W1800234

ANONYMOUS

Witness Name: GRO-B
Statement No.: WITN2203001
Exhibits:
Dated: 27th February 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 1947 and my address is known to the Inquiry. I am living independently with family support nearby. I intend to speak about my hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together. My wife of 41 years, GRO-B, died 10 years ago from cancer. She was always fighting for justice for me and trying to find out what happened and sadly, she is not here to see justice. We struggled financially for years and when I finally

received money, she had already passed away and I am too ill to use the money for anything. I do GRO-B wish to be anonymous for this statement.

Section 2. How Infected

2. I have severe haemophilia A, which I was diagnosed with when I was about 2 years old.

3. I have received blood transfusions, plasma and then in about 1968 I went onto factor VIII along with my brothers, GRO-B: B1 GRO-B: B2 and GRO-B: B3 who also had haemophilia. I thought factor VIII was the greatest thing that had happened to our family. It was curing our bleeds, the quickest it had ever been, in our lives. Then about 10 years later this all happened all the infections started to come out.

4. I was first treated at Princes Margaret Rose in Edinburgh. When we had bad knees when we were there and they used to put a plaster cast on our legs and straighten them out. We were in pure agony and could not do anything about it. It took about 9 months for us to get better in those days, when there was no factor VIII. I would be in hospital for 9-10 months a year with bleeds in my knees and hips. We then moved to the Royal Infirmary, Lauriston Place, Edinburgh where I was treated by Dr Davis and then Dr Ludlam. There was a meeting one night in Edinburgh in 1984, which my brother, B1 and I went to, and someone asked if we could be infected by the blood we had been receiving. Dr Ludlam reassured us saying, *"No, no, you will be okay"* and then about 5 or 6 years later we all found out that we were infected. The hospital wanted to reassure us that nothing would happen to us, we were told that what had happened in other countries with the blood products, wouldn't happen to us. Dr Ludlam said that because Scotland was 'self-sufficient' we were safe. In the 1980's, Dr Ludlam put me onto the new factor VIII. He came in one day and said, *"I am going to change you onto something else."* I was then put on a different treatment to my brothers. I always wondered why, why did he

change me there and then? I think back and I think he was trying to keep me alive. I was in the hospital one day, just after that conversation took place and a doctor came to give me my factor VIII treatment. I said *"What's this?"*, he said *"factor VIII"* and I said *"You can't give me this."*. He replied "*Why not?*". I said "*I am not going to argue with you, just get Dr Ludlam down here right now.*" Dr Ludlam came and I said *"Look what he has given me"*. Dr Ludlam turned to the doctor and said "*Go back to Haematology, you don't give him this treatment, you give him this one*". I have always questioned this. My brothers and I all had severe haemophilia A, so I question why my brothers were all kept on the same treatment but mine was changed. B1 died of HIV and he and I used to use each other's factor VIII in the 1970's and 1980's, so how did I not get HIV? My opinion is that Dr Ludlam was trying to keep me alive for research.

5. In 1990, I was diagnosed with hepatitis C. I do not know when I received the infected blood products. Everything important in my medical notes is blacked out so I cannot get answers about this, I cannot see what blood products I received. When GRO-B and I were trying to get answers about my hepatitis, she contacted the hospital and asked them why my records were all blacked out and they said it was for security reasons. The updated medical records that have been recovered are still all blacked out so I have still not been able to get clear answers.

6. There was no conversation from Dr Ludlam about the risks around the factor VIII or anything regarding hepatitis C or HIV. He did not even tell my brother B1 that he had HIV for years. B1 found out when one of the doctors said to him, "*I can't go near you, you have HIV*". B1 went mental. He phoned GRO-B his wife, to come through and take him home until he calmed down. He had a bad bleed at the time but he just went home, he didn't care, and he sat in his house with no treatment from that day onwards. Over a year later the hospital got in touch with him and asked to him come in and told

him that his HIV was terminal and that was him. He had never drunk before but when he was told that, he must have drunk a bottle of whisky every day until he died; he was that depressed. He said, *"I'll kill myself or the HIV will kill me."* I do not know about when B3 was diagnosed because he fell out with our family when I was about 16 years old, but I know he did have hepatitis C and that it was the cause of his death. My brothers found out about their infections before I found out about my hepatitis C, around the early 1980's. We started getting factor VIII in the late 1960's, either 1968 or 1969. In the 1980's when it came out in America about people getting HIV, it was said it was to do with homosexuals so we were told we would all be ok. In the late 70"s or the early 80's, B1 wrote to Dr Owen and asked him to look into the situation that we were in. He tried to help B1 but then he got transferred to a lower position. That is what happened; the people above, tried to put a stop to us asking too many questions.

7. I found out I was infected in 1992 when they brought me into hospital. Professor Ludlam was there, as was Dr GRO-D a liver specialist. He said to me *"You have got hepatitis C in your system"* and I said "*How did I get that then?"*, and he replied *"You must have had a bad blood product."* I asked *"What is going to happen now?"* he said "*Before you go home, we will give you a couple of pills and we will get you back in again to discuss"*. Later on he clarified that *"It's in your system but it won't come out just now"*. I said *"What do you mean, it won't come out just now?"*. He said *"Well I can't tell you when it will come out"*. I asked when could this blow up to full hepatitis C and he said *"We have no idea"*. I went back 5 or 6 years later to see Professor GRO-D to discuss things and he told me that the hepatitis C in my system was lying there but he didn't not know when it would come out. He said, "*It could be any time, tomorrow morning, a week or a year"*. Now, every hospital I go to, they put down that I have hepatitis C because it is in my system but has been dormant. I was more worried about my brothers. I do not know about B3 as I was not in contact

with him since I was 16 years old. B2 passed away from a motorbike accident and not from any of this.

8. When I was diagnosed, Professor Ludlam would not tell me the amount of years that he had known I was infected for. I asked them *"When did I get infected?"* and they said *"We don't know that"* I walked out of there in rage. They were not giving any answers but they knew what was going on, they knew what was happening with us all. When the whole story came out, GRO-A and his wife GRO-A, came to see me, he had hepatitis C and HIV and he has a lot of problems. We were trying to find information out but we were not getting answers. I remember that we went to a demonstration in Edinburgh at the Scottish Parliament. During the demonstration, we were talking to the other haemophiliacs and the MPs, I stood up and shouted "*You are just waiting for us to all die*!" the Government and doctors knew about the infection well before we did, we were the last to know.

9. It was getting to the stage that we were told nothing. I went back about 5 years later to see Dr Ludlam and he denied that he had given me those two pills, it hadn't been put in the records you see. He denied it saying, "*I didn't give you two pills, what would I give you two pills for?*", I said "*For the hepatitis C!*". he kept denying it, and it ended up with me saying, "*I am not going to argue with you because you are just all a bunch of bloody liars, don't you ever get me back here again ever*" and I walked out of the door. Alison Richardson, she was a clinical psychologist at the Royal Infirmary Edinburgh. She was in the room that day and ran after me and said GRO-B *they are sitting there telling lies. You can remember this better than them*". She was my psychologist and B1 s psychologist for years; she has become a friend, a support network more than anything over the years.

10. GRO-B was told to separate everything, clean the toilet when it was used, wipe down the seat. It caused total panic and it made GRO-B OCD about everything. She was quite hyperactive about keeping everything clean. She also decided that we had to stop having sex. That went on for a long time and even though we had condoms, she refused to have sex with me. She did not want any of the risk. It put a lot of stress on her as she was very conscious of it.

11. I think it was all lies. I should have been told earlier, my brother, B1 should have been told about 5 or 6 years before the point when found out he had HIV, but no one told him until it slipped out. B1 only found out through that doctor in the ward that just said, *"You have HIV,* B1. Professor Ludlam should have told him himself, not a doctor just mentioning his HIV in passing. When B1 died, the funeral directors would not come in and lift him. They sent special people in to put him in a body bag, he was taken away and he was cremated. I was in hospital at the time he passed away and I ended up just walking out the hospital, but I did not get home in time. That was a shock to everybody. We could not mention HIV anywhere as there was such a stigma. I did not tell anyone about the hepatitis C. I have kept a diary which I only stopped about 10 years ago with all the details of everything that has happened. That is how I know I was given two pills from Dr Ludlam but when I said that to him he said I was wrong. In Edinburgh, they would not give answers.

Section 3. Other Infections

12. The doctors do not tell you everything. There could be anything in my system. They told B1 that he had Hepatitis C as well as HIV. The doctor told his wife that he also had hepatitis C, a long time after he died.

Section 4. Consent

13. I think Dr Ludlam has given me something to stop me getting HIV and active hepatitis C in my system; an antibody. He was using me as a guinea pig. I do not go often to the hospital now because I have my home treatment. A long time ago, you would have to phone an ambulance and tell them who we were and they would come and get you.

14. I was sharing factor VIII treatment with my brother B1 we would swap treatments, so how was I not infected? B1 could not understand it either. He thought they were treating me like a guinea pig to keep me alive. I am lucky to be alive, I am the only one alive now out of my brothers.

15. I do not know why I am not dead. I do not know how I got hepatitis C, nobody can tell me. I do not know how, but they made sure the virus remained dormant. In my opinion, they kept me alive for research.

Section 5. Impact

16. When I was diagnosed, GRO-B said, *"We need to do what we've been told to do"* So then we cleaned out the scullery, the bathroom was cleaned out and we separated our toothbrushes. When it came to sex, I got condoms for us and she said to me, "*What have you got those condoms for? You are not making love to me again. That is, it, finished, because you have it in your system. A condom might burst and cause me problems*". Our lives changed completely. GRO-B and I had a good sex life at one point but everything changed all at once. GRO-B was trying to do two jobs, there was no support. GRO-B suffered all the time I spent in the hospital. It was a nightmare. My sons GRO-B and GRO-Bs life was spent worrying about me and GRO-B and how we never had much money. I could not work. We applied for shoes for

the children, they were only young, but we could not afford new shoes.". We applied for all sorts of assistance but we were never recognised as a family who needed financial support, even given my medical circumstances. We needed the money years before it was made available. It is not the money I am bothered about now, I want the recognition of what has been done to my family and everyone. When my own boys were at school, they did not take a penny from us the whole time they went to school. There were a lot of sacrifices. When we got the financial assistance from the Government, we never kept the money, we just spent it on our boys. GRO-B and I both agreed that there was no point in giving us money now. GRO-B has now passed on and I am getting old.

17. I did not want to end up with a bleed and end up having to go to the hospital. When you are in the hospital, you had to wait 3 or 4 weeks before you settle down after you come back from treatment. When Dr Davis retired in the 1970s and Ludlam came, he was meant to be very clever. We all thought it was brilliant but it did not work out that way. When we had bleeds there was no point in asking for information, all the information was blanked out. My medical records have certain sections in them blanked out.

18. Sometimes I feel terrible and other days I feel fine but I am not sure if the cause of that is the hepatitis C. I get checks on my liver, which is currently fine. There was a slight complication where I was told my liver was scarred, there is a letter from the hospital in the past, saying this.

19. I think the doctors knew about the infections before they told people. The doctors gave the impression to GRO-B my brother's wife, that they knew of his infection years before the family was told.

20. The only treatment I have received is those 2 pills I was given in 1991. When I went back a month later, after I was given the pills, that

is when I was told that the hepatitis C was lying dormant. No other treatment was offered. Treatment does not matter now, I am 72, it will not make much of a difference to my life. I do not really go to hospital now, only if it is serious for a bad bleed.

21. The doctors and nurses never come to my bed without gloves on. When I was younger, the people who treated me used to wear red gloves.

22. I could not go out with children to play football or do activities with them, like every other child was able to do. When I was by myself, it did not bother me if I had a bleed but when I was married and my children came along, everything changed. I was scared to get a bleed because I had two children to take care of but when you are scared to get a bleed you always seem to get one.

23. My son GRO-B used to take me to hospital when I had bleeds. He was very conscious of my haemophilia. I get quite depressed in the hospital which means my family often visit me if I am admitted with a serious bleed.

24. Myself, my wife and my brother's wife all got called in to get tested for HIV which was an incredibly stressful time.

25. I was scared to go anywhere because of the stigma. It got around that B1 had HIV, after a story in the newspaper was published last year. People asked how I was and were very concerned about my welfare after this came out, but they did not want to say 'HIV' or 'bad blood' when asking about my wellbeing. Not to my face but to family friends. The community is now supportive though. In my mind the fear of stigma was the main thing, nothing directly happened. We did not tell anyone other than immediate family.

26. The family tried to find answers. Years ago, there was no help for GRO-B and I. We asked for help but never received any. Though, years later we got money, it was not at the time it was really needed.

Section 6. Treatment/Care/Support

27. When GRO-B and I asked for outside support, we did not get it. I think now, what is the point? What difference can this make now? We dealt with this ourselves and tried to get answers ourselves.

28. We did eventually get support from Alison the RIE psychologist, who would come and talk to us. She would come to the house to look after my welfare and also help with applying for financial assistance, she became a good family friend really.

Section 7. Financial Assistance

29. I found out about financial assistance from GRO-B B1 s wife, she was receiving money from the Macmillan Trust because B1 died early. I was unaware financial assistance was available to me while I was living. It was all through GRO-B I found out about financial support.

30. I received £16,000 from Skipton Fund in 2001. I received a further £20,000 from the Scottish Infected Blood Support Scheme, however, I gave that to my sons. Starting in November 2018, I now receive £1500 a month. I cannot go out or do anything, so what is the point in having it? These funds should have come before, it is crazy. Receiving the money at this age seems pointless; it should have been years earlier when I was raising my children, when it could have made a difference in all our lives. There is no apology, it is just money.

31. To apply for financial assistance, they sent the forms to me and I filled them in. When I was claiming for one type of financial assistance,

GRO-D, told me, *"There's no point in you claiming, for support. Your hepatitis C hasn't come out yet, it is just in your system"* and I said *"I thought I'd try"* but in the end I threw the form back in her face and didn't end up applying for this, what was the point when that was the response.

32. I think we should have had money years ago. I do not understand why I am getting it now, it is no use to me now. There was no point in me using the money when I received it, it can't make a huge difference in my life like it would have done, years ago when my sons were children. It leaves a bad taste in my sons, GRO-B and GRO-Bs, minds. They are always going to think about how their family did not have support when they were young, when it was needed.

Section 8. Other Issues

33. I have no other issues to raise for the Inquiry.

34. Thompsons Solicitors are recovering my medical records for which I will be given the opportunity to review.

Statement of Truth

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

Signed GRO-B

Dated 13/3/19