Witness Name: GRO-B
Statement No.: WITN3691001
Exhibits: WITN3691002 - WITN3691024
Dated: February 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 November 2019.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is name is GRO-B. My date of birth is GRO-B 1957 and my address is known to the Inquiry.

2. I can confirm that I have chosen not to have a legal representative and that I was happy for the Inquiry team to take my statement.

3. I can confirm that the anonymity process has been explained to me and that I GRO-B wish to apply for anonymity. I have no shame about what happened GRO-B I want to tell my father's story.

4. The Inquiry Investigator has explained the Right to Reply process and I understand that any medical professional or hospital who I may criticise in this statement may be given the opportunity to respond.

5. In this statement, I intend to speak about my father, GRO-B: F, who was born on GRO-B 1929 and he died in 2011, aged 81.

6. I make this statement with the benefit of access to a set of my father's medical records from both Singleton Hospital and his GP, GRO-B Surgery,

Swansea. I have made these records available to the Inquiry, and have used some of the entries to assist me in my understanding of events that led to my father's death.

Section 2. How Affected

7. My father was born and brought up in Swansea, Wales. The name registered on his birth and death certificates is actually F but he was known to everybody during his life as F

8. My father worked in various jobs during his lifetime, including as a breadmaker at a bakery. For the last 30 years of his working life, he worked as a trainer on machines which made aluminium wire and cable. He retired from this job in 1996 when he was 65 years old.

9. My father enjoyed gardening, decorating and going for a pint with his friends. He was an exceptionally private, proud, kind, and generous man, and was very much loved by his family.

10. I was born in South Wales. I was the baby of the family and I have an older brother and sister. My father was 28 years old when I was born.

11. Unfortunately I do not have any recollection of events prior to around 1970, when I was around 13 years old. Before this, I was either too young to remember anything to add, or not yet born. Furthermore, when I was younger, the adults would send the children out of the room whenever they were discussing anything. This was because they did not want to worry us, so there may have been things happening that I was not aware of. Therefore, 1970 is the starting point of my father's story, that I am able to tell.

12. I worked as newsagent for most of my working life. I got married in 1978 and my husband and I moved to Germany where we lived for five years. We had two daughters in 1979 and 1981, and later returned to Wales in 1983.

13. I believe my dad was diagnosed with mild Haemophilia A in around 1976 when he was around 47 years old, while he was waiting to have an operation on a duodenal ulcer.

14. It is strange that dad went so long without this diagnosis as I understand his mother was a carrier of haemophilia, and my uncle also has haemophilia. However I do not recall there ever being any mention of my father having haemophilia when I was a child growing up, so this timescale would fit with my working memory.

15. In my father's medical notes, there is a letter dated 06.11.1979 from Dr H.S Winsey, Consultant Physician at Singleton Hospital, to Dr GRO-B **[Exhibit WITN3691002]**. An extract from the letter states;

16. *'It was, however, discovered in the intervening time that he was a mild haemophiliac. In view of this, I think we should review the question of surgery, though in some ways his symptoms certainly justify it'.*

17. I do remember in around 1976 that my father's diagnosis of haemophilia was starting to be mentioned within the family, and there were discussions around having younger male members of the family checked for it. I remember my dad used to say he was classed as a '*bleeder*'. We knew he wasn't supposed to use an open razor, but I can remember him using one on occasion and bleeding like mad, and he would then be walking around with bits of paper all over his face.

18. In January 1980, my dad underwent an operation for a duodenal ulcer. Dad's notes describe the surgical process as a vagotomy and pyloroplasty. According to his clinical notes, my dad was admitted to Singleton Hospital in Swansea on 12 January 1980, and received Factor VIII assay and packets of cryoprecipitate in preparation for the operation. He also received Factor VIII during and after the operation [**Exhibit WITN3691003].**

19. He was also given a blood transfusion during this operation. Unfortunately I do not know the volume or number of units that were used on this occasion. A document entitled Clinical Summary Sheet dated 19.01.1980 **[exhibit WITN3691004]** confirms the following information;

20. *'Three episodes of haematemesis and melaena over last 18/12. 3 units blood transfused on one occasion. Patient… haemophiliac.'* and *'Pre and post op. regular Factor VIII assay and administration cryoprecipitate.'*

21. The operation did not work as it could have and unfortunately my dad continued to have problems, including at least two haemorrhages, and he had to have subsequent stays in hospital for further blood transfusions.

22. On 19 November 1984 at 5.20am, he was taken in to hospital as an emergency admission with a history of vomiting, coffee ground in nature. Point 5 of dad's hospital notes from this occasion show that he was given a transfusion of one unit of whole blood on 19 November 1984 11.30am. An entry on 20 November 1984 at 5am shows a second unit of blood transfused, with a query as to third unit to be given. There are then additional entries on the sheet demonstrating Factor VIII was also provided **[Exhibit WITN3691005]**.

23. A Continuation History Sheet dated 19 November 1984 shows the following; '*First unit of whole blood commenced. Donor Number 480732. Expiry date 23 November 1984… Second unit whole blood. Donor number 505270*' **[Exhibit WITN3691006].**

24. A Nursing Care Plan dated 21 November 1984, point 3, identified potential problems. The section is noted with *'potential for adverse reaction to blood transfusion.'* The nursing care plan solution section has three points; *'1 - check each unit of blood prior to transfusion; 2 - observations to be recorded for the first hour of each transfusion unit; 3 - Blood filter to be used'* **[Exhibit WITN3691007].**

25. Dad's medical hospital medical notes show that blood product Factor VIII was provided on five occasions from 19 November 1984 – 23 November 1984. Serial numbers are shown on the exhibit **[Exhibit WITN3691008]**.

26. A further hospital record dated 19 February 1998, also entitled Continuation History Sheet, shows that my dad was known to be Hepatitis C positive by this date **[Exhibit WITN3691009]**.

27. A letter on my dad's file notes that he was in fact diagnosed with Hepatitis C in 1996, and the doctors believe my dad acquired the Hepatitis C from one of the transfusions he had in 1984. I exhibit a letter from Dr Puli to Dr GRO-B dated 16.04.2010 suggesting my dad had had Hepatitis C since 1984 **[exhibit WITN3691010].** An extract is shown below.

28. *'I reviewed this gentleman in the clinic today. He is known to have chronic Hepatitis C since 1984, secondary to blood products.'*

29. A further letter from Dr Kochar to Dr Al-Ismael dated 22 September 2003 suggests my dad was diagnosed with Hepatitis C in 1996 **[exhibit WITN3691011]**. Extracts from this letter paragraphs 1 and 3 are recorded below;

30. *'Thank you for referring this gentleman to Dr Kingham's clinic. He is known to have mild haemophilia and in 1980 underwent surgery for a bleeding duodenal ulcer in the form of a vagotomy and pyloroplasty. He received some blood transfusions and cryoprecipitate then. He again had some blood transfusions and cryoprecipitate administered to him in 1984. Almost certainly he acquired his Hepatitis C during that. He was first found to be Hepatitis C positive in 1996 and since then he has been found to be positive on both antibody and RNA testing. He was found to be immune to Hepatitis A previously and non-immune to Hepatitis B. As far as his liver function tests are concerned he hasn't had an abnormal AST since as far back as 1982. His gamma GT however has been elevated from time to time since 1996. He does not have any symptoms pertaining to liver disease and from the history there does not appear to be any other portal of acquisition of Hepatitis C. He has got a family history of haemophilia... Medication wise he is on Zantac only. He smokes 10 cigarettes a day and drinks about 3 pints of alcohol per week.'*

31. *'In summary this gentleman has chronic Hepatitis C which has probably been lingering in his system for more than 20 years. However he has not had any significant enzymatic abnormalities or significant signs of symptoms pertaining to chronic Hepatitis C infection. I discussed this gentleman with Dr Kingham and we agree that at the moment we should not offer him treatment, but adopt a wait and see policy. I am checking his Hepatitis RNA PCR, Hepatitis B, full profile and prothrombin time today. We will keep an eye on this gentleman and should his enzymes become abnormal and should he develop any new signs or symptoms we may reconsider the decision regarding treating him. We will see him in a year's time.'*

32. I do not know at what point my dad was told he had Hepatitis C, or how he was told. I have asked my mother questions over the years, but she doesn't know either. My dad was very private and would not have been very open to talking about these issues with his family.

33. I was not aware of my dad's hepatitis until around 2006, which was around the time I started to play a bigger role in respect of my dad's medical care. I can remember we were sitting and chatting at my parents' house and we were talking about infected blood. My dad started talking about his duodenal ulcer and that he'd had a transfusion during the operation as he had lost a lot of blood. During this conversation, my dad told me about where some of the blood products he had been treated with had come from, and I remember him mentioning prisons and prostitutes in the USA. This was when he told me that he had contracted Hepatitis C and Hepatitis B from the blood products. That was the first I knew of it.

34. As I mentioned, I was living abroad from 1978-1983, so I was not around during the time of my father's operation in 1980. I do recall in the months following the operation, hearing from my mother during telephone conversations that my father was unwell when we spoke on the phone, but she wouldn't expand much on this. I believe she was frightened I would come home if I knew more, and my parents were very keen for me to get on with my life.

35. I returned from Germany in January 1983. My two children and I lived with my parents for the first three months of being back, while my husband was tying up the loose ends in Germany. During this time, I noticed something was off with my father. I recall observing him being tired all the time. I would try to keep my children out of the way as much as possible as I thought two toddlers running around was too much for my parents, especially my dad. My father was a very private man and so did not discuss health issues with me at this time.

36. My main memory of him when my children and I were living there was him sleeping a lot on sofa, he could fall asleep at the drop of a hat. He would need to sit down a lot. He was still helping mum in the house, but was finding things difficult.

37. My dad loved gardening, this was his favourite hobby. But he started to find this more and more difficult. They had a big garden and I can remember he would be cutting the grass, puffing and panting, struggling for breath. I can remember him having difficulty catching his breath very often, he would always be gasping after expending any energy.

38. I can also recall my dad being listless and lacking in energy, sometimes he would say couldn't be bothered to do things. He used to also talk about his sleep patterns being disturbed, he would regularly say he couldn't sleep last night or that he'd had a bad night's sleep.

39. He would tell us his skin was itchy; he would sit on the settee scratching, not all the time, but every now and again. At one point he was jaundiced, I can remember him looking yellowy in colour. I can't place when this was but at some point he was definitely yellow. The jaundice did subside, but after that I can remember him often looking pasty.

40. My dad would regularly say his stomach was bad but again wouldn't go into detail. I remember him regularly taking Zantac or Rennies for his stomach, as well as buying medication for constipation, which he really suffered with. His

stomach was physically larger and he would rub his tummy when it was feeling uncomfortable.

41. He kept things from me and my siblings. He was a very private man and didn't want to worry us, so I don't know much about any medical appointments or treatment at this time. He took a protective view of his children, so I wasn't told much.

42. As time went on and my own children were at school, I would go shopping with my parents. I was working part time, and would use some of the time when I wasn't working and my children were at school to take my parents in to town.

43. On these trips, I can remember my Dad would sometimes spit up blood. He would always have a handkerchief with him. I can't remember him coughing, more that he would take out his handkerchief, wipe his mouth, and then blood would be on it. Sometimes my parents would cut the shopping trip short and take a taxi home, as my dad was embarrassed about spitting up blood. Furthermore because he was always tired, he started to find the trips into town exhausting.

44. By the late 1990s, I had begun to take my father to medical appointments sporadically, but would generally just drop him off and then I would leave.

45. However from 2006, my dad's health and needs changed. I started to go in to appointments with him. This was to assist both my father whose health had deteriorated a lot by this point, and also to save my mother from needing to go with my father, as this was becoming more difficult for her due to her own health and mobility issues. So 2006 was when I became much more involved with my father's care.

46. It was also in 2006 when the hospital first saw the shadow on my dad's lung, and then he was subsequently diagnosed with lung cancer.

47. My Earliest memory of this was in Summer 2006, with Dr Ishamel at Singleton Hospital sitting my dad down and informing him that they had seen a shadow on his lung. We had been there for my dad's usual haematology appointment. But then they sat my dad down and said they had seen a shadow at the top of the x-ray, and this would need to be investigated further. He must have had a scan before this appointment, and had been asked to go in for the results. I hadn't been there for the x-ray, but I went with him for the results.

48. My dad was sent for a lung biopsy at Singleton Hospital. I went with him and I can still remember him coming out with blood on his pyjamas. I had to go outside as I nearly fainted as I don't like the sight of blood.

49. Soon after this we had to go to Morriston Hospital for the results and he was diagnosed with cancer. My sister and I were sitting in the room with my father. Dr Rowley told my dad that he had lung cancer which was obviously bad news, and this of course upset my dad. Dr Rowley was very nice and we felt she handled the situation as well as possible. She told him they were going to do some treatment including an operation to remove the tumour.

50. My dad had a lobectomy in October 2006. This was an operation to remove the tumour on his right lung. Soon after this, we had an appointment with Dr Rowley at Singleton Hospital; my dad, my mother and myself were there. We spoke about my dad's haemophilia and Hepatitis C.

51. This is the first time I clearly remember the hepatitis being talked about with a doctor. I am not sure who it was out of all the people in the room who raised the hepatitis; Dr Rowley, my dad or me. I know it was not my mother as she didn't really say anything throughout the whole meeting. Dr Rowley called Dr Ishmael on the telephone and discussed what action to take regarding chemotherapy. They had a conversation while we were in the room with Dr Rowley.

52. The doctors were concerned about my dad's liver because of how the chemotherapy might affect it. They discussed it between them and it was

decided not to give my dad chemotherapy at that time. My dad was consulted about this and did play a part in the decision.

53. My dad started getting even more tired after this. It was clear his health was taking a turn for the worse. His and my mother's activities curtailed, they didn't go to town anywhere near as much. My dad did try hard to keep his fitness levels up, for example he was attending the gym at his doctors, which he had been advised to do to try to increase his lung capacity. He enjoyed this but found it very difficult.

54. Around two years later, in December 2009, my dad was sent to have a positron emission tomography (PET) scan at Cheltenham Hospital, this was on 21.12.2009. I remember we went in a taxi, he got scanned and then we left. Soon after this, it was confirmed that they had found a secondary tumour, this time on my dad's left lung.

55. We were told they couldn't operate as the tumour was too close to my dad's heart. Because they were more limited in terms of options, this time, chemotherapy was more encouraged and my dad did have this treatment, although unfortunately he was not able to finish it. In a letter from Dr T Rackley to Dr GRO-B it confirms *'He has had three cycles of Gem/Carbo but could not tolerate the full cycle due to poor blood counts'* **[Exhibit WITN36910012].**

56. Dr Rowley was very good in that she explained everything to my dad at the outset. I do think it was down to my dad to make the decision on chemotherapy for the first tumour but after the information he was given about the concerns regarding his hepatitis, he decided against it. There is a letter in my dad's file from Miss Jones to Dr GRO-B dated 16 November 2009 which confirms my dad *'was not treated with chemotherapy in view of his Hepatitis C'* **[Exhibit WITN3691013].**

57. I do not doubt that chemotherapy at the outset would have prolonged his life as he wouldn't have developed the secondary tumour approximately two years later. I therefore feel that the decision not to give my dad chemotherapy at that first opportunity was very significant.

58. If my dad hadn't had hepatitis, the conversation in that room between Dr Rowley and Dr Ishmael wouldn't have happened. I do believe they would have given my dad chemotherapy for the first tumour if it wasn't for the hepatitis. Moreover, there would not have been the difficult balancing act between the cancer treatment and the Hepatitis C had my dad not been infected with blood products in the first place.

59. Soon after we received the news of the second tumour, at one of my dad's appointments, I followed one of the nursing staff into the photocopier room and I asked her how long he had to live. She said *'A year, tops'*. Then I had to go back into the room with my dad and pretend I didn't know.

60. I told my sister what the nurse had said but we made a conscious decision not to tell our dad and mum. We were worried he would have given up and also how my mother would cope. So after this, every time we had appointments, we spoke to the doctors and asked them not to tell dad his life expectancy.

61. This was obviously a really difficult judgement call to make, but we felt that my dad would just give up and not see the point in trying to carry on if he knew how little time he had left. We felt it was better for us to focus on the positives. This situation really took an emotional toll on me and my sister as well, even though we had my parents' best interests at heart, we knew we were withholding important information from them.

62. In February 2009, my dad was sent a generic letter from Abertawe Bo Morgannwg University Trust, regarding the fact that there may have been a risk of vCJD from blood products **[exhibit WITN3691015]**. This letter had been sent to all patients with bleeding disorders and in it, it states '*This new information will not change the way you will be treated'*. It makes me so cross because he absolutely was treated in a different way.

63. In January 2010, my dad was sent for a bronchoscopy at Morriston Hospital to look at his lung. He had fasted for a day to prepare for the procedure. We arrived at the hospital, and my dad had undressed, had put a gown on and was

on the bed ready. Then all of a sudden, a nurse came in to the room and said to my dad '*You might have CJD, I have found a letter on your file, so we can't do the procedure'*

64. Soon after this, a consultant, Dr Evans, followed the nurse in and said *'These instruments cost £36,000, and we would have to throw them away if we used them on you'*, and as a result, they couldn't do it. He said they would give my dad an x-ray instead. My dad had prepared mentally and physically for the procedure only for it to be cancelled in this most cruel way. It was not my dad's fault he may have been exposed to vCJD, and because of this he was not able to have the treatment he needed.

65. My dad got upset and he cried as he was getting dressed. Its awful seeing your father cry. He felt dirty. He didn't know what vCJD was, he just knew it as Mad Cow Disease. The whole experience was really upsetting and I was very cross, and I had a go at them and challenged them in respect of the way they spoke to us, which I felt was careless and with no thought for my dad's feelings. There is a letter from Dr Evans to Dr **GRO-B** dated 6 January 2010 which outlines this event **[exhibit WITN3691014].** The letter states as follows;

66. *'This gentleman attended for bronchoscopy today to assess whether or not he would be suitable for any endobronchial therapy. During the pre-procedure clerking a letter was found dated February 2009 from Dr Said Ismail stating that* **F** *is potentially at risk of variant CJD following receiving contaminated blood products in the 1980s which also resulted in him getting Hepatitis C.*

67. *The strict protocols with regards to variant CJD would have demanded that our bronchoscope would have been placed in quarantine for an undisclosed period of time. I therefore felt at this stage I was unable to proceed with the bronchoscopy. I explained this to Mr* **F** *and his family who were clearly very upset on hearing this but they did understand the rationale in that I was unable to justify effectively destroying one bronchoscope just to assess whether or not he was suitable for further therapy.'*

68. I think the whole situation could have been handled very differently. They must sterilise equipment between patients anyway. We were so angry and upset that my dad was treated differently to everybody else, and it wasn't his fault. He didn't do anything wrong. That was the worst part. I was so upset for him because he was so private and he was crying in front of his daughters, which was awful for him and he would have hated this. It was terrible for us to have to witness my dad suffer and be treated in this way and we felt so helpless. The whole experience was traumatic for us all.

69. For the most part, however, my family and I do feel that my dad had wonderful care from his GP at GRO-B Surgery, and the Haematology and Cancer Care units at Singleton Hospital and Cancer Care unit at Morriston Hospital.

70. In respect of the chemotherapy for the secondary tumour, my dad underwent one full course, followed by another part course. By this point, his platelets were very low so he couldn't finish it. He wasn't well at all, he found any exertion exhausting and was always gasping for breath. My dad had nebulisers in the house with medication to help clear his lungs as well as a mobile oxygen machine to assist him with breathing. By now the cancer had started moving up his chest. He ended up with a large mass under his neck that was actually visible. It was so awful to see him suffer.

71. My dad remained at home for as long as possible. There were nurses coming in to provide care for my dad, I am unsure if they were McMillan or palliative care nurses. We had a stairlift installed to assist my dad as he couldn't walk, but he wouldn't go to bed as he was afraid he was going to die. We took it in turns to sleep on the floor or in a chair next to him on the sofa. This went on for a couple of months. The family were doing all the personal care for him. We had been told to wear gloves and wash hands after seeing to dad. My dad didn't want people in the house so the nursing care was quite fleeting. Even at the end, my dad was still very private and didn't like people to see him ill.

72. By the beginning of GRO-B 2011, my dad had started hallucinating and he was in a lot of pain. It was horrendous. We were struggling to cope so we contacted

Ty Olwen End of Life Hospice, which is part of Morriston hospital, for help. My dad passed away three days later on GRO-B 2011 at the hospice. We didn't leave him at all during the time he was there, we took it in turns to be with him so he wasn't on his own. We were all there when he passed away, my mother, brother, sister, myself, and some other family. I can remember his eyes were closed but he was crying. I found this incredibly upsetting. That was the hardest bit to cope with.

73. When my dad passed away, he was taken to GRO-D Funeral Home in Swansea. We were told he couldn't be embalmed because of the infections. We were also initially told we couldn't go in to see him, but in the end, we actually were able to. I remember being told by a family member that dad would have to come out in a body bag, because of the fact he may have had vCJD and something to do with bodily fluids. I am not aware that any family member was served a form about this course of action by the undertakers.

74. My brother, sister, myself and mother went to obtain the death certificate. This was issued on GRO-B 2011 **[exhibit WITN3691016].** The cause of death is noted to be *non-small cell lung cancer*. I do wonder if this could have been different had he been treated with chemotherapy in the first instance, and wonder whether he could have lived longer.

75. I am unsure medically if this is correct, but perhaps on the death certificate it would have been more appropriate to have mentioned hepatitis and maybe question vCJD as potentially these may have contributed to the cancer. I'm not a medical person, but this is a just a thought.

76. My dad's funeral was on GRO-B 2011, and he was cremated.

77. My mother recently paid in advance for her own funeral plan and wanted to use the same provider that we used for my dad's funeral, so we have been in contact with St James' Funeral Home again. In discussions regarding my mother's funeral plan we got talking about my dad's funeral.

78. I was interested to find out more about the restrictions that were in place in respect of my dad. I asked the representative from the funeral home to look at my dad's file, and he did.

79. He said there was a form on the file, which had been issued by the hospital (Swansea NHS Trust) entitled Notice of Infection Risk, dated GRO-B 2011. The undertaker provided me with a copy of the form **[exhibit WITN3691017]**. An extract, shown below states the following;

80. *'Please be informed that the body of the late* F *could be an infection risk and should not, under any circumstances, be removed from the sealed plastic bag. The body should NOT be embalmed. Furthermore the body can only be removed from the Mortuary in a sealed, finished, leak proof coffin.'*

81. I only obtained the copy of this form a few months ago, in August 2019. I had not had sight of this form prior to this.

82. The form makes me feel very sad. I know my dad would be appalled at it. As I have mentioned, he was very private, and he would think as a result of this form that people would think he was dirty when in fact, he was so clean. I don't even like looking at the form, it makes me very unhappy.

83. I'm not sure if the form is in relation to the hepatitis or the vCJD, or potentially both. Of course I wouldn't want anyone to catch something from my dad if that would be a risk. However if he hadn't had the infected blood, there would never have been this issue. Someone somewhere is to blame. Someone signed on the dotted line, and has caused this situation. It has affected all of us, not just dad. This form really upset us, and the implication of people thinking my dad is contagious.

84. My dad was treated differently to everyone else in both his life and his death. In my view, he was treated with disrespect. How my dad's body was treated after he passed away was very distressing for all of the family. It felt like they had put him in a bin bag. My mother was heartbroken.

85. I do not believe a post-mortem was carried out on my dad, as he was in a hospice when he passed away and his death was not unexpected.

86. A letter dated GRO-B 2011, from Dr C Lawton at the Department of Palliative medicine to Dr GRO-B states *'I'm sorry to inform you that he died peacefully with the family present.... The cause of death was notified as 1A non small cell lung cancer. Coroner was not informed – Expected Death'* **[exhibit WITN3691018].**

Section 3. Other Infections

87. In around 2006, I was told by my father that he had contracted Hepatitis B and Hepatitis C, as a result of infected blood products he had been treated with. I filled in forms at the hospital with this information. I have not seen much documented in his medical notes in terms of the Hepatitis B, but I am sure from the conversations I had with my dad that he thought he had Hepatitis B as well as Hepatitis C.

88. I note from my father's medical notes that he was tested for HIV on at least one occasion. It is noted that this was negative on 20 February 1998 which I referred to earlier, at exhibit **WITN3691009.** I do not know if my father was aware of this, or if he knew that he had been tested.

89. As I mentioned, my father also received a couple of generic letters regarding the risk of vCJD which I understand were sent to all patients with haemophilia. I don't know whether my dad had vCJD. Whether he did or didn't have it, there was some negative reaction from medical professionals as a result of it, for example the cancellation of my dad's bronchoscopy by Dr Evans, that I believe to be somewhat unnecessary.

Section 4. Consent

90. I am not in a position to answer whether my father was tested or treated without his knowledge, as there are many gaps in my knowledge about my father's

story, particularly in the earlier years when he would have received the diagnosis.

91. Similarly, I don't know much about what information was or wasn't given to my father.

92. I know my dad was generally very helpful and compliant regarding treatment. I am sure my father would have consented for treatment if the doctors had asked him, unless they said there may be adverse reaction. If he was poorly he didn't want to feel worse. He trusted the all the doctors to do what was best for him.

93. I do believe, however, that when my father was given the infected blood in the first instance, I think this may have been something to do with research. I don't think his care after being infected was anything to do with research, and I know my father had full confidence in Dr Ishmael and the Haematology Department he was under the care of.

Section 5. Impact

94. There were significant mental and physical effects for both my father and our family.

95. Physically, my dad got tired a lot. He became unable do his normal activities, like his gardening, which he loved, so he missed out on things he enjoyed. Tasks he could do easily before, he became unable to do. He could potter around but not do much before becoming breathless or exhausted. He couldn't walk far at all. He just had no energy. I took over all the gardening which included cutting the grass and tending to the hedges, which was hard work.

96. The family having to be careful about hand washing and wearing gloves when caring for dad made him feel dirty. This was a really big deal for him as he was such a clean man. He was fastidious about his personal hygiene, he always looked nice and well groomed. He loved his shower and brill cream. He really was such a lovely man. He hated the thought of being perceived as unclean, so he didn't like people knowing about the Hepatitis C.

97. The whole ordeal has been so hard for my mum. Not long after my dad passed away, she couldn't live on her own and had to go into sheltered housing. She felt very lonely and the house was too big for her on her own. She really didn't want to move because she had made a life in that house with my father so she had lots of good memories of her life with my father and her children growing up there. But sadly she quickly became frightened of living on her own, and the only option was for her to move.

98. Emotionally, the experience took a huge toll on my mother as well. It was hard for her, as it was for all of us, to have to watch my dad suffer. How my dad was treated after he passed away was mortifying for her as well. So, in all, there was a huge impact on my mother.

99. There was a big impact on our family life. For example my siblings and I would take turns to visit my parents with our children as it became too much for my dad to have us all there at once, so it became very rare we would all be together. There was also an impact on dad's relationship with his grandchildren, in that he was too tired to cope and so did not spend as much time with them as he otherwise would when they were small.

100. It even had an effect on his palliative care. My dad was a private man, so he dismissed the nurses who could otherwise have provided more help for all of us.

Section 6. Treatment/Care/Support

101. I am not aware of any treatment being provided to my dad for the Hepatitis C or B.

102. As far as my dad's notes show, he was diagnosed with Hepatitis C in 1996, however there is no discussion of any treatment, further examination or follow-up until 19 September 2002 where there is a letter from Dr Al-Ismail to my father stating *'I will be discussing the issue of Hepatitis C with Dr Jerry Kingham who*

specialises in this field and he may send you an appointment to attend his outpatient clinic for review' **[Exhibit WITN3691019].**

103. I understand that treatment for Hepatitis C was considered by the doctors in the years after this, as it is mentioned in several letters in my dad's file. In a letter from Dr Al-Ishmael to Dr J.G Kingham dated 17.04.2003 **[exhibit WITN3691020]** it states;

104. *'I wrote to you in September of last year about this patient with Haemophilia A and Hepatitis C. I suspect that the letter has gone astray. The only abnormality he has on the liver function tests is a raised Gamma G.T, the ultra sound of the liver which I did on him last year was normal.'*

105. *'According to our current guidelines, he will need to be counselled about the need or otherwise of treatment with Interferon, and I would be grateful for your advice.'*

106. In a letter dated 22 September 2003, which I mentioned earlier and exhibited at **Exhibit WITN3691011**, it is clear that treatment for HCV was being considered, but a decision was made to take a 'wait and see policy'.

107. There is a letter dated 18 March 2004, from Dr Al-Ismail to Dr GRO-B there is another mention of treatment, but states my father 'declined it' **[Exhibit WITN3691021].**

108. In a letter from Dr Kingham to Dr GRO-B dated 20 September 2004, it states *'Mr F and I talked again about the possibility of antiviral treatment for Hepatitis C and agreed that treatment would not be appropriate in his case'* **[Exhibit WITN3691022].**

109. Treatment was still being discussed in 2009. In a letter dated 17 April 2009 from Dr Chin Lye Ch'ng to Dr GRO-B Dr Ch'ng states *'Given [Mr F age and co-morbidity, I don't propose to treat his Hepatitis C'* **[Exhibit WITN3691023].**

110. I don't know what, if any, other treatments may have been available to my dad. We are not from a medical background so we would rely on trained medical professionals who know better to guide us through such decisions.

111. In terms of dental treatment, my father had had all of his teeth out when he was young, I am aware he had bled like mad when this was done. I don't know exactly when or why this was done, but I think it was to do with his haemophilia. I do know that my dad had all false teeth for a lot of his life. He therefore did not really need a lot in the way of dental treatment.

112. My father missed out on some available treatment for other conditions as a result of the infected blood, including the incident with the cancelled bronchoscopy. The cancellation of this procedure was so demoralising and had a huge effect on my dad and us.

113. My dad didn't like anyone knowing about his Hepatitis C. He was ashamed of it. He felt unclean. It stopped him doing as much as he used to do before the Hepatitis C.

114. He used to drink a lot of milk to settle his stomach. If he was going to go out for a drink or to play bingo or game of cards, he would always have a glass of milk before he went. He did this to try to avoid having any issues with his stomach while he was out.

115. He cut down on his beer as it affected his stomach, and he had been a man who had enjoyed a pint with friends, so his social life suffered.

116. The family found it really hard. We didn't really know what to do to help him. We would do as much as we could around the house to assist in that way. Before becoming ill, he used to be really proud of his garden. The garden was situated by a bus stop, and the people getting off the bus would often comment on it and compliment my dad on how nice it looked. He found it hard when he could no longer do this and it was a big loss for him when he could no longer do his gardening.

117. For me, taking my dad to the hospital all the time was very difficult. I could see how it was impacting him emotionally and physically, and he would get upset. I found it very difficult to see him like that, and that made me upset.

118. It impacted on my family time. I had to pay people to work my shifts in my shop to allow me to be able to take my dad to the hospital. Although of course for me, family is more important than money, there was a financial impact for me and my family as well.

119. Mentally, it used to play on my mind a lot and I spent a lot of time thinking about the situation and worrying about my dad and mum as well. Emotionally it was hard as my sister and I kept a lot from my parents. We hid facts from my mother and father in order to shield them. To try to act normally when I found out information about his life expectancy was so hard. I just really didn't want him to give up.

120. My dad felt there was a great deal of stigma. He didn't like people knowing he had Hepatitis C. He didn't mind talking to people about his haemophilia, but not the Hepatitis.

121. The Inquiry investigator had discussed with me the existence of the Hepatitis C Trust as a useful confidential source of information and support which may assist me in navigating my way through this experience.

122. In terms of any counselling, I myself do not feel counselling is appropriate at this stage. I am very much a suck it up and get on with it type of person. Furthermore, I am a great believer in talking through issues, and I do talk about things with my husband and sister in particular.

123. The Inquiry investigator has discussed with me the presence of the counselling and psychological support service provided by the British Red Cross which is running in collaboration with the Inquiry. I have been provided their contact information and will consider using it if I feel it is appropriate.

124. As far as I am aware, no counselling was ever offered to my father or mother in respect of assisting them to cope with my father's illness.

Section 7. Financial Assistance

125. My father received £20,000 from the Skipton Fund on 05.10.2004, but on an ex gratia basis.

126. My father felt strongly that someone should recompense him and the family for the infected blood he had been given. He felt someone should pay. I think the ex gratia payment he received is rather underhand. Its like a backhander to be quiet and not make trouble. I also don't understand why payments are different for people living in England, Scotland and Wales. Why is one person's life worth more than another's across a UK border?

127. He was told about this financial assistance via a letter from Singleton Hospital. I had also joined him up to the Haemophilia Society so he got some information about the payment scheme from them too.

128. There was a further application made to the Skipton Fund in an additional payment application form on 03.12.2010. In a response dated 14.12.2010, the application was deferred **[exhibit WITN3691024]**. It states the following;

129. *'As you will be aware, this second stage application provides a number of fairly complex means of determining whether the effect of the hepatitis C infection on the applicant's liver has reached a stage, or 'trigger point', at which the ex gratia payment scheme permits the second payment to be made. In your case, the form completed by your consultant indicates that the trigger point has not yet been reached.'*

130. *'In the circumstances I am returning your application to you and advising you that at the moment your request has been deferred. Please be assured that we cannot reject an application for a second stage, only defer approval until the trigger point is clearly reached. You are welcome to re-apply at any time in the*

light of changes in your medical condition, as the fund has no closing date; we understand, however that it is unlikely that the disease will progress so quickly that you should consider re-applying in less than 12 months from now. May I suggest that you discuss this with your consultant.'

131. Sadly, my dad died GRO-B after receiving this letter in GRO-B 2011.

132. I knew how ill my dad was and how limited his life would be when we made the application for the additional payment, and I knew it would help my mother after my father's death. I also knew my father was mindful of wanting things to be in place to look after my mother after his death, so it may have made him less worried if he knew my mother would have had a financial cushion. So it was very sad when his second application was rejected by Skipton Fund because he wasn't deemed to be ill enough.

Section 8. Other Issues

133. The illness inflicted on my father has totally taken the shine off my memories of him. I remember all the bad things and have to struggle to remember happier times.

134. My opinion is that somebody is responsible for the infected blood scandal. I know there are a lot of different departments involved but someone must have signed off that this was safe. Was it for financial reasons? Surely they knew where the blood was coming from and the type of people it was coming from and the level of risk this brought?

135. I wouldn't get medicine from a prison for example, I would go to a decent pharmacy. So I think it needs to be decided who is going to take responsibility for the decisions that led to this situation. Who decided to gamble with peoples' lives?

136. The scandal has affected a hell of a lot of people's lives; old and young. It wasn't any of the victims' fault that they ended up with these terrible illnesses. The mental and physical anguish that people have had to go through has been awful, and it simply wasn't their fault. This is what really gets to me.

137. There are lots of people infected who were a lot younger than my dad, who have to live their whole lives with this. Is it ever going to go away?

138. In my opinion, the payments are not enough. The ex gratia payments are like hush money. Its about time someone stands up and is counted. I know victims of this scandal in other countries have had vast payouts, so what makes British lives less valuable?

139. In my opinion there has been a lot of buck passing. No one stands up and says they had done something wrong and says sorry.

140. I believe this would make a big difference to people living with illnesses as well as their loved ones, and provide some hope for the future.

141. I have exhibited the following documents:

Exhibit number		Date
WITN3691002	Letter from Dr Winsey, Consultant Physician at Singleton Hospital to Dr GRO-B advising that F had been diagnosed with haemophilia whilst waiting for his duodenal ulcer operation.	06.11.1979
WITN3691003	Clinical Notes – FVIII given before, during and after operation.	12.01.1980
WITN3691004	Clinical Summary	19.01.1980
WITN3691005	Continuation History Sheet – Transfusions given on 19 and 20 November	20.11.1984
WITN3691006	Continuation Sheet – Showing donor numbers	19.11.1984
WITN3691007	Nursing Care Plan – potential adverse reaction to blood transfusion	21.11.1984
WITN3691008	Blood Product List	19.11.1984

WITN3691009	Continuation History Sheet – Hepatitis C positive, HIV test negative	19.02.1998
WITN3691010	Letter from Dr Puli to Dr GRO-B	16.04.2010
WITN3691011	Letter from Dr Kochar to Dr Al-Ismail – confirms brief surgical history and diagnosis of Hepatitis C in 1996, as well as 'wait and see policy' on treatment.	22.09.2003
WITN3691012	Letter from Dr Rackley to Dr GRO-B – [Mr F had three cycles of chemotherapy but could not tolerate the full cycle due to poor blood counts	24.05.2010
WITN3691013	Letter from Miss Jones to Dr GRO-B – [Mr F was not treated with adjuvant chemotherapy in view of his Hepatitis C.	16.11.2009
WITN3691014	Letter from Dr Evans to Dr GRO-B	06.01.2010
WITN3691015	Generic letter from Abertawe Bro Morgannwg University NHS Trust re vCJD – confirming that the risk will not affect the way patients are treated.	February 2009
WITN3691016	Death Certificate	GRO-B 2011
WITN3691017	Notice of Infection Risk	GRO-B 2011
WITN3691018	Letter from Dr C Lawton at Dept of Palliative Medicine to Dr GRO-B – confirming Mr F had passed away and that the coroner had not been informed due to it being an expected death.	GRO-B 2011
WITN3691019	Letter from Dr Al-Ismail to Mr F – confirming he will be discussing Mr F Hepatitis C with Dr Kingham who may send an appointment to attend his clinic.	19.09.2002
WITN3691020	Letter from Dr Al-Ismail to Dr Kingham regarding Interferon	17.04.2003
WITN3691021	Letter from Dr Al-Ismail to Dr GRO-B – [Mr F was offered treatment but he 'declined it'.	18.03.2004
WITN3691022	Letter from Dr Kingham to Dr GRO-B – Had discussed antiviral treatment with Mr F and agreed that it would not be appropriate in his case.	20.09.2004
WITN3691023	Letter from Dr Chin Lye Ch'ng to Dr GRO-B – due to co-morbidity and age, don't propose to treat Mr F Hepatitis C.	17.04.2009
WITN3691024	Letter from Skipton Fund – deferring application for additional payment as 'trigger point' had not been reached.	14.12.2010

Statement of Truth

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

Signed GRO-B

Dated 19/2/2020