Witness Name: GRO-B
Statement No.: WITN2154001
Exhibits: None
Dated: 22nd November 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 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 1954. My address is known to the Inquiry. I am widowed and work for GRO-B GRO-B I intend to speak about my daughter GRO-B: D. In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and our lives together.

## Section 2. How Affected

2. My daughter D was born on GRO-B 1979. She was diagnosed as having acute lymphoblastic leukaemia on 5 December 1980. My daughter received a blood transfusion with infected blood on 6 December 1980. This was at Yorkhill hospital and was due to issues with the platelets of her blood levels. She was bruised and this may have had something to do with it. The consultant who was treating D was Dr Michael Willoughby. He did not warn of any risk. We were told that D had a 50-50 chance of survival.

3. D started exhibiting flulike symptoms when she was around 11 or 12. She had been on treatment for around three years at Yorkhill for her leukaemia as a baby. This involved chemotherapy and radiotherapy. I believe that my daughter found out when she was 15 that she had been infected. It would have been myself and her father that explained this to her. At the time she was treated by Glasgow Royal infirmary. She had ongoing check-ups following her childhood leukaemia. This was when she found out that she had hepatitis C.

4. Near Christmas of 1994 my daughter was still being seen at Yorkhill for check-ups. The doctor at the time was Dr Brenda Gibson. I recall Dr Gibson said something was happening with D blood. She wanted to do a liver biopsy. I recall she said something to the effect of having known of this for some time. My first reaction was to ask if it was HIV. Dr Gibson said no. I do not recall if she then said about hepatitis C. This meeting took place in a corridor at Yorkhill.

5. D had blood tests all the time. I believe that I would have signed a consent form for the liver biopsies she had but not for the blood tests. I do not recall the date of these biopsies beyond one having taken place in February of 1995. I believe that given the comment that was made by Dr Gibson they had known for some time about

something being wrong with D blood. They must have tested her without her consent or mine as I did not consent to a Hepatitis C test being done.

6. I do not believe that we were told at the time of the meeting before Christmas about D hepatitis. I recall going on a holiday that Christmas to Tenerife. I believe that it was several appointments after that that we were told about D having Hepatitis. It would have been a meeting some weeks after that meeting before Christmas that we were told. I believe that Dr Gibson told us. Within D medical records there is a letter from her GP, GRO-B which was dictated on 10 December 1994. It states the date of dictation on the letter. This was telling him that my daughter had tested positive as having hepatitis C. We were not made aware until shortly into the New Year of 1995. GRO-B was our GP at the time and he was based at GRO-B

7. In terms of symptoms I recall that there were times when it seemed as if D was absent. You would say something to her and she would not be paying attention. I believe this was a lack of being able to concentrate.

8. We were given no advice about managing the infection nor any advice about the risk of cross-contamination. Dr Gibson just said they would do a biopsy and go from there.

9. I don't remember when they said interferon treatment would be the next course of action. I believe it would have been shortly into the New Year of 1995, after she was diagnosed. I believe she went to the Glasgow Royal infirmary for the interferon treatment.

## Section 3. Other Infections

10. I am not aware of D having any other infections beyond her Hepatitis C diagnosis.

## Section 4. Consent

11. As I have advised, D required blood tests due to her having leukaemia as a child. I believe that they may have found out during this time or tested her during this time and may have simply not told us.

## Section 5. Impact

12. I don't remember when they said interferon treatment would be the next course of action. I believe it would have been shortly into the New Year of 1995, after she was diagnosed. I believe she went to the Glasgow Royal infirmary for the interferon treatment.

13. I recall that I took D to Glasgow Royal Infirmary in early 1995. This was an HIV clinic. D was not well, but this was a routine check up following her liver biopsy. I recall that I went to get a cup of tea for her but when I went back a doctor had taken her in. A young Swiss doctor, who I do not know the name of, had taken into a treatment room. She was asked by this Doctor how long she had been on the streets. He was implying that she was a prostitute. I recall my daughter was crying because of this question and this was extremely upsetting. She told him that she was infected because she had a blood transfusion when she had treatment for leukaemia. This Swiss doctor then found another doctor, who I do not know the name of, to continue with the check-up. If we required any help we had to go to the HIV clinic.

14. I believe interferon had been discussed that appointment and started shortly thereafter. I believe D was on interferon for a year and a half. It was during this that D was very unwell. She was very flulike and lost a lot of weight. She was sitting her O levels at the time and I recall that during this this time she went GRO-B GRO-B It was just before this she had her first epileptic seizure. This was completely out of the blue. She could not concentrate and was sent home GRO-B

15. Interferon had to be injected every day. After that year and a half were told that it had not worked.

16. Ribavirin was mentioned but that had not been licensed so we would have to wait 8 months. We sent D on holiday to my sister in GRO-B before she would have started any further treatment.

17. D was going down to Glasgow with a friend and was going to go to Glasgow Royal infirmary to start the new ribavirin treatment when she was about 16 or 17. It was when she was there as nurse, Sister Neilson, who told her that there had been a mistake, the interferon had worked and she was cleared of hepatitis C.

18. That same nurse was at a meeting for infected blood Inquiry two weeks ago. It was in her medical papers that she was in remission but no one had bothered to say. If it hadn't been picked up she could have been on the ribavirin treatment for no reason at all. At no point did we receive any official apology for this. I think we were mostly just relieved. It was a real rollercoaster.

19. I do feel inadequate information was given at the time. My husband had a heart attack not long after and I think this would have been in no small part due to D diagnosis and what went on after with the doctors.

20. My husband GRO-B We used to live over in GRO-B GRO-B

21. Additional information should and given earlier. Given the blood tests D had, Dr Gibson should have known.

22. The advice given about managing the infection consisted of telling us not to share toothbrushes.

23. My husband did a lot of research into D condition. He was GRO-B and when he was medically retired he became a GRO-B I am not sure when exactly this was.

24. I have two other children. I have younger son and daughter. My daughter's name is GRO-B and she was born 1977 and my son GRO-B was born on GRO-B 1983. We always talked openly in the house about D s condition. I remember having to explain to them why D had the symptoms that she did. I think it mostly affected GRO-B

25. I believe that we should have been told at that meeting before Christmas, which I think was on 10 December 1994, about D hepatitis. We should have been told what was going on. Dr Willoughby had left by that time and had gone to Australia. I believe that the communication was better when he was still there and was poor after he left. I believe that he left in the mid 80s and this was a huge loss. The communication was generally not good and got worse when we moved to GRO-B I believe we moved to GRO-B in 1991.

26. The whole time while D was ill we were trying to be normal for her and for our other children. There was a general lack of knowledge of hepatitis at the time when D was diagnosed. The world

knows so much more now. We felt it was a dirty thing that she had been infected by blood from prisoners. I believe D has knowledge of the batch of blood that was used on her. It was unbelievable.

27. I do have some anger about how the transfusions were not screened when they were screened in Europe.

28. I think we put down D symptoms initially to being the aftermath of chemotherapy. I had no knowledge of hepatitis C before my daughter's diagnosis. I'd heard a lot about HIV and AIDS in the 1980s. There was an advert around this period that I recall scared children and this was associated with hepatitis C. It detrimentally affected us all that D had leukaemia and then to be told should hepatitis C is teenager was huge blow. She was angry about that as well. It's very difficult to try and treat a different child as normal. I recall that D was very upset during this time. She felt dirty. I think she was aware of the connotations of hepatitis C in the press. We did not sit and talk about it all on a daily basis.

29. In terms of the stigma D did not want anyone to find out. We had to make sure the other two children would not tell anyone. GRO-B is a small place and we lived in a place called GRO-B at the time. No one else did find out. We did tell the school and the headmaster GRO-B was very good. I believe that the school nurse was also told. There was always the worry that people would find out.

30. I believe that D epilepsy may have been caused by the treatment she received. I believe that D epilepsy started getting much worse 4 years ago. At one stage she blacked out at the wheel while driving and is no longer allowed to drive. She has started having epileptic and non-epileptic seizures. She was diagnosed as suffering from these after spending a week at an epilepsy centre

called GRO-B I am unsure exactly when she went to there. I believe D was referred to this centre by a Dr Catherine Taylor. There has been mention of her being referred to a neuropsychologist, but there is a 3 year wait list from what I understand.

31. I believe that my daughter's condition had a huge impact on her school performance. She required a lot of time off and was a good student prior to this. We got tutors and she would work very hard. D wanted to go and be an occupational therapist after school. She did not get enough Highers. She went GRO-B and studied GRO-B She did this as an HNC and then an HND and thereafter the degree. I believe that this may have been with the GRO-B

32. Prior to this my daughter did try and study at GRO-B but she could not last beyond 6 months there. She still had her concentration problems at that time.

33. As I said my daughter was a good student. I believe the condition stifled her ambitions about becoming an operational health therapist. At one time she did want to be a nurse but she was told she couldn't be because of her condition. I believe that this was a big blow for her.

34. There was a nurse who treated her in the 80s when she had leukaemia. She is still a friend of D I believe. I do not know her name. She said that the fact D had survived her leukaemia was monumental.

35. I recall that there was a dentist called GRO-B GRO-B were D tried to be treated. D said she would never go back there after how she was treated personally. They said that because of D condition they would have to replace equipment. They said the entire place would need sterilised. They also said she would have to go when there were no other patients

around. This had been in the year 2005 I believe. D would have told me about this

36. In terms of interferon treatment I believe it was very difficult mentally and physically for my daughter. It is very difficult for her to go out and be seen with her sister who was normal. D was not well and looked unwell. She had hair coming out and lost a lot of confidence. This made her unlike her sister.

37. As a family it all had a big impact. It was a constant battle for my husband to get something better for D in terms of treatment. He was always pushing her to be normal. I don't think he ever accepted for diagnosis.

38. We just kept trying to keep everything as normal as possible. I learned allowances needed to be made for D This could impact on the other two children. GRO-B always said that D ruined every birthday she had. This is because D didn't know how to cope. She never wanted a birthday party of her own. She did not have a wide circle of friends. She only had a couple of good friends when she was younger. She did not try to make friends. I believe this is partially because she did not want people to find out that her condition. I believe that she was paranoid about people finding out. This Inquiry is huge and I'm surprised D wants to be involved as she did not want to be involved before. I believe that she wants answers and for the people involved to be honest.

39. In terms of my husband and I's social life it affected my husband more. He felt responsible and was practically on a crusade to try and make things better for D. My husband was not psychologically well and he wanted answers. Due to my husband's GRO-B GRO-B and he did in terms of D treatment. .

40. My work was never affected by D condition. I just put one foot in front of the other.

## Section 6. Treatment/Care/Support

41. No counselling was offered at any point after my daughter's diagnosis. I believe we would have benefited from counselling. It's just about having someone to talk to. I think D went to an art therapy thing of her own volition somewhere. I feel that as nothing was offered in terms of counselling, this was dealt with inadequately by the NHS.

## Section 7. Financial Assistance

42. In terms of financial assistance I believe that my husband GRO-B dealt with applying to the Caxton fund. I believe that we got our lump sum through Skipton about 10 years ago of £20,000. We received another £30,000 in the last two years. This is very helpful to D as she has epilepsy and has been on benefits. I have not been involved in any of the funding applications but I am not aware of any difficulties or how these applications were done. I believe my daughter gets heating paid for through Caxton. I am unsure, but I think my daughter may have got some money towards furniture as well. D recently applied for a new Scottish fund and she is waiting to hear back. I believe my daughter did not qualify before but if she does not get something she will be appealing.

43. Funds would have been very helpful to have when D was younger but we were dealing with her condition. Nothing was ever made available to the family specifically.

44. I recall my husband applied to the GRO-B and we were given of £20 which we had to pay back.

## Section 8. Other Issues

45. My daughter was not involved with the Penrose Inquiry, so I believe it is a huge deal for her that she has decided to be involved in this. I have nothing else to add.

### Statement of Truth

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

Signed GRO-B

Dated 5/6/19.