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Witness Name: GRO-B

Statement No: WITN0899001

Exhibits: None

Dated: May 2019

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 21 March 2019.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1963 and I am 56 years old. My address is known to the Inquiry. I am married to GRO-B: H and have been for 31 years. We have one much-loved child together, GRO-B who is 22 years old. I currently work part-time as an English teacher.
2. I intend to speak about H, who was infected with HIV, Hepatitis B ('HBV') and Hepatitis C ('HCV') as a result of receiving contaminated blood products during treatment of his haemophilia. In particular, I will speak about the nature of H infections, the treatment he has received and the impact it has had on H, our family and me.

Section 2. How Affected

3. H is a haemophiliac. As a child, H regularly had bleeds which required treatment with blood products. This continued into our married life until relatively recently when H began treating his haemophilia prophylactically with a new

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recombinant product. During his childhood, there was never any suggestion or advice from the doctors that the blood products were dangerous.

4. [H] found out about his HIV infection shortly before we met. Understandably, it was a huge thing for him to come to terms with. As far as I'm aware, [H] wasn't given much information at all about the risks associated with the infections and living with HIV, HCV and HBV.
5. [H] and I met at university around 1984. A mutual friend introduced us. Shortly after we met, I became aware [H] was a haemophiliac but did not know about his infections. It's not really something you tell someone straight away.
6. I was very keen on [H] from the outset but he seemed to want to take things at a much slower pace, which made me doubt his affection for me. He seemed uncertain about pursuing a relationship with me. In hindsight, I realise that his hesitancy, and the slow pace at which the relationship progressed, was because of his concerns about his infections and the impact they might have
7. [H] and I eventually got together and started a proper relationship. In late 1985, I started working as a teacher in [GRO-B] and [H] used to come and visit me on weekends and eventually moved in with me. As our relationship progressed but before we slept together, [H] told me about his HIV infection. I was shocked at the time but not really sure about the long-term implications. It was all very new. Despite this news, I was determined for the relationship to continue.
8. Later on, I started accompanying [H] to reviews of his treatment at the Royal Free Hospital in London. I think he was under the treatment of Dr Christine Lee. [H] and I were repeatedly told by the hospital staff never to have unprotected sex.
9. Dr Eleanor Goldman, one of [H] physicians, approached me a number of times over the course of a year to discuss our sexual habits. The focus of these conversations was on our sexual relationship only - the kind of sex we had, how frequently we had sex and similar questions. I imagine that she was trying to find out about the transmission of HIV. Her view was that we should not have unprotected sex.

10. When [H] and I decided to start a family, we saw [GRO-B] the haemophilia social worker at the Royal Free Hospital. She provided us with more information about the risks of transmission of HIV. The general attitude of [GRO-B] and [H] physicians was, "are you sure you want to do this?"
11. This attitude was quite shocking to me at the time. [H] and I were in a relationship and we wanted to have children, to have a normal family life, I began to think, "What have I got myself into?" and question what was going to happen with our relationship in the long term.
12. In terms of the information that was provided to us, I think that the Hospital probably gave us the information that they had at the time. They were still learning about HIV and discovering the long-term health consequences for patients.

Section 3. Other Infections

13. [H] was infected with HIV, HCV and HBV from contaminated blood products. In 1987, he started showing symptoms which indicated he had also contracted the Delta virus, which I understand caused an issue with his platelets. When doctors discovered that [H] also had the Delta virus, he was treated with transfusions of platelets at the Royal Free Hospital. Following this treatment, in conjunction with the hepatology department, led by Dr Howard Thomas, it was decided that [H] should be treated with Interferon.
14. [H] is on the variant Creutzfeldt-Jakob disease ("vCJD") register, which he found out about in the late 1990s when he received a letter from the Royal Free Hospital. [H] was gutted when he got the letter and kept thinking, "Here we go again".
15. While [H] HIV, HBV and HCV diagnoses were devastating for him, the side effects are essentially physical. vCJD on the other hand, destroys the patient's mind and personality and causes them to die an awful and untreatable death. I think this makes it potentially a more frightening infection.

Section 4. Consent

16. The issue of consent is tricky as [H] was absolutely reliant on those blood products and had no choice but to be treated with them. [H] parents provided

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consent on his behalf for all treatment he received as a child. Since becoming an adult, [H] has always consented to blood product treatment following his bleeds. The question is whether the consent was informed, as neither [H] nor his parents were ever informed about the risks associated with the blood products prior to the emergence of the HIV/HCV scandal.

17. As discussed earlier in my statement, I believe that Dr Goldman was trying to find out about HIV transmission by approaching me at the Royal Free Hospital to discuss mine and [H] sexual relationship and our sexual habits. If we were part of any kind of study into the transmission of HIV, I do not recall that we consented to this.

Section 5. Impact

18. The impact of [H] infections have been significant, particularly the side effects of the various medications he has had to take over the years. [H] was on Interferon to treat his HCV and Delta Virus for seven years. My memories of this time are horrific. I remember [H] lying on the sofa all the time and being ill. It was as if he had the flu for seven years; he had no energy, he was drained and weak.
19. While [H] was being treated with interferon, he tried to continue go to work and lead a normal life. He was working full-time as a civil servant, but he had to have time off when the side effects were particularly bad.
20. In 2006, [H] became very unwell and was in a lot pain. I took him to the Royal Free Hospital where he underwent some scans, which were unable to find the source of the pain. I took him home and over the course of a couple of weeks or so he became extremely ill. I took him back to the Hospital and he was admitted. Ultimately, he had to have an emergency operation to have his gallbladder removed as the bile ducts had been blocked with a fatty substance, it had turned gangrenous and he was going to die.
21. [H] survived the operation but when I went to see him in the Intensive Care Unit, I could see he was not in a good way. He had gone into septic shock, one of his lungs had collapsed and he was very unwell. I was devastated.

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22. The doctors cannot say with certainty that the complications with [H] gallbladder were a result of his infections or the associated medications but they cannot rule it out. I am absolutely convinced that it was because of the medication he was on at the time and is connected to his lipodystrophy.
23. During this time, the Royal Free Hospital did not provide us with any support, such as counselling. We got a free parking spot, but that was about it.
24. I also believe that [H] weakened immune system has caused him to have a predisposition towards catching infections. On one occasion, [H] caught chicken pox from our niece despite the fact he had it as a child. He became so unwell he was off work for the whole summer. He eventually required antiviral medication from the Royal Free Hospital as the infection would not go away.
25. [H] has had pneumonia too, which required him to be hospitalised at Northwick Park Hospital in Harrow. He was segregated and I had to speak to him through a glass wall.
26. [H] still struggles with his breathing and has a permanent hacking cough. He sounds like he has smoked 40 cigarettes a day when, in reality, he has never had a cigarette in his life. This is probably also connected to the collapsed lung he suffered during the gallbladder episode.
27. A side effect of one of [H] earlier HIV medications was terrible diarrhoea. He was prescribed Loperamide which eased the symptoms but a consequence of persistent and long-term diarrhoea is malabsorption of calcium and [H] now has issues with low bone density. He has to be monitored and take calcium supplements. This is another concern for us because of the effects of osteoporosis and fragile bones in conjunction with the bone damage that he has already suffered as a result of his haemophilia.
28. [H] HIV medication has caused him to suffer from lipodystrophy, which is the abnormal redistribution of fat around the body. As a result, [H] has very skinny arms and legs, a hollowed-out face and a huge tummy. He looks as though he is nine months pregnant.

29. The lipodystrophy has had a significant psychological impact on [H] in terms of his confidence. People mention his appearance all the time. For example, we were at the butcher's buying some meat and trying to choose what cut of beef we were going to have for a stir-fry. The butcher sarcastically told me that I needed a bigger portion as [H] needed 'fattening up'. [H] used to swim a lot when he was younger, but no longer does, as he feels self-conscious and doesn't like his body.
30. Aside from his physical ailments associated with the infections, one of the main mental impacts has been that [H] has become much more shut down over the years. He doesn't speak readily about what he has been through, and continues to go through. While we have never been offered counselling, I don't think [H] would accept it or seek it out anyway. He tries not to think about the infections or talk about them - not even to me.
31. In terms of the wider effects of [H] infections on me and our family, one of the main issues we had was in conceiving our son, [GRO-B]. [GRO-B] is our only child.
32. [H] and I were married on [GRO-B] and decided to try to start a family a couple of years afterwards, particularly as [H] health was not too bad at the time. I come from a large family and have always wanted children. [H] wanted to start a family too, but we were both extremely anxious about conceiving. The message from the Hospital seemed clear: if we had unprotected sex, then I would be infected with HIV and we would both die.
33. We had unprotected sex for a few months to try and get pregnant naturally. We limited the unprotected sex to just when I was ovulating, to try and minimise my risk of infection. However, I kept feeling like I was at risk the whole time and [H] struggled with this too.
34. After about four to five months of trying without success, we decided to pursue artificial insemination. At the time that we went down this path, we had to have tests to check our fertility levels and everything was fine. In normal circumstances, we would have been able to have a family on our own, without the need for medical intervention.

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35. Dr Lee helped us through the process of finding a suitable fertility clinic. Most clinics would not accept us due to [H] HIV status. At the time, they did not perform IVF on single parents and the rationale for refusing us was they could not be certain how long [H] would live for.
36. Eventually, Dr Lee put us in contact with Professor Gedis Grudzinskas at St Bartholomew's Hospital. Professor Grudzinskas agreed to help us conceive, but we were not allowed to use [H] sperm and had to use an anonymous donor because of his HIV infection. Sperm washing was not something that we knew about at that time or something that was offered to us.
37. As I was fertile, we initially tried donor insemination, which was cheaper than IVF. This involved me having to take fertility drugs to increase my egg production and then attend the fertility clinic while they squirted donor sperm inside me. This whole process was horrific for me.
38. I failed to fall pregnant through donor insemination and we made the decision to try IVF, which was far more expensive at roughly £3,000 per round.
39. The first two IVF rounds didn't work. After the second unsuccessful round, I was deeply depressed. People at work told me that I was not well and that there was something wrong with me. I was coming into work and not talking to anyone.
40. No one knew that I was undergoing fertility treatment, aside from my boss, and even he didn't know the extent or the reasons why. At that time, I was of the mind that I just couldn't go through another IVF round. I was in a dark place and even questioned what I was doing in the relationship. This was a deeply difficult time.
41. The fertility clinic offered a counselling service, which I attended on one occasion. I just sat and cried for an hour, which was traumatic as I was used to keeping everything inside. I didn't attend again as I thought time would heal the depression.
42. [H] was really keen to try one more round of IVF. That's when we conceived [GRO-B]. [GRO-B] is now 22 years old and is a joy to us. From the beginning, we told him that he was a special baby that he is deeply loved. When he was old enough to understand, we told him he was conceived by IVF.

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43. I don't know whether GRO-B knows that H is HIV positive. I think we told him but I can't remember and I don't want to have the conversation again. GRO-B knows that H has viruses and that there are things in H blood. He also knows that he is not H biological child, which creates a slight separation in the relationship between GRO-B and H family as GRO-B feels they are not his biological family. I don't think H is aware of this dynamic. No-one else in my family or H is aware that GRO-B is not H biological son.
44. After GRO-B was born, when the time came to think about having another child, H was going through some health issues and we simply could not afford to go through IVF again. The whole process to conceive GRO-B cost approximately £10,000, which was a huge amount of money in the 1990s I would have loved to have had a bunch of children and I think it would have been beneficial for GRO-B to grow up with siblings.
45. H is a brilliant father and is very close to GRO-B. However, he was less keen to have a second child as he was concerned about his ability to run around after a small child again. The sleepless nights of having a newborn really affected him because of the fatigue associated with his infections. When GRO-B was an infant, I was the one who had to feed him and nurse him during the night as H simply didn't have the energy to help.
46. H infections have also had a significant impact on us financially. H is not the kind of person who wants to be on benefits. He is independent and has always worked and paid his own way. He's also very bright - much smarter than his academic record and career as an executive officer in the civil service would suggest.
47. H limited himself due to his health issues. He never pushed for promotions in his career as he simply didn't have the energy to cope with a more demanding job. He also retired early at the age of 56 because of worsening fatigue. This has significantly affected our finances as H never earned over £30,000 per annum while he was working. This will also have a long-term impact as, H pension forecast is a rather modest £12,000, which is not a lot of money to retire on.
48. I have worked as an English teacher for most of our relationship. I dropped back to part-time work when GRO-B was young, as I wanted to enjoy GRO-B early years,

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especially after we made the decision to only have one child. Also, I was essentially a carer for both [H] and [GRO-B] and ran the household too. [H] was tired all of the time, which meant that the overwhelming majority of the domestic work fell onto me.

49. In terms of my career progression, I have largely held myself back as I have had to balance my work and my role as [H] carer. This has also affected our family finances, as I was never able to achieve my full career potential.
50. [H] infections have also affected our enjoyment of life and the experiences we can have. I come from a well-travelled, highly educated family but travel outside the UK has been very difficult for us due to a combination of finances and [H] need to be near haemophilia centres. It is also difficult to get visas to other countries because of [H] HIV and it is very expensive to get non-standard travel insurance.
51. Our financial circumstances and [H] health difficulties have also affected our son's life. I absolutely think that [GRO-B] life would have been different if [H] hadn't been infected with contaminated blood products. We could never afford to send [GRO-B] on big school trips or take him on expensive long-haul holidays. We have never travelled outside Europe and most of our holidays have been in the UK, centred on proximity to medical centres. As a result, I think [GRO-B] life is quite home-centric.
52. The stigma associated with [H] infections has also affected us. There was a common perception that HIV was a terrible disease you could catch simply from sitting next to someone on a train.
53. [H] mother knows about his HIV as well as his doctors, but it is a need-to-know basis only. [H] never told his brother, [GRO-B], about his infections, even before [GRO-B] died. [H] also never wanted me to tell my family because of the stigma and because he didn't want to be treated differently. This has been enormously difficult for me because it has meant that I have never had the support of my family in this respect or anyone to confide in, even when things got really difficult, such as when [H] was in hospital for his gallbladder.

54. None of [H] friends know about his infections either. As a result of this, he has isolated himself. [H] doesn't go out with friends very often. He doesn't socialise. His entire social life is based around the family and me. This has considerably narrowed his life and also means that [H] has no outlet for any of the feelings he has about his health problems.

Section 6. Treatment/Care/Support

55. I don't think [H] has had obstacles in getting treatment for his infections. Initially, the doctors didn't seem keen on putting him on HIV medications as the side effects were an issue and his doctor at the time was of the opinion that he wasn't doing too badly on his own. In those days, you basically went on HIV medication when you had AIDS and were going to die.

56. Aside from the previously mentioned conversations with [GRO-B] and Dr Goldman, [H] and I were not offered any counselling or further information about managing any of his infections from the Royal Free Hospital.

57. I think most of the medical professionals that [H] and I have dealt with over the years have offered appropriate treatment and care. The only person who was less than helpful was [GRO-B] the haemophilia social worker at the Royal Free Hospital. Her role was to be supportive but I didn't find her to be so. She wasn't somebody that I would have talked to ordinarily.

58. In later years, I had some limited support through the Haemophilia Society and the MFT. They ran some weekends for partners of infected people and also ran the odd weekend for infected men. [H] attended one of these.

59. I went to a couple of carers' weekends, which at first, I found helpful, as caring for someone with these infections can be very isolating. The weekends allowed me to be able to talk to people who were going through a similar experience to me. However, I did find that the weekends, although well intentioned, were very intensive and it was sometimes difficult and challenging, emotionally.

60. I don't think there was any other support offered to the partners of infected people. To be honest, it would have been nice if there had been somebody that partners could have approached, just by ourselves, in those early days. For example, if

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there had been someone at the Royal Free Hospital that I could have turned to on a regular basis to talk about everyday issues, that would have been helpful.

Section 7. Financial Assistance

61. [H] has received financial assistance from the Macfarlane Trust. In the early 1990s, [H] received £30,000 from the Macfarlane Trust. It was never described as compensation, instead it was ex gratia and seemed like a 'go away' payment. In other words, "we'll give this to you if you go away". At the time though, we were grateful to have the money and used it to pay off some of our mortgage.
62. [H] was also eligible for discretionary, one-off payments to cover things such as new mattresses. We found the process of applying for such money to be a degrading 'cap in hand' process.
63. Not too long ago, [H] started receiving regular payments from the Macfarlane Trust, which are now paid by the EIBSS. The regular payments total around £1,800 pounds per month, for both infections.
64. It is a relief to receive regular payments, rather than go through the degrading process of applying for one-off payments. [H] and I have worked hard throughout our lives and don't want to feel like we're begging. [H] has achieved a lot in his life, given his physical ailments. Having to debase ourselves in such a way was a true insult.
65. When we were trying to conceive via IVF, we received £1,000 from the Macfarlane Trust to contribute towards the cost. Also, the GP I was seeing at the time prescribed all the fertility drugs I needed to go through IVF, which meant that I didn't have to pay for them.
66. In the early 1990s, a lot of people commenced litigation against the American companies who produced the infected blood products. [H] never went down the litigation route. In fact, I understand [H] waived his right to be involved in any kind of litigation when he accepted the Macfarlane payments.

67. I think the money that we're getting now is ok. It would be nice if it was a bit more because then I could retire and we could really enjoy what is left of [H] life. I can't imagine [H] is going to have a full life span and I think he deserves compensation for everything he has been through. [H] infections have had a colossal impact on our life.

68. I think that there ought to be proper compensation. As I understand it, if there had been enough blood supplies in the UK, we wouldn't be in this situation. The fact that the government knew about the risks and continued to use imported blood products and not communicate the risks to patients is terrible. I'm not saying that they were knowingly infected, but mistakes were made and they ought to be compensated for it. That's the bottom line.

69. I think it is appalling that there is no on-going financial support for partners of those who have died as a result of infections from contaminated blood. As I understand it, they receive quite a modest one-off payment but no regular support. I think this is definitely something that should be addressed by the inquiry. I'm not sure if the situation has changed but this was certainly my understanding under the former Macfarlane Trust. This is obviously a personal concern going forward but it seems to me to be a key injustice.

Section 8. Other Issues

70. One of my biggest concerns is that the scandal has been brushed under the carpet and nobody has taken responsibility for it.

71. What I really want is for the government to say, "This happened and it was our fault". I want an acknowledgement that it was the fault of the government of the time and, therefore, a full, open and formal acceptance of responsibility. To accompany that, there should be compensation.

72. In terms of compensation, I think there ought to be parity across the UK in terms of how much money people are receiving. For example, I understand that if we had lived in Scotland we would be far better off.

73. My other hope for the Inquiry is that it won't just be about looking into the past, but will also include recommendations for the future. The key point is that this should

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never happen again. In my view, given all the cuts to the NHS and regulatory bodies, there is a likelihood that something like this could happen again, because corners get cut.

74. Lastly, I want to note that I still have great faith in the individual doctors and nurses of the NHS. I genuinely do. I think that they are doing the best that they can in the circumstances in which they find themselves. I don't think that they always do a 'great' job, but that is more to do with the time and resources available to them.

75. By contrast, I don't have much faith in the broader NHS system. There are managers who don't know enough about what's going on to manage. There is miscommunication. There are also decisions being made with regard to money, as opposed to the best interests of the patient.

Statement of Truth

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

Signed GRO-D _____

Dated 8-5-19.