

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN3230001

Exhibits: 0

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B and I live at GRO-B
GRO-B with my husband, GRO-B: H My date of birth is GRO-B
1954. I met H in GRO-B 1980 and we married three months later on GRO-B
GRO-B 1980. I have three children, GRO-B from a previous marriage, who H
adopted and GRO-B and GRO-B from my marriage with H
2. I make this statement as an affected person. My husband H is a severe
haemophiliac and as a result of receiving contaminated blood products he
was infected with Hepatitis B, Hepatitis C and HIV. H has given his own
witness statement to the Inquiry and his witness number is GRO-B
3. This witness statement has been prepared without the benefit of access to my
husband's full medical records. If and in so far as I have been provided with
limited records the relevant entries are set out in the medical chronology at
the end of this statement.

Section 2. How infected

4. [H] has severe haemophilia A with a clotting factor of less than 1%. I was aware of his haemophilia from the early stages of our relationship.
5. [H] was treated with Factor VIII concentrates, more specifically Koate, Kogenate, Bayer. This was non heat treated and we were informed that my husband would have to use up the old stock of Factor VIII before he could get heat treated products for his Haemophilia. I believe that before his Factor VIII concentrate he was treated with plasma and cryoprecipitate.
6. He received care and treatment at the Manchester Royal Infirmary. I believe he was initially under the care of Dr I.W. Delamore and Dr R. Wensley. Thereafter, he was transferred and under the care of Dr Hay at the Royal Liverpool Hospital (RLH). He was also treated at the North Manchester General Hospital (NMGH) under the care of Dr Wilkins.
7. On numerous occasions [H] and I had to get a bus to Manchester to pick up his Factor VIII treatment, however [H] was only allowed ten boxes at a time and he could only treat a bleed when he had one. If [H] had a bleed and couldn't walk I would go on my own to collect treatment. One time, I was seven months pregnant. If [H] had a particularly bad bleed he would phone for an ambulance, which would always take hours of waiting.
8. In or about 1985 [H] received a letter from Dr Wensley asking [H] to come to hospital for a blood test. I do not recall if he was informed of the purpose of the hospital visit. At the time we had two young children, so I did not attend the appointment with him as I was busy looking after them. I cannot remember him coming home that day. He had been told at that appointment that he had been infected with HTLVIII (now known as HIV). I cannot remember him telling me but when he did I did not know what HIV or AIDS was and I was not good at absorbing information. I did not understand how serious it was or the implications of it. I remember being positive and thinking that they'll no doubt find something to cure it. I tend to be an optimistic and positive person.

9. At the consultation when [H] was informed, the doctor said I should also visit the hospital for a blood test. I wasn't too worried as I didn't know much about it but then we started seeing advertisements on the TV, with the prominent message that AIDS can kill you.
10. We knew about the risk of transmission between us as I think [H] had been told at his hospital appointment. [H] didn't like using condoms so we used the withdrawal method. The doctors kept advising us to use condoms but [H] did not want to go out to get them.
11. [H] was infected with Hepatitis B, Hepatitis C and HIV.

Section 3. Other Infections

12. [H] did receive a letter regarding vCJD, but as far as I am aware he was not implicated. I refer to [H]'s statement in this regard.

Section 4. Consent

13. I refer to my husband's witness statement with regards to this section.

Section 5. Impact of the Infection

14. When [H] was told of the infections I saw changes in him; he became moody with me and the children. He was extremely wary if he cut himself whilst shaving and wanted his own towels and items to minimise the risks of passing on infection. Once he cut the mole on his face which would not stop bleeding and I remember he was extremely careful in protecting us.
15. In 1989 we moved from my home town [GRO-B] [GRO-B] to be near [H]'s parents and sisters as I knew, one day, I was going to need their help, even if

it was just for a bit of childminding to enable me to be with [H] when he had to go to hospital.

16. In the early 1990s [H] had a mental breakdown. The hospital suspected it was manic depression and then diagnosed it as an AIDS related depression. This had a significant effect on all the family. [H] was moody with me and I was unable to do anything right. He had lost his appetite and when I tried to present him with food, he thought I was trying to poison him. Nothing I said would convince him otherwise. It was like living with another person.

17. As a result of his breakdown he was sectioned in NMGH, and I had to wash, dress and feed him. I used to take him out in the hospital gardens in a wheelchair to give him some fresh air. During that time [H] was on slow release morphine and MST. At one point, the doctor decided to stop giving [H] MST to see what happened and his heart stopped. I came with my eldest son to see what happened, and found him flailing up and down in bed.

18. All our married life [H] has suffered with arthritis in his knees, elbows and ankles. As the pain in his knee was the worst, [H] asked [GRO-B] from MRI if it was possible to have a knee replacement. It was preventing [H] from participating in days out with the children who were very disappointed when we would have to cancel last minute. Unfortunately, [GRO-B] refused and said [H] was too old. We thought that was a stupid excuse and were very confused as [H] was only 29.

19. [H] and I started getting involved with the haemophilia society attending meetings and children's Christmas parties. We were also offered a trip to [GRO-B] to stay in the [GRO-B] which was subsidised. This was very beneficial as, living on mainly benefits, we could not afford holidays. It was also an opportunity to discuss contaminated blood. Everybody was divided into groups of six to talk about this and I was separated from [H]. We all sat in a circle, and some of the people in my group were young single men who had never been in relationships and had no children. It was embarrassing for me and I felt very uncomfortable. I didn't ask [H] who was in his group, but

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to be confronted to talk about the impact contaminated blood has had on my private life in front of strangers without warning was wrong. I just wanted to get though to day and get back to the kids who were kept entertained in another room.

20. That evening we were given a banquet followed by going to the bar. This was another opportunity to get to know other haemophiliacs. While we were there we met Dr Hay from RLH. [H] told him about Dr Wensley refusing to let him have a knee replacement as he said he was too old. Dr Hay said if [H] transferred to the RLH, he would perform the knee replacement for him. We did just that, and it was like getting a new life for [H]. The pain in his knee had ceased and he was able to walk again. When he was fully recovered we took our children for days out.

21. In 1993 we arranged a holiday with [H]'s friend [GRO-B: F], who is also a haemophiliac, and his wife [GRO-B: F]. [GRO-B: F] have 3 daughters. We were with people who knew what we were going through as [F] also had contaminated blood but suffered more from hepatitis C. We all had a fabulous time with the children, even though [H] was left on bed rest one day due to a swollen leg. We later found out that DDI can cause this problem so he had to come off this.

22. In 1993, [H] was feeling quite well. Then he was told he had kidney stones because of the parathyroid gland so he went for a scan which revealed a tumour. We were told he would have to have an operation to remove it, we were both unhappy about that. We asked the surgeon if there was an alternative but he insisted that the only way to treat the tumour was by surgical means.

23. [H] was admitted and had the operation in which he was cut from one side of his neck to the other – an incredibly dangerous procedure for a Haemophiliac to undergo. It necessitated large volume of Factor VIII treatment before and after the operation. A young surgeon came to the ward to see [H] and apologised as they had mistakenly taken [H]'s lymph gland instead of the parathyroid. They said we need to do the operation again

but [H] was furious and rang me as soon as he could. He said he couldn't go though that again and I agreed. I too was upset and furious. I told [H] to refuse and to come home as soon as he was well enough.

24. While he was recovering at home he had been told to reduce his Factor VIII. Unfortunately, following a sneeze, his wound reopened and started to bleed. From then on [H]'s health started deteriorating massively. He became very lethargic and had uncontrollable shivers. His body temperature fluctuated and he would experience awful night sweats. His pillow sheet was wet right though.

25. It did not stop there and [H]'s condition got worse. He stopped eating and started acting strange accusing me of poisoning him. He would start having a go at our thirteen year old daughter for not getting a good report from school forgetting that she had learning difficulties. For this reason, our daughter would stay out as much as possible to avoid her dad. Then he started spending money on things we didn't need like an African grey parrot. It was hard getting [H] to go the RLH and if we succeeded in getting him there, he would not remain there.

26. [H] also refused to sleep at night. Instead he stayed up messing about with the kitchen cupboards. When I got up in the morning, I found that the pots had been rearranged.

27. [H]'s health was getting worse and worse, particularly his mental health. He thought a white van was coming to pick him up at any moment. He became very unreasonable and would call his social worker in the early hours of the morning, and when I needed the social worker, she would no longer respond to my calls. It was as though she had abandoned us.

28. Dr Hay had left RLH and gone to MRI. Thereafter, [H] had no trustworthy consultant who was familiar with him; therefore it was difficult for them to see that he had a mental health problem. Eventually [H] agreed to stay in hospital and asked to see his file. While he was sat in the hospital grounds he tried making his way to the car park, but security stopped him and he was

sectioned. I received a letter letting me know what had happened. The letter advised that if I wanted to see [H] I would have to ring the number provided. I did ring one day to let them know I was coming and after an hour's drive I was let into his room to find him sedated. They couldn't wake him up. I was furious at them and asked them not to sedate [H] if I or other members of his family were visiting.

29 [H] was sectioned for quite a few months, but the hospital was confident I could care for him at home. He was still taking tablets to help him but it took 12 months before he had the confidence to answer a phone or open the door. He had gone from one extreme to another. I had to have most bills put in my name and took over looking after his medications. If I had to go out, if there was no one to look after him, I would make sure he had something to drink as I knew he wouldn't be able to get one himself. Life had changed again, but we had to adjust to the way things were. We did not know if he would ever get his confidence back. I had to be both Mum and Dad to our children. [H] had very little interaction with the children, and they didn't communicate with him much either. I kept wondering if things could ever be normal again in our family. There was very little communication with the kids and they didn't communicate with their Dad which I wondered if things could ever get back to normal,

30. I asked our GP if he would write a letter to Dr Hay at the MRI asking if [H] could be transferred back to his care which he did. His health still wasn't good, but he was confident enough to drive again as I had done all the driving while he recovered from his experience at RLH. Whilst at the MRI, [H] had Phencyclidine (PCP) about three times and [H] was placed in an isolated room.

31 [H] was in hospital a second time as he had septicaemia. Prior to this, [H] had complained about his ear having liquid in it on numerous occasions but the registrar said she couldn't see anything in his ear so he was sent home. Then I phoned for an ambulance as he wasn't well, but on arrival to the hospital we were informed that there were no beds on the wards so he lay in a treatment room next to the haematology department while I was sat at his

side waiting for a bed. I saw blood coming out of his ear and that's when they performed the tests confirming that he had septicaemia. He was put on intravenous antibiotics straight away. This was another few weeks [H] spent in hospital.

32. [H]'s lungs were getting worse and he had to go for a pulmonary function test. He needed to use a nebuliser three times a day. At this time no one was telling him about his T cells or viral load.

33. The most worrying time was during a heatwave in the UK. [H] became ill again so I took him to see Dr Hay who said [H] should be admitted. Unfortunately, no beds were available. Dr Hay advised that we go for dinner and return every now and then to see if the bed manager had found space for [H]. I pushed [H] around in a wheelchair, kept nipping in to see if any beds came available until about 2.00pm then told them we had to go home as the children will be home soon. We agreed that I would bring [H] back the next day so that is what I did. I came the day after, but there were still no beds available. I waited until after dinner and asked again so they said come back tomorrow. I did for the third time and it was exactly the same answer - no beds. This was making me ill as the weather was very hot and I can tolerate quite a lot but [H] had given up and there was nothing I could do about it.

34. I took him home and rang [GRO-B] who got in touch with the [GRO-B] [GRO-B] Trust. They sent some people to see us and I explained our situation. They instantly recognised that [H] wasn't well. I was told to get him transferred to North Manchester Hospital but that I would have to go to our GP to do it. I did just that but my GP asked why go to another hospital when [H] was going to die anyway. I shouted at him in response, "So what has he got to lose". I think my comment shocked him as he had known us for a long time and was a friend of our family. Reluctantly he wrote a letter to North Manchester Hospital and [H] was asked to see Dr Wilkins who admitted him as soon as a bed became available on the infectious disease ward. Having undergone tests, we were told that his viral load was in the millions and his T Cells were very low. He weighed about six stone and looked like a skeleton. We were told he was dying.

35. [H] was in North Manchester Hospital for a long time as he was so ill. I would see the children off to school then make my way to the hospital to look after him until dinner. Then I would return home to feed the children. This was not the sort of life we expected but we just got on with it. It affected [GRO-B] the most as she had been drinking with school friends and also taking drugs without my knowledge. [GRO-B] [GRO-B] I was bringing the children up on my own as well as looking after [H] in hospital. Sometimes it could be about 11.00pm at night and [H] would ring me asking me to ring the night staff on his behalf. I had to ask the staff to give him his MST which he should have had at 9.00pm.
36. When [H] started taking therapy drugs his viral load improved. [H] was able to come home for the weekend, and I drove him back to hospital on Monday. Adjusting to life at home took some time to get used to. For example, getting back into regular routine and eating meals at different times.
37. Over and above what I have already discussed, [H] was admitted quite a few time's with different problems such as chronic diarrhoea, kidney stones and breathing difficulties. The hospital changed his therapy drugs but [H] had to stay in until they found out what was going wrong with him. Overall, we spent quite a few Christmas' at the hospital. I wouldn't let the children open their Christmas presents without their father. Instead, I put the children in the car and the presents in the boot and drove them to hospital so that we could spend Christmas together.
38. It was like living with a ticking time bomb. I spend most of my time watching for any signs of illness so that I could be there to help him. If he had a high temperature, I would have to give him Panadol and if it was more serious, and he had been exhibiting other symptoms, I would ring the hospital.
39. Once he was in a lot of pain in his chest so I rang the hospital and they said they would send an ambulance to take him to North Manchester Hospital. We

waited for six hours and he was in agony. He had taken medication but it was not easing the pain. When they arrived, the paramedic suspected that his lung had collapsed. I couldn't go with him because it was so late at night and I had two young one's to look after. [H] said when they arrived at hospital they gave him some diamorphine which helped. Apparently [H] swore at the radiology department as he was unable to keep still while they tried to x-ray his chest. The next day, when I came to see him, he told me they said he had pleurisy with a blood clot in his lung, so that was another long stay in hospital.

40. Another time he had to go into the MRI to have one of his kidney stones shattered in order to alleviate the pain in his kidneys. [H] was in a lot of pain so had to ring for an ambulance. [H] had a very high temperature, was extremely clammy and sweat was running down his face. They took him down to [GRO-B] A&E to get him stabilized and I followed behind in the car. I had a word with the doctor who advised that he could give [H] Aspirin. As soon as I heard this I was surprised. I told the doctor that he cannot give a haemophiliac Aspirin and told him to ring Haematology at the MRI. They said Panadol would be fine to take his temperature down.

41. Only a few years ago, [H] had a blockage in his kidney so they had to put a drain in and have this bag tied round his leg which made it uncomfortable going out. He started feeling ill while he had this bag on and found blood in the urine bag so we went to the MRI. After a few hours waiting they could see the tube was blocked and his kidney had swollen so they kept him in. On his ward, one of the nurses asked [H] not to use the patients toilet and to ask for a bottle when he needed the bathroom. We should have reported it but didn't as we just wanted to get home.

42. He still has pain in his kidneys but he was so fed up with hospital that now he only goes for his scheduled appointments. He is frustrated as the hospital does not seem to listen to him. Even though he gets angry over little things I have to calm him down and make him realise that we are lucky to have grandchildren who love him and make him happy. If it wasn't for them, I don't

think he would look after himself. We keep to a routine with meals, medication and sleep which I think keeps him going.

43. [H] now has problems with pains in his chest just underneath his rib, and whenever my husband mentions his condition to the hospital they say he has cleared HCV and do not want to treat him or refer him for further testing.

44. In terms of the impact [H]'s infection have had on his dental care and other medical care, [H] appears to always be the last person of the day taken in for an operation and I feel he is prejudiced. On my hospital notes it reads on the front cover "hepatitis C risk". I told the social worker about this and they took it off but it was very embarrassing. I have also had a lot of operations and I am always the last of the day to go in. When [H] had to have some teeth taken out, which had to be done at MRI, he was put in a room with notices warning people to wear protected gown and gloves, which they did alongside wearing visors.

45. In terms of the stigma involved with HIV, we have informed a few close friends who reacted fairly positively. In fact they joked that Lucozade AIDS recovery.

46. When [H] was first informed about his diagnosis, I didn't know whether to laugh or cry. I was worried, particularly about the neighbours finding out. Living on a council estate you never knew how people would react if they found out. From then on, our lives changed completely and the more I saw on TV, the more I would worry. Even sharing food with [H] concerned me, and if he cut himself and bled, I would panic. [H] and I had lots of upsetting and heated arguments which would result in [H] crudely saying; when I'm dead you can do what you want.

47. After he was diagnosed, I knew that I had been put at risk and that if I had been passed the infection, the likelihood was that my children may have the infections too. I was so anxious about the results, but I didn't feel any

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differently inside and I never experienced any symptoms of HIV or Hepatitis C. Luckily, I tested negative and felt relieved.

48. Through stress I lost a lot of weight and the doctor asked me if I wanted to try Prozac. However after a week of taking it I had pains in my stomach and I could not eat. I used to be able to sleep well before [H] had all those health complications; however I now find it difficult to get enough sleep.

49. I have also been in hospital a few times. At the same time as [H] was having difficulties in the early 1990s I kept getting negative smear results and I knew there was something wrong. I had a hysterectomy as I had cancer of the womb.

50. In 2002 I was diagnosed with breast cancer and I had a mastectomy. Fortunately the lymph glands were clear and I did not need to have radiotherapy. The doctors are not sure whether the cancer was caused by stress. Fortunately our son was around to be with [H]

51. One of the largest impacts of [H]'s haemophilia on us was the fact that we wanted children. When we got married in [GRO-B] we were visited by a woman from haematology, Olive Redding, who brought a bottle of antibacterial liquid to sterilize the sides. I thought she didn't trust me to make sure the side was clean. Then she asked us a few questions, although I can't remember what she wanted to know. I believe we informed her that we wanted children as soon as possible as we were trying for a baby. [H] had explained to me if we had a girl she would be a carrier with faulty gene and would be a carrier of haemophilia. We decided to face that problem if it arose. In 1981 we had [GRO-B] and we were over the moon. Then [GRO-B] was born 1983. Even though [H] wanted to have more children, I was not so sure as I already had a six year old child before we were married [GRO-B] who [H] adopted and took on as his own.

52. During [H]'s breakdown he kept picking on our daughter [GRO-B] about her exam results. She had not been performing well at school and delivered some

poor exam results and [H] got very angry. He shouted at her saying that she might as well stay at home and we would educate her ourselves. He didn't know that he was being like this and it had a bad affect on [H]. She started drinking alcohol and taking amphetamines. She was living at home but had tried running away a couple of times but the police kept bringing her back. She was involved with bad people on the other side of [GRO-B] and this was an extremely stressful time for me. I did not know what she was doing at the time and I feel so guilty because I was worrying more about [H] and his illness. She fell pregnant and gave birth to [GRO-B] in [GRO-B] 2004.

53. [GRO-B] was sectioned in 2007; she was not looking after herself after she had had the baby and was hearing voices in her head.

54. [GRO-B] was handed over to his biological father who was also an alcoholic. He didn't really want [GRO-B], he just wanted the extra money that he got for looking after him. We cared for him on the weekends and would sometimes do the school run. We wanted full custody, [GRO-B] hated going back to his Dad's home. Social services would not allow us to have custody. It took three years to get custody and that was because [GRO-B]'s father had hit him.

55. Meanwhile, [GRO-B] was in and out of hospital and had to go into rehabilitation a couple of times. She still drinks, and we help her as much as possible. Her addiction stems directly from the fact that her father was not well at a vulnerable time in her life; we were not there for her. [GRO-B] has since had another child and she stays with us sometimes to give [GRO-B] a break. [GRO-B] wants to stay with us all the time, although he never lost contact with his mum.

56. As [GRO-B] had been drinking heavily during her pregnancy, [GRO-B] was born with what we think is Foetal Alcohol Syndrome although this has not been properly diagnosed. He has bad eye sight. It has been a stressful time as his first school were constantly on the phone with us saying [GRO-B] has gotten into trouble. Kids would say something to him and he would retaliate but I explained that he didn't think the same way other children did. He has

difficulties. We have now got him in to a school that is able to cater for his needs.

57. I feel like I started my life all over again given my new commitment to **GRO-B**, he doesn't want to stay with his mum and he needs a lot of attention. It is difficult for us as we are unable to do things that a normal retired couple do, such as go away on weekends.

58. Our son handled things much better than **GRO-B** did but he was very upset and stressed with what happened to **H**, the two of them have a close bond.

59. In 1997, while **H** was recovering at home, we heard his friend **F** had passed away. By then **F** had moved to Scotland so going to the funeral was out of the question as **H** wasn't well enough to get there. He felt really bad about that as not only was **F** his friend from school, they had also lived together with **F**'s mother whilst **H**'s parents found a home.

60. **H** had always dealt with all the financial matters within the family and whilst he was in hospital I had to transfer everything into my name. I found this particularly stressful as I had not dealt with anything financial before.

61. There is a requirement at the Department for Work and Pensions that if your husband is in hospital for a certain amount of time you have to let them know. This enables them to reduce your allowance. They did not consider that I brought food and drink for my husband or that we had to purchase our own dinner in the hospital canteen.

62. I also had to get in touch with Income Support to let them know **H** was back home and ask whether they could send me a form to claim benefits for him again.

Section 6. Treatment/care/support

63. I have not had any counselling. I am quite a strong person. I don't let things worry me. Having dealt with [H] when he broke down has made me stronger. I coped with that; I can cope with anything. I am the main carer for [H]

Section 7. Financial Assistance

64. I refer to my husband's witness statement regarding information on financial assistance.

Section 8. Other Issues

65. [H] was party to the 1991 HIV Litigation and had to sign a waiver in order to obtain financial assistance. The waiver stated that we would be unable to make any further claims into my husband's health conditions. At the time, my husband was very poorly so I was left to deal with this and I found this stressful.

66. This whole scandal has made us both angry and upset. If Jason Evans had not started the campaign, we would have carried on doing nothing about it. Some time ago [H] did an interview with [GRO-B] on the television. This was done anonymously but [H] ended up breaking down because of the questions they asked. He went on this with a couple of other haemophiliacs but I think all of them have died apart from [H]

Anonymity

67. I would like to apply for anonymity and I do not want to give oral evidence to the Inquiry. I understand the statement will be disclosed to and published by the Inquiry.

Statement of Truth

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

Signed.....

GRO-B

GRO-B

Dated

14-8-2019