done that, she wouldn't even have had the chance to receive a transplant.

42. In general, I believe that there was a stigma around having sickle cell in the medical profession at the time of D s illness, which may have caused doctors to believe everything wrong with D was due to her sickle cell. When she was at Kings College Hospital awaiting a transplant, I felt that doctors kept referring to her sickle cell as the reason why she was deteriorating, or why she couldn't have a transplant. They said things like "oh, well she is a sickler" when she showed signs of worsening as if that explained her whole illness.

43. D had a happy and normal childhood until she began to show signs of jaundice, aged about 14. However this changed once her eyes grew

more and more yellow, as she started to be bullied at school by other children.

44. At the time she was admitted to hospital in June 2002, D had just finished her GCSEs and was preparing to go to sixth form college. She had been accepted to a college of art and design in Plymouth to study fashion design, and had put down rent for a student flat near the college. However, she never left hospital and was never able to take up her place at college or live in the flat.

45. D's illness and death have affected me tremendously, as I have lost my daughter at a very young age. D would have been 34 years old now. There's not enough words to explain how someone feels when that happens to them. The whole time was so traumatic, I can't really remember all of it or express how I felt.

46. Additionally, D s illness has cost me my relationship with my other daughter, D s younger sister. She grew up being told of the story of D s transfusion and subsequent infection, and was influenced by my sister who is a Jehovah's Witness, to become a Jehovah's witness herself. She is now highly sceptical of doctors, and has raised her daughter (my granddaughter) as a Jehovah's Witness as well. I cannot visit her for holidays or birthdays as they are not allowed to celebrate them, so we don't spend too much time together. I understand her loss of faith in doctors as a result of what happened to D However it is also a great loss for me to no longer be close with her, as I feel I have lost both of my daughters.

Section 6. Treatment/Care/Support

47. I do feel D was not treated as quickly as she could have been, and therefore had less of a chance to survive her illness. Much of this seemed to be because the doctors did not know what was wrong with her. If

D did have Hepatitis C and could have received treatment for this before she became so ill, perhaps she would be alive today.

48. I have never been offered any counselling to do with D's infection, illness or death.

Section 7. Financial Assistance

49. I did not receive any payments arising out of D's infection, nor was I part of any schemes.

Section 8. Other Issues

50. I think that the Inquiry should address the responsibility of the government for what happened and decide who's going to be made accountable.

51. I find it odd that there has not been any advocacy in the media about people with sickle cell anaemia becoming infected by blood or blood products. I wrote to the Sickle Cell Society after the Panorama programme on infected blood, asking why sickle cell anaemia hasn't been mentioned in the discussions about infected blood? I think the Society should take a more active role in advocating for these members of their community who have been wronged. I do not know anyone else personally who has been affected, but D cannot be the only one.

52. The reason I am fighting for someone to be made accountable is I want compensation for my daughter who's lost her sister, and for my granddaughter without an auntie. My daughter has had to grow up her whole life hearing about the sister she lost. I want this for them.

53. I am concerned about the amount of time it has taken to hold this Inquiry. As I understand it, the government has accepted responsibility for infecting many individuals when they knew the blood was contaminated. In view of

the current pandemic, I am sure that there are people who are suffering currently because of what happened to them. I am hoping that there will be a swift conclusion to all of this, as it has been going on for years now. I do not wish to keep reliving the events which led to D 's death and would like closure.

Statement of Truth

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

Signatur GRO-B

Dated ……19 May 2020…………….