Witness Name: Brian Ahearn
Statement No: WITN0165001
Exhibits: **WITN0165002-9**
Dated: 11-04-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BRIAN AHEARN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6 February 2019.

I, Brian Ahearn, will say as follows: -

Section 1. Introduction

1. My name is Brian Ahearn. My date of birth is GRO-C 1966 and my address is known to the Inquiry. I intend to speak about how I was infected with Hepatitis C through contaminated Factor VIII.

2. I am a retired painter/decorator. I had to give up work many years ago due to my ill health. I live with my wife, Jacqueline Ahearn ("Jackie"), at our home in Manchester. We married in 2001 and we have two children together. I also have a daughter from a previous marriage.

3. I suffer from severe Haemophilia A. Because it is a genetic condition, a number of my family members were also diagnosed with Haemophilia, including my older brother, Kevin Ahearn, and my cousin, Andrew Forbes. They both contracted HIV and Hepatitis C from contaminated Factor VIII. Andrew died in 1991 and Kevin died in GRO-C

4. Since being diagnosed with Hepatitis C, it has been one trauma after another for Jackie and I. As soon as things seem to start improving, something else is thrown at us. I have suffered from cirrhosis of the liver for a number of years and this causes me constant fatigue. I also suffer from depression and anxiety. These conditions were already having a significant impact on my life.

5. Then, just a week and a half ago, I was diagnosed with terminal liver cancer. I am still coming to terms with this recent diagnosis and what it means for my family and I.

6. Although we have previously tended not to tell people about my Hepatitis C, I have decided that I do not want to be anonymous. I feel like it is time to tell my story.

Section 2. How Infected

7. I was diagnosed with severe Haemophilia around the age of one. Kevin had already been diagnosed when he was about three years old and so my parents were aware that there was a risk I may have it too. I have three other brothers GRO-C

8. I have always received my treatment at Manchester Royal Infirmary. I have been going there since birth and have never been to any other hospital.

9. Before Factor VIII was introduced, I was treated with cryoprecipitate, or cryo as we used to call it. This was administered through a bag and syringe at hospital and each treatment would take about four hours. I loved cryo as I never had any hassles with it and it didn't make me feel sick. However, when I was about 10 or 11 years old, the doctors told us that it was being phased out as it was being replaced with Factor VIII.

10. At the time, I assumed that Factor VIII was cheaper than cryo and that this was why they were giving it to us. Even though I told the doctors that I preferred the cryo, I was not given a choice and had to start using Factor VIII.

They told us that it would be much easier to use, especially because they could teach us to administer it ourselves. It was seen as ground-breaking at the time because I didn't have to go to hospital every time I needed treatment. I could even use it at school. Although it did get rid of the bleed quicker and made me feel better, it left a metallic taste in my mouth that made me feel sick.

11. Over the years, I received a multitude of different Factor VIII products. There were so many. I remember a couple of the brand names, such as Alphanate and Elocta. I have kept a record of all the treatments I received, which I produce as **Exhibit WITN0165002.** It dates back to 1971 and shows I first received Factor VIII in 1977.

12. I have also kept two letters from Manchester Royal Infirmary about a recall of Alphanate Factor VIII. I was sent the first letter on 5 November 1998, which I produce as **Exhibit WITN0165003**. I was then sent a further letter on 25 November 1998 about an Alphanate Post Marketing Inhibitor Study I was taking part in. I produce this letter as **Exhibit WITN0165004.** I can't recall the details of this study but the letter said that, due to the recall, the study was being terminated. However, they asked me to come in for a final blood test.

13. My family and I were never told anything about the risks associated with Factor VIII. We were never told that there was a risk of contracting Hepatitis or any other infection.

14. When I was in my early teens, I found out I had contracted Hepatitis B through contaminated Factor VIII. I suffered from jaundice but then cleared the infection relatively quickly.

15. Then, around 1994, I found out that I had also contracted Hepatitis C. This was after I had met Jackie. I was told by my haematologist at the time, Dr Charles Hay, during a routine appointment. He just came out with it as though he assumed I already knew. He said something along the lines of: "Well you know you have Hepatitis C, don't you?" Dr Hay insisted that I had already

been told about this around 1986, even though this was definitely not the case. I am certain I was with Jackie when I was first told I had Hepatitis C and I did not meet Jackie until 1990.

16. When I was diagnosed, Dr Hay kept telling me that everything was fine and he definitely did not give me the impression that it was anything serious. It was just as if to say, "by the way you've got a cold, there's absolutely nothing to worry about."

17. I had no idea how severe Hepatitis C was until Kevin told me about it. I thought it would be similar to Hepatitis B and that I could expect to get jaundice again. However, when I spoke to Kevin he told me I wouldn't be able to get rid of this one that easy. By this time, he had contracted both HIV and Hepatitis C and so he had dealt with it all before. It was Kevin, not the doctors, who told me everything I needed to know about Hepatitis C.

18. I do not feel that I was given adequate information by Dr Hay to help me understand and manage the infection. I was never told what symptoms to look out for. I also do not remember Dr Hay telling me anything about the risk of passing the infection on to others. I am certain that at the time of my diagnosis, we were unaware about the risk of me passing it to Jackie GRO-C

19. GRO-C

Section 3. Other infections:

20. As far as I am aware, I have not contracted any infections other than Hepatitis B and Hepatitis C. Because Kevin had been diagnosed with HIV, I was tested for this as well but it came back negative.

21. I was, however, sent a letter by Central Manchester Healthcare NHS Trust on 22 January 2001, which explained how a blood donor whose plasma had been used to make clotting factor concentrates had been found to have variant Creutzfeldt-Jakob disease ("vCJD"). I produce this letter as **Exhibit WITN0165005.**

22. I was then sent a further letter by the Health Protection Agency on 7 September 2004, which said there was a possibility I had been infected with vCJD. I produce this letter as **Exhibit WITN0165006.** Central Manchester and Manchester Children's University Hospital NHS Trust also sent me a letter about this with an enclosed information leaflet on 20 September 2004. I produce this letter as **Exhibit WITN0165007.**

23. It was quite a shock to be told all of this by letter. It felt like they were just trying to cover their own backs. We had already been through so much by this point and I remember thinking at the time, "is there anything else you want to throw at us?"

24. I later attended a routine appointment with Dr Hay. He explained that a person with Haemophilia had died and his autopsy revealed that he had vCJD. I remember Dr Hay saying that they weren't sure that he had contracted it through contaminated blood and that it was possible he could have "caught it from a burger".

Section 4: Consent

25. In the early days, when I was very young, they used to do a lot of research on Kevin and I. It did feel a bit like we were used as guinea pigs. From what I can recall, they always asked our mum for permission and they would ask us as well. It was a day off school so I was always happy to do it. The studies related to Factor VIII and would involve taking our blood.

26. I remember one of the studies looked at how Kevin had contracted HIV but I hadn't, even though Kevin and I used to share our Factor VIII treatments all

the time. We weren't aware of what was going to happen later so, even after Kevin married and we didn't live together anymore, I used to have one of his treatments or he would have one of mine.

27. I also had a few lumbar punctures done when I was about 13 or 14 years old. From what I can recall, these were also for research purposes but I'm not sure exactly what they were testing for. The doctors often discussed that sort of thing in medical terms I didn't understand.

28. As far as I am aware, I was not treated without my knowledge or consent. However, I do feel that I was often not given enough information by my doctors, particularly around what tests were being done. They always did our bloods every six months but they never sent us any reports with the outcomes. I always assumed they were just testing factor levels.

29. I don't know how or when I got tested for HIV; I was just told at some point that I didn't have it. Similarly, I don't know when they first tested me for Hepatitis C. I only know that it was around 1994 when I was first told I had it and yet they acted as though I had already been diagnosed. For all I know, they could have been testing me for years.

Section 5. Impact

30. After I was diagnosed with Hepatitis C, Dr Hay initially tried to manage my treatment on his own. I should have been referred to a hepatologist straight away but he wanted to control everything and was not letting anyone else in. It was ridiculous.

31. Dr Hay did not offer me any treatment for the Hepatitis C until 2000. The treatment was called Interferon and I started it the same year. I found the Interferon terrible. I had to inject it into my stomach and it made me feel so ill. It gave me a fever and made me nauseous. Certain smells would make me feel sick. It made me sweat a lot, which is something I still experience even now. I was constantly tired. I lost a lot of weight and all my body hair. I was

yellow for a full year. If you had seen me, you would have thought I was on chemotherapy.

32. I understand that any drug carries potential side effects but I didn't expect it to be that bad. After six months, they told me I could come off it if I wanted to but, as terrible as it was, I was willing to try anything after seeing my brother so unwell. I stuck with it for 12 months. At the end, they told me that it had given my liver a rest but hadn't cleared the infection.

33. I finished this first course of Interferon in 2001. This was already a tough year for Jackie and I. Although it was the year we got married, it was also the year my brother died. On top of this, we also found out shortly after our wedding that GRO-C She is okay now but we had to cancel our honeymoon so she could have it removed. My mum had also passed away two years earlier so it was an extremely difficult time in my life.

34. Before Kevin died, he made me promise that I would make an appointment to see a hepatologist. His death made me realise I had to buck up and start looking after myself.

35. I started seeing a hepatologist and I was put back on Interferon in 2004. This time, I took it in combination with Ribavirin. This second course was not as bad as the first but it still gave me mouth ulcers and thrush of the mouth. After three months, the hepatologist told me that it had brought my liver function back to normal but they could see it wouldn't clear the virus. I asked them why I couldn't stay on it for the full 12 months as I wanted to persevere with it to give my liver a rest. They told me that there was no point; that it was a waste of money because it wasn't going to cure it. I had no choice in it. It was essentially "off you go, see you in six months".

36. I was later told that there was a further Hepatitis C treatment available. However, my hepatologist said that, for funding reasons, I was not eligible for the treatment until my cirrhosis had progressed to stage two. A couple of years ago, my cirrhosis reached this stage and I was started on the treatment.

I can't remember what it was called but I do remember it was in tablet form. I believe it may have been Ribavirin in combination with something else.

37. I was initially meant to be on this treatment for six months but, after three months, my hepatologist told me it wasn't necessary for me to stay on it that long and I was taken off it. They said that my results showed that the treatment may have cleared the virus but they could not confirm this until I have a further check up in 12 months time. I have never been called back in for this.

38. Although I may have now cleared the Hepatitis C, my cirrhosis still causes me extreme fatigue, which has only gotten worse over time. I now sleep for most of the day and spend a lot of time in bed.

39. My mental health has also suffered since being infected. For many years, no one had informed me that depression could be a symptom of Hepatitis C and so I hadn't realised that I was suffering from it myself. I thought that the way I was feeling was normal. It wasn't until a couple of years ago, when I spoke to my GP about depression, that it all clicked. I realised I had been battling with it for many years. I think it probably started after Kevin died. When we lost him, things had sort of spiralled out of control and I didn't have a chance to grieve for him properly.

40. I have put on loads of weight on because of the depression, which only makes me feel worse. More recently, I have also started suffering from anxiety. It makes me not want to go out and be around other people. I also worry and have difficulty sleeping whenever I receive letters about medical appointments. The doctors do not seem to realise that how they word things can make me feel so much worse. On top of all this, my short-term memory is getting worse and I worry that this could also be due to the Hepatitis C.

41. Initially, I refused to go on anti-depressants as I was worried about destroying my liver. Kevin had been on so many tablets and I was frightened to death that I would end up like him with my liver packing up. However, eventually the

depression became so severe that I realised I had to sort myself out and go on medication. Although I have been on anti-depressants up until very recently, my depression and anxiety have only gotten worse and, at times, I experience suicidal thoughts.

42. Aside from Haemophilia A and Hepatitis C, I also suffer from sleep apnoea and arthritis. I do not know how much these conditions have been caused or worsened by the Hepatitis C but they are, at the very least, further complications on top of everything else.

43. I am now full of arthritis in every joint and it doesn't help that I spend all day in bed due to the fatigue from my cirrhosis. I have had particular trouble with my ankle and, although it's been fused twice, it has basically crumbled now. It's a mess, a proper mess.

44. Most recently, my hepatologist has been Dr Shaun Greer and I have been seeing him every six months for monitoring. As part of this, I have an ultrasound scan every six to twelve months. The radiographers who take the scan have told me that my liver is quite high up under my ribcage so it can be difficult for them to get a proper reading. They have also mentioned a number of times that they think there is fatty tissue on my liver.

45. I also used to have endoscopies many years ago; however, at some point I was told I could no longer have them as I could contaminate the machines and infect other people. I found it bizarre that they couldn't just disinfect the machine. I know that endoscopies show more than an ultrasound and so I was disappointed that I couldn't keep having them. I was terrified given what had happened to my brother and wanted to do whatever I could to prevent the same thing happening to me. It wasn't until recently that I asked my consultant about endoscopies and was told that there is no reason I should have been denied them in the past.

46. Having Hepatitis C has taken a real toll on my private, family and social life. I used to have a good social life. I loved going out to play pool and darts. Now, I

like to be on my own or with Jackie. I also love spending time with my children and grandchildren. However, I don't like going out or being with a lot of people because of the fatigue, depression and anxiety. We therefore don't often go out on family days. It has gotten worse over the last five years and I hardly ever leave the house now. I don't even go to the supermarket anymore. I just can't be bothered. I don't drink either because I know every drink would only make my liver worse.

47. When I was first diagnosed with Hepatitis C, I was working as a painter/decorator. I have also worked as a joiner in the past. The doctors had told Kevin and I when we were teenagers that we had to get an office job because of our Haemophilia. However, I had always been a physical person and so I decided that I wouldn't just do what the doctors told me to. I was able to work through the Haemophilia; it didn't bother me because I learnt to live with the pain. I was constantly working around 15 hours a day and would come home exhausted. Now, there is none of that. I had to give up work around 1996. The fatigue and depression from the Hepatitis C stopped me from working more than anything else.

48. I always knew deep down that I wouldn't be able to work until I was 60/65 years old and so I have saved money over the years. However, I still never expected to be giving up work so early and this has made a big impact. I find it difficult having to deal with the stigma associated with the husband of the family not working. Generally, when you get married and have children, you want to make sure your family is financially secure and looked after. However, having to give up work so early has put financial pressure on us and has meant I am not in a position to provide for my family.

49. Although the stigma attached to Hepatitis C does not bother me as much now, it is something that we have struggled with in the past. I didn't want people to find out, particularly when the kids were still at school. For this reason, so many of our friends still do not know that I have Hepatitis C and close friends that I have known for 20/30 years have only found out recently. It has only

been in the last few years that I haven't minded my friends knowing. Life's too short. I just take it as it comes now.

50. I don't worry about disclosing that I have Hepatitis C to other medical professionals, like my dentist. However, I also have to tell the receptionist when I am filling out forms and I now have to tell them that there is a possibility I have vCJD as well, which leads to everyone in the practice knowing my business. For that reason, I go to a dentist far away from where I live.

51. I have also had to inform the bank about my health. I've never had life insurance. I simply can't get it. Travelling is also an issue as travel insurance is always so expensive. I also think it's ironic that I probably would have difficulty getting into the United States even though the contaminated Factor VIII probably came from there.

52. In relation to Kevin and Andrew, the stigma around HIV was horrific. We tend not to tell people that they had HIV. Andrew had worked in and lived above a bakery owned by his family. When he died, his family told everyone he had died of cancer as they were worried that it would absolutely ruin the business if people found out the truth. They couldn't even tell the other employees.

53. When Kevin died, his body was put inside a body bag with a hazardous label on it. It was shocking. Kevin's wife wanted to view the body but they wouldn't even open the bag. By the time they got an undertaker to the do the funeral, Kevin's body was in no fit state and they couldn't even embalm him. They had to put the bag straight into the coffin to be cremated.

54. My infection with Hepatitis C has had a devastating impact on my family. Jackie takes the brunt of it. She has supported me through everything. About eight years ago, when my health got worse, she gave up work so she could spend more time looking after me. I know that she worries about me a lot and, because of this, she is always on edge. Often, the furthest she goes is to the supermarket because she worries about what she may come back home to.

55. Jackie spends a lot of time on her own because I am always so fatigued. It has seriously affected our relationship and we even split up for a while. We have never had a normal, married life and this is largely due to my Hepatitis C and the fatigue and depression that come with it.

56. Similarly, our kids never had a normal upbringing due to my ill health. GRO-C GRO-C I feel guilty GRO-C GRO-C and I feel a massive amount of pressure to help them. I'm the last in line because my mother, father, brother and cousin have all died. I am the only person left who knows what it is like growing up with Haemophilia so it has all fallen onto my shoulders. My eldest daughter depends on me GRO-C It is a big pressure and I do worry about how they will cope without me. I just want to make sure they get through it all.

57. I feel like it has just been one trauma after another for my family. It was 1991 when we lost my cousin, Andrew, through HIV. He was only 28 years old. Shortly after this, we found out I had Hepatitis C. At that stage, we already knew that Kevin had both HIV and Hepatitis C.

58. Before Kevin died, he went through a horrid period. Dr Hay was also Kevin's haematologist and he tried to manage Kevin's treatment on his own, as he did with me. By the time a hepatologist got involved and visited my brother, they said there was nothing they could do to help him. They did look into whether he could have a liver transplant as they had managed to get his HIV infection under control. However, by then he was too far gone. His liver was failing and he had terrible varices. They eventually said there was no way he could have a liver transplant.

59. As a family, we bought Kevin home for Christmas in 2000 but by Christmas day, he was already back in hospital. Kevin died in GRO- He was GR years old. He left behind a wife and two children.

60. **GRO-C**

61. At times, I've felt like I was pushed to one side due to having Hepatitis C and not HIV. It always seemed like the patients with HIV were the priority. However, given what happened to Kevin and Andrew, I have always felt as though I am the "lucky one." I've made it to 53. I've got a wife, kids, and grandchildren. I've done well. Andrew never got to have any of that. There is always someone worse off. Yet, in spite of all this, I can't help but wonder whether Kevin and Andrew may have got the better end of the stick. What happened to them was horrible but they haven't had to live through as much as I have. I miss them both terribly and it affects me more than I like to admit.

62. I was there when Kevin and Andrew died and, since then, I have been terrified that the same thing will eventually happen to me. I often felt as thought time was just ticking down until the day when they say there is nothing more they can do for me. Unfortunately, that day has now come.

63. I had my most recent ultrasound scan in January 2019. The trainee who was taking the scan called in the radiographer and I heard them discussing a mass up on the right side of my liver. I overheard them say that they weren't sure whether it was just fatty tissue. When they finished the ultrasound, I was waiting for the usual reaction, that everything was fine, but this never came. They asked me whether I had an appointment booked with my consultant and I told them I wasn't due to see him for a few months. They told me not to worry and that an appointment would be arranged for me to see him sooner. I knew something was not quite right.

64. I then had an endoscopy in late January or early February 2019. This was the first one I'd had in about 14 years. My hepatologist, Dr Greer, did the procedure himself. At the time, he seemed quite happy with the results. He mentioned that he had seen something in the bottom of my stomach but it didn't sound as though it was anything serious.

65. I then received a letter saying I had an appointment for a CT scan. I called Dr Greer to find out why and was told it was because they couldn't get a proper reading from the ultrasound so they wanted to do a CT scan to confirm everything was okay.

66. I had the CT scan around the end of February 2019. The radiographer told me that a radiologist would have to review the scan and write a report but my hepatologist should receive the results by the following week.

67. I waited a week but didn't hear anything from Dr Greer. I decided to chase it up myself and spoke to Dr Greer's secretary on the phone. She said that they hadn't yet received the results.

68. In the end, I think I called Dr Greer's secretary three or four times and every time I got the same answer; that they still didn't have the results back from the radiologist. It was nerve-wracking having to wait for so long and I was absolutely terrified about what they were going to come back with.

69. Then, on Saturday 30 March 2019, I received a call from Dr Greer. He first said that he wanted to apologise that I had to chase up my scan results. He admitted that this wasn't right and that things should have been done quicker. Dr Greer said that he wanted me to come in to see him on Monday afternoon and that I should bring somebody with me. I knew instantly that something was wrong.

70. That weekend was tough. It felt like a long, long wait from the call on Saturday to the appointment on Monday. Jackie and I knew it would be bad news and we tried to prepare ourselves for the worst.

71. We visited Dr Greer on Monday 1 April 2019, as he had requested. He gave us the news we had been dreading. I have liver cancer. There are several tumours on my liver and it is terminal. As soon as he said this, Jackie and I stopped taking much in. I don't remember all of the details of what was said but they certainty didn't have anything positive to say.

72. Dr Greer said that there also appears to be a tumour in my portal vein; however, they weren't certain whether it was a tumour or a blood clot. He said that if it is a blood clot, they might be able to give me a liver transplant. However, he explained that nine times out of ten, it will be a tumour and, if this is the case, I won't be able to have a transplant. Dr Greer said that there are medicines they can give me to slow down the progress of the cancer but he didn't mention chemotherapy or radiotherapy.

73. Dr Greer said he would send my results to Leeds because they are the specialists in this area and will be able to confirm whether the mass in the portal vein is a blood clot or a tumour. He also said I would now be under the care of Dr Prince, another hepatologist at Manchester Royal Infirmary, as he specialises in patients with liver cancer.

74. I asked Dr Greer how long he thinks I have left. He took forever to answer. He eventually said it could be two months or two years. Apparently they will know more soon but, at this stage, they just don't know.

75. I questioned why the cancer was only just being picked up now given I have regular ultrasounds. Dr Greer said that the cancer would have grown quite quickly and so may not have been there when I had my ultrasound six months earlier.

76. I also told Dr Greer how annoyed and frustrated I was about having to chase up my results. He apologised again and told me that I can contact the Patient and Liaison Services to make a complaint. However, from what we have heard, this would be quite a process and we would have to make a complaint in writing. As angry as I am, that is the last thing I want to be focussing on when I have just received news like this.

77. Although we had spent all weekend before the appointment worrying and preparing ourselves for the worst, we at least thought we would have had more options. I wish Dr Greer had given us more information. I don't like to

look online as I know what's on there isn't always reliable. However, Jackie has been doing online research about liver cancer and she feels she has learnt more this way than she did from the doctors.

78. Although Dr Greer told us that the cancer may not have been there six months ago, from what Jackie has read online it sounds as though I wouldn't have many of my symptoms unless I'd had the cancer for a while. For instance, I have suffered from itching for years and Jackie saw online that this can be a symptom of liver cancer.

79. I also had told a number of doctors about pain I was experiencing in my abdomen, around where my liver is. I have had this pain for a number of years; however, it has become a lot worse in the last couple of months. Before my liver cancer diagnosis, I told Dr Greer and two GPs at Unsworth Medical Centre that I was concerned about this pain. However, I didn't really get an answer from anyone.

80. One of the GPs I had a telephone consultation with, Dr GRO-D told me it was just because I had changed my diet recently. After this consultation, the pain got worse and I was in total agony. It felt like I had broken ribs. I therefore had a further telephone consultation with another GP, Dr GRO-D GRO-D and explained my history of Hepatitis C and cirrhosis. However, he just told me that I was "looking into it too much".

81. After I was diagnosed with liver cancer, I called the GP Practice GRO-D to complain about the advice I had received. The Practice GRO-D called me back and told me she had spoken to the GPs involved and "it was something they could learn from". There was no apology.

82. When I saw Dr Greer on 1 April 2019, he recommended that I double my dose of morphine to help with the abdomen pain. I tried this the following day but it completely knocked me out. I have reduced my morphine back down to my original dosage and, although I am still suffering from pain in my abdomen, at least I am not asleep all day.

83. What frustrates me more than anything is the possibility that we could have known about the cancer years ago, before it would have gotten to this point. I can't help but wonder whether there is more that they could have done. If it was picked up earlier, maybe I could have had a liver transplant. At previous scans they have told me that they "think" it's just fatty tissue on my liver. If they weren't sure, why did I not have a CT scan or endoscopy back then?

84. I appreciate that I am angry and upset at the moment but surely the medical professionals should have picked this up earlier. Everything the doctors are telling us suggests the cancer is at an advanced stage and so we find it really unbelievable that it has only developed within the last few months. It definitely puts a bit of doubt in your mind. I have six monthly ultrasounds, regular appointments with multiple specialists and blood tests every couple of months. Why has no one put two and two together until now?

85. We appreciate that there are millions of people being treated by the NHS but I feel like I have been let down yet again. I wonder how long it would have been before we found this out had it not been for me chasing up the results myself. Would it have been the week before I died? The day I died? It is not right.

86. Since the diagnosis, I feel like things have gone completely downhill. It has been devastating for Jackie and I. My depression and anxiety have gotten worse; I've completely and utterly hit rock bottom. The first few days after the diagnosis were really hard. It was especially difficult having to tell our family and friends.

87. Jackie has taken it particularly hard. On the way home from the appointment, we called our kids and asked them to meet us at the house. In the car, Jackie and I were discussing whether we should wait to tell them but Jackie knew that she wouldn't have been able to hide how upset she was. She made me drive around the block because she wasn't ready to tell them. They were at the doorstep waiting for us when we arrived but Jackie couldn't' even get out of the car.

88. It was devastating telling the kids. My son has taken it particularly badly. My two girls are very positive and trying to stay upbeat but I think they may be in denial. One of my daughters seems to be hoping that they've got it wrong, that they have mixed me up with someone else.

89. I am a practical person and so, in the past week, I have been putting all my finances in order. My main worry is how my family will be financially supported once I die. I know that it might be old-fashioned of me but I can't help feeling like I have failed Jackie and the kids. I don't have life insurance; however, I am currently in the process of buying our house with the stage two lump sum payment I received from the Skipton Fund. At least then Jackie can have the house.

90. I am trying to focus on the fact that I'm doing okay at the moment. I'm not like Kevin and Andrew were at the end. Knowing this is keeping me going for now. However, it is extremely difficult to see how devastated my family is. When Jackie is in bits, I can't help but get upset and, when I see my kids and my grandkids, I can't help but wonder how long I've got with them.

91. We still have a lot of questions and hopefully they will be answered soon. I have an MRI scan and an appointment with Dr Prince over the next couple of weeks. In the meantime, life has to go on. I just want to get on with things and live as normal a life as possible. Every morning I don't want to get out of bed but I am dragging myself to get dressed. This is the hand I was dealt and I have to get on with it. I am not going to sit here and wait for the end to come. It will have to chase me. It's as simple as that.

Section 6. Treatment/Care/Support

92. Although I have been offered a number of different treatments for my Hepatitis C, I do find it bizarre that I had to wait until my cirrhosis was bad enough before I could qualify for my last treatment. I was infected with Hepatitis C because of what the Government did and so I feel I should have been offered

any treatments at the first opportunity. I do wonder whether I would still have these tumours if I had been offered this treatment at an earlier stage.

93. The support that has been offered to my family and I has been completely lacking. Years ago, we had a coordinator at Manchester Royal Infirmary who, from what I can recall, was there to provide support to patients like Kevin and I. She was kind of like a social worker. However, we soon found out that she had been telling everybody about Kevin's HIV. She ended up being sacked from the hospital for telling people private information about other patients.

94. I have received counselling in the past but I do not feel that this was adequate. About four years ago, my GP referred me to counselling but I didn't realise that it was a group session until I arrived. My GP hadn't told me. There was no way I could sit in the room and tell everyone what had happened to me so I left straight away. I went back to my GP and asked for face-to-face counselling but I was told there was a six to ten month waiting list. They offered me phone counselling instead, which I did try for a few months. However, I was only given ten-minute consultations. It felt like an utter waste of time. In the end I told them not to bother.

95. Trying to get proper counselling was like banging your head against the wall. There was nobody who understood what I was going through and I was not properly supported. I feel there should have been a service offered for people in this particular situation.

96. Jackie and I were not offered any counselling or support at my recent appointment when I was diagnosed with liver cancer.

Section 7. Financial Assistance:

97. I first found out about the Skipton Fund through a letter from the Department of Health, which was sent to me on 26 January 2004. I produce this letter as **Exhibit WITN0165008.** I had never been told about any financial assistance

before then. I think the Department of Health must have received my details through solicitors I had visited with my brother years earlier.

98. I got in touch with the Skipton Fund about applying for the initial £20,000 lump sum payment. They said that they had been trying to contact me for five years. I told them that I had been living at the same address the entire time and hadn't received anything from them so I did not understand how this could be the case.

99. Other than this, the people at the Skipton Fund were brilliant. I found the application process for this first payment straightforward and I received the payment not long after I applied. I can't remember the exact date. I've never touched this £20,000 as I decided to save it for my family.

100. After I received the lump sum payment, I started receiving a monthly payment of £250 pounds. I was elated at first but then it sunk in that maybe I should have received this support years earlier. I did ask them whether I could receive a back-payment but they said they could only backdate it to when I had submitted the application.

101. A few years after I received the first payment, I was sent a letter saying that I may be entitled to a stage two payment if I had developed cirrhosis of the liver. The application process for this second payment wasn't as straightforward because we had to get evidence of the cirrhosis from my hepatologist. I remember having a Fibroscan done and I was only just over the reading required to be eligible for the stage two payment. The Skipton Fund therefore made me have the scan a further two times before finally saying that I qualified. I received a lump sum of £50,000 and my monthly payments also increased to £1,500 per month.

102. I am still receiving this monthly payment; however, I now receive it through the England Infected Blood Support Scheme ("EIBSS"). I also receive an additional top up payment for low-income earners of around £134 a month. Now, I just have to re-apply for this top up payment each year.

103. On top of the lump sum and monthly payments, there are also certain things you can claim for, such as a bed or anything that benefits your health. However, generally speaking, if Jackie and I have the money and can afford to pay for it ourselves then we will. We don't like having to rely on benefits.

104. Although I was told the Skipton Fund payments would not affect my entitlement to the sickness benefit, I received a letter from the fraud squad of the Department for Work and Pensions after receiving the £20,000 lump sum. I was terrified when I received the letter. It said that if I didn't respond I could go to prison. I was worried I was going to get hauled off to court. At the time, it made my depression and anxiety so much worse. After I went in and explained my circumstances, they apologised and told me I never should have been called in. They said there must have been a breakdown in communication. However, despite all this, I was called in again when I received the second payment of £50,000.

105. Kevin and Andrew also received financial assistance. Kevin was made to sign a form and was given £100,000 through the Macfarlane Trust as hush money. He invested the money because he wanted to make sure his wife and kids would be looked after.

106. My cousin, Andrew, didn't have a wife or kids and so he was only given £36,000. It didn't seem fair. He was only 28 when he died; he didn't even have the chance to marry and have children.

107. Since being diagnosed with liver cancer, I have contacted EIBSS to ask whether Jackie would continue to receive any support when I die. They told me that she would receive a £10,000 lump sum payment and that my funeral would be paid for. They also said that the £1,500 monthly payment would stop but that, depending on Jackie's income, she could still be eligible for a low-income monthly top up payment of between £81 – £1,400.

108. It is quite a financial loss for Jackie. Although the money isn't a priority for her, it is still another thing to worry about on top of everything else. She has been my carer for many years and so has been out of the work force for a long time. I worry about how easy it would be for her to find a job if she were suddenly in a position where she had to return to the work.

109. Although my main concern isn't the money, I do not feel that the financial support that has been provided to me and my family is in any way adequate. I am grateful for what I have received but I do think it's shocking that, after all the millions of pounds the Government probably saved by using Factor VIII, they are now buying us off for £20,000. Is that really what our lives are worth?

Section 8. Other Issues

110. On 14 March 2019, the National Haemophilia Database sent me a letter about a previous request I had made for my personal information. I produce this letter as **Exhibit WITN0165009.** The letter says that, when I made the request, they may not have sent me all of the information they hold about me because they have since discovered some paper forms that had not been entered into their electronic record. The letter says I should receive any additional information they hold in several weeks. I cannot even recall making this information request and so I must have made it many years ago. It does seem suspicious that they are suddenly telling me this now, particularly given we were also told shortly after Kevin died that his medical records had been "lost".

111. I have never bothered with any other inquiry or campaign. It was always Kevin GRO-C used to get involved with that sort of thing, including the HIV litigation. At one point, I did go along with Kevin when he spoke to the solicitors. GRO-C GRO-C

112. I would like answers as well. Although I would like to make sure my family will be financially secure, this isn't really about the money for me. I just want

someone to hold their hand up and admit they imported the blood products because it was cheap. It makes me angry to think that the Government knew they were buying infected blood and yet they continued to use it. Someone needs to be held accountable for it and put away.

113. I would also like Dr Hay to be held responsible for what he has done. He is still at Manchester Royal Infirmary but I refuse to see him now. Both Kevin and I should have been automatically referred to the appropriate people. I have heard that this is what happened for patients in Leeds who were infected; they were referred to the appropriate specialists straight away. It was not right that Dr Hay tried to manage our care on his own. It's frustrating to think about whether things may have been different today if Dr Hay had referred Kevin and I to a hepatologist earlier. I am sure that he did the same thing with a number of other patients like us too. It makes me wonder how many people could have survived an extra ten years with their family if it wasn't for him.

114. There is not an awful lot that can be done for me now and I understand that. I know that I may not be here for the end of the Inquiry but I still want to stand up and be counted. What is most important is for the Government to make sure that all future products are safe. I never want my grandsons to go through what I have been through.

115. I am providing this statement not only for myself, but also for Kevin, Andrew and my grandsons. I hope that it can help to ensure that the Government learns from its past mistakes so something like this will never happen again.

Statement of Truth

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

Signed GRO-C

Dated 11-04-2019