

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN2231001

Exhibits:

Dated: 11<sup>th</sup> December 2018

INFECTED BLOOD INQUIRY

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FIRST WRITTEN STATEMENT OF GRO-B

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

I, GRO-B will say as follows: -

**Section 1. Introduction**

1. My name is GRO-B. My date of birth is the GRO-B 1941. My address is known to the Inquiry. I am currently living at home with my wife, I am retired now but I currently also work in a part-time job GRO-B  
GRO-B I intend to speak about my son GRO-B: S's infection of hepatitis C and infection of HIV. In particular, the nature of the illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Section 2. How Affected

2. [S] was diagnosed with haemophilia A when he was 11 months old. This was a complete surprise to us as we had no idea at the time that haemophilia was in our family.
  
3. Following a minor to his mouth which would not stop bleeding, [S] was diagnosed as having "moderate" haemophilia A at Addenbrookes hospital, Cambridge, sometime in July 1970. Treatment was by infusion of cryoprecipitate with painkillers when required, a stressful procedure for an active toddler. In June 1973 we moved to [GRO-B] and the same treatment was given at the local hospital - we have no records of his treatment while living [GRO-B] but have not attempted to find any. In June 1979 we moved to the [GRO-B] and [S] was registered with the Haemophilia Unit at the Royal Infirmary of Edinburgh, the in Lauriston place. His haemophilia was reassessed from "moderate" to "severe" by his consultant, Dr Ludlam, and treatment if needed was provided either in Edinburgh or at the paediatric department at [GRO-B] now closed. During his schooldays and early working life [S] was monitored by Dr Ludlam at Edinburgh Royal Infirmary.
  
4. I cannot give an exact date of infection because of the missing records. There were two lots of infected products in the 1970s. He believes that he was infected with hepatitis A, B and C in the 1970s and then in 1983, with HIV but these are all vague dates. It could be that at some point the hepatitis ones were at the same time as the HIV but we can't get to the original records to confirm. Medical people knew miles before they told [S] about his infection, I know for sure, that the medical people knew before [S] because there was a tremendous amount of work being done at the time on haemophilia and HIV as it was a killer disease that the media were alleging. From our point of view, we thought he had got away with it until he told us in 1996.

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5. [s] was infected with hepatitis A, B and C, we believe, in the 1970's and then in 1983, with HIV but those are all vague dates. [s] was told he was infected in 1991 with HIV by Dr Ludlam, there was no other legal representation at the time present in this meeting. It was just him and Dr Ludlam and he was quite boldly told that he had got it and he was asked to sign a piece of paper that said that because he had been infected he would get £20,000. He was told he would have to sign the paper then and there and the paper would then bring an end to the matter and he would not be able to make any other claims and the whole thing would be done and dusted. He had no counselling or representation at the time. He was told he had hepatitis C at roughly the same time as the HIV. Originally, no one was sure what HIV was, there was a lot of research around it at the time, I suspect the medical people did not want to tell him before 1991 because he would have told us when he was underage, which is when he was infected and we would have made quite a fuss. Bear in mind that he was told when he was diagnosed that he would be dead within a year and to take the £20,000 and have a good time with it, which is what he did. He was born in 1969, so he was underage when he was infected. I think that was the other reason he was not told. [s] was working in [GRO-B] at the time he was diagnosed and he would go into the infirmary periodically for supplies of Factor VIII as he was treating himself. They would say to him "*Do you want to know what your counts are?*", and he would say no, he had to go back to work and also because he didn't know what all the counts meant, it was technical medical jargon to him. It did not cross his mind it could be anything sinister. It was not until 1991 when he was boldly told he had HIV and it was like a blow from the sky. He had no symptoms of anything at that point, he was fine apart from the haemophilia.
6. I am not sure if this was at the time of diagnosis or later on but I believe that Professor Ludlam offered him treatment for HIV, AZT, which he declined because he was in denial of the illness. He had no symptoms up until that point; his attitude was if there is nothing wrong do not fix it. With hindsight, that was possibly the right answer because people on

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AZT treatments were dying because of the side-effects. He was subsequently put on it, but not on the tremendous doses that were offered to him originally. I only know a limited amount of information about this period and when the treatment began because [ s ] did not tell anyone for a very long time. He did not tell us he had HIV until 1996. He did not tell anybody, in 1996 he was under the care of Dr Hanley; we knew something was wrong him at this point because he had lost his eyesight in 1994. We went to see him [ GRO-B ] and I remember he was talking about that he was going to see an optician because he could not read the millimetres on his tape measure anymore. He had an eye test and they prescribed him with very expensive glasses, he did not get them because they made no difference. Then he was driving home from a friend's house one night shortly afterwards and he went to overtake someone and there was something coming the other way. This frightened him because he could not actually see if something was coming from the other way or not, he managed to drive home to [ GRO-B ] and that was the last time he ever drove. The following morning, he could barely see at all. One eye, he can see a bit from the side and the other eye is not working at all now. Ultimately, he was offered a Council house in Edinburgh as he had to give up working and financially he was 'up the creek', so we supported him with this. He had a social worker in Edinburgh and he went to visit her in Edinburgh in 1995, he got on the train and he could not speak properly, the ticket collector thought he was drunk and left him. The next thing he remembered he woke up and the carriage was empty. He managed to stumble off the train and find a social worker and that is the last thing he remembers. He woke up 2 or 3 days later at the [ GRO-B ] Edinburgh, where he found out he had had a stroke. Because of this, we were aware that there were a lot of problems but we did not know the exact cause until the following year.

7. We were not involved as we didn't know for many years. But I believe upon speaking with him now, no adequate information was provided, he felt as though he didn't want to think about it, he thought it would go

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away, he was told he was infected and he was going to die, that was it. I was in contact with Dr Hanley asking him what is wrong and Dr Hanley was a bit vague with me and I thought he must know. Then by 1996, [s] had moved to Edinburgh. I phoned Dr Hanley the day after [s] finally revealed that he had HIV and I told him that [s] had told us last night that he been infected and he said "*Thank goodness for that, I have been nagging him for ages to tell you as he would not tell anyone.*" Then he said "*Now we can talk about it, I could not before because he told me not to*". So I asked him "*What is the prognosis?*", He said "*Well, he will need a lot of support; he's got weeks to live rather than years because he has progressive multifocal leukoencephalopathy, a viral infection of the brain.*" It is a virus and if you don't have HIV it doesn't do anything to you and if you have lost your immune system, you can be vulnerable to it. His friends helped him as much as they could but it was not long after that that he had told us.

8. I do not know what information was given to him, he may have been given information and he was too shocked to take it in. He was given a death sentence in that meeting and he did not tell anyone at all.
9. I do not know how the information was communicated because we were not party to that conversation for many years.
10. He was more concerned about the problems with his joints at that point. He thinks there was a talk about if you were in an intimate relationship with someone else and given advice, but I do not think he was at the time. I am not sure. I do not know what information was given to him about this; I received information from the Haemophilia Society in the 1980s and 1990's from their leaflets and their newsletters. Bear in mind, it was a big scare in the media, I was a blood donor for example and the blood donor service asked me to fill in a form. On that form, I was asked if I knew anyone who had received blood products, I said yes, my son, and as a result of that I was banned from giving blood. Later on, a couple of years later maybe, they looked again and said, "*Wait*

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*it's fine, you can give blood"* and I was reinstated but I missed a couple years.

### Section 3. Other Infections

11. The only thing he has received that is related to the infection is the cancer. He had to have a colostomy and that is a result of having a reduced immune function. He was diagnosed with this in the early 2000s. First of all, they thought it was anal cancer and it was treated and then it was found later on that it wasn't okay and he had to have a full colostomy which has had a huge impact on his life, particularly when you can't see. He gets psychological support at the Royal Infirmary but otherwise I find him quite stoic about things. He is not the sort of person who pours out his heart. The only thing he has told me when the correct support is not in place is that he is scared; he is frightened about what the future will hold for him because he cannot manage it all. He is under the care for the cancer at the GRO-B Edinburgh, under the care of Professor Dunlop and he now has an annual check-up with him. He was considered to be in remission from the cancer about five years ago, approximately.

### Section 4. Consent

12. I am pretty sure yes, he didn't know. He would have routine blood tests which for haemophiliacs is normal, I think it was just for the haemophilia that he had the tests. I do not think he was told about the risks of HIV but he would have given consent to the other blood tests as he would have thought it was routine. He would have had blood tests regularly but not for that specific thing.
13. Yes, further to the above if they did not give him the knowledge of the tests, he didn't give his consent.
14. No, he was given no information on this subject as far as I know.

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15. Yes. His records show from the bits we have uncovered that he was a part of a group of 16 haemophilic patients who were not being treated with commercial Factor VIII but were identified as a research group and they were infected with commercial Factor VIII. That is a serious allegation but it does appear this is what has happened and it was a research project. This was under Professor Ludlam. I do not think anyone knew the dangers, but there is evidence to suggest that he is part of the 16, most of whom are now dead. There is only one other person alive, it is known as the Edinburgh cohort.

### Section 5. Impact

16. It was devastating, it wrecked his life. He lost his job, he could not drive at the time he was told, he had a close girlfriend and he ended the relationship without telling her why. It has had a severe mental and physical effect on him. He cannot see, he has had a colostomy, he has had many intravenous shots, he is desperately needing support which is slowly being withdrawn. He is managing but it has had a severe effect on all sorts of things. He is on a cocktail of medication for the HIV and finds that the doctors will change the dosage of the medication suddenly and no one tells him why. He will end up taking a double dose because he cannot understand what is going on and no one explains the change. I would also note that his quality-of-life is very limited and he is very lonely as a result. He bought his house in 2002, however he has had a number of problems with social work over the years.
17. The further complications, which I have discussed above, are the blindness, the colostomy bag and the bowel cancer.
18. At the moment he has a series of checks but he is stable. He went along to see Dr Hayes and he was told that his liver is in pretty bad condition. Dr Hayes recommended that he undergo some treatment for the hepatitis C as a result. S decided that because he was not

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suffering from any symptoms at the time, he would not do anything with it because there was nothing, so why make it worse. He is also under the care of Professor Leen in the Infectious Diseases Unit at the Western General and Professor Leen also looked at his count and said, *"I don't agree with this, I don't think the liver count is as bad as what they're saying, I think you have done the right thing, just leave it and monitor"*. Then Harvoni came about and Professor Leen said to him *"This is an experimental treatment, it is a six-month course and you will feel grim but it might squelch the hepatitis C"*, so he did and it worked. He is now clear of the virus and has been for about four years, he was declared clear approximately 2014/2015.

19. [S] is on a tremendous cocktail of drugs now for the HIV, it is quite terrifying. For the Hepatitis C [S] was on Harvoni and prior to this, he was offered interferon and ribavirin. There is a whole list of drugs that he has been offered and that he takes now, but I don't have the list to hand, this will be something that [S] will have to provide you himself.
20. The only difficulty is that there is some strange rule that any pharmacy can only prescribe a set amount of pills, so no pharmacy can prescribe any more than 10 types of the pills per patient. So [S] gets some of his medication from the [GRO-B] pharmacy and then another from a local pharmacy who do the remaining. It is quite often there is a problem where he becomes dangerously low on one pill and he cannot access it. A lot of the issues have now been resolved but again, it's a constant battle. He is registered with [GRO-B] [GRO-B] Edinburgh. He has never met her; it is just a technicality. If anything is wrong on the HIV side he gets in touch with Professor Leen, if liver it's Professor Grant and they are not bad, you could phone them and they phone you back and give proper advice.
21. No, as far as I know, all the treatments he should be getting he is getting.



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22. He was not well at all when he was on the hepatitis C treatment, he was nauseous all the time and lethargic and generally not well, it is very debilitating, it was destroying his systems. It is practically a poison but it did get rid of the hepatitis C. It made him feel very grim, down and worse than he already did. He did go through this reasonably well considering and they did warn him that this could happen so he was prepared that. It was a six-month course and now he is considered clear.
23. Generally no, he has a regular dentist at the Royal Infirmary, they know his conditions. The only nasty thing is that on occasion, he has started getting spasms in his leg and when they take him to hospital and the doctors see all the prick marks in his veins, he is treated like a drug addict; people presume he is a drug addict. If they speak to him, he can explain it easily enough so it is not a big factor.
24. We did not know about [S]'s infection of HIV until 1996, [S] still maintains a policy of not telling people as in the past some people have divulged their infected status and there has been a certain amount of prejudice evident. He tells close friends but we do not tell people either. We have friends in the medical profession and they have put two and two together but they never ask us questions. We have had no stigma from our point of view and neither has [S] but risks are there, that is why he wants to be anonymous for his own statement.
25. Our daughter has a son and he is a haemophiliac. My granddaughter is possibly a carrier; we do not know because the medical profession will not tell her until she is of childbearing age. It is very likely that she is and that has an effect on that side of the family but the HIV does not have an effect, just the haemophilia. Our daughter worries that if something happens to us, that she will have to help [S] and look after him and she already has a family to look after so there are ramifications.

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26. It affected us, it made us sad. We are sad he is in this situation; we cannot do anything about it though. In the main, [S] is normally quite cheerful and positive given what has happened to him. He has his down moments but our time with him involves mainly helping him. I visit him once a week to help them with his financial affairs and I hold his power of attorney.
27. We moved here in 1979. [S] was bullied in [GRO-B] because he was a haemophiliac. The headmaster thought he was being kind and announced in assembly, "Here is [S] you will have to be careful with him as his blood does not clot", that was an invitation to the local bullies, he couldn't play sport, this followed him on to secondary school where he was bullied as well. There was an incident where [S] was challenged to a fight, which [S] was very worried about, but he hit this bully once in the nose and it knocked him out. After this, the other children left [S] alone and he had no more problems in school.
28. [S] had [GRO-B] and used to work for various people. He became very good at his job and when he was [GRO-B] he was working for someone who would [GRO-B] [GRO-B] [S] was the one who always went back to do [GRO-B] he was good at that. He was beginning to make a name for himself but then he lost his eyesight. [S] was employed by other people on an occasional basis and was self-employed towards the end of his working career. He had his own business.
29. There has not been an impact on my career. I retired in 1997, but it was nothing to do with [S]'s illness. The only impact on me is that I go through to Edinburgh once a week and assist him with his paperwork.

### Section 6. Treatment/Care/Support

30. [S]'s treatment was generally okay. People are generally helpful. The thing that is causing issues just now is issues with his care plan. [S]

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was in hospital for about a month, about a year ago. If you are in hospital for more than 28 days, the Council stop your care plan and it takes 90 days to reinstate it so you are stuck in hospital. You cannot get out of hospital if you have no care plan and they cannot initiate a care plan until you are out of hospital, so the only way we could get him out of hospital was to pay for private support. The private agencies have problems recruiting staff as well so there is competition to get the best carers. [S]s social worker has now been cut as well. His original social worker retired earlier this year and has not been replaced. The Council are backing out of support, they give you the money to buy your own support as it is cheaper for them to do this rather than hire their own staff.

31. Psychological support has been made available to [S] a psychologist at the Haematology Department at the Royal Infirmary, Edinburgh, speaks with him. It helps as he chats with her about everything and I think that this has been good. We have had no psychological support otherwise. I have never felt the need for psychological support myself, when these things happen I just get on with it and we managed it as a family. It is what life has thrown at us.

### Section 7. Financial Assistance

32. [S] was told about the financial support at the Royal Infirmary, Edinburgh, and I completed the forms on [S]s behalf, they all went through fine and standard. I cannot recall the exact dates when this happened.
33. [S] received £20,000 when he was first diagnosed and that was fine. Then the MacFarlane Trust was set up and he received a payment from them for the HIV. Then the Skipton Fund was set up to help people with HCV. Recently it was deemed that there have been so many different organisations involved with distributing the payments, that in Scotland these would be abolished and replaced with one agency distributing

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payments. [s] now receives a monthly amount from the NHS directly; he now gets just over £3000 a month.

34. We filled in the forms for [s] and it happened. We have had hiccups with the DWP, which I'll describe below, but we now have a letter from the NHS saying that this money is not taxable and should not be considered when means testing anything.
35. [s] has never had compensation, that money is almost under the table that he has received from the NHS, you can have the money, you can do what you like with it but you don't have to tell anybody about it. It is not means tested, the authorities know he is getting this, they are paying it. We had an incident years ago when we had to go for an interview at the DWP in the [GRO-B] and the officer involved said there is a problem. *"We do not understand why [s] is paying income tax; if he is on benefits, he should not be accruing enough money to pay income tax"*. I had already guessed what this meeting was going to be about so I said, *"Well, he is getting this extra money and you are not supposed to know about it"*, I then produced a letter from the funds at the time setting this out. The DWP's officers' response was; *"This looks very dodgy; we have never heard of this"*. I told him, *"Yes, it does look dodgy but that is the way it is"*. Paul Bateman, who was a solicitor at the MacFarlane Trust at the time, I contacted him for advice on the matter, he told me to tell the DWP to mind their own business. He said to me, *"The money is invisible to them and furthermore it should not be taxed at all, there is a mistake somewhere"*. Paul spoke to the DWP officer and about 10 minutes later, the DWP phoned me and said it is all sorted out now. The thing he has to do to keep this money separate is run a bank account, separate from his own benefits bank account to prevent the two crossing.
36. Only one precondition, when [s] was diagnosed with HIV he was given £20,000, he was told to sign a waiver against further claims. We have later on found out this was quite illegal. He thought at the time, if

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I only have a year to live, I might as well take the money and have a good time. The minute [S] signed this form though, the room was full of lawyers signing this and that.

37. At the moment the financial assistance is quite good for [S] however, he can't do much with it as he is so unwell. In the future, he will need a lot more support than now and he will be able to pay for it in the future if the assistance keeps going. So this will help them.

**Section 8. Other Issues**

38. The only thing I would like this Inquiry to do, that the Penrose Inquiry did not do is look at the Edinburgh Cohort. It looked as though [S] was part of the Edinburgh cohort and I want to know the truth. I do not believe it was a conspiracy experiment on my son but I believe it should be investigated and published, if anyone is guilty of any offences the people responsible should be prosecuted. We do not know what happened because it was so long ago but we feel it is now time to have the full truth.

Thompson Solicitors are recovering [S]'s medical records for which I will be given an opportunity to review, I am aware that elements of [S]'s records have been redacted.

**Statement of Truth**

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

Signed [GRO-B]

Dated 11 MARCH 2019