Witness Name: GRO-B
Statement No: W3927
Exhibits: WITN3927002
Dated: 23rd June 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 February 2020.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1968. I reside at GRO-B Northern Ireland, GRO-B I married my husband in 1988, and I have three children and three grandchildren. My eldest sister is GRO-B:S GRO-B **(See WITN0096001)** and my mother is GRO-B (**See WITN3544001**). They have provided statements to the Inquiry. I am currently a housewife.

2. I intend to speak about my Von Willebrand's Disease. I also intend to speak about my sister S infection with Hepatitis C ("HCV"), after she received contaminated blood product in 1983 at the age of eleven years old. In particular, the nature of how she had learnt about her infection, how the illness had affected her and our family thereafter, and the treatment she had received.

3. I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I wish to seek anonymity due to my sister's wishes.

4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Affected

6. Around 1985, when I was aged approximately seventeen years old, I visited Dr Mayne at the Royal Victoria Hospital, 274 Grosvenor Road, Belfast, BT12 6BA, for a face to face consultation. She was treating me for another complaint concerning a cyst on my ovary. During the consultation I had a conversation with Dr Mayne about the severity of my bleeds when I sustained an injury. As a result, I was sent to undergo three blood tests and a bleeding time-test.

7. When the results returned after a few weeks, I was told that I had an extended bleeding time of over sixteen minutes. Also, that I had a high platelet deficiency. As a consequence of these results, I was diagnosed with Von Willebrand's Disease, type one.

8. I have exhibited my Special Medical Card (Haemorrhagic States), which was issued on behalf of the Health Departments of the United Kingdom (**WITN3927002**). This is an information card which is issued to all patients registered with bleeding disorders, in case of emergency or trauma.

9. Before this point, I was unaware that I had Von Willebrand's. However, in retrospect, there are a number of times where I would bleed profusely after having an operation.

10. For instance, in 1975, when I was aged seven years old, I had my tonsils taken out at the Royal Belfast Hospital, 274 Grosvenor Road, Belfast under Dr Mayne. After the operation, I can recall being placed on a ward and being surrounded by children who were very unwell and kept for 7 days.

11. As I was in hospital for quite a while, I tried to make friends with the other children in the ward. I took a distinct liking to another child in the bed opposite me, and we used to play tag running around the ward when we were well enough. I used to run around chasing the other child with a drip in my arm, and pretending it was a scene out of Doctor Who.

12. I have since learnt that I was placed on a ward after having my tonsils taken out, as a preventative measure in case I had Von Willebrand's Disease. This is despite the fact that I had not been tested for the presence of Von Willebrand's before this point.

13. Also, in 1984 when I was aged sixteen years old, I was placed on the ladies' ward at Royal Victoria Hospital, Belfast, as after examination the doctors believed I was pregnant. Instead, after further tests, I was diagnosed with cysts on my ovaries as mentioned earlier. Here, I was placed on a drip.

14. Furthermore, in 1988 when I was aged twenty years old, I had my four wisdom teeth taken out at the Royal Victoria Hospital, Belfast. As this was after my Von Willebrand's diagnosis in 1985, I was kept on the ward for three days.

15. I would now like to discuss my sister S HCV infection.

16. Growing up, myself and S were very close. We did everything together. We had a very close bond. Perhaps it was due to the fact that we could not really mix with the other children. The potential for a bleed was always in the

background. There was no playing with bikes or climbing or games where there may be a risk of injury. We always had to be cautious. To an extent we missed out on the normal childhood interactions but for us being just the two of us was the norm and we were happy enough.

17 [redacted] was diagnosed with Von Willebrands Disease at the Royal Victoria Hospital, Belfast, by Dr Elisabeth E Mayne in 1972, six months after her birth.

18. Twenty-one years later, in 1993, my mother and [redacted] were at the Royal Victoria Hospital on their way to [redacted] appointment with Dr Mayne when she stopped to talk to them in the corridor and asked how [redacted] was. When [redacted] outlined her problem, much to their surprise Dr Mayne replied with something along the lines of; "Oh, if it's not your ME, it must be your Hepatitis C". Later that day, my mother and [redacted] eturned home and mum and dad told me of her diagnosis. I was completely devastated.

19. As far as I am aware, [redacted] nd my parents were not given any information about her diagnosis, which would be considered adequate enough for her or our family to understand and manage her infection. Instead, Dr Mayne simply said that the virus was nothing to worry about. I was not present at the time, so I cannot say as a matter of fact what exact information was relayed to [redacted] and my mother.

20. I also do not believe that any information was provided to us about the risks of others being infected as a result of her infection. I certainly was not made aware of any precautions.

21. We became more aware as a family of the seriousness of [redacted] HCV when my mother, and [redacted] attended a number of Northern Ireland Haemophilia Society Conferences. These took place in Coventry and York. I also attended with them at Killyhevlin Lakeside Hotel & Lodges, Dublin Road, Killyhevlin, Enniskillen, around 1995.

22. It was the conference at Killyhevlin Lakeside Hotel & Lodges, where we first realised just how much of an impact HCV has on the body, and how likely it was to have a cumulative effect on S in the future.

23. We were originally led to believe that S was infected with HCV as a result of a blood transfusion she received in 1989 at the age of seventeen years old, after having her tonsils removed.

24. However, since the Infected Blood Inquiry commenced, we have found out that the clotting factor that was given to S for a suspected appendicitis in 1983, when she was aged eleven years old, was contaminated with HCV. It is this blood product which we now believe is the cause of her infection.

25. My family were also not provided with any information or advice beforehand about the risks of being exposed to infection associated with the blood products she received. This is absolutely disgusting.

26. I do believe that information about S HCV infection should have been provided to S and our parents at an earlier point in time. They were told in such an off the cuff or throw away manner in 1993 by Dr Mayne, about the blood test S had undergone which showed that she had tested positive for the presence of HCV. This demonstrates that Dr Mayne was aware of her infection for a period of time before this point, and had not told anyone this news. How could she keep this to herself? Why was S not told?

27. The way in which S and my mother were told about S HCV was absolutely disgusting. They were told by Dr Mayne so blatantly in a hospital corridor. There was no privacy. There was no decency. The whole world and their friends could have overheard her diagnosis. For such a sensitive piece of information to be relayed to a patient in this way, which would have life-long lasting effects on both her health and the people around her, is wrong.

Section 3. Other Infections.

28. Alongside HCV, we were led to believe that S had also received a batch of blood product which was contaminated with CJD. We only found out about this from the blood database in 2020.

29. In 1998, my mother and myself received a letter from Dr Frank Jones, which had stated that we were both at risk of having contracted vCJD. This was due to the blood transfusions or blood products we had received as treatment for our Von Willebrand's Disease in the past. We also received a similar letter in 2006. Unfortunately, I no longer have a copy of either letter.

30. At the time, vCJD was constantly in the news. Articles had shown the true extent of the disease and the effect it would have an on the human body. I had a fear that it was not only me who was going to die with pain and suffering, but also my mother and sister.

31. In my sister S statement S it states that she has also received the same letter in standard format from Dr Frank Jones, which notified her that she may have received a batch of blood with was contaminated with CJD.

32. However, since the point of making her statement, I believe S has now confirmed the fact that she did receive blood products from a batch contaminated with vCJD.

Section 4. Consent

33. In 1983 when S was given clotting factor for a suspected appendicitis at Royal Victoria Hospital for sick children, she was only eleven years old. Therefore, as a child, she could not have provided consent herself in order to receive this treatment. Consent should have come from my parents.

34. However, at the time my sister was given her treatment, my mother and father were at our home collecting a number of S things. They were not able to provide consent before it was administered. When she returned to the Hospital, I know from my mummy that she was shocked to see that S was attached to a drip.

35. I am so cross that the doctors and nurses who were overseeing S care took it upon themselves to administer blood product without my mother or father having been present or aware. It was the first time she had been given blood product, and she was only a young child. She was all alone and must have been so worried.

36. I cannot say whether the blood test which was taken prior to 1993, which had made Dr Mayne aware of S HCV, was made with S knowledge. If S had been made aware of the reason for this blood test having been carried out and had been given adequate or full information surrounding the purpose of the test then she would not have been in such a state of shock when diagnosed with HCV.

37. I also cannot say whether S was treated or tested for the purposes of research. If she had, then I was not made aware of this.

38. As far as I am aware, I was never tested for the presence of HCV or HIV. If I have been, then I am not aware of the result.

Section 5. Impact.

Mental/Physical Effect.

39. S HCV has had such a physical effect on her body. She is constantly tired and fatigued, has continual pain all over her body, and suffers with insomnia. This adds to the strain she feels on a day to day basis as she struggles to walk and do everyday tasks.

40. She also experiences severe brain fog. Whenever we see each other, we talk to her about everyday things and sometimes she becomes pale and dazed. When she comes around, it is as if she remembers nothing which was said previously. Her brain fog is only getting worse and worse over the years.

41. Her HCV has also caused her immune system to become so low, to the point that she now experiences infection after infection. This has a knock-on effect as the weakened body becomes even more susceptible to the next bug to come along.

42. S has fought hard to stay healthy. She also experiences severe break outs on her skin, and ulcers in her mouth which are painful and uncomfortable. She is on a large amount of medication, and cannot lose weight. It is so upsetting to see my own flesh and blood trying to live like this.

43. Alongside her physical effects, S suffered with her mental health as a result of being diagnosed with HCV. She regularly attends S, a psychiatric hospital, to help with her severe depression and post-traumatic stress disorder. She has had a life from hell from such a young age so it is no wonder.

Treatment

44. In 1994, a year after her diagnosis, S was told that she could start treatment to clear her HCV. She was advised to start on a course of interferon, but as this drug came with a possible side effect of infertility, she wanted to wait. S had just got married, and wanted to try for a baby before she started on her treatment, just in case she was unable to have children after that point.

45. I knew how desperate my sister was to have both a child and to start her treatment so she could clear her infection as quick as she could. Therefore, I

offered to be her surrogate so that she could do both. I would do anything for my sister. Being a surrogate felt like a small price to pay to see her happy.

46. Two years later, in 1996, S had a liver biopsy. She was told that she had chronic HCV, so she decided to start her first course of treatment for her HCV. This was a six-month course of Interferon, where she would inject Interferon into her stomach three times a week over the course of each week.

47. As much as starting her treatment was the best thing she could have ever done, it came with side effects which made the length of her course unbearable. Unbearable for her physically, but also unbearable for us to watch.

48. S spend the length of her treatment lying under a duvet shivering as she was so cold, despite the heating being constantly on full blast. She was also sore all over her body, she was constantly vomiting due to the nausea she experienced, and she had Migraines which made her both blind and unstable due to the pain.

49. After all that she had gone through, and the heightened side effects she experienced, the real kick in the gut, was that her treatment did not work. She had not been cleared of her HCV. The virus was still very much alive in her body. It was a crushing blow for the whole family.

50. Then, after eighteen months, S started on her second course of treatment in 1998. This was a six-month course of Interferon and Ribavirin, where she would inject Interferon three times a week, and ingest Ribavirin in tablet form six times a day from what I recall.

51. Not too dissimilar to her first course of treatment, S experienced severe side effects. In essence, it was back to months of hell for her again. We prayed that she would get better, but she suffered even more with her second treatment. She developed insomnia, which meant she was constantly tired and fatigued. She also developed a skin irritation where she had rashes all over her body. This meant she was constantly in discomfort.

52. After several weeks, S had undergone a blood test to determine the presence of HCV in her blood, to see if her treatment was working. When the results returned, it had shown that her treatment was working, but it had not quite cleared.

53. A number of weeks later, S had undergone the same test as previously. When the results returned, it had shown that the levels of her HCV had gone into remission.

54. Thankfully, after six-months, S was still in remission. We could not have been happier for her. She could finally move on, and start living her life.

55. I cannot say that S faced any difficulties or obstacles accessing treatment. A year after her diagnosis in 1993, she was offered her first course of treatment. However, as she wanted to have a child before commencing this, she waited until 1998. If she did experience any obstacles then I was not made aware of this fact.

56. I also do not believe that there are treatments which ought to have been available to S but were not.

57. With S being PCR negative, I thought everything with regards to S health would go back to normal. However, it soon became apparent this would not be the case. Her treatment had left her with a list of long-term side effects she would have to deal with. It is devastating that not only did she suffer whilst she still had HCV, but was destined to do so for such a long time thereafter.

58. To name a few, S long-term side effects includes the development of Fibromyalgia, a condition that causes widespread pain and extreme tiredness which she still suffers to this day. She has also developed paralysis of the bowel, arthritis, and problems with her kidney, that left her with life-long catheterisation.

59. To this day, S is still extremely debilitated. She is now losing her eyesight. This is something we have only found out recently is a side effect of her treatment with Ribavirin or Interferon.

Impact

60. Whilst we do not believe that S HCV affected her growing up, in retrospect, she did not have much of a social life as she was tired all the time. My parents used to believe that this was just her exaggerating her tiredness, or, that she did not want to get out of bed. They could not have suspected that this was anything associated with HCV, as it was not known at the time.

61. When she started work, she had to take so many days sick and used her holiday days to do so. Eventually, she had to leave her job as a book binder as her health was just too bad for her to continue. This affected her self-esteem, not being able to provide and to earn.

62. From the point of S having been diagnosed with having HCV in 1993, or not long after, her first husband completely switched with regards to his personality. Over time, he started to treat her badly. After work, he would come home, and become abusive and vile towards her. However, as she was so unwell with her HCV, she did not have the energy to fight back.

63. He would say things to her along the lines of "you are not ill, you are making it up," "you are just lazy," or "you are attention seeking." He also accused her of trying to give the virus to him and their son, a despicable thing to say to any mum and that she was not fulfilling her marital duties. This in essence, meant GRO-C - probably his main gripe and the reason for the other nastiness.

64. After S diagnosis, her husband told all of his friends and their neighbours about her HCV. As they lived in a small village with a small community, news and gossip spreads so easily and almost like wildfire. Naturally when stories are passed person to person, they can be manipulated

and exaggerated. It was not long until rumours started to circulate around the community that S was an alcoholic with liver cirrhosis and AIDS.

65. This was heart-breaking as S was being judged by everyone around her for having HCV, which was unfairly given to her through treatment with a blood product. It destroyed her life.

66. After a while, S husband finally left the family home after numerous affairs, abuse and ridicule. S was granted a divorce not long after, and got custody of her son GRO-B

67. S and her son GRO-B came to live near my mother and myself not long after. She was still very unwell but she knew she needed to be closer to us so that we could help her when she needed it. GRO-B became very much a part of my home which I shared with my husband and three children. We gave him a nickname of "poppy" as he popped in and out of the home all the time.

68. In 2010, S remarried. This time to a man named GRO-B who was amazing. She told him all about her illness and the associated risks. He totally accepted that everyone has a past, and that she was PCR negative. He took S and GRO-B under his wing and she has never been happier.

69. Not long after they were married, S became pregnant quickly. She gave birth to her second son GRO-B in 2011, at the Royal Victoria Hospital, Maternity Ward, Grosvenor Road, Belfast.

70. S infection had a great impact on myself and my family. When we found out about her HCV, it was a complete shock. However, the way in which we found out about her infection was disgusting. I am devastated that one of my family members can be treated in the way she was.

71. Ever since I became fully aware of her diagnosis and the real effect it would have on her life, I have cried a lot. I feel so helpless and want to do more than I can. I see how badly my sister is suffering and this is hard to comprehend.

72. I have a constant fear of losing my sister and consequently my new nephew, both of whom I love very much.

73. We have always put on a brave face. My mother, my father, and myself would always try to convince S that she would beat this infection. However, we could see it in her face that she had given up trying. In our hearts, although we put on a brave face, we were broken too. I would do anything to see her get better.

74. Around this time, because of what was going on with S and how it was impacting on my family, I was diagnosed with depression. I have been on medication for my depression since that time.

75. The impact on myself has had a knock-on effect on my daughter. She has since been tested for Von Willebrand's Disease. When the results came back, we were told that she had "borderline" Von Willebrand's, but they would not put that label on her as it is not that severe. In my heart of hearts, I know she is just like me, as she haemorrhages all the time.

76. Whilst giving birth to her first child, she haemorrhaged so badly, that she lost three pints of blood. However, because of what has happened to her Aunt S in the past, she refuses to accept blood transfusions.

77. I left work in 1994, which was only one year after S HCV diagnosis, I have experienced losses which are difficult to quantify as a result of her diagnosis. There was the financial impact I suffered through petrol costs and time travelling back and forth. More significant was the loss of income from time at work lost at work through my depression, which I attribute to S condition, prior to my leaving altogether. Then there is the fact that I would probably have returned to employment if it was not for everything that was going on within the family and the consequences of S infection that made it impossible to do so.

78. After S was diagnosed, myself, my mother, and my father would drive a twenty-mile round trip from our home in GRO-B Northern Ireland, to her home in GRO-B Northern Ireland. She suffered with her ill-health, so we travelled to her every day to look after her during her pregnancy, helping with housework, cooking, looking after the baby, shopping and all the other everyday domestic tasks.

79. Also, during both o S treatments for her HCV, due to the side effects she experienced, it was difficult for her to look after GRO-B We would travel the twenty-mile round trip every day to S house to attend to her, and care for her and the baby. She was so weak and very depressed. I travelled the long journey in all weathers over the mountain to help her as she was family.

Stigma:

80. At the time of S diagnosis, the stigma attached to HCV was unbearable. Myself, my mother, and S used to take trips to the local shop in her village. When people saw us, they would all stare. They would also whisper to one another saying things along the lines of “oh look that’s S sister” or they would say to their children “stay away.” We felt shunned in a community where we were well known.

81. S always loved showing off her children, but, it became apparent that no one wanted to look at her new baby. It was obvious that they knew about her infection after the rumours her husband had circulated. They would look at her as if she was dirty. I was heart-broken to see the way she was treated in those days.

82. I cannot say that the stigma attached to my sister’s HCV impacted on my social life. Growing up, I did not have much of a social life as I met my husband when I was fourteen years old, and we were engaged by the time I was seventeen years old. It was never a problem for him.

Section 6. Treatment/Care/Support

83. S faced difficulties in obtaining appropriate treatment, care, and support as a consequence of being infected with HCV. This was particularly felt when she gave birth to her two sons GRO-B and GRO-B at the Royal Victoria Hospital, Maternity Ward, Grosvenor Road, Belfast, NT12 6BA, in 1995 and 2011.

84. In 1995, S gave birth to her first son GRO-B at the Royal Victoria Maternity Hospital. However, I have to say, that during the time in which my sister stayed in the hospital, she was treated as a Leper. In a time, which was otherwise meant to be magical for her, it could not have been further from the truth.

85. When we arrived at the hospital, she was escorted immediately to a private room in the corner, where she had her own toilet facilities. She was also not allowed to mix with other new mums on the ward. She was strictly told to stay in her room, behind a door which was sign posted with big black letters "hazardous."

86. When S gave birth to GRO-B she felt very isolated and alone. When the nurses attended to her, they were gowned up from head to toe, with masks and gloves. We would have to help her with bathing, and all her personal care needs as there was no official assistance forthcoming.

87. After GRO-B was born, he was left in the corridor outside the nursery in one of those hospital cots all by himself. People who were walking past him, would have to dodge past his cot. He was not taken into the nursery with the other babies as was usual. I was absolutely devastated at the way he was treated as he was just a little baby. Where was the compassion for him and his mother?

88. She would hear him cry sometimes. This could go on for a very long time with everyone being able to hear, but no nurses would go to attend to him. She would always have to go outside of her room and bring him in herself. It was as

if none of the nurses wanted to touch him. This must have had emotional consequences for my sister to see her baby left practically uncared for.

89. All of GRO-B nappies, and S pads, bedding and clothing were placed into hazardous waste bags at the end of her bed when they were dirty. Myself and my mother took their belongings home to wash them and return them as we feared that the nurses would just throw the bags away or they would be destroyed.

90. It got to the point where we saw how badly she was being treated in the hospital, so we could not wait to get them back home to treat them like human beings.

91. In 2011, S gave birth to her second son GRO-B This was also at the Royal Victoria Hospital. Yet again, she was treated in the exact same way as previously.

92. As soon as she arrived at the hospital, she was placed into a private room. All of her belongings were placed into hazard bags. There was no hazard sign on the door as before, but really this was the only difference.

93. As soon as GRO-B was born, I went into the delivery suite to see him, and I was told that I should not be in there as it was hazardous. It was my sister I said. All the more I wanted to make sure she was okay, so we still went to see her.

94. On the rare occasion, when the nurses went into her room to check on her, she felt different. As though she was being constantly judged. After this point, it felt as though they were ignoring the fact that S was in the hospital, the whole time she was there. She was just left in her room. It was almost as if she was out of sight and out of mind. Still a lack of empathy and compassion.

95. Alongside the treatment S received whilst giving birth to her two sons, her infected status also impacted on the dental care she received.

96. S, my mother, and myself would always attend the Royal Victoria School of Dentistry, Royal Hospitals Site, 6BA, 274 Grosvenor Road, Belfast, for any dental treatment we were due to receive. This was because of the bleeding complications associated with our Von Willebrand's Disease.

97. My mother and myself would always be taken to the main surgery for our dental treatment. However, S would always be taken to a private room, where all the surgeons and nurses would wear gloves, masks, gowns, and all the equipment would be covered from floor to ceiling in plastic. I can still see it so vividly.

98. On the outside of S door, there was a sign which stated "hazardous." This provoked people who were waiting in the area to whisper to each other, give us all glancing looks, and move away from us. One day, I asked S for a drink of her coke tin. I took a drink from the same tin to prove to other people that she was just like them.

99. Personally, I have always felt that the staff at the hospital treated us all with contempt, they would whisper between each other, and watch every move we made.

100. I was not offered any counselling or psychological help as a result of my sister's diagnosis or treatment. I also do not believe that my sister was provided with any counselling or psychological help, either at the point of her diagnosis or thereafter until the Inquiry in Belfast.

Section 7. Financial Assistance

101. I have been made aware through my family members that S received £20,000 in financial assistance from the Skipton Fund.

102. I cannot pass comment on when and how she found out about financial assistance being available to her. I am also not aware of the details surrounding the process in which S had gone through to obtain her financial assistance, other than that she received a lump sum payment.

103. I am not aware of any problems she had faced as a result of applying for financial assistance, or whether any preconditions were imposed on the making of her application.

Section 8. Other Issues

104. I have signed my consent form, on the premise that I understand it will not be used until my signed statement is submitted to the Infected Blood Inquiry.

105. In 2012, my sister, my mother, my auntie, and myself were all told that we no longer had Von Willebrand's Disease. We had in fact completely grown out of it, despite the range in our ages. This is so surprising. As far as we are aware, if you are born with Von Willebrand's, it stays with you until you die. I have researched this extensively, and my beliefs have been confirmed.

106. If I had outgrown my Von Willebrand's, then why does my GP or the consultant in charge of my care still avoid prescribing nonsteroidal anti-inflammatory drugs, which we have always had to avoid due to our condition? Why are we still not permitted to undergo operations? My sister needs both a hysterectomy and a knee replacement, and my mother needs a hysterectomy. I also need various procedures and to fix my broken septum, due to the pain I experience daily. However, nobody will operate on us as they believe that we still have Von Willebrand's.

107. As a result of the Contaminated Blood Scandal, I have lost all trust in the National Health Service ("NHS"). Even now, with the technologies and advances, I would refuse a blood transfusion due to the trauma and suffering my sister has experienced.

108. The contaminated blood product she received has not only destroyed my sister's life, but it has caused our family upset, depression, and uncertainty for the future. It is heart-breaking and cruel. We need justice but so do the many others who have been infected and affected by these terrible events. Even more important is the need to ensure that such an occurrence never happens again.

Statement of Truth

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

Signed GRO-B

Dated

Table of Exhibits:

Date	Notes/ Description	Exhibit number
Undated	Special Medical Card (Haemorrhagic States), Issued on behalf of the Health Departments of the UK.	WITN3927002