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Witness Name: **GRO-B**

Statement No.: WITN3540001

Exhibits: WITN3540002

Dated: October 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

I, **GRO-B** will say as follows:

Section 1: Introduction

1. My name is **GRO-B**. My date of birth is **GRO-B** 1968 and my address is **GRO-B**, Norfolk, **GRO-B**. I am married with four children, two of whom live with me and two of whom live away from me, one of which is married.
2. I am making this statement about my mother, **GRO-B**, who was born on **GRO-B** 1943 and was a Haemophiliac and she had Von Willebrand's Disease ("VWD").

Section 2: How Affected

3. From my early childhood, I can remember that she always had bruises. If she knocked herself even lightly, she would have a huge bruise to show for it. My

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mother was from Birmingham, and this is where our family lived, and where I grew up.

4. As far as I can remember, my mother had always bled profusely. I have always known that she had a bleeding disorder although I do not know when she was diagnosed with this. She began to tell us more about her condition when she moved to Norfolk, which I discuss later below.
5. I know that my mother and her four brothers all had the same bleeding disorder, which I presumed was VWD, although now I think about it, it may be that they all had haemophilia and my mother was the only one that had VWD.
6. I remember that when my brother was born in 1970, my mother did have a conversation with me about her condition. She nearly died because she lost so much blood. I do not know much more about the detail of this incident. I am aware she was given blood transfusions in 1979 for a varicose veins operation. It is possible she also had blood transfusions when my brother was born but I do not know this for certain. Her medical records confirm that she was treated with Factor VIII concentrate in 1979.
7. I cannot say whether she was warned about the risks of a blood transfusion before her operation in 1979 as I was unaware that she had even had it until I came across it in her medical records.
8. I do not remember my mother attending many hospital appointments and she never really spoke about her health. I think this was because she was embarrassed and she did not want us to worry about her. To my knowledge, she was not injecting herself with Factor VIII treatment.
9. I cannot recall that she ever said to me out loud that she had VWD. She had spoken to me about haemophilia and I had noticed that the letters "VWD" were

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written on a silver bracelet that she had. I was young at the time and did not appreciate what that meant.

10. I moved to Norfolk after I left college in approximately 1986. Both my nan and my mother's brother lived in Norfolk too and so I had family around me. Later, in the mid-1990s, my mother and father divorced and so my mother moved to Norfolk as well. My brother and I had to go to the hospital for blood tests before we moved to Norfolk, I presume to determine whether my brother had haemophilia and whether I was a carrier. These tests were negative.
11. After my mother moved to Norfolk she lived in a mobile home, first in GRO-B then in GRO-B I remember that she became more ill after she had moved to GRO-B Having said that, my mother had never really been a well woman. I cannot say that this is definitely because of the bleeding disorder that she had, but I can remember that she was always unwell in some way or another.
12. I do recall that my mother was diagnosed with diabetes at a later stage, and this and her weight became bigger health issues as she got older, in particular her weight gain caused significant back problems. I do not know exactly when she was diagnosed with her various health problems as she was always very reluctant to talk about them. I think she was diagnosed with diabetes before she moved to Norfolk, although I did not become aware of this until after she moved here. She did eventually become insulin dependent.
13. My mother always complained that she was not well enough to look after her grandchildren in the way that she wanted to and was often quite depressed about that. My family and I would go to see my mother at her home in GRO-B but we would not leave the children with her for more than a couple of hours as we were worried that her unstable health could cause her to collapse or become unwell and the children would be on their own.

Hepatitis C

14. I found out that my mother had Hepatitis C in the mid-1990s, a few years after she moved to Norfolk. She was in and out of hospital but she did not tell me anything about it. I cannot recall how I found out that she had Hepatitis C, I just recall that she kept all her things separate from anyone else's in the bathroom and was very picky about that. It may be that I simply put two and two together and worked out she had Hepatitis C myself, and she may not have told me directly at all.
15. My mother had always been touchy about the grandchildren sharing her drinks or touching her toothbrush. Now I know that was because of the Hepatitis C infection, suggesting doctors had told her about the risks of cross-infection at some point.
16. There are two letters I had found in my mother's medical records, dated 18 March and 19 March 2009 [WITN3540002]. These tell me that she was diagnosed "many years ago" at Queen Elizabeth Birmingham hospital ("QE"). The letters also explain that she was presenting with a bleeding problem at the age of 11 years old following a tonsillectomy. This required a blood transfusion. It is also apparent that 38 years ago she was given blood concentrate for a dental extraction and other procedures, including incisions were undertaken with Factor VIII cover. She has been a diabetic since at least 2001, and the letters confirm she was started on Metformin and then Insulin to manage her diabetes. The letter does refer to a test for Hepatitis C being positive, and she was diagnosed with genotype 1B following a blood transfusion.
17. There is a lot of information in my mother's medical records about her illnesses that I have only now become aware of because, as I have said above, she rarely spoke to me about her health problems.

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18. Some years later my mother began to suffer from chronic itching and it was at that point that she began to let on a bit about her Hepatitis C diagnosis. I do not know when she was diagnosed with this infection because she never told me. I have seen some medical records which refer to the chronic itching in 2009. In my memory, she had had it for a long time before that. I believe that it had been a persistent problem since she lived at GRO-B. I think my youngest two children were at school at the time.
19. At first we thought the children had nits and this was what was causing her itching. I checked their heads frequently and there was nothing there. She would spray herself head to toe with flea spray because the itching was so bad. We had the Environmental Health Department around, and she also had her home cleaned frequently. It was spotless. On three occasions she also had flea bombs carried out at the house because she was adamant that there was something there. The itching started on her leg and she would make herself bleed from scratching. It drove her insane.
20. Eventually, I took her to the doctor. She was sent for a liver biopsy in the mid-2000s I believe, and it became apparent that the itching was caused by liver cirrhosis.
21. After her diagnosis, she would not let me go to the hospital appointments with her. There were some that she missed which was obvious from her medical records, and as a result I do not know what she was told following the biopsy and what the doctors were doing about it. The biopsy itself was an "okay" process. Neither of us knew that the itching problems were due to her liver failing. The doctors kept giving her topical creams and nothing worked. Most of the bad episodes I remember were in the last few years of her life.

Deterioration of my mother's health

22. She spent a lot of time in hospital before Christmas 2012, and we lived in **GRO-B** **GRO-B** at the time. I recall that, by then, she was walking with a walking frame for support. I had said I would take her for lunch one day. She came over to our house and had forgotten her walking frame in the car. She was at the end of the driveway and did get her walking frame out of the car but then tripped over it as she was walking. She fell flat on her front and broke both arms.
23. I remember that she was struggling to breathe after she fell and so we called 999. A neighbour put a cushion under her head. She cried and screamed so much, I was embarrassed for her. She was a big lady and the paramedics could not move her and so they put an airbag under her to pump it up and then lift. She was taken to hospital and her health went downhill from there.
24. From around November 2012, which was when she fell, she spent a fair amount of time in hospital. She went into hospital again before Christmas 2012. Her breathing had got worse so she was placed on an asthma pump. The hospital said at the time that she was struggling to breathe and so they were not prepared to let her out of hospital until she had a better place to live than the mobile home that she was in. In my view the heating was fine in her home, but the hospital were not happy about it. I do not think she was ever formerly diagnosed with COPD, but breathing was certainly a problem for her.
25. Eventually we found her a place in a warden controlled maisonette. Everything was alarmed and there were pull cords in every room. I emptied her mobile home and bought everything new to ensure that there was no contamination from the products in the old house. We bought her a mobile chair which had buttons to press to move into position. We also bought her a new cooker which arrived two days before Christmas.

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26. She was pleased with her new place. It was very near to my house and my girls could just walk over to see her. The grounds were perfect for picnics in the summer. She had had all these ideas in her head about how perfect things would be living so close to us. I remember when she came out of hospital that I looked at her and did not recognise her. She looked like she had aged ten years.
27. Her health was not great over Christmas 2012. I would always cook for her and take food over to her. However, it became too hard for me to take it by Christmas. Emotionally I struggled to see her in such poor health so I would cook the food and my husband would take it over to her.
28. One day, during the Christmas period, he had come home having taken food over to her and said to me, "*you had better come over*". We went to her maisonette and she was lying in bed. I would say she was completely, "*away with the fairies*." I do not think she recognised me.
29. I called 999 and she was taken into hospital again. This was the James Paget Hospital, Gorleston, Norfolk. I believe that at the time her illness was a combination of her condition and the medication that she was being given. She had been prescribed liquid morphine and was probably taking too much. She was supposed to have a carer to manage medication however the settings for the medication were by the side of her bed and therefore within easy reach. A combination of her diabetes medication and various painkillers obviously affected her.
30. Through that Christmas period I went back and forth to hospital two or three times a day. She remained in hospital until early GRO-B 2013. The final time I went in to hospital was on the Thursday before Mothering Sunday. For some reason I had decided to take a card and gift for her early, and my daughter did the same.

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31. I recall that when I arrived she was out of bed and in an armchair. She had just been fed jelly because she did not want to eat that much. She was really bright and knew we were there. She was so happy with her gifts, one of which was a bracelet, and we had a laugh and a joke. It was a lovely afternoon.
32. When we were leaving, she pointed at her bracelet and said, "*I better take this off, it might get in the way*". I dismissed it and said the nurses would take care of it. She kept the bracelet on.
33. We went to see her again on Friday and she had no clue who we were. I do not even think she realised we were there. On Saturday, the hospital called me in and said that my mother had been ill during the night and that I should come and see her today. I remember that my husband was on a course and I had the children with me at the time.
34. I got to the hospital and a consultant asked me to sign forms when I got there. I think it was an end of life care plan. I refused to sign the documents and said that if something could be done then they should do it. He told me that I needed to read this leaflet about placing my mother on a drip with an auto release pain killer. Her kidneys and everything else had failed. He made it clear that there was very little they could do now. I signed the papers and she was given morphine. I sat with her all day and tried to laugh and joke with her, but I do not think she knew who I was. She died that night, on GRO-B 2013.

Section 3: Other Infections

35. I cannot answer questions about other infections she may have had as she did not tell me about these at any time. This information will be contained in her medical records.

Section 4: Consent

36. I cannot answer questions about consent or treatment without my mother's knowledge as we knew very little about her illness.

Section 5: Impact

37. I remember that my mother's mental health condition was awful. When she lived at GRO-B she always seemed ill and very depressed. I do not know if this was because of her Hepatitis C infection, but it is possible.
38. To improve my mother's mood we often arranged to go to see her with the children, and take her out for the day. Unfortunately, this soon became an issue as well as she could not walk far and would become short of breath. I offered to get her a Red Cross wheelchair which she initially refused, but eventually relented.
39. One day we went for a 15 minute drive, parked the car and took a wheelchair out. It was not electric and unfortunately I could not push it. It was one of the worst days because I had wanted to take my mother out and I could not do it. It was a basic chair and she was a big lady. She was fine about this and waited in the car for me to finish some shopping, but I felt terrible.
40. Soon afterwards, I bought her a mobility scooter and this gave her a little independence. We also bought her a car with a flat back so that she could go out on her own and transport the mobility scooter with her. I secured a disabled badge for her and her local supermarket, gave her her own key to collect a shopping scooter because they knew her well.

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41. I have discussed above how I struggled to watch her health deteriorate in the period before her death. My husband would take food to her every day because I just could not bring myself to see her like that.
42. I do not know what prompted me to go to see my mother on the Thursday before she died but I have always been glad that I did spend the day with her, because she looked so well even if it was short-lived.
43. I left the hospital the night she died and it took a few days to sink in. Eventually I had to start planning her funeral. We were living in [GRO-B] at the time and I wanted a funeral director from [GRO-B] to deal with the funeral. I think this was because I knew she would have a longer ride from [GRO-B] to the funeral home.
44. At first I was undecided if I wanted to see her in her coffin. My husband did not want me to as he thought I would really struggle with it. I remember that a man from the funeral home came around to discuss the funeral. I told him that I had not made up my mind yet about whether I wanted to see her. He replied, *"I can help you with that, we cannot allow you to see her anyway"*. I remember that he said to me, *"you cannot see her because she is infectious"*. I was furious and had no idea what he was talking about.
45. I had been struggling with that decision but then someone took that decision away from me, and this upset me very much. There were earrings and other things that I wanted her to wear. The gentleman from the funeral home said that he could make sure that she had those with her. I do not know if he actually did this. I always wanted to know if she had been wearing her Mother's Day bracelet, however I had no way of knowing. The gentleman from the funeral home said they could not treat her body as usual because of an infection, which I now presume was Hepatitis C. He only allowed us to open the top part of the

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casket, nothing more. After this conversation I knew I could not see her in that state and so I do not know how she looked before she was cremated.

46. When my mother's body was collected from the hospital, the papers said that she was infectious. To me it was just wrong that they had labelled her this way. We were with her until her last breath and I had seen the medical staff undertake various procedures and care for her. I cannot understand how they did this if she was "infectious". My mother's funeral was the first experience I had of her "*infection*" being an issue.

Stigma

47. I believe that the reason my mother never told us about her infection was the stigma that she thought it would bring. I do not think that stigma would have come from others because people did not know about her illness.
48. I do not tell people about my mother's Hepatitis C because she did not. Aside from the neighbours that I have spoken about later in this statement, I do not think anybody else could really relate to the situation that she was living with.

Impact on me and my family

49. The impact of my mother's illness and death on me was somewhat delayed. I did not understand about her having Hepatitis C until much later because she did not tell us anything about it. Obviously, the infection shortened her life. She has four grandchildren who loved her to bits and she now has four great grandchildren that she never met. Contaminated blood stole this from her.
50. My daughter, GRO-B, received her exam results recently and they were very good. She began crying because her nan was not here for her to tell her about this. She still misses her and I do too. She missed my daughter's wedding and I know many do, but this is what our family had lost. My children get upset every day. My mom's life was taken away and this someone's fault.

Section 6: Treatment/Care/Support

51. I have never been offered any counselling and I do not know if my mother was. I do not think she would have taken it had it been offered to her, but I cannot say.
52. I know that for dental treatment, my mother had to go to James Paget Hospital. I do not know if this was because of the VWD or the Hepatitis C. I do not know if she ever encountered any obstacles in her treatment. She never told us.

Section 7: Financial Assistance

53. My mother had worked for many years in domestic care at the local hospital. She stopped when I was quite young because she was constantly ill.
54. I recall that it was my mother's GP that told her to apply to the Skipton Fund. She was living off her pension and she was keen to obtain the money that he had told her about. I remember the doctor helped her with her first set of applications, and the second set were completed with our help. It was when we were helping her fill the forms in that she said *"this is because of the infected blood"*.
55. The process of applying to the Skipton Fund itself was fairly easy. There was one pay-out which she was given without much discussion. I think that was when she bought the mobility scooter. My mother was quite good with managing her money, and better in the later years than when she was newly married.
56. It was not until after the payment was made by the Skipton Fund that she found out about the liver cirrhosis. A Stage one payment was given to her for the

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Hepatitis C diagnosis. She then had the biopsy and was diagnosed with liver cirrhosis at which point she made the application for the Stage two payment.

57. After the biopsy, when she made the application for the Stage two payment from the Skipton Fund, I remember that there were options when filling the form in, either to receive payment as a lump sum or on a monthly basis until death. At that point it was not even in my head that she might die.
58. I believe my mother received £50,000 and then monthly payments thereafter, in 2012 and onwards. She died about a year later. It is sad that she did not have the time to enjoy any of the money that was given to her.
59. I did not think there was anything more to her illness after we had dealt with The Skipton Fund. She died soon afterwards and that was the end of the matter for us. I did not realise the depths of this scandal until I saw it on the news and began reading into it.
60. There is a couple who live a few doors away from me who lost their son and have been going through the same process for seven years. It was when my neighbour began to tell us about his son that I knew my mother had suffered from the same illness. We have been helping each other out through this process. I have been in touch with the EIBSS as a result.

Section 8: Other Information

61. At the time, I did not realise the scale of the contaminated blood scandal. I thought she had just got unlucky and had had a blood transfusion with a bad batch. It was only when I saw something on the news about people that were given blood transfusions within a certain timeframe that I looked into it in more detail.

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62. It does not matter what the Inquiry do now as it will not bring my mother back. It is not going to make mine or my children's lives easier or fix our loss. I do hope that there is some admission that what happened should never have happened and will never happen again.
63. It would help my children continue her memory if any compensation were to be paid out. After all, this is the least they could do.

Statement of Truth

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

Signed:

GRO-B

Dated:

20/10/20