V18G0227

ANONYMOUS

Template for written statements – Affected

Witness Name: Mrs GRO-B

Statement No.: WITN2202001

Exhibits: **N/A**

Dated: 13th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1944. I am retired but did not work after I married my husband. My address is known to the Inquiry.

2. I am giving this statement in relation to my late husband GRO-B: H H My date of birth is GRO-B 1944 His date of birth was GRO-B 1944. He died on GRO-B 1992 aged 47. H worked as a Labourer. H and I were married on GRO-B

1964. We had one son who is GRO-B and he was born on GRO-B GRO-B 1967. I intend to speak about H s infection with HIV, how his illness affected him, me and our family, the treatment he received and the impact that that treatment had on all of us. I also intend to speak about H s death and how that has impacted on the lives of the family he left behind.

Section 2. How Affected

H s haemophilia and treatment

3. My husband suffered from severe haemophilia A. I met H when in 1963 when I was aged 19. I met him at the dancing. I didn't know anything about haemophilia when we got married. He told me that, when he was a child, he would spend time in hospital for bed rest as treatment for his haemophilia. I remember that when we were first married, my husband's treatment was mainly bed rest at home. He had a bed downstairs in our house.

4. My husband was treated in the Edinburgh area. I remember that he told me that he was treated at the Princess Margaret Rose hospital when he was a child. During the time that I knew H his haemophilia care was managed at the Royal Infirmary of Edinburgh.

5. I remember that my husband was treated once in a hospital in Coventry. We were down there for his niece's wedding. He fell off the pavement and had to go to the hospital for Factor VIII concentrate treatment due to an ankle bleed. I cannot recall the date of this incident. It would have been in the 1980s.

6. My husband was one of four brothers who were all severe haemophiliacs. He had two older brothers, GRO-B and GRO-B and a younger brother GRO-B I think GRO-B passed away from AIDS the year after H died. However, I cannot confirm this as we did not have much

contact with him. GRO-B would know more about this. GRO-B died in a motorcycle accident when he was 22. GRO-B contracted Hepatitis C, which now lies dormant as I understand it. GRO-B is still alive.

7. Because H s Mum had four boys with haemophilia, she couldn't mollycoddle them. They were brought up to do their own thing. H loved animals and being outside. He was brought up to have as normal a life as possible.

8. He was treated for his severe haemophilia A initially with cryoprecipitate and then with Factor VIII concentrates. I cannot remember when he started receiving Factor VIII concentrates. Some weeks he would have to be treated one or two times and I felt like he was on treatment constantly. As far as I can recall, he took treatment in response to bleeds rather than prophylactic treatment. He suffered from bleeds quite often. He could take a bleed anywhere but it was mostly in his knees. He wore elastic bandages on his knees as his knee caps were wasted from the bleeds he had when he was younger.

9. In the early days of his treatment with Factor VIII concentrates, he would have to go to hospital for his treatment. When he needed treatment he would go to the Royal Infirmary of Edinburgh where his haemophilia care was managed. He was later treated at home when home treatment became available. Although I cannot recall exactly when he started receiving home treatment, I have a copy of a treatment sheet from his medical records which lists batch numbers of Factor VIII concentrate. The first entry is on 31/01/1983 and the last entry is 2/01/1992.

10. I did not go to hospital with him when he was getting his treatment so I was not party to any conversations that my husband had with his doctors about his treatment regime or the risks involved. I remember that my husband said to me that he had been told about the risk of either Hepatitis A or Hepatitis B and that these were mild. He never mentioned that he had been informed about the risk of Hepatitis C or HIV. My husband would have told me if he had been informed of these risks.

11. I remember that my husband and his brother GRO-B would share Factor VIII concentrate treatment amongst themselves. By this I mean that, if H was running low on his Factor VIII concentrate, he would ask if they could use of some of GRO-B s until he got a new supply, and vice versa. This only happened on the odd occasion. I cannot remember the exact arrangements for collecting the Factor VIII concentrate from the hospital. He would order it when he needed more. I think he returned it to the hospital if it was unused by the expiry date. The treatment sheet I referenced above mentions that batches were "returned unused".

12. It was a Dr Howard Davis who treated him at the RIE from childhood when he was first diagnosed. He was then treated by Professor Ludlam from around 1980. There was also a Dr GRO-D who was a haematologist there who worked under Professor Ludlam. It was Dr GRO-D that my husband asked about having hepatitis C or HIV. My husband asked Dr GRO-D as he was not able to get hold of Professor Ludlam. I believe that was in December 1986. We later found out that he actually had been diagnosed with HIV in May of 1984. I discuss this further below.

13. I remember when Professor Ludlam took over from Dr Davis. It was in around 1980. Dr Davis was old school. My husband had a good relationship with him. He had known him since he was a child. When Professor Ludlam took over, my husband did not like him. I told my husband that he was not giving him a chance. My husband said that Prof Ludlam was not a people person and he was more interested in research. He did not find him to be very approachable. He felt that he didn't want contact with people. I remember H talking about having blood samples taken when he came home from hospital but can't remember specific dates.

H's HIV diagnosis

14. I remember in visiting my GRO-B in the summer of 1984. I saw a Canadian newspaper about haemophiliacs contracting AIDS there. I remember speaking to my husband who said that that couldn't happen here. He always believed that Scotland manufactured their own products and did not import products from abroad. Around that time we received information from the Haemophilia Society about safe sex. It felt like things were filtering through about how haemophiliacs can contract diseases such as HIV without being completely explicit about it.

15. I recall that H attended a big meeting in Edinburgh. This would have been in 1984 or 1985. I think that it took place in the hospital auditorium. I think that more information was coming through at that time about HIV and the link with haemophilia. H wanted to find out more about this. I do not know who organised the meeting. I did not attend as it was just for the haemophiliacs themselves. H told me that there were two doctors from Glasgow there. H told me that he stood up and asked what this was all about. They said that the infection of Scottish haemophiliacs couldn't happen. They said that people could not be infected with contaminated blood because Scotland did not import blood. The doctors said that it was imported blood that was the problem. My husband said at the meeting that they had to have permission to give people imported blood. The doctor responded that stocks were low and so imported blood sometimes had to be used. My husband also met a really young boy at the back of the meeting who said he was just married. He asked the doctors why he and his wife had to have safe sex. From what my husband told me I believe that they were quite cagey with information and divulging anything. He certainly left with the impression that he was ok. I do not recall there being any further meetings taking place after this and before my husband was told of his HIV diagnosis in December 1986.

16. At the end of 1986, my husband went to the Haemophilia Unit and asked for an HIV test. He was becoming more anxious because of the information in the press about AIDS. He also asked for our son and I to be tested at the same time. My son was aged 19 at the time. I along with my husband and son were tested for HIV. When I was tested for HIV it came back as negative. My son's test was also negative.

17. My husband told me that he spoke with Dr GRO-D in December 1986 to obtain the results of the HIV tests that we had had. Dr GRO-D said his family was okay then paused. He said "but you are not asking about yourself?" He replied that he had assumed that when the doctor had told him that the family was okay that that meant all of us. My husband was then told he had HIV. He asked why he wasn't told before and he was told by Dr GRO-D that Dr Ludlam didn't like telling people unless they asked.

18. We subsequently went to see a lawyer at Balfour and Manson. They obtained a letter from Professor Ludlam dated 15 September 1989. This confirms that he was found to be HIV positive on 29 May 1984 and was told of his diagnosis in December 1986. They knew in 1984 that my husband had HIV but they did not tell him for 2 and a half years.

19. My husband was so very very angry that he was not told about his HIV diagnosis. He was angry about the fact that he could have infected both me and our son. We were his main priority and he was very upset at the thought that he could have harmed us. He wondered how long it would have been before they told him if he hadn't asked for us all to be tested. When were they going to tell him?

20. I feel that it wasn't H that put me at risk – it was the doctors who put me and my son at risk by not telling him about his infection.

21. About a year after my husband died, I was going in to hospital for an operation. I went to my GP and asked for another HIV test to make sure

that I wasn't infected as I didn't want to put anyone else through what had happened to our family. The test was negative.

22. It was only in 2002 I found out that my husband had hepatitis C as well. I discuss this further below.

Infection with hepatitis C

23. I realised about risk that H might have been infected with Hepatitis C in around 2002 when I read that 90% of haemophiliacs had hepatitis C as well. I believe this information may have come from the Haemophilia Society bulletins. Neither H nor I had been told that he had hepatitis C. Neither he nor I were aware of him ever being tested for hepatitis C. His death certificate said that he had died from pneumonia and also mentioned septicaemia and haemophilia. I spoke to my GP about the death certificate not mentioning AIDS. I was told that "we don't put that on it".

24. I went to my own GP to begin with to say that I was worried that I might be infected with Hepatitis C. When I asked if the HIV test I had undergone had also tested for hepatitis C, they said no. I asked to be tested for Hepatitis C. I also telephoned Edinburgh Royal Infirmary and spoke to a nurse called Rosie. I asked whether H had had hepatitis C. I mentioned that I had got a test as I was worried.

25. I then received a letter from Professor Ludlam asking if I wanted to go and see him. I went over to the old Edinburgh Royal Infirmary at the time and Professor Ludlam was very nice. I said I wanted to know if H had hepatitis C. I was given medical charts that I am certain a normal non-medically trained person could not make sense of. Professor Ludlam turned around to me and said that you can't get hepatitis C through sex. I did not understand what he was trying to tell me. I still do not know when or how H contracted hepatitis C or what contribution it made to his final years or to his death.

26. My GP told me that Professor Ludlam called to check what was going on with my results. Apparently Professor Ludlam called to ask if I had contracted Hepatitis C. He was never my doctor so I wondered why he should be asking that. I believe that Professor Ludlam was interested to know if I had it as he knew that H did and was interested to know if he had passed it to me somehow. I think that there was no good medical reason why Professor Ludlam should have been accessing medical information about me. My test came back negative for hepatitis C in any case but I do not believe that H was ever told that he had hepatitis C or that he had ever even been tested for it.

27. My late husband's medical records contain a Hepatitis C antibody positive test result from the East of Scotland Hepatitis and HIV reference laboratory. It states that the sample was taken on 18/07/1989, that it was received on 22/11/1991 and that it was reported on 12/01/1992.

Information supplied about H s HIV infection

28. In terms of my husband's HIV I believe that hardly information was given at the time he was told he was infected with HIV. No information was given to him about how he had been infected. Very little was provided about what he could expect or how he should manage the infections. He should have been told about his infections earlier.

29. My husband was one point referred to a psychologist Dr Alison Richardson and she specialised in this area having dealt with people who had contracted HIV. I think that she gave him more information about what was going to happen to him as he had been kept in the dark. She would come to our house.

30. Dr Alison Richardson told me that at one point that my husband had contemplated suicide. I had discussion with Dr Richardson about this and she said that he had seemingly gotten over that idea, and she did

not think he would hurt himself. Dr Richardson did say that my husband could get pneumonia. It was pneumonia that eventually did kill my husband, according to his death certificate. She mentioned that he could get cancer such as brain cancer. The doctors told my husband nothing as far as I know. They should have told him earlier about the fact that he had been infected with HIV as they knew in 1984 and they just didn't tell him until 1986. No-one never gave my husband any prognosis in terms of his life expectancy. My husband passed away in the February of 1992 having had his health breakdown in January of 1992. I believe he was told in January 1992 that he had six weeks as a prognosis. Other than that he was never told as far as I am aware how long he had.

31. As far as risks to his family were concerned, there might have been some mention from Dr Richardson about a not sharing razors but GRO-B never used H s razor anyway. Other than that I was not really aware of any information being passed on about how to lessen risks to me or GRO-B other than what I have mentioned.

32. In terms of any possibility that he may also have been infected with hepatitis C, any information my husband had would be from the Haemophilia Society far as I know. As I have said, he did not know about the risk of becoming infected with this or any virus when he was being treated for his haemophilia. He did not know he had been tested for hepatitis C or that he had it. The doctors never provided him with this information, as far as I am aware. He would have shared information about infection risks or the fact of him having been tested for or infected with hepatitis C with me. He did not.

Missing medical records

33. There are three years of notes missing from my husband's medical records. I asked why and they said the never had any notes from that time. The notes missing were from 1985, 1986 and 1987. I received a

letter from Professor Ludlam which said that, as far as he could ascertain, he had not had any treatment during that time. As a severe haemophiliac, he did attend and there should be notes from this time. I would like to know what happened to them.

Section 3. Other Infections

34. My husband was infected with HIV and hepatitis C. I believe my husband may have had a letter about mad cow disease/ vCJD but I cannot remember if it said he was at risk.

Section 4. Consent

35. I do believe that my husband was tested without his consent given that they knew many years before he was told that he had HIV. I think given Professor Ludlam's interest in research my husband was like a guinea pig for him. GRO-B GRO-B GRO-B I also think that he was tested for hepatitis C without his knowledge.

36. I also think that he was treated for many years without having bene given any information about the risks of infection from the treatments he was receiving.

Section 5. Impact

Symptoms and treatment

37. I think the first symptoms I remember noticing of what would have been HIV was when H started losing weight. I noticed that he was not eating. He had fatigue and tiredness but this is something he had often he had a bleed anyway. There was a little girl who lived locally and she was over for her dinner. She was about 8 or 9 at the time and she asked

her mum if H was anorexic. Apparently H would put his food on her plate so that he did not have to eat it.

38. He continued to get flulike symptoms but had never previously been the type to have the cold or a flu. He suffered from dry skin on his face and he did have mouth ulcers. Before his diagnosis he did have aches and joint pain down to the bleeds. The biggest noticeable thing after the diagnosis was losing weight and not being able to eat properly.

39. In terms of other medical complaints that came as a result of my husband's condition I would say that he was really bothered by pneumonia at least three times. Were told by Dr Richardson that some people did not get through the pneumonia that was brought on by HIV/AIDS. I remember the first time that H got pneumonia we were about to go on holiday to Ireland. We had got a caravan through the Haemophilia Society but H took badly ill. It was just at the time that he was told his HIV had developed into AIDS that he had his first bout of pneumonia. I think he was told in 1990 that he now had full blown AIDS. He had to go in to hospital for treatment for the pneumonia but I do not know exactly what this treatment was.

40. My husband told me that Dr GRO-D did the tests at the time of his diagnosis with AIDS but it was another young doctor who told him he had AIDS and walked away from him. They sent for Dr GRO-D who then sent for Dr Alison Richardson. Dr GRO-D said that she could handle it better. Dr GRO-D did say that H should have never been told like that. Dr GRO-D said he might not make it back from Ireland if he went on holiday. We did manage to take a trip some weeks later than we had initially planned.

41. H got pneumonia twice after that first bout. His body could not take any more and he passed away after the third bout of pneumonia. I knew and he knew that he was dying. I don't know how he coped with it in his

mind. I was trying to cope with his ill health. He was getting more ill each day. He really suffered at the end.

42. In terms of treatment I do recall that Dr GRO-D said that my husband had asked whether if he kept taking Factor VIII, that would that make him worse. He was told that they did not think so. He continued to take it as he had done before. I believe in terms of treatment for my husband's HIV, he was on AZT tablets. His treatment was started in 1990. These tablets were taken every day. I believe that it was the only thing they ever gave him. They did tell him to try and eat healthy. I do not recall any symptoms specifically coming up from his treatment. It's hard to tell if it was just his existing symptoms of HIV and thereafter with AIDS making symptoms worse. It is hard to know what the cause of the symptoms was. I do believe that he should have been given treatment as soon after 1984 (when they first knew that he had HIV) that it became available.

43. When my husband got pneumonia I never heard anything that made me think he was being treated differently by others. I think at that time H might have been too unwell to see if others were treating him differently as a result of his being HIV positive.

44. My husband had a friend who was 30 years old with 3 children who died in the December from AIDS just before he passed away. I believe this man was another HIV infected haemophiliac in a similar situation to him. H was heartbroken. I remember that "AIDS Bastard" was scrawled on the man's family's door after he died.

Employment

45. My husband had worked at factory at GRO-B prior to being diagnosed but he left that job before he was diagnosed with HIV.

Impact on family and social life

46. I do believe that my husband's condition did have a have big impact on our lives together. My husband and I stopped having any relations once he was diagnosed with HIV. I remember there being a conversation about the fact that we lived in such a small community, with Dr Richardson, and whether or not this would be a positive thing. I remember my husband telling one of his friends or so-called friends, and this friend told my husband not to touch or kiss his young grandchild who was there at a New Year's party. This destroyed H His confidence went down after this and became scared to tell anyone about his diagnosis. I think as the understanding got better across the country it would have been better but in those early days in a small community people were ignorant. My husband was worried about other people's ignorance. My husband was also worried about what my son and I would face if it came out about his condition.

47. I remember that after my husband passed that I spoke with an undertaker called Mr GRO-D said that he would sort out H s funeral but then I told him that my husband had AIDS they said they could not deal with him. It was our son, GRO-B then 24 who put his dad in a body bag, if definitely affected him and it took years for him to try to come to terms with it.

48. In terms of the impact on my son, I would say that my son is very deeply impacted and was really quite badly at the start. I know that my husband spoke to our son prior to passing and must have said something to him about getting married. I remember GRO-B asking if I would go with his fiancée to register for them to get married. I believe that H told them to get married and they did in the GRO-B after H passed away.

49. Months after my husband's death my son's then-wife GRO-B asked me to go down and see him as emotionally he was in a bad way. He would not talk about things. He was keeping people at arm's-length. He's better

now but for years he was really bad at coping emotionally about his father's death. I believe that GRO-B told my son soon after his diagnosis about having HIV. We have two grandchildren who came after my husband passed. GRO-B at one point thought she was pregnant prior to my husband passing but that turned out not to be the case.

50. In terms of the impact on H's social life, he was never much a drinker. The only time he would have drink would be at New Year. We did start going out together more prior to his diagnosis. H did start drinking more when he was diagnosed and I think at times he was using it to cope. H was a talker so he would talk to me about anything. When he tried to talk to GRO-B about it, but GRO-B was not really ready to talk about it. They know that his brother GRO-B also knew about his diagnosis.

51. H became very angry and aggressive. When I look back, I think about what must have been in his mind. What did he have to look forward to? He had tried to make a good life and he did not deserve what he went through.

52. I was diagnosed with depression and attended a counsellor/psychologist during 1992 after my husband's death. I didn't wish medication at that time as I tried to work through it myself. Sometimes I haven't been able to do that and have required medication.

53. It has now been 27 years since my husband died but I will never forget it and it will never leave me.

Insurance

54. We did not have travel insurance as we never went abroad. H did have life insurance, this was not a big policy. As far as I recall his death certificate said he died from pneumonia, haemophilia and septicaemia. I explained to a worker from the insurance company about this case and asked if this was going to be an issue. Whoever it was that I spoke to

said that this was not a problem and if I did not hear in three weeks that I was to call to get it sorted. We got an amount from this with no real bother. I think we got a couple of thousand pounds.

Section 6. Treatment/Care/Support

55. I believe that Dr Alison Richardson was only support for my husband that was ever offered. What was offered was inadequate. I do believe my husband would have benefited from having someone there to talk him through his condition and what may happen with things. I think he would have taken counselling and he wanted to know things about what might happen. I am sure that he would have given anything offered a try.

Section 7. Financial Assistance

56. I believe we received a monthly stipend from the McFarlane Trust. I think it was around £100 to £200 per month. They told me that this money was going to stop six months after my husband's death. I wrote a letter to the government and said that I had no dependent children at that point, but I still had bills. The only thing that changed after my husband died was the amount of food I bought. They said if I could get a sick line from a doctor I could get something. I ended up getting £80 a month for a time which went up to about £200 a month and up to £600 a month at one stage I believe that I received a payment of £20,000 from the Skipton fund in 2004. It was an easy process to apply for this as I believe the hospital took care of much of the application.

57. I did not receive anything from the Caxton fund.

58. With the new Scottish Infected Blood Support Scheme I received £2,300 per month which amounts to £27,000 per year. I found that the application process went quite smoothly. They said it would be changing from the file into SIBS. I got a letter with the amount I would be getting

shortly after. I think that financial assistance was poor before but it is getting better now.

59. After H was diagnosed with AIDS, our own GP, who is now retired, said that he wanted to get disability allowance for the terminally ill for H He said there would be no medical examination and they would base a decision on what our own doctor had written and payment would be made in a couple of weeks. This would have been on 6th October 1990. December came and we still hadn't received any word.

60. H was taken back into hospital in January 1991, and he mentioned to his social worker, Geraldine Brown, who said that she would look into it, as it usually only took a couple of weeks to process. She said that they hadn't received any letter from our doctor. He wrote another letter and more weeks went by. They still claimed that they had not received our doctor's letter. Our doctor said that he could not write again as he had done so twice.

61. By this time H was in and out of hospital with illness, and I recall at one stage he came home with a drip to feed him as he could not eat. We ended up writing to our MP, Gordon Brown, and we then got a phone call from Geraldine who said that they had the letter, but they still wanted H to undergo a medical examination. I told them that we'd had enough and that we didn't want their money that we would manage. They ended up sending a doctor to H while he was in Edinburgh Royal Infirmary to examine him. They decided that they would refuse him the allowance we were applying for, but that they would give us the night and day allowance, which amounted to a similar payment. H felt that they were waiting on him dying to make a decision. We only started receiving this money in September or October of 1991, and H passed away in GRO-B 1992.

62. We did not receive the money for very long, and I believe this is a clear example of the barriers that were put in H s way in terms of financial support.

Section 8. Other Issues

63. I did go to the Penrose Inquiry and I remember at one stage Lord Penrose was behind me and he asked how I was doing. He mentioned he had relatives in GRO-B He said the doctors were upset about what had happened and they said they were going to try and find out more information. Nothing else really came from that.

64. I have referred to various entries from my late husband's medical records and can produce these in evidence if required.

Statement of Truth

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

Signed GRO-B

Dated 27. 4. 2019