Witness Name: Ms GRO-B
Statement No.: WITN2011001
Exhibits: WITN2011002- WITN2011018
Dated: 15 October 2019

WITNESS STATEMENT OF MS GRO-B

INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is GRO-B and my date of birth and address are known to the Inquiry. I am married and I work as a community worker in South London.

2. I am making this statement in memory of my father GRO-B: F who died on GRO-B 2010.

Section 2: How Affected

3. My father F was infected with Hepatitis C (HCV). In 2010 at the

age of 67, he died a horrific, slow and tortuous death and I watched it. He had been severely ill for approximately six years before his death.

4. I do not know and he did not know how he became infected. It is my belief that he had a blood transfusion during a goiter operation he had on his neck in around 1975 or 1976 at the Queen Elizabeth Hospital's predecessor, and that this was when he contracted the virus. I do not know for sure which hospital it was. It could have been Greenwich District or the Brook General Hospital. I visited my dad as an inpatient after he had the operation when I was about 8 years old. I am 51 now.

5. My dad had no tattoos, my dad did not use needles or drugs, my dad was in a long term relationship caring with his partner for his severely disabled step daughter; he did not sleep around. My dad had to care for his step daughter, he had to be home. As my dad had no idea how he had become infected with the virus, we had honest discussions about it; he would have told me the truth as he had nothing to lose.

6. My dad was told that he carried the virus by his consultant at Queen Elizabeth Hospital in Woolwich around 2006. When he was told, he was alone, very ill and likely very confused.

7. I understand from his GP records that he was tested for HCV in April 2006 **WITN2011002**. The letter confirming this states that "blood tests done in December of last year [2005] show that his anti HCV status was reactive", meaning that he tested positive then. The letter also says "He also informs me that he has not had any blood transfusions in the past, is not an IVD user, and he has not had any contact with anyone with hepatitis."

8. In July 2006, his consultant wrote to his GP "*I have given him some information on hepatitis C. I think he would be a good candidate for antiviral treatment and I will arrange for him to be seen with the results of HCV RNA genotype in our specialist nurse clinic in around two months' time.*" **WITN2011003.**

9. My dad's death certificate indicates that he passed away from (a) liver cirrhosis; (b) alcoholic liver disease and hepatitis c; and (c) ischaemic heart disease and chronic renal failure. **WITN2011004**. My dad did drink alcohol but I do not believe that this was the reason for his death.

10. I believe that information about his diagnosis should have been provided to him earlier, as he could have been treated earlier and could still be alive today.

11. I think that his diagnosis should not have been communicated to him when he was alone and in a vulnerable state. He was likely to be confused so needed someone with him.

12. I do not know if my father was given any information about the risks of infecting others.

Section 3: Other infections

13. I believe that my dad was infected with HCV only.

Section 4: Consent

14. I do not know whether my dad was treated or tested without his knowledge or

whether he was treated without proper consent or for the purposes of research. I do know that my father was extremely shocked when he was told that he was carrying the infection, and he never considered that the goiter operation might have resulted in a blood transfusion which might have led to the infection, so I assume that he never consented properly to the transfusion.

15. As my dad is now deceased, I cannot say whether any information or advice was given to my dad beforehand about the risk of being exposed to infection.

Section 5: Impact

16. The illness tore myself and my dad apart. From around 2005 onwards I gradually watched him die. His condition got worse and worse and he was constantly in and out of the hospital.

17. My dad's liver failed, so he was constantly filled with fluid and when he lay down he couldn't breathe because the fluid filled his belly. He was constantly itching, confused, and jaundiced.

18. I recall my dad constantly calling paramedics and filling up with litres of fluid where his liver was failing. I looked after him and 8 years later I still cannot forget the withered and frail man he turned into. It was and still is the saddest thing I ever witnessed. My dad could have been in his 90s when died. Nine years after his death, I can still see his pleading eyes. And each day they became more and more lifeless. He knew he was leaving me and I knew too. He went from being my big, strong tough dad to a decaying bent over yellow tinged frail man.

19. I remember my dad needing to have the fluid in his stomach drained on a frequent basis. Please think about this for one moment. He had to have nine litres of fluid drained from his stomach. When this happened he was not able to breathe properly, I often had to stay with him to care for him while it happened.

20. I also recall that I was called by a consultant at the hospital to decide whether the medication should stop my dad continuing losing control of his bowels or to only take enough to control confusion. In the end I thought his mind should be clear, he had lost control of everything physical anyway.

21. My dad was an 18 stone man who wasted away to the point where he was diagnosed with malnutrition. His belly swelled and his legs filled with fluid too, so much so that I could not find shoes to fit him. He had to get ugly big velcroed shoes at the cost of £100 which he had to pay for himself.

22. I watched my dad wear a nappy. He was still proud enough to try to hurry to the toilet, except his arthritic knees would not always let him. In front of me, his bowels opened explosively and I saw the embarrassment and shame in his eyes. When I turned away, tears fell off my chin. Those are my last visions of him and the pinnacle of physical impact of this on his life.

23. His beautiful flat became a hovel, where he was living in one room. He was too weak to go to the kitchen. Finally, before long, carers came in four times per day to check that he was still alive. I was there too, but I was a professional carer and needed to work; my clients needed me too.

24. I was told that the imbalance of the potassium and salts in his body as a result of the HCV caused him a heart attack.

25. From November 2006 to January 2007 he was given what was considered to

be a "ground-breaking" treatment consisting of 12 weeks of pegylated interferon and ribavirin **WITN2011005**. I get the feeling it was too late. I am aware that his condition deteriorated at the time, which may have been due to the side effects of this treatment. I understand that around week 4 of his treatment he had to stop taking the ribavirin due to intolerable side effects **WITN2011006**, and that the treatment ultimately failed. **WITN2011007**.

26. In 2010, my dad was in the QE Hospital for 5 weeks, and then transferred to a hospice for 10 days before he died. Prior to his time in hospital I had to fight for a community matron to visit him at home. I did this because I was looking after him alone and could not cope because of my own work. At this point my dad was confined to bed, he could not wash, he could feed himself. His state led to him requiring the carers four times per day. He was offered a liver transplant at the hospice in the day before his death.

27. The mental impact of the illness was huge. The overriding factor that destroyed him was the HCV, because whatever surgeries he had he was not going to get better. He was worried, scared and frightened; I saw him cry. It is heart-breaking to remember this. I became the parent to him in the end.

28. He should have been told sooner about his HCV, and with someone with him, by then he was confused and could not ask questions. He should have been treated earlier and offered his liver transplant sooner.

29. My dad was embarrassed about the HCV and didn't want anyone to know. I do not and my dad did not discuss the disease with anyone because of the stigma. He felt alone with this awful disease.

30. In the end he had no social life; he became too ill too leave the house. In

terms of family, my father was alone in this; apart from having me. We were alone in this together. My dad was my hero; I was daddy's girl and he meant the world to me.

31. My marriage failed; I was not at home with my husband and he sought comfort elsewhere. I was constantly crying, I could not do enough for him. I would overdo the care, keep visiting, keep ringing, I would buy him stuff to try to make him feel comfortable. I lost weight, I didn't have time to eat.

32. It almost destroyed my relationship with my mum. She was incredibly selfish asking, what about me. I had to tell her she was well, that there were priorities. She would not visit him as they were divorced. My dad and I needed the help.

33. It ruled my life then and continues to rule it now. He was so sick. He was so sick at my first wedding. It was debatable as to whether he could make it. For the first five years following his death, I smelled my dad's death from the paperwork. I opened his paperwork and smelled him, my dad's smell you see which made me feel like he had come back to me and was standing next to me. The sweet smell of HCV.

34. The impact I cannot even describe – I watched my dad die a horrible and painful death. I remember visiting him once in the hospice, I was in my carers uniform and he was not expecting me as I had already visited him in the morning. I remember he looked up at me and called me his angel.

35. My sister and I have never really got along, she and I had huge arguments during my dad's chronic illness. She did not visit him very much at all. Yet when he died, as the eldest she thought she wanted to dictate how arrangements should be made and how the funeral should be. This devastated me, this was unbelievable. How can you not be involved and then dictate the

funeral. I know I did the right thing.

36. My need to care for my dad meant that his illness had a significant impact on my income. I kept my working hours low so that I could see my dad as much as possible. I did not care about the money; that was a secondary consideration for me.

Section 6: Treatment/Care/Support

37. My dad had been carrying the virus for years before he was told he had it. By the time he started treatment it was too late. It did not work. He suffered through it, it did not work and he died. I cannot understand why he was told in the days before he died that he might be able to have a liver transplant.

38. I could have got counselling at the hospice, after he died, but I couldn't face it. They offer that to all families anyway. I don't know if it was offered to my dad. He desperately needed counselling and psychological help at home when he was terminally ill.

Section 7: Financial Assistance

39. While going through my father's paperwork after he died, I found a Skipton Fund application, which he had signed and dated. On his behalf, I decided to pursue this. I completed this application in September 2010, and sent the application to my dad's treating hospital, Queen Elizabeth Hospital, to fill in the details relating to his blood transfusion.

40. I received a letter from a nurse to Dr McNair, my dad's consultant at Queen Elizabeth Hospital, on 13 October 2010 stating that she would need to confirm

that my dad received blood products or a blood transfusion before 1991 in order to qualify for compensation from the Skipton Fund and asking me for proof of this. **WITN201100**8.

41. I then wrote to the Skipton Fund asking them what I should do, as I had contacted my dad's GP, Greenwich Primary Care Trust, Kent Primary Care Trust, Queen Elizabeth Hospital, and PHSE regarding his pre-1991 records, but none were able to provide me with any. **WITN2011009**.

42. A Skipton Fund representative, Nick Fish, emailed me back telling me to submit the signed application with proof that he had Hep C (which I had) and copies of the letters stating that there are no records available pre-1991. **WITN2011010**.

43. At this point I briefly put off preparing the application as I was struggling with my father's death and the subsequent breakdown of my marriage. When I was able to turn to it again, in early 2016, I contacted Dr McNair and asked him to fill in the sections of the Skipton Fund form relating to my father's transfusion.

44. In response, I received a letter from him which states **WITN2011011**:

> *I have reviewed your father's medical record and can find no evidence that he had a blood transfusion or any other blood product. As the form states, its purpose is "to confirm that the infection most probably arose through treatment with NHS blood or blood products' and I am afraid I can find no evidence to support this application. There does appear to have been a gap in his medical records from 1986 to 1998 and naturally if you are aware that he received a blood transfusion at another hospital prior to routine testing for hepatitis C in blood products in 1991 then you should take the application form to a doctor at that hospital.*

45. I was surprised that Dr McNair had mentioned a gap in the records, as I had still not been granted any access to records pre-1991 so didn't know how Dr McNair had been able to review them. I hadn't been in touch with my dad from 1986 to 1998, so I'm not sure what medical care he was receiving then; he could well have had an operation at some point between 1986 and 1991 when they started testing the blood that required a blood transfusion.

46. I did not know what to do about the Skipton application, because Dr McNair was not willing to fill in the treating consultant section. I decided to submit the application as it was on 2 September 2016, with copies of the letters confirming there were no records available, but with the section to be filled out by a doctor left blank. **WITN2011012**.

47. My application was immediately refused, "due to the lack of supporting medical records to confirm that your father received treatment with NHS blood or blood products prior to September 1991." **WITN2011013**.

48. Later that month, I appealed the Skipton Fund's refusal of my application. However, this was rejected as well. The rejection letter states **WITN2011014**:

> *The Panel noted that Dr McNair could find no evidence of a transfusion in the records although there was a gap in those records between 1986 and 1998. Because of the absence of evidence there is no explanation of why or when your father might have needed a transfusion. In some cases where it is known, for example, that an appellant had a particular condition or needed a particular medical procedure the Panel is prepared to accept that condition or treatment would probably have necessitated a transfusion and to make an award but in your case I am*

> *sorry to say there is simply no evidence at all on which to make an award.*

Section 8: Other Issues

49. I have repeatedly requested copies of my dad's records, mainly for the purpose of my Skipton Fund application, but I have not been able to gain access to any records dealing with his operation in the 1970s.

50. I requested records from my GRO-B where my dad had briefly stayed, in August 2016. I spoke to a lady on the phone at the time who told me that the records should have been on the system and were not. She said she worked there 20 years ago, when my father had been there, and was surprised because expected to see records for him from that time but they weren't there.

51. I also contacted my dad's GP surgery to request GP records. I exchanged email correspondence with a GRO-B, Practice Manager at my dad's GP surgery, and let her know that I was looking for records pre-1991, of any hospital stays my father had. She told me in an email on 7 September 2016 **WITN2011015**:

> *We will need to request your late father's notes from the archives which I believe are now in Leeds and this may take some time. These will only have GP letters and hospital discharge summaries but this may have the info you are seeking. I have checked your father's electronic records and we do not have any info on our system electronically pre 1991.*

52. I asked for a copy of everything that they did have. I received the electronic

records, but they did not contain anything before 1991. I wrote to PCSE, but they didn't respond. So I emailed the GP surgery again asking if I could request the paper records from the archives in Leeds. I wrote on 19 September **WITN2011016**:

> *PCSE still not acknowledged my emails or written letter. I believe you mentioned dads records pre 1991 were in Leeds? Can we get hold of pending an appeal October/November?*

53. The response I received, that same day from Karen Powell, the staff member responsible for medical at NHS Greenwich CCG, was "*Sorry to hear that you have not heard from PCSE. I do not recall mentioning Leeds. I would suggest that you keep making contact with the PCSE. I am sorry but we are unable to do anything from this end* **WITN2011016**.

54. Two years later I still hadn't received my dad's paper records, so I emailed the GP surgery to follow up on my earlier emails. On 12 September 2018, I was told that the paper records had arrived but had not been sent to me and had remained in the surgery in my dad's file. The consultant also noted **WITN2011017**:

> *I can see from your first email that you were looking for operations and hospital admissions pre 1991 but these cannot be made available. This will be something you will need to take up with PCSE but it seems those are the restrictions that they have to work to.*

55. I have repeatedly been told that I cannot access any of my dad's records prior to 1991 either because there is a gap in the records, or because relatives of a

deceased person are only able to access records pertaining to that person after that date. I even wrote to my MP, Clive Efford, but he was given the same response from NHS England: that the legislation allowing relatives to request records for deceased people only allows for access to records post-1991. **WITN2011018**.

56. However, Dr McNair was clearly given access to my dad's medical records prior to at least 1986, as he was able to comment on a gap in the records between 1986 and 1998. I would like to know what records Dr McNair has seen, because even if they do not contain documentation of my dad's transfusion, they may contain some information about which hospitals he was seen in and any operations he had.

57. Despite my many enquiries, I cannot pin down where my dad was given blood. However, I know that he had the goiter operation in the 1970s and in the absence of any other possible cause I believe this is where he was infected. I want to know what exactly happened, where he was infected and I want the Inquiry to take responsibility for what happened to my dad.

Statement of Truth

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

Signed **GRO-B**

Dated …15 October 2019..