



Witness Name: **GRO-B**  
Statement No.: WITN5406001  
Exhibits: **WITN5406002 - 4**  
Dated:

**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 3 December 2021.

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 my address is known to the Inquiry. I am a retired civil servant. I live with my daughter who is 15 years old.
2. I intend to speak about my late husband **GRO-B: H** **H** was infected with HIV and Hepatitis C (HCV), following receipt of contaminated blood products to treat his haemophilia. In particular, I intend to discuss the nature of his illnesses, how the illnesses affected him, the treatment received and the impact this had on him and our lives together.
3. I am being supported today by my friend **GRO-B** with whom I have been close since we were 19 or 20 years old. **GRO-B** is one of the few people who knows intimately about the circumstances surrounding **H** s infection with HIV and the devastating consequences this has had on

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our lives together. She is able to fill in some details of which I have forgotten over the years.

4. I can confirm that I would like to be anonymous.

### **Section 2. How Affected**

5. [H] was born on [GRO-B] 1960. When he was two years old, he was diagnosed with severe haemophilia A, with zero clotting factor. It was also discovered that his mother was a carrier. After his diagnosis, his parents decided not to have any more children. The chance of having another haemophiliac was 50/50. One is either a carrier or has the condition.
6. As a severe haemophiliac [H] was given numerous blood products. Initially, he was just given ice for a bleed. As time progressed, he was given whole blood transfusions. He was subsequently given cryoprecipitate and then Factor VIII concentrate, the latter of which he self-administered at home with the help of his father.
7. [H] was initially treated at [GRO-B] Hospital. When he reached 18, his care was transferred to the Sheffield Haemophilia Centre at the Royal Hallamshire Hospital. Up until 5 years ago, I kept years and years of records of his batch numbers.
8. [H] never went to any special schools. He attended mainstream school but wasn't allowed to take part in P.E or football, which I know he found difficult. He was constantly going to hospital covered in bruises. The staff were frightened to death that he might have a bleed, particularly as the only treatment available at the time was ice packs or blood transfusions.
9. Between 1984 and 1985, before we became acquainted, [H] was diagnosed with HIV. He later explained to me that all the haemophilia

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patients at the Royal Hallamshire Hospital were gathered together in a meeting room. They were told that they were HIV positive and that they only had a couple of years to live.

10. In 1993 [H] and I became acquainted as we worked in the same building. I was married at the time. He did some of my training courses. He was extremely popular as he was an amusing and entertaining person. On nights out, people would almost be fighting each other to sit next to him. This was the 'old [H]', before his illness inalterably changed his personality.
11. I announced to work colleagues that I had separated from my husband. [H] offered me a solicitor's phone number. He was also going through a separation and divorce. In around 1994, he introduced me to his friends. Four of us would regularly socialise together.
12. In early 1995, we became a couple. Before we became intimate, he told me that he had HIV. I can still picture him shaking with anxiety and nerves. I think he expected me to end the relationship. He started explaining a bit about the virus and how he believed he was infected, of which he had very strong feelings.
13. [H] was never an intravenous drug user and only got a tattoo years later on his fortieth birthday. He did not have any piercings. I think the general population were vaguely aware of HIV but didn't know about it in any great detail. I'd seen a TV programme about the virus. Then the infected blood scandal began to receive mass media exposure.
14. He told me that stored blood samples traced his infection to the early 1980s'. Nevertheless [H] remained convinced that he contracted the virus in the late 1970s' when he was given American product. He quite clearly remembered the transition from British to US Factor VIII. There wasn't a great amount of publicity about the American product nor the clientele they were using. He was left to draw his own conclusions.

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15. It was a huge decision as to whether I embarked on a relationship with [H] I was 32 and had already been through a divorce. I didn't have any children but this was still something I wanted. I didn't have a lot of time to hang about.
16. Yet, at the time, embarking on a relationship precluded the possibility of children as unprotected sex was not a possibility. It was a massive decision for me to give up my dream of having children. He let me think about it and was prepared for me to walk away.
17. When [H] and I were only friends, one of his close friends from work confided in a close friend of mine. He was emphatic that I would never enter into a relationship with [H] My colleague suspected that it was something sexually related but could not glean any more information.
18. [GRO-B] worked in a medical library at the time. HIV and AIDS were very topical. She guessed my dilemma before I explained the situation as she knew that [H] was a haemophiliac. Everybody was so frightened. We were constantly inundated with public notices about the risk of AIDS. People were worried about sharing the same cup with someone who was infected.
19. While I thought the decision over, [H] arranged for us to stay with friends of his for the weekend. I was trying to be bubbly and make a good impression whilst at the same time experiencing an enormous dilemma. I spent about 2 hours in their bath thinking about my decision.
20. I remember sitting on a bench on the street one day, pondering the situation. It wasn't so much about deciding whether or not to begin a relationship with someone with HIV, but rather the prospective loss of children. One of the only times I get upset is when I think about this.
21. I didn't want to give up on this person who absolutely adored me. He treated me like a princess. I didn't think life would ever get much better than what I had with [H] apart from of course, having children. I had



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fallen for him at this point. After a week of thinking it over, I went with my heart.

22. H was always angry with the secrecy surrounding his diagnosis. He was an adult when he was diagnosed yet he was given very little information. I never fully understood his misgivings as he wasn't always very good at explaining things, but I gleaned that he was unhappy with the lack of transparency surrounding his diagnosis.
23. No minutes were taken nor any record of the meeting (where they were told they were infected) were kept. He always found this to be very suspicious, as if the staff were trying to deny that the meeting had taken place. He felt this way in the 1990s', before everything that we know today. It's going to be hard to verify because most of his fellow patients have since died.
24. H felt that throughout his time as a patient at the haemophilia centre, that the staff adopted an approach of 'divide and conquer'. He suspected that the staff intended to keep the haemophilia patients apart so that they couldn't discuss their circumstances with one another.
25. H was seen at the same haemophilia centre from age 18 to 52. One of H's fellow haemophiliacs, GRO-B: F1 was one of the few patients with whom H had any contact. He lived in GRO-B and has sadly also since died.
26. For years I accompanied him to his monthly appointments and yet I never saw another haemophilia patient on more than one occasion. I always wondered where they were and why the waiting room was perpetually empty. It dawned on me that perhaps H wasn't just a conspiracist about their methods.
27. H and I became acquainted with GRO-B: F2 through a Haemophilia Centre newsletter in which F2 had shared some information. He was seen at the Birmingham Royal Hospital. We began

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to socialise. F2 and H had similar experiences regarding their treatments and the way in which they were treated at their individual haemophilia centres.

### **Section 3. Other Infections**

28. On 2001 as H and I were embarking on fertility treatment, I noticed that a letter referred to his infection with Hepatitis C. This was the first I heard about it. He might have known all the time but just didn't mention it. The hospital didn't try to clear the virus because it wasn't causing him any health problems.
29. On one occasion, the haemophilia centre mentioned a drug they were using which was getting good results. They explained that should the virus start to manifest, he should seek treatment.
30. Around this time, the haemophilia centre warned H of his potential exposure to vCJD. He was then informed that Factor VIII he had been given could be traced to a patient who tested positive for the virus. Nevertheless, as he couldn't be told definitively if he was infected, the news paled into insignificance because of the HIV. F2 received a similar letter.

### **Section 4. Consent**

31. As part of the Sheffield haemophilia protocol, I was regularly tested for HIV. I felt as if I didn't have any choice in the matter although I believe that my HIV status should be the concern of a sexual health clinic not the haemophilia centre. Again, it comes down to their need to control.
32. Back in the early days, even having a HIV test could be detrimental to getting an insurance policy. Yet, the haemophilia centre were doing this

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as part of a protocol in situations in which I didn't provide my fully informed consent.

### Section 5. Impact

33. HIV was the demise of [H] and progressively led my life to become a living hell. Whilst his infection did not appear to manifest physically, it had a grave impact on his psychological wellbeing, with devastating consequences on our lives together.
34. At the time of [H]'s diagnosis in the mid 1980s', he was in good health. He had no intuition about his infection and remained asymptomatic until his death. I watched the film *Philadelphia* decades ago where Tom Hanks' character breaks out in all sorts of lesions. However, [H] never experienced any of this.
35. When I first met [H] in 1995, he was having Dihydrocodeine and Temaepan sleeping tablets as a result of his haemophilia which caused severe joint pain. I can remember on our first holiday, him counting out his tablets on the counter every morning.
36. As a result of all the bleeding over the years, [H]'s joints, particularly his elbows and knees, were very distended. He also walked terribly, like an 'elderly man'. He couldn't stand up straight. He was in agony all the time.
37. We would lie to friends and family, attributing his walking issues to arthritis. Shortly after we married, [H] was unable to work as a result of his joint issues. My mum asked me if [H] told me about his arthritis before I married him. I just thought, if only you knew!
38. [F2] had similar experiences with medication to treat the pain in his target joints. I can remember him sitting on our settee one day, complaining that the haemophilia centre, having got their patients

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hooked on various medications, had no interest in weening them off the drugs.

39. In 2000, aged 40, [H] had a heart attack. As a haemophiliac whose blood doesn't clot, this was very unusual. I took time off from work to look after him, which was very stressful. This was exacerbated by the stress of not being able to fall pregnant, which I will discuss in more detail later on in my statement.
40. His consultant Mike Makris was shocked. As a haemophiliac, this should never have happened. When they explored his medical records, they discovered that a triple-therapy he received for HIV in 2000, raises lipids which in turn raised his cholesterol levels. Why didn't the staff treating [H] know this?
41. The Genito-urinary and Sexual Health Clinic served all HIV patients with the exception of the haemophilia patients with HIV, who were ring-fenced within the haemophilia centre. We never received any information. [H] was denied the benefit of HIV specialists discussing his treatments with him.
42. We only saw the Professor of the Genito-urinary and Sexual Health Clinic three times, one of which related to my fertility. This caused [H] further mistrust. He felt that the haemophilia clinic wanted to keep their patients to themselves.
43. Surely the experts in HIV should have been directly involved in the care of haemophiliacs with HIV? They might have been aware that this particular antiretroviral causes raised lipids.
44. [H]'s infection with HIV prevented us from conceiving a child naturally. Between 1995 and 1996, through a Haemophilia Society newsletter, we learnt that a doctor in Italy, Dr Augusto E Semprini, had developed a then new technique of sperm washing. I believe that



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something like a centrifuge separates the fluids from the HIV infection so that the sperm is safe.

45. We contacted Dr Semprini. We also contacted F2 We discussed the procedure with the Royal Hallamshire Haemophilia Centre who were not familiar with the technique.
46. Herein began our 10-year journey of trying to have a baby. The NHS haven't been very helpful at all, particularly in relation to fertility matters. The GP contributed to the initial blood testing phase but was not very involved subsequently.
47. Indeed, we were very much on our own. The only medical support we received in the UK was when the Royal Hallamshire referred me to the professor at Genito-urinary (GU) unit, who undertook the fertility tests required by Dr Semprini. In Italy we also met a couple from London undergoing the same process.
48. We contacted our local social services team who funded another round of treatment. We met a member of the team in a café. She was dedicated to helping those with HIV. She handed us an envelope for £800. We didn't have to fill in many forms. It was bizarre yet amazing! This mostly covered all our travel, hotel and hospital expenses.
49. I was working at the time which was really difficult. I didn't want to tell my manager why I wanted time off. It was very stressful trying to coordinate a convenient time to take leave from work so that I could arrange all my travel and hospital appointments, also at the right point in my cycle. I also had to take hormones, which were administered subcutaneously by H
50. After the first round was unsuccessful, we went to Milan in Italy again. This time, we didn't get support from social services. On this occasion, they discovered that I'd developed a cyst. They advised that we return home to deal with this before returning.

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51. Between 1996 and 1997, I went to see my GP, Dr **GRO-B**, who has since retired, at **GRO-B**. He also had obstetrics qualifications and so I expected that from a gynaecological perspective, he'd be pretty clued up. He told me that cysts come and go and so I'd be best to leave it alone.
52. He also advised that to get pregnant, I "should just have sex with **H**", who was also his patient. I was astounded and sat in stunned silence. Such a decision wasn't just going to potentially infect me but could also infect the unborn child. I was a younger then and not as confident to challenge those in positions of authority.
53. **H**'s experiences with the haemophilia team, particularly the secrecy surrounding his diagnosis with HIV, permanently affected his relationships with medical staff and hospitals. From thereon, he would always avoid hospitals or would discharge himself prematurely. This wasn't always in his best interests but the trust was gone.
54. We didn't have unprotected sex but we were stuck as my GP wasn't doing anything about the cyst. We consulted with **GRO-B** Fertility Centre privately. They put me on the NHS waiting list. I was getting older and we opted to pay privately for the cyst to be removed. We considered returning to Italy but by this point, two places in England were discussing about sperm washing.
55. We got onto a waiting list at a clinic in Birmingham. This was an extremely protracted process as it took months for the procedure to receive ethical approval. We were constantly being told that another ethics committee meeting lay on the horizon. We considered instead returning to Milan.
56. During this time, I wrote to the fertility guru at the time, Professor Lord Robert Winston, to request whether he could exert his influence to expediate the process. I received a very curt reply to the effect that he

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could not help us. If I see him on the television now, I feel very angry. He portrays himself as being caring and invested in helping those with fertility issues, yet he was completely unhelpful to us.

57. Between 1999 and 2000, the clinic in Birmingham opened for sperm washing. I was 37. Whereas in Italy, they washed and injected the sperm; in Birmingham, I was to produce multiple eggs, which were then fertilised separately using traditional IVF. A couple of eggs would then be returned to my womb. I was given a plethora of drugs to multiply my eggs.
58. They found out that it hadn't worked out as expected as I was going through early menopause. We had to abandon our efforts. We'd lost time as we waited for the cyst to be dealt with and while the Birmingham clinic could officially start the process. If we'd been a normal couple, we might have had a baby by then the natural way.
59. We pursued another route. In 2000, [H] and I sought a second opinion from the [GRO-B] Fertility Clinic. They confirmed that I was undergoing an early menopause. The only option they could suggest was a donor egg, which wouldn't work because of [H]'s HIV status.
60. Our alternative was to procure a donor embryo. That sent me into a bit of a tailspin. I was very sceptical about having a 'foreign body' entering my own. It seemed unnatural. [GRO-B] asked me why I was agonising over the decision.
61. She reminded me that it was quite simple and really came down to whether I wanted a baby or not. After much discussion with [GRO-B] I changed my mind. If I hadn't had her to discuss this with, I might not have a daughter today. My own parents didn't know.
62. With the [GRO-B] Fertility Clinic, it was mandatory to have one of their counselling sessions at least once before we embarked on potentially

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receiving a donated embryo. This was probably just to make sure that I was mentally stable.

63. I decided to progress with the donor embryo which we paid for privately. Around about this time, there were new NHS regulations about how many cycles the NHS would cover. They would fund IVF for patients who were under 36. We didn't fit this criteria and so social services gave us some £400-£500 funding for a cycle.
64. Thankfully, there were people who had gone through fertility treatment and who donated their excess fertilised eggs. They had to be compatible with my body, my blood type and my general build and looks. The absolute crux of it was the biological compatibility; as my body could have rejected an incompatible blood type.
65. I wanted to have a child so desperately, that it became an obsession, and one that I couldn't share with anyone except **GRO-B**. Falling pregnant was more important to me than for **H**. He was a little bit selfish in some ways. He just went with the flow but didn't really contribute.
66. I was determined to succeed. I can remember the disappointment of repeatedly phoning the clinic only to find that the pregnancy test was negative. We were just concerned with trying again as soon as possible. Yet, we could only embark on one attempt a year. Time was such a factor. If I was going to be a mum, I was getting to be an older mum.
67. Having first sought treatment in Milan in 1995 or 1996, I didn't have **GRO-B** until the end of 2006. We had two treatments in Milan, one in Birmingham; then 3 or 4 attempts with the donated embryo at **GRO-B** Fertility Clinic. We were then informed that this wasn't successful.
68. As **GRO-B** didn't have any more available embryos, we sought treatment in Leeds. We had 2 or 3 attempts. I don't recall receiving any



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counselling. At the end of March, I received my severance package at work. I had my embryo implanted towards the end of March. It was successful.

69. It cost about £2000 to £2800 for each cycle, including all the hormones. It's all so time-consuming and expensive. This amounted to 11 attempts over 10 years. The final treatment in Leeds cost about £2.8K. GRO-B was an expensive baby!

70. H and I were on holiday in Cyprus when I found out I was pregnant. I packed a couple of pregnancy tests. H knew a pharmacist and doctor very well. We could be open with them because they were overseas. The Greeks discovered haemophilia; they had more understanding of it and weren't uptight about the condition.

71. I explained our situation. The pharmacist provided me with their best pregnancy tests. When H was fast asleep, I did a test. I saw a very faint line. I woke up. H After so many disappointments, I was expecting it to be negative.

72. By this time, I was approaching 43. I had decided that if this wasn't successful, I would give up. I didn't want to be an even older mother. H was more hopeful. I phoned the pharmacist, who said that he was 99.9% percent certain that I was pregnant. I handed the phone to H because I was going to cry.

73. I phoned the clinic in GRO-B to request blood tests. They booked me in for a scan. I was hoping I would have twins because it was my last chance, even though at 43 this wouldn't have been an ideal scenario. My daughter is an absolute delight.

74. With the exception of a few close friends, H didn't tell many people about his infection. Some of his best friends still don't know. It must have been difficult for him not to be able to discuss his infection with

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others. When a friend of his from the early 2000s' found out, he gave

H a kiss. That would have been marvellous for him.

75. I don't think H's parents shared his infection with anyone, perhaps not even his aunt and uncle. He had an odd relationship with his parents. His dad was very protective but his mum was emotionally detached. I think she might have blamed herself for H's infection.

76. Neither of his parents were particularly nurturing. Later in life, his mother developed Alzheimer's. At the same time, it can't have been easy raising a child with haemophilia, later infected with contaminated blood.

77. I had to construct lies to account for H's behaviour. I don't think he wanted to be treated differently. HIV was associated with homosexuality which was very stigmatised at the time, and haemophilia was conflated with HIV. We were all frightened by it, thinking we were going to be next.

78. He didn't want people to see the side of him that was unwell or vulnerable. I think that's why he could be a bit flippant and juvenile, like a big kid. He was a lovely, nice guy, but as time went on, he became unrecognisable.

79. Only one colleague from his work knew, as did a member of senior management and the first aid officer. I know it hurt him that people needed to know. What compounded this was that during a management meeting, his senior manager announced his HIV to all the senior managers. It just slipped out. I'm not aware of any adverse reactions but he wasn't happy that it was out in the open.

80. My mum still does not know about H's haemophilia or his infection with HIV and HCV. She thinks I am at a physio appointment today. A lot of my friends do not know, nor does my daughter. When H first

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told me about his infection, he asked that I only share it with my close friend [GRO-B].

81. Even [GRO-B]'s husband doesn't know. Since then, our lives have been shrouded in secrecy. [GRO-B] and I were discussing our prospective meeting with the Inquiry the other day and had to lower our voices so that my daughter would not overhear.
82. My daughter is not biologically my own. She does not even know about her father's haemophilia. She's an anxious teenager; as much as I'd like to tell her, I feel the need to protect her as I know she wouldn't take it very well. We have a fantastic relationship but I'd be terrified if she ever found out that I'm not biologically her mother.
83. I messaged a very close school friend of [H]'s this morning. He told me that he didn't learn of [H]'s infection with HIV until the late 1990s when they were on holiday in Turkey. This was some 15 years after [H]'s diagnosis. He only told him out of necessity as they were sharing a room and [H] had all his paraphernalia out.
84. Shortly after [H] was diagnosed, he was part of a group that each received a pay-out of £50,000. I don't believe that this was framed as 'compensation'. He blew the £50,000 very quickly. He spent liberally and frivolously because he knew that he might not be around tomorrow.
85. I worked all the time as I sought financial stability. However, [H] very rarely worked. I'd come home to find another car on the drive. At one point we had 7 cars. He even had a garage built for them yet he'd never touch them.
86. The postman was constantly delivering parcels to the house. He would order very bizarre items such as toy submarines, train sets and guitars that he couldn't even play. He'd open them and never look at them

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again. He wanted to enjoy life while he had the chance. Most of those who were paid out, blew the money in no time.

87. [H] followed Rod Stewart around the world. He drank several different types of champagne. The two years passed and he was still alive. By this point, he didn't have any money left. He was generous with it too. That might have been partly why he was so popular at work. He wanted to be liked. People took advantage of that.
88. Unfortunately [H] unwittingly infected his now ex-wife [GRO-B: W] with HIV before he knew that he was infected. He carried a lot of guilt about this, although it was not purposeful. I've spoken with [W] a few times since [H]'s death. She is greatly affected by the circumstances surrounding both [H]'s and her own infection.
89. As previously mentioned, [H] was asymptomatic for HIV. In the early days, he managed to put his infection to the back of his mind. Although he took about 8 painkillers a day for joint pain, he remained a fun-loving and popular person. As the assays developed and they could detect the level of the virus in his blood, it became more difficult for him to ignore his infection.
90. One of the few times we saw the professor from the genitourinary unit at the Royal Hallamshire, I remember him quite clearly saying, 'you're not a non-progressor but you're a slow progressor'. Shortly afterwards, they initiated him onto daily antiretrovirals. He couldn't ignore his infection any more. That's when he started to psychologically go downhill.
91. He used to refer to his HIV medication as 'toxic waste'. He hated taking them as it was a constant daily reminder that he had HIV. This sent him into a downward spiral from which he would never return. As the assays continued to improve, he knew exactly how much of the virus he had in his blood. This caused depression and panic attacks.



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92. He had medication for depression and Diazepam for panic attacks. To try and block the virus from his mind, he also relied heavily on opiates which were prescribed by the haemophilia centre. He just wanted to numb himself.
93. He was asleep more than he was awake. We were glad when he was asleep because he was a pain when he was awake. Especially as I knew the person he used to be. It was so sad to witness his deterioration. These days, we only talk about the old H We don't want to talk about the one who died.
94. Once the antiretrovirals came into the picture, that's when we started to notice a difference in H's personality. He became incapable and uninterested in doing anything. He took Temazepam at night to sleep and Diazepam in the day for anxiety, and he'd drink Red Bull to stay awake.
95. He didn't receive any psychological support for his depression I think he spent so much time in hospitals and doctors throughout his life that he just wanted to self-treat. He returned to his doctors complaining of breakthrough pain, so that he could get higher doses of painkillers. He was absolutely addicted to them by then.
96. Alcohol in the mix was horrendous. If the old H drank, he was the life and soul of the party. Add in prescription drugs, painkillers, panic attacks and depression, and he was horrendous to be around.
97. He was misusing the drugs, taking them even when he didn't have panic attacks. He was so numb that he would usually fall asleep with a cigarette or cup of tea in his hand. I bought so many carpets and duvets that never made it to the second wash.
98. I pleaded with him to be more careful. I showed him magazine photos of burnt children, but nothing worked. I became a very light sleeper as

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a result. As soon as I heard his cigarette lighter, I'd pretend I was turning over in my sleep, when really I was keeping an eye on him.

99. He had burns all over his chest. Because he was so out of it and drugged up, he didn't even notice. It wouldn't even wake him. We had a candle in the bedroom once. He passed his hand through the flame and didn't even notice. He suffered a terrible burn.
100. [redacted] H [redacted] then started accessing prescriptions from his GP and the Hospital at the same time. He was on double doses of everything. As he was friendly with the pharmacist in Cyprus, he would also take home boxes of diazepam, which he would line up and count as if they were blocks of gold.
101. Our GP, Dr [redacted] GRO-B [redacted] GRO-B [redacted] medical practise, also prescribed him a drug called Palfium, which he warned was extremely addictive. [redacted] H [redacted] would make an appointment every week as he would have more in a day than he should have done. We got to a point where the doctor was doing daily prescriptions.
102. Eventually, I had to take charge of his medication. I locked everything away in a lockbox. Although, unbeknownst to me, he had a spare key. He would take medication while I was at work. He was truly addicted. I thought I was in control and then he resented me for it. We would get into horrendous arguments.
103. After a year of doubling up on his prescriptions, the hospital and his GP finally communicated. He never admitted to having double the dosages, remaining convinced that people believed him. he claimed that he threw the extras down the toilet.
104. His medical notes noted an opiate dependence. He started having weekly hospital appointments where he was given liquid morphine. He would literally swig it.

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105. He was referred to a psychiatrist in Sheffield. He was admitted to a drug rehab clinic alongside all the run of the mill street addicts admitted for methadone dependency. It was a horrible place to find myself. I sat in the waiting room thinking that this wasn't quite the life I envisaged as a young adult. The staff had to ween him off Palfium. He was then given methadone.

106. Eventually they decreased his dosages infinitesimally. I didn't think he'd ever be finally clean. I started diluting his medication with water. He never cottoned on. When I was in charge of his sleeping tablets, I decided to experiment by shaving two paracetamols to the size of his Temazepan. He never noticed and went to sleep. I told him, but it didn't make any difference. He wouldn't listen.

107. I watered down his morphine too. My life was terrible at this time. The only positive thing that came out of it was GRO-B. H was either asleep or taking Red Bull to wake up. He would literally fall asleep with his fork mid-air, only to deny it second later. Even when GRO-B was born, he was like this.

108. August 2006 was the first time I experienced physical abuse from H. He would go weeks and weeks without alcohol and then he'd go on binges. He had a drink and became a completely different person. Out of nowhere, he aggressively asked me how many weeks into my pregnancy that I could still have an abortion. He tried to drag me from the bed.

109. I tried to kick him off me. He was saying the nastiest things about aborting the baby. To some extent, I fought back. I didn't really know how to respond in the best way but I didn't want it to continue. It was a dream come true that I had finally fallen pregnant and then there was a massive cloud over it.

110. Due to the drug addiction, he lost a lot of weight. Physically I could have overpowered him, although this wasn't in my nature except

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when I went into 'mother bear' protection mode. Once I regained my balance, I pinned him up against the wall by his throat. I said, 'don't you ever, ever do that to me again.'

111. I knew this couldn't happen again and that I couldn't be viewed as being weak. I was protecting the baby I had fought to have for 11 years. He was shocked by my reaction. This incident wasn't as severe as later occasions, although it changed my feelings towards him.

112. We'd been together 11 years by then, he had never shown any signs of being violent or abusive. This is the person who used to cry every Christmas in front of his aunt and uncle because we were getting negative pregnancy results. I later discovered that the Diazepam he took for depression and panic attacks could lead to personality changes.

113. When we married, H was about 11 to 12 stone. When GRO-B was a baby, he was like the Michelin man and very bloated. He then became very emaciated, suddenly dropping to about 7 stone. Surely such a fluctuation should have rung alarm bells for the hospital. I could lift him up; he looked like a sparrow.

114. The domestic violence continued periodically. He became a hard man to love. I had feelings for him, but towards the end, he was merely my responsibility. I think even his parents stopped loving him. It's not easy for a wife to say that, especially now that he is dead. I obligingly looked after him.

115. He didn't take much interest in GRO-B when she was born. I think he was just unhappy that the attention was deflected from him. I wanted him to love her as much as I did. If GRO-B was crying, occasionally he'd say nasty things like, 'your pet's crying. Go on.'

116. On another occasion, I'd fallen asleep on a bed beside GRO-B cot as I read her a story. H fell asleep all the time yet thought it



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wasn't right that I was sleeping next to [GRO-]. He tried to drag me off the bed by my feet. With a cigarette lighter in his hand, he tried to set my hair on fire. He emptied the cupboards and threw things around the room. It came out of nowhere. I then phoned the police, something I never envisaged being part of my life.

117. By this time, he'd lost all his friends. We were no longer invited anywhere. He'd fall asleep at the dinner table. If friends had a party, he'd never want to go home. We stopped getting invites. These were his long-standing school friends, and yet even they had had enough. Nobody wanted to be around him.

118. On another occasion, when we had a handyman at the house doing some work, [H] demanded that I make him ([H]) a cup of coffee. I told him that I wasn't his slave and that he could make it himself. He chased me around the garden, blasting me with a hose pipe until I was soaked.

119. I've found myself in many desperate situations as a result of [H]'s mental decline. I've run out of the house bare foot pleading a neighbour for help. I've left my home to stay with my in-laws and my parents. I've called the police. I've begged [H] to turn his life around, as otherwise he could put me in hospital. I even lived in Cyprus and with [GRO-B] and her family.

120. I then sought advice from the Royal Hallamshire as to what could be causing [H]'s manic episodes. He was given an MRI scan, which indicated some some changes in the brain, albeit they couldn't identify the cause. They referred him to their in-house psychological services which didn't work as he was expecting the psychologists to relay everything to his consultant, of whom he didn't trust.

121. I'm not one for giving up but I had run out of places to turn. I just wanted to make him better. I sought help from the Haemophilia Society and MacFarland Trust. To some extent, they were helpful in explaining

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the long-term effects of Diazepam usage, which included a personality change. They paid for his in-patient stay at the GRO-B. They were brilliant.

122. It was not ideal taking my two-year-old child into a rehab centre. He was doing really well. He stayed for two to three weeks before discharging himself. I asked his dad to persuade him to stay as he was meant to remain for a month. His dad was useless.

123. The Royal Hallamshire arranged for him to stay in hospital for a week for monitoring. He was really reluctant to do this. I had to plead with him to get him in. He eventually agreed. He went in on the Thursday or Friday and by Saturday, he rung me to say he'd been discharged. I was confused as he was supposed to be in for a week.

124. I brought him home. On Monday I spoke with the specialist haemophilia nurse, who apologised for a miscommunication. She explained that he shouldn't have been discharged. If I recall correctly, H was denied pain relief on repeated occasions, although the occurrence of this was later denied by the hospital.

125. We considered going on holiday. The hospital encouraged this and explained that they would arrange for him to go in again in a few weeks. He was a bit like his original self although he kept feeling light headed. He continued to feel unwell when we returned. He had a haemophilia appointment a few days later but he didn't feel well enough to attend.

126. A few days later, he still didn't feel well. I made him some strawberries and cream. Even though I didn't like him as a person anymore, I was thrilled that he was eating. He went to bed, complaining of chest pain. I was just exhausted.

127. I woke up the next day and when I looked in on him, I noticed that something was wrong. He was facing the wrong side of the bed. I

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started to panic and looked closely for indications of breathing. One of his cheeks was discoloured, although he had been bruising an awful lot while we were on holiday so I thought it might be attributable to this.

128. I couldn't see his chest moving and so I called 999. All the time, I knew I needed to get somebody to look after GRO-B I stopped my neighbour who was a nurse. She asked if he was dead. The paramedics were brilliant, arriving in no time.

129. H died on GRO-B 2012. The death certificate lists cholesterol and perhaps COPD as the cause of death. As it was sudden death, I had a lengthy interview with the police. I phoned my parents, his parents and the coroner's office. Eventually, they took him away.

130. Later on in the day, I had to tell GRO-B that her father had died. This was the hardest thing I've ever had to do. I tormented myself for a while about not calling an ambulance when he mentioned the chest pains the previous night.

131. Nevertheless, having contemplated how the situation could have panned out, I'm glad I made the decision that I did. I am grateful that we were spared witnessing him having a catastrophic heart attack. Even if he did go to hospital, he was so frail, they couldn't have saved him anyway.

132. I think that when he was in hospital, there were missed opportunities. He should have been in there for a week. There seemed to be no attention paid to his past cardiac event. He was swigging liquid morphine and taking all sorts of drugs; if he was experiencing angina pain, he would have been too numb to feel it.

133. When H died, my GP said to me, 'GRO-B this does solve a lot of problems for you.' Even his best friend said that this could be the best thing that ever happened to me.

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134. From time-to-time, I would catch glimpses of the old **H** I knew something was responsible for his drastic change in behaviour. The tears that I had when he died were that I was never able to fix him. I felt that I had failed.

135. As I said to **GRO-B** shortly after **H** died, although I was upset, I really cried most of my tears years ago when I lost the old **H** **GRO-B** advised me to leave him but we also had a child together. He adored **GRO-B** although he didn't do anything to help.

136. Ever since his initial diagnosis with HIV, **H** lost trust in the medical profession. He stole his own medical records because he wanted to know what the doctors were saying about him. We were taking them from one department to another when he slipped them under his jumper. The last entry is June 2001. His consultant accused him of selling his opiates. He'd be the last person to sell them.

137. I have shown the Investigators some of **H**'s medical records which he stole. The have taken copies of the following as exhibits:

Exhibit number    Contents

**WITN5406002**    Letter dated 5.7.2001

From Dr. M Makris to Dr. N. Seivewright  
(Consultant Psychiatrist).

Details **H** abusing opiates and lying to us repeatedly by obtaining medication from us and his GP. **H** admits doing this but states he throws the extras away.

**WITN5406003**    2 Pages Letter dated 5.7.2001

&                      From Dr. M Makris to Dr **GRO-B** GP

**WITN5406004**    Reiterates the same details but adds going to register **H** as an addict and refer to a drug abuse specialist. They (the hospital) will not issue **H** further medication



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138. [H] was treated at his parent's dental practise because he had trouble finding a practise that would treat him. They said they would treat everybody the same as every patient poses a possibility of infection, for which they implement safeguards. This was a positive experience.
139. [GRO-B] was not quite six years old when she lost her dad. I constantly fought to get help for him. She lost her dad but I'm grateful she didn't witness the traumatic experiences that I have been through. She had a fantastic relationship with [H] and harbours positive memories of her dad. I'm not going to muddy those waters.
140. What really bothers me is that my daughter blames herself for her father's death. She witnessed all the furore going on before going to school. When she returned home, I told her that her father died. She thinks he wouldn't have died if she hadn't gone to school and that if anything were to happen to me, only she could save me.
141. A consequence of [H]'s infection with HIV is that I have since been diagnosed with PTSD. I still struggle with depression, which began prior to his death and worsened after [GRO-B] was born, when the abuse started. I still have scars on my body from [H]'s cigarette burns.
142. For [GRO-B] losing her dad has affected her greatly. She had massive separation anxiety and panic attacks. She would scream and cry whenever she went to school. I couldn't leave her anywhere. That persisted for years. She used to be so fun loving and bubbly and now she is so riddled with anxiety. I think this stems from suddenly losing her dad.

**Section 6. Treatment/Care/Support**

143. In October 1995, [H] was scheduled to have an operation at the Royal Hallamshire to have his knee washed out, as a result of complications from his haemophilia. At the same time, I was due at the [GRO-B] for women to have pre-cancerous cells of the cervix removed.
144. I experienced a lot of discrimination at the [GRO-B]. While I was waiting for the procedure, I filled a form out in which, in answer to whether I had been in contact with anyone with HIV, I declared that my partner was HIV positive.
145. Shortly after, the consultant surgeon, [GRO-B] asked me, in front of all the other women in the bay waiting for their surgery slot, if it was true that my boyfriend was HIV positive. I confirmed. I wondered how this could have been such a shock for someone working in the medical world.
146. She told me that my appointment would have to be moved to the last of the day because I was high-risk and would require a different surgical procedure. She explained that the planned laser treatment involving 'bits of skin flying around', would not be ideal for someone in my circumstances. Instead, I was to be given a Knife Cone Biopsy which entailed cutting part of the cervix away.
147. I didn't understand why I was high risk. As I knew that [H] was infected, I took special precautions to ensure that I was protected. Conversely, the other women at the hospital may have been unknowingly exposed to the virus. Why should I have been deemed higher risk than them? This is in addition to the fact that I was not HIV positive.
148. I like to think that form I had to fill out no longer exists and has been consigned to the archives. I hope that people undergoing a pre-

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operation assessment aren't being asked nowadays if they have had any exposure to HIV. They should take the same precautions for everybody.

149. The discrimination to which I was subjected as a result of **H**'s HIV status, has had huge implications on my health and wellbeing. Shortly after the procedure, when I was home alone, I began to haemorrhage. I got a taxi to the hospital. I thought I was dying as I lost so much blood. It took them a while to stop the bleeding.

150. The next day, **H**'s parents took me home to their house. They were only gone 5 minutes when I started bleeding again. This was about 24 hours after the first haemorrhage. By the time they returned, they had to rush me to hospital again. I just made it to the doorway before I nearly collapsed.

151. They put me straight onto a saline drip as my pulse rate was extremely high. They tried to stop the bleeding again. I had to stay in for about 4 days. I was in so much discomfort. **H** got his friend to get him out of the Royal Hallamshire to visit me in **GRO-B**.

152. At a follow up appointment, **GRO-B** referred to me as a 'bleeder'. I thought it rich that my haemorrhaging was attributed to my own physical vulnerabilities rather than the hospital's aversion to administering the laser treatment as planned. This was all caused by the HIV status of my boyfriend and because I was trusting enough to declare this.

153. Over time, I learnt to be less placid in my interactions with authoritative medical figures. But in my early 30s, I didn't think to challenge **GRO-B**. She was a consultant. When she made a mistake, I assumed that I must be wrong.

154. This experience has absolutely affected my ability to answer such forms honestly. If I'd known the consequences, I would never

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have put that as an answer and I haven't since. I would like to think the hospital weren't sharing equipment anyway. Only six months into my relationship with [H] and I was facing terrible consequences as a result of his illness.

155. A couple of years later when I explained to [GRO-B] that [H] and I hoped to have children, she was horrified. She couldn't understand why we would take such a risk given that (in her misguided perception), if we had a girl, she would be haemophiliac. She had the sexes mixed up as of course it is boys who are afflicted.

156. We reported her ignorance to the haemophilia centre who put her right. She wasn't my favourite person. It terrified me that a medical person could have been so ignorant about haemophilia and genetics.

157. I also have misgivings about the paucity of treatment [H] received in relation to his deteriorating health. With the exception of one follow up cardiac appointment a year after his heart attack, [H] was monitored exclusively by the haemophilia centre. This was worrying as he was physically deteriorating, yet we had no idea as to the cause.

158. His blood pressure was also extremely low. He was referred to a dietician who prescribed calorific, fatty foods. However, this was probably not a good idea given his high cholesterol issues. It reached a point where they literally said that they were out of ideas and were scraping the bottom of the barrel.

159. They gave him a lumbar puncture. But once again, there was no indication that they were communicating with the HIV or cardiac specialists. As his viral count was almost untraceable, his health wasn't deteriorating because of his HIV. He was always asymptomatic.

160. In 8 March 2013, I filed a complaint against Sheffield Teaching Hospital NHS Foundation Trust regarding the negligible treatment he received from mid 2012 until his death in 2013. I hoped that if another



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patient should inexplicably drop to 7 stone, with negligible blood pressure, a more thorough investigation might be conducted.

161. I also filed a complaint based on the immediate treatment H received shortly before his death. I didn't think he was given adequate pain relief, although he repeatedly requested this during his admission for monitoring a couple of weeks before he died.

162. Another point that I feel pertinent to make is the little support I received during my years of fertility treatment. Some people think that couples with HIV infection have access to more information and assistance in becoming parents, but this wasn't true for us. I did this all alone. The internet wasn't what it is today.

163. I was taking so much time off work, sourcing lists of embryologists that I could contact to ask if they had any spare embryos. I felt so alone. I got no support. The only support we had was in the first stage, when my GP and the Genito-urinary clinic conducted fertility tests to send to Dr Semprini.

### Section 7. Financial Assistance

164. In the 1980s, H received £50,000 from The Macfarlane Trust. At some point he also began to receive monthly payments. He was also eligible to apply for grants for domestic services and items. He got a few things through this scheme.

165. H then received the stage 1 ex-gratia payment under the Skipton Fund as a result of his infection with HCV. I don't think he qualified for stage 2 as he didn't have liver cancer.

166. MacFarlane also provided a one-off grant of £2-3k for funeral costs. For approximately 9 months I continued to receive this payment in addition to the top-up payment for GRO-B. Then, nine months after H's death, that stopped.

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167. I then needed to apply in my name rather than as H's beneficiary. I couldn't face it as I knew I would have to fill out all the paperwork. I got a friend to do it just over a year ago.
168. I don't even want to consider how much money I've lost by not facing filling out the new forms. The payments stopped in the summer of 2013. I didn't apply again until 2019. I lost 6 years of payments. I asked if they could be backdated but they wouldn't even backdate it for a month.
169. The monthly payments have increased. In December I received about £1,800. This went up to about £2,600 this month. A large portion this is for GRO-B. She's my biggest priority.
170. I'm applying for compensation on GRO-B's behalf. I have no intention of enlightening her to her dad's medical situation. The secrecy and caution have not ceased even after H's death. I've got an awful feeling that that Pandora's box will open. I don't know how or when. I don't want to think about it.

### Section 8. Other Issues

171. I would hope that an outcome of the Inquiry would be to highlight what went wrong and why. I would hope that lessons would be learnt so that certain things could be done differently. I see the purposes of today as learning constructive lessons for the future.

### Statement of Truth

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

Signed

GRO-B

Dated

9/9/22