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Witness Name: **GRO-B**

Statement No.: WITN3152001

Exhibits: None

Dated: October 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

1. I, **GRO-B**, will say as follows:-

Section 1: Introduction

2. My name is **GRO-B**. My date of birth is **GRO-B** 1974 and my address is **GRO-B**. I currently work part-time and volunteer. In my spare time, I like to run, read and generally be outdoors. Until three and a half years ago I lived in **GRO-B**, but moved with my husband to **GRO-B** to be near to close friends.

3. I met my husband, **GRO-B:H**, just over 19 years ago **H**. At the time, I was working at **GRO-B** Airport. We got married in May 2009 and we have no children. I make this statement about the effect on me of my husband's infections with HIV and Hepatitis C. This statement is based on my recollection of events.

Section 2: How affected

4. Before I met **H** I did not know much about haemophilia or its impact.
5. I met **H** on the second night of a **GRO-B** in June 2000. I found out that **H** was HIV positive and had Hepatitis C almost as soon as I met him. We discussed it on the third night we met **GRO-B**. He was aware that he needed to be upfront about it if we were to become physically intimate.

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6. We decided to keep in touch when we **GRO-B** and as time went on, our relationship grew. He seemed level-headed and mature and I saw no reason not to continue the relationship just because of his haemophilia and infections.
7. Over time, I have learnt more about **H** condition through speaking to him and his family. He told me that he was three or four years old when he was infected with HIV, and he found out about it when he was 12 years old at a meeting at Great Ormond Street Hospital ("GOSH") with his parents. I am not sure when he was infected with Hepatitis C.
8. I am fortunate in that I get on well with **H** family and have been able to ask questions to get more information from them. They did not speak much about it initially, but as I have got to know them over the years they became open to answering my questions and talking about it. The Inquiry has been good and has given them a chance to speak more openly and I am not sure they have really had a chance or opportunity to do this.
9. **GRO-B: Husband's Brother** also have haemophilia, and so I get the sense that they were all in it together. They went for treatment together and his mother was around to talk about it with **H** and his **HB**. They were, and are, very much a unit. Although counselling was offered to **H** he did not use it. This was probably due to not wanting to upset his mother, as well as both his parents being around to talk to him, although his Dad has admitted to struggling with **H** condition.
10. **H** is always very positive and is very driven. I think this stems from when he was told as a young child that he would not live past his teens, as well as people saying he could not do certain things. He went on to complete his degree at the **GRO-B** in **GRO-B** and he became a **GRO-B** **H** approach to his condition has had a very positive impact on me; I do not know what we would have done if he had been more negative about it.

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Haemophilia

11. [H] haemophilia is type A and severe. He has had a couple of bad bleeds during our time together which have required him going into hospital to rest and receive treatment.
12. I am not sure of the exact year but after 2007 [H] began exercising more by running and going to the gym. This helped him and he began building his strength up which in turn seemed to help with minimising bleeds.
13. To manage his haemophilia [H] takes prophylaxis factor products (Advate), injecting himself three times a week into the back of his hands.

HIV

14. Although [H] has HIV, ever since I have known him, he has been very well with it.
15. [H] has received various combinations of treatments for his HIV. He started with Azidothymidine ("AZT"), which he said the doctor at GOSH fought tooth and nail to get for him. He does not remember any side effects from this, but I do recall him saying he had thrush at the back of his throat. The drug was originally taken in a liquid form, but then became available in a tablet form.
16. [H] did once have a combination of drugs which gave him vivid dreams and loose bowel movements, although I cannot recall the name of the drug. He still has these side effects from time to time, but nothing that prevents him from doing anything.
17. [H] was also prescribed Didanosine ("DDI") until about 2017 or 2018. He had no side effects with this.
18. [H] has now found a good combination of tablets which works well for him. Since I have known him, he has been on triple therapy. I cannot recall the specific names of the drugs he takes.

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19. On a positive note [H] CD4 count rose after starting the triple therapy, as this was originally at zero. CD4 is used to measure his immune system's ability to fight off infection. His viral load has also remained undetected for the time that I have known him.

Hepatitis C

20. [H] is not sure when he was infected with Hepatitis C or told about his infection. At some point before 2010, maybe 2007, he did have treatment for Hepatitis C and cleared the virus. The name of the treatment was Interferon and it lasted for 6 months. I recall that he had to inject the drugs into his stomach.
21. During treatment, [H] was ill and there was a period of around two to three weeks where he could not work. The side effects were like having the worst flu and feeling suicidal. I remember thinking it was unusual as he had always been very positive, but he was unable to do much in that time and was mentally quite low. [H] was frustrated as he was busy at the time with work. I do not remember taking time off work to look after him but just helped where I could. We just carried on and got through it. I did think that this was an insight into how things might be if his HIV worsened, which ironically had been the least troublesome of the two conditions.

Section 3: Other infections

vCJD

22. I recall some concern around [H] developing vCJD, in approximately 2004, but I do not know if it was confirmed. [H] was at risk of vCJD based on the blood products he received.

Section 4: Consent

23. [H] recently requested his medical records and discovered that he was tested for HIV in December 1984 and September 1985. He was not aware of this at the

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time, and nor were his parents. The test taken in December 1984 was negative, but the test in September 1985 was positive.

24. [H] parents were told about his test results in October 1985. The doctors at GOSH had asked them to come in for a meeting as there was a problem. [H] parents were not told [H] the meeting related to, but [H] mother has said she knew it was about [H] as his lymph nodes had been swollen.

Section 5: Impact

Psychological impact on me

25. I have always admired [H] positive attitude. While he does have some low moments, on the whole he has always been very positive. I used to get angrier than he did over certain situations, for example, when we were interrogated on our trips to the United States, which I refer to below.
26. [H] positive attitude has reflected onto me. He does not grumble about the position he is in. If his health deteriorated or if I had to become a carer, I would find this difficult. As I referred to above, when [H] was receiving treatment for Hepatitis C, this was an insight into what this would be like.
27. I admire [H] as this is something that has happened to him through no fault of his own, and he has turned it around. Rather than the infections dictating what he does, he does not let it define him or put obstacles in his way, and where there are obstacles, he has dealt with it. In all honesty, had his approach been different, I do not think I would be with him. That is quite hard to say but [H] positivity is one of the things that makes him who he is and he has been very supportive of me through some difficult times; helping me, other people and friends and just not feeling sorry for himself.

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28. When I have asked [H] how he felt about his diagnosis, he said that when he was told about being HIV positive at the age of 12, he just asked if he was going to die.
29. We have had openness between us from the beginning and [H] has dealt with things responsibly and level headedly. We do not know what the future holds, but are focussing on the here and now.

Physical impact

30. Physically [H] has suffered from muscle wastage due to his haemophilia on his left leg as he was on crutches when he was younger. Very gradually over the years, he has started running and exercising more, generally for his wellbeing. He has built up a lot of physical strength with the help of his Royal Free physiotherapist, which has had a positive impact on him physically.

Impact on family life

31. I have noticed that [H] family do not talk about the infections much, but are happy to talk if you raise the subject. It is a difficult topic to talk about, and is upsetting for everyone.
32. I was 26 years old when I met [H] and had not had serious thoughts about children. The information at the time on the transmission of HIV was limited, and I felt like not a huge amount was known about having children. [H] and I discussed having children, and gradually took the decision not to have children, as we both felt it did not bother us. As time went on, friends had children and we kept to our decision. It could have been, subconsciously, this was partly to do with the thought that we could not have children. However, we both had good jobs and enjoyed holidays and trips away, so children did not feel like a priority or a burning issue for either of us.
33. Around 10 years ago [H] had attended an appointment with his HIV doctor at [H] in London and had discussed studies published by the National

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Institute for Health and Care Excellence ("NICE"). The study had stated that for people who had an undetected viral load for more than six months, could have children through sperm washing. Only one hospital in the UK offered sperm washing, Chelsea and Westminster Hospital in London, which was close to where we lived at the time.

34. We had a long discussion about the treatment and decided to try it. It almost felt like a lightbulb moment for me. Where previously the thought of having children was a "no go" or had not been thought about seriously, we had someone telling us it could be a possibility but there were a few hoops to jump through first. I almost felt quite excited at the time thinking we could have something, which previously had felt out of reach and not possible. We were referred through our primary care trust and had a few visits to Chelsea and Westminster Hospital. In effect, the process was quite similar to IVF. I had a lot of appointments at the hospital, but did not tell anyone at work the reason for these. [H] also had to juggle appointments with his work.
35. After three cycles of sperm washing, I did not fall pregnant. I do not know how I felt about this, whether I was relieved or sad. [H] HIV tablets may have had an impact on his sperm quality. We talked through different options with a consultant, but at that point I did not want to try again. I remember after that meeting, I came out of the Chelsea and Westminster Hospital and said that I did not want to go through more tests, possible drug therapy and the whole process. [H] also felt the same, from memory, so that was it. Although at the Inquiry I have seen families together who have been through the hurdles and challenges of having children, I thought about the risk that, if we had children, they could be infected. I did not know how they would then react, when we told them. Passing on the burden, guilt or the legacy of the contaminated blood just did not sit well with me and I do not think I could have lived with those feelings and thoughts.
36. [H] specialist HIV doctor was always clear that although there was a risk of transmission to a child or to me, it was very low. We now know that the risk was next to nothing, but there was not much information or data at the time, only the NICE guidelines.

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37. We were given the option of more cycles of sperm washing, but we would have had to pay for these. The cycles were expensive, in the thousands of pounds. We might have been able to afford it, but it was the principle of it; we were only going through the process because of [H] infection, which was not his fault.
38. Thankfully the decision as to whether or not to have children has been something that [H] and I have been able to talk about with each other. We have talked about whether we have regrets about this, and what our children might have been like, but always had similar thoughts on it. I did not want the stress or have to put my life on hold while we waited to see if the next cycle was successful. We have just learnt to have a life without our own children. We like to look after our nieces and nephews for our siblings. I am still not sure if we should have "bitten the bullet" and tried to have children; it is something which I think about every now and then and it can make me sad.

Impact on private and social life

39. I do not feel that [H] infection has had an impact on our private life. We have always been very honest with one another.
40. On a couple of occasions during sex in the early years of our relationship, condoms have split about twice. After each occasion, I had to be tested for HIV and there was a three month wait to see whether I had been infected. It was an anxious wait for the results, even though deep down I knew I would be fine as [H] viral load has remained undetected for the time I have known him.
41. Out of my friends, [GRO-B] knows that [H] is HIV positive. Another two friends are aware, one of which is my [GRO-B] so it was quite natural that she should know. There is no particular reason for my other friends not knowing, time and life takes over, but it is part of who he is and I have never felt a need to tell others. Life goes on. I have been fortunate that [H] has been well and so, on a day to day basis, I almost forget about it. I would like to be more open and

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honest with all of our friends, but also wonder whether it would make a difference. I do not think it would but it is finding the right time to do this.

42. It does not define who **H** is or who we are. We have an active social life, enjoy travelling and have a large circle of friends.
43. Our friends are aware that **H** has haemophilia, and the marks on his hands from his treatment are apparent.
44. Some of our joint friends are aware of **H** HIV. When we have told friends, this has purely been **H** decision. The reaction of friends has been positive and I would personally like to tell more of our friends, more to show how he has overcome obstacles in such a unique situation. I have never felt ashamed or felt like I have wanted to hide away from the situation, probably the opposite in fact. I am so proud of how he has handled everything that I do not care what other people think and how they might react. Other friends may have put two and two together, particularly in light of their knowledge about his haemophilia and the media attention the Inquiry is receiving, but they have not raised this with us.
45. In relation to travelling, we have had no issues when travelling abroad with receiving treatment. We have had no difficulty in obtaining travel insurance, but we do have to pay a premium. This is more of an annoyance, rather than it preventing us from travelling.
46. We have travelled to the United States a couple of times, and on the first visit **H** had to declare his HIV infection as part of his ESTA application. Although I cannot recall exact dates, this was after we got married in 2010, around 2012. When we arrived in the United States, **H** was pulled to one side and I went with him. He was asked about his condition and we were held for approximately 20 to 30 minutes.
47. On the second time we visited, in roughly 2014, although it no longer had to be declared for an ESTA application **H** still had a mark on his passport and again we were taken to one side and made to wait, before they asked about his

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infection. During this questioning, they were not very discreet and I remember a man being asked about his cancer treatment in front of us. [H] dealt with this calmly, but I was quite incensed. As a result of an infection which was through no fault of his own, it felt like we were dragged to one side and being interrogated. It felt that everyone was guilty regardless of how they had contracted their "condition."

Impact on employment and finances

48. We have been fortunate and are in a good financial position. With [H] drive, he made a good career for himself and I have also held good jobs. I appreciate that our circumstances could have been different had [H] not been as well or had as positive an outlook.
49. As [H] is self-employed and always has been, he has not had to declare his condition to prospective employers. I have not found that it has impacted me in terms of employment and I have not had to declare it.
50. In terms of big financial commitments, I was concerned that it would affect us getting a mortgage. In the end, it was not something we had to declare and we did not have to explain the additional income we received through the Macfarlane Trust, which I refer to below.
51. [H] has always been very proud and conscious that he is okay from a financial perspective. He did receive Personal Independence Payments from the Department of Work and Pensions, but these were taken away upon reassessment. These payments have since been re-awarded, and although [H] is entitled to them, he has written to say he does not want the payments. He would rather this money go to someone in greater need.

Section 6: Treatment, care and support*Treatment*

52. [H] has been fortunate in that he has received the best treatment and has always had good care. I do not think he has anything negative to say about his treatment. He is still in contact with the nurses and doctors from when he was younger, and has a good relationship with his physiotherapist and previous hospital staff now.
53. For treatment for his HIV, [H] goes to [H] in London. His doctor is due to go into semi-retirement soon, and so he will transfer to a hospital closer to where we live in Leeds. It can be difficult to manage his treatment for his HIV when his clinicians are based in London and we live in Leeds, but it is just another thing that he deals with.
54. For treatment for his haemophilia [H] goes to the Royal Free Hospital. He went to GOSH when he was younger. Although the Royal Free is some distance from where we now live, he fits this in around his work commitments in London.
55. There was one occasion where [H] needed a hernia operation. I was frustrated at the approach taken by the doctor. The operation was cancelled last minute as the doctor said he did not have the correct equipment to deal with [H] condition, despite having access to his medical records and knowing about it prior to the operation. When the doctor was speaking to [H] there was only the curtain between his bed and the next, so others could easily overhear and the doctor was not very discreet.
56. [H] did have to declare that he had HIV on one occasion when visiting the dentist, but there was no issue as such with this. There is now an approved list of dentists available which has been helpful. People do ask questions, but more from a curiosity point of view as to how it happened, rather than because they would refuse treatment.

Psychological support

57. I have not been offered any psychological support; I would question who would be able to provide this. However, I have been to a few appointments with [H] and have been able to ask questions. The doctors have always been fine with this and answered my questions.
58. [H] mentioned a few times when we first met about available support groups when I have asked him about support, but I have not really felt the need to go, as I suppose I do not wish to dwell on the matter too much. I do not want the meetings to remind me about it when it is a silent partner anyway and always there. I know I can speak to [H] or his family if I need to and because my relationship with his medical team is good, I can go to them. My feelings on the matter would probably have been different had [H] not been well.

Stigma

59. I do not feel that I have experienced stigma, as not all of my friends know about [H] HIV and Hepatitis C infections. I do not have any fear in telling my friends, as I believe they would be supportive; if I were to tell friends and they were derogatory, then I would deal with it at that stage.
60. With [H] his infections do not define who he is. If friends were asked to describe him, they would say he was a [H] competes in triathlons and a nice guy. His haemophilia or infections would not be the first thing they describe. Although I say they do not define who he is, I guess they have, and have had, to to a certain extent. Most of the time each day is living life as "normal" but there are situations where we need to focus on it for example travelling abroad, checking entry requirements as we like to travel, and just being aware that health issues need to be checked.

Section 7: Financial assistance

61. Throughout the time I have known him [H] has received regular payments from the Macfarlane Trust. These payments have just been increased following the recommendations of Sir Brian Langstaff.

62. [H] received a lump sum of around £20,000 in the 1980's during the Pannone litigation, which his parents accepted on [H] behalf due to his age at the time, on the condition that they signed a waiver and could make no further claim against the Government. I recall his mother saying they were happy to go to Court, but the decision had to be unanimous and it was made collectively with others, and some at that time did not have long to live.
63. Overall, [H] has had a positive experience when seeking financial assistance. When he was younger, his parents were able to get money to go on holiday, which his mother had applied for on his behalf. He also received payments to assist with university fees and his first year of [H] from the Macfarlane Trust.
64. During his studies, he applied for money for a laptop and although the application was granted, the response received was along the lines that they would do it this time, but they knew how much money [H] earned. The inference was that may not receive any further financial assistance. This felt so judgmental, especially for someone who was trying to make the very best of a bad situation and trying to make a career for himself.

Section 8: Other

65. I would like to know from the Inquiry if there was a point where Government ministers or health care professionals knew what the consequences of continuing to provide American and British blood products could have been and if they could have said or done something about it. I understand it is easy to look back on things with hindsight, but I am curious as to whether the authorities realised things would get as bad as they have and whether someone in authority could have stopped it from happening. I would like to know how much people knew at the time.
66. It is also important for Government ministers or health care professionals to be physically present at the Inquiry when it comes to their turn to give their

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statements. Those affected or infected have had such bravery and courage to testify, without knowing the wider impact of this. Politicians should be made to attend and be present during this, and not able to hide behind a written statement. We need to treat people with respect and let everyone give their version of events as to how it was at the time.

67. Although I have been affected, I have still managed to lead a normal life. Others have been badly affected and they need some form of relief or compensation. It is heart wrenching to listen to others' stories at the Inquiry, and support is needed for those who struggle every day.
68. I think people are seeking apologies from those in authority, to say that they did something wrong and they are sorry for it. In essence, we need the truth, as hard as it might be for some to hear.

Statement of Truth

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

Signed.....

GRO-B

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Dated.....19/10/19.....