23rd JUNE 2021

GRO-B

Witness Nam GRO-B
Statement No: W3544
Exhibits: WITN3544002-7
Dated 23 June 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT O GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 09 March 2020.

I GRO-B will say as follows: -

Section 1. Introduction

1. My name is Mrs GRO-B My date of birth GRO-B 1948. I reside at GRO-B I married my husband in 1967. We have two children, five grandchildren, and three great grandchildren. My youngest daughter is GRO-B:D1 GRO-B and eldest daughter is GRO-B GRO-B Both have provided statements to the Inquiry.

2. I am currently retired. Before this, I was a buyer for a number of companies until I married my husband. After this, I became a housewife until 1975, when I joined the Haemophilia Society. In or around 5 years after I joined, I became the GRO-B

GRO-B
GRO-B

3. I intend to speak about my Von Willebrand's Disease. I also intend to speak about my daughter D1 infection with Hepatitis C ("HCV"), after she was given contaminated blood in 1983 at the age of eleven years old. In particular, the nature of how she had learnt about her infection, how the illness has affected her and our family thereafter, and the treatment she has received. D1 date of birth is GRO-B 1972.

4. 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 to adhere to my daughter D1 wishes.

5. 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.

6. 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.

7. I have constructed this statement with limited access to my daughter D1 medical records.

Section 2. How Affected

8. From a very young age, I was known amongst the local medical profession as a "bleeder." My local hospital in GRO-B would refuse to treat me if I ever had an accident, due to the amount of blood I would lose. Instead, I was consistently sent to the ear nose and throat Hospital twenty miles away for treatment. This was more commonly known as the GRO-B GRO-B

9. The doctor in charge of my care at GRO-B used to tell me that there was no such thing as a "woman bleeder," so I could not have had a bleeding disorder.

10. Instead, my doctor would send me for vitamin K injections, which would show that I had very low levels of vitamin K in my blood. I was given vitamin supplements in an attempt to help with the clotting of my blood.

11. When I had teeth extractions or fillings, I was sent to my doctor to receive vitamin K injections prior to treatment. After I had undergone the operations, the dentist and doctor would have to plug the holes in my mouth due to extreme bleeding.

12. In 1958, when I was ten years old, I attended GRO-B to undergo surgery to have my tonsils taken out. The operation went as planned. However, in the middle of the first night after my surgery, I suddenly haemorrhaged and lost a great volume of blood. My parents and the minister were sent for immediately as, I believe, the staff feared for my life.

13. I was then transferred to GRO-B where I was given treatment of three blood transfusions. These contained one pint of blood in each transfusion.

14. In 1971. My General Practitioner ("GP") GRO-B referred me for special medical care at GRO-B Here, I underwent a number of tests to determine the cause of my excessive bleeding.

15. I was then referred for further blood tests and bleeding time-tests, at the Haematology Unit at the Royal Victoria Hospital, Grosvenor Road, Belfast, BT12 6BA. Eventually, in 1971, I was diagnosed with Von Willebrand's Disease.

16. Within a letter dated 10 July 1972, from Dr Elizabeth E Mayne, Senior Registrar, Department of Haematology, Royal Victoria Hospital, to Mrs GRO-B my

diagnosis is reaffirmed. This also confirms that I was given a special medical card for my Von Willebrand's. Exhibited as **WITN3544002,** it was stated:

Para 1

> *"I enclose the small Special Medical Card for patients who suffer from haemorrhagic states, as the results of the tests carried out recently confirm the fact that you suffer from a mild degree of Von Willebrand's disease."*

17. I also exhibit a letter from Dr Elizabeth E Mayne, Consultant Haematologist, Department of Haematology, Eastern Health and Social Service Board, Royal Victoria Hospital, to Mrs GRO-B entitled "to whom it may concern for medical consultation." Exhibited below, (**WITN3544003),** outlines that I had to carry blood product abroad, when I was visiting New Zealand.

Para 3:

> *"In case of ontoward events during her holiday in New Zealand I have asked her to take with her 1000 units of NHS 8Y. This is reasonably high purity Factor VIII with an adequate content of Von Willebrand activity."*

18. When I was diagnosed with Von Willebrand's Disease, I was told that I had type one, which I understand to be the mildest and most common type. My understanding is that it is an inherited bleeding condition which is attributed to Haemophilia, where essentially, our blood does not clot.

19. I cannot recall whether I was told that I could pass Von Willebrand's disease on to my children through the hereditary line. However, as they asked about persons in my family having the disease, I can only assume that this was mentioned. Thereafter, this did not impede my ability to give birth to my oldest daughter GRO-B

20. My younger sister GRO-B was diagnosed with Von Willebrand's disease. However, my older sister was not ever tested. Thereafter, my youngest daughter D1 was tested six weeks after her birth and found to be positive. However, my oldest daughter GRO-B was not tested when born. She was tested much later, when in her teens.

21. When my youngest daughter D1 was born in 1972, I received my first treatment for Von Willebrand's. I cannot pass comment on exactly what this treatment entailed due to the passage of time.

22. I would now like to talk about the circumstances surrounding my daughter D1 HCV infection.

23. Initially we thought that D1 was infected in 1989 following a tonsillectomy. She had to return to hospital, the Royal Victoria, two weeks after release as she suffered a haemorrhage. At that point she was given cryoprecipitate. We were reluctant for this to happen due to the earlier experience which I will go on to cover below. Both D1 and I were assured it was completely safe and she reluctantly accepted the treatment. However, information which I will outline later, came to light which cast doubt on this being the actual catalyst for her infection, albeit was also a potential source.

24. Six years earlier, in 1983, when D1 was around eleven years old, she experienced a severe and persistent pain around her stomach area. After a while, the pain had not subsided, so we decided that we should seek medical assistance.

25. After taking her to the doctors we were advised to take her to hospital, D1 was taken immediately to Royal Victoria Hospital in Belfast. Following preliminary assessments by medical professionals, it was believed that she had appendicitis.

26. As we left home in such a rush with D1 I was unable to collect any of her belongings which she needed whilst staying in the hospital. Therefore, when I

was made aware that she was stable and in safe hands, I returned home with my husband to pick up a number of items she would need such as pyjamas. I was gone for about an hour and a half and had left shortly after D1 was admitted when I knew she was in a stable condition.

27. However, much to my horror, when I returned to the hospital where D1 was located, she had a drip attached to her arm. I was completely in shock. She had undergone a treatment without me present or aware. As she was only eleven years old, the doctors and nurses in charge of her care would have needed consent from her guardian or parent. There had been mention of a possible need to operate and about consent when she was initially admitted but I don't recall signing anything and most certainly nothing was said about it being imminent or I would never have left the hospital. There was definitely no mention of the need to perform a blood transfusion or administer blood products and I was given no information about what that may entail or about any risks that may be attached to the procedure. It is this procedure that I now believe was the source of the HCV infection.

28. I should also say that neither my husband, myself or D1 albeit she was a child, was provided with information or advice about the risk of being exposed to infection, before she was given the blood product.

29. Although I was flabbergasted by what had taken place, I did not challenge the doctors I just thought; 'oh well, this is what we have to do now'. It was not a time when you questioned the behaviour of doctors and medical staff. After all, they knew best when it came to treatment.

30. In 1993, myself and D1 attended the Royal Victoria Hospital, Belfast for a routine appointment for D1 chronic fatigue syndrome ("ME"). Whilst we were walking down the corridor to our appointment, we bumped into Dr Mayne, who was in charge of my family's regular care.

31. I can recall having a conversation about D1 persistent tiredness. Dr Mayne said to D1 something along the lines of "how are you now

D1 replied saying; “no better! And I am very tired.” Dr Mayne replied “Well if it is not your ME then it must be your Hepatitis C.”

32. We were all so confused by what Dr Mayne had just told us. What did she mean? I looked at her with amazement, to which she stated “I don’t know why you are looking at me so stunned, you probably have it too, and so could you all.” Dr Mayne then walked away, leaving us in a state of shock. I can recall this as clear as day, as if it was yesterday.

33. This was all the more hurtful as myself and my family all looked up to Dr Mayne as she took care of all of my family’s medical needs. How could she tell us this life changing information in such a heart breaking and awful way? In a hospital corridor! Did she not have a heart? Or did she simply forget that she had not told us this information previously? Little did we know that our whole life was going to change from that day forward.

34. As we were not informed about D1 infection in a conventional way such as during an appointment with Dr Mayne, I set up a face to face consultation with her to discuss this. I asked Dr Mayne not only about D1 HCV – but also about her throwaway comment that we might all have it. However, I did not get much of a response. She simply stated that it was nothing to worry about, it was just a little virus and wouldn’t harm us. At the time, I did not know any better as I was unaware of much information surrounding HCV so I did not push her for further explanation.

35. No one ever questioned Dr Mayne. She was not a very approachable person. I tried to be as nice as I could. I was dependant on her for care and treatment for both myself and my daughters, so I did not want to antagonise her by asking too many questions or seeming to doubt her.

36. As a result, we did not get the chance to ask for the relevant information we would have liked to have known about HCV. We were also not told any of this information expressly. Therefore, I do not believe that the information we have

received would be considered adequate enough for us to understand and manage D1 infection.

37. We were also not given any information about the risks of others being infected as a result of D1 HCV. We were simply told that D1 had a liver problem, and that it was a small infection. Myself and my husband used to put plasters on D1 when she was bleeding, and she may have shared our toothbrushes. I now know this was such a big risk, but of course was unaware then.

38. I believe that the information given surrounding D1 infection should have been provided at an earlier point. Dr Mayne should have given us this information when she was first made aware of D1 having tested positive for the presence of HCV.

39. It is the blood products D1 received in 1983 at the age of eleven years old, which we believe was the cause of her HCV infection. We believe this, as in 2019, I gained information from Doctor Gary Benson at Belfast City Hospital, Lisburn Road, Belfast, about a database run by the Haemophilia Society. This database contains all blood and blood products administered under the National Health Service ("NHS") from 1992 onwards, the person who received this treatment, and their respective batch numbers. I applied for information.

40. The results we received, provided information that D1 had received contaminated blood products prior to 1988, thus ruling out the 1989 operation.

41. I am also aware from D1 that her medical records show that the Royal Victoria Hospital knew earlier than 1987 that D1 had contracted HCV or at least had been given contaminated products. It is a tragedy that she was not told until that meeting in the corridor.

42. After D1 time in hospital in 1983, we started to notice that she took longer to shift illnesses such as the flu or a common cold. When she was sick, she was really sick. However, it is only now that we see that this could be attributed to her HCV having an adverse effect on her immune system.

43 D1 does not have tattoos, she has not had dental treatment outside of the United Kingdom. She has never used any illegal drugs.

44. Whilst I have received many blood transfusions and blood products over the years for things such as a heavy period, I have been tested for the presence of HCV and the results have returned as negative. She could not have received her infection from myself through cross-contamination.

45. Therefore, the contaminated blood products she had in 1983, must have been the cause of her HCV infection.

46. Since that point, I have made it my quest to find out as much information as I could about D1 virus. After leaving my position as GRO-B GRO-B due to depression, I re-joined in 1997 to determine whether it would help me uncover information about D1 HCV.

47. I had previously been made aware of the existence of Non-A Non-B Hepatitis ("NANBH") at a meeting of the Haemophilia Society in London in 1988. However, I was not made aware of the details surrounding the infection.

48. Between 20 and 22 October 1995, the Haemophilia Society put on a conference at the Killyhevlin Lakeside Hotel & Lodges, Dublin Road, Killyhevlin, Enniskillen, which included a weekend stay. This was organised by Dr Mayne and a number of drug companies such as Bayer, Alpha, Bio Products Ltd, Armour and Speywood. The purpose of this conference was to discuss matters such as the prevalence of HCV in haemophiliacs, Von Willebrand's Disease, and blood products.

49. I exhibit a programme from the Haemophilia Society, entitled "Northern Ireland Haemophilia Weekend," which affirms the conference having taken place. (**WITN3544004**).

50. During the course of the conference, I gained quite an in-depth understanding of what HCV was, and what effect it would have on D1 body over time. When the speakers were discussing the prevalence of HCV in blood products, I plucked up the courage and took it upon myself to make myself known. I then asked the question "who is responsible for the contaminated blood?" The speaker then replied saying; "good question, who knows?"

51. In 1995, D1 also became GRO-B GRO-B

52. Later that year, D1 and myself attended a conference in Coventry, England. We were so astounded by what we found out and heard. There were so many people dying of the infection, due to the adverse effects it was having on their body. This was such a worry, as at around this time, we had recently found out about D1 being pregnant with her first son. The only glimmer of hope, was the Interferon treatment discussed.

53. In 1997, there was a meeting at the office of the Haemophilia Society, where fourteen members were in attendance. They had stated that they wished to know more about HCV, so D1 and myself were sent to a conference in York, England.

54. At the conference, the truth came out about their knowledge surrounding the presence of HCV in blood products and blood transfusions. We decided to bring back a number of documents which were given out at the conference, so that they could be presented to the Northern Ireland Committee.

Section 3. Other Infections.

55. On 27 February 1998, I received a letter from the Northern Ireland Haemophilia Comprehensive Care Centre, Royal Hospitals, to all patients attending the Northern Ireland Comprehensive Care Centre. It stated that there was a concern for the potential risk of new variant CJD amongst patients treated with inherited bleeding disorders. Exhibited below **(WITN3544005),** it states:

Para 2: *“At that meeting in November the POTENTIAL RISK of new variant CJD being transmitted by blood products was discussed in all aspects.”*

56. I am aware that GRO-B and D1 had received the same standard letter. However, I cannot pass comment on the exact dates when my daughters received their letter.

57. However, I believe that this risk of nvCJD may have been notified to Dr Mayne the year before in 1997, although late on. This knowledge stems from a letter I have in my possession which is dated December 1997. Within a letter from Tony Wilson, Chief Executive, The Haemophilia Society, exhibited below **(WITN3544006)** it states:

Para 4: *“A number of blood product batches were recalled recently by BPL as a precautionary measure when it was found that one of the donors had later developed nvCJD.”*

58. Also, attached to the above letter, is a letter from Dr Christopher A Ludlam, Chairman, United Kingdom Haemophilia Centre Director’s Organisation, entitled “New Variant CJD and the Treatment of Haemophilia.” Exhibited below **(WITN3544006),** this letter states:

Para 1: *“There has recently been concern about the possibility that blood and blood products might pass on the agent responsible for new variant Cruetzfeldt Jakob Disease (nvCJD)”*

59. After I received the letter on 27 February 1998, I made an appointment to see Dr Frank Jones who worked with Dr Mayne, to discuss the letter and the risk of

nvCJD. At the face to face consultation, I asked him whether anyone had been exposed to nvCJD in my family. He reassured me that no members of my family had received a batch which was contaminated with CJD.

60. However, we now know that D1 did in fact receive a batch of blood which had been contaminated with CJD.

Section 4. Consent

61. In 1983 when D1 was given clotting factor as treatment at the Royal Victoria Hospital, for sick children she was only eleven years old. Therefore, as she was still a child, she could not have provided consent herself in order to receive this treatment. Instead, either myself or my husband should have provided consent, but this was not the case.

62. When the treatment was administered, I had returned home to collect a number of D1 belongings in case she was hospitalised. When I returned to the hospital, I was shocked to see that D1 was attached to a drip.

63. How in their right mind could they have not followed the correct procedures of gaining consent from either her guardian or parent before her treatment was administered.

64. It makes me so angry and upset that the doctors and nurses who were overseeing D1 care took it upon themselves to administer blood product without her mother having been present or aware. It was the first time she had been given a blood product, and she was only a child. She must have been so worried.

65. I cannot say whether the blood test which was taken prior to 1993, which had made Dr Mayne aware of D1 HCV, was taken without D1 knowledge or consent. However, if she had been made aware of this blood test being carried out, I am sure she would not have been given adequate or full information surrounding the purpose of the test. The reason for that is the

degree of shock D1 – and the rest of our family experienced when she tested positive for the presence of HCV. There was just no expectation that such a thing could happen.

66. I cannot pass comment on whether D1 was treated or tested for the purposes of research. If she had, then I was not made aware of this.

67. Additionally, as far as I am aware, D1 has not been tested for the presence of HIV.

68. After I GRO-B in 1975, in early 1986, I attended a Haemophilia Conference in London, at the Haemophilia Society offices. I was amazed to hear about the presence of HIV and AIDS amongst haemophiliacs. Around that time, it had still not been discussed in Northern Ireland so I was stunned at the prevalence of the infection.

69. I also became friendly with a number of individuals in attendance, who told me that they had AIDS, but I was not allowed to tell anyone. This made me wonder whether I have ever been tested for the presence of this infection, so on the way back to my home in Northern Ireland, I asked Dr Mayne whether I could undergo a HIV test.

70. In January 1986, I had undergone the blood test to determine whether I had been exposed to the presence of HIV. On 24 January 1986, the results had returned back as negative. I felt so sorry for my friends who I had met, but I was silently relieved that I was clear.

71. Within a letter I received on 24 January 1986, from Dr Elizabeth E Mayne, Consultant Haematologist, Department of Haematology, Royal Victoria Hospital, my test results are confirmed. Whilst the letter does not make specific reference to HIV, I have added this note to the top of the document for reference.

72. Exhibited below **(WITN3544007),** the letter states:

Para 1: *"I am pleased to be able to inform you that your blood test carried out last week has come back negative."*

Section 5. Impact.

Mental/Physical Effect.

73. From the point in which we believe that D1 was infected with HCV in 1983 at the age of eleven years old, she started to feel the physical effects of her infection. However, myself and my husband had previously explained these symptoms away through alternative means. We had no reason to suspect that this was due to HCV, as we were not aware that she had received contaminated blood at that moment in time.

74 D1 was always very tired and fatigued. However, we assumed this was due to something as simple as not getting enough sleep. After her HCV diagnosis in 1993, her symptoms had become more obvious and past problems she had made more sense. Her tiredness increased, to the point that she had to give up work.

75. Alongside her physical effects, D1 suffered with her mental health as a result of being diagnosed with HCV. She regularly attends GRO-B a psychiatric unit, to help with her severe depression and post-traumatic stress disorder.

Treatment

76. Sometime in 1996, three years after her diagnosis, the family noticed that D1 was starting to become very yellow in complexion around her eyes. We thought that this was very odd and it had never happened before, so we pushed for her to get an appointment with Dr Mayne at the Royal Victoria Hospital, Belfast.

77. At a face to face appointment with Dr Mayne, it was suggested that she undergo a liver biopsy. I was not able to attend the liver biopsy with her, as I was told by Dr Mayne that "she was a big girl now and could do it alone." Surely it was D1 decision whether she wanted someone with her during the appointment? I was later told by D1 that the biopsy went well, and that the results had returned, demonstrating that she had chronic HCV.

78. A short while later, in 1996, D1 decided that she would commence her first course of treatment with Interferon. This was part of a trial with a Pharmaceutical Company. The exact name of the company we were not told. This was a six-month course, where she would inject herself with Interferon three times a week into the stomach.

79. During the treatment, she experienced severe side effects which made the duration of her experience unbearable. She was always cold, despite constantly lying on her sofa wearing pyjamas, with her duvet covering her and the heating on full blast. She also consistently experienced nausea, vomiting, and diarrhoea.

80. After six-months D1 was told that her treatment was not successful, and that it had not worked to clear her infection. We were both absolutely gutted, at what this meant not only for herself, but our family.

81. In 1998 D1 started her second course of treatment. This was a course of Interferon and Ribavirin. She would inject herself three times a week in the stomach, and take daily oral tablets of Ribavirin, for a duration of six-months.

82. Not too dissimilar to D1 first course of treatment, she experienced severe side effects. If I am honest, the side effects she experienced this time, were the same as before, but on a much higher level.

83. D1 had stopped eating, as she lost her appetite. This meant she had lost a lot of weight, so she became very weak. She was constantly tired and fatigued, as she suffered with insomnia. Cast this with her vomiting and

dizziness on her feet and it meant she was often too exhausted to carry out day to day tasks she would have otherwise been able to do.

84 D1 was also constantly cold, despite sweating profusely. It must have been her treatment having an effect on the temperature of her body. As well as this, she could not stop itching her skin all over her body. It was awful to see her this way, fighting with her own body.

85. Every week, the Royal Victoria Hospital, Belfast, would send the Haemophilia Nurse to D1 house. She would take her blood, so that they could test it to determine whether the treatment was working to clear the presence of her infection in her body D1 was not able to travel to the Hospital herself due to the debilitating effects of the medication to get the bloods taken, so the Hospital decided the safest way was to send a nurse to her home.

86. After six months, she had her final blood test taken. When the results returned, it showed that D1 second treatment had finally been successful at clearing her HCV. We could not be any happier for her. She could finally move on with her life.

87. As far as I am aware, D1 has remained to this day, clear with regards to her HCV. I am still so scared that her D1 s going to come back again. For now, it is just lying dormant in her body. As her mother I will always fear for her health due to this virus – the fear doesn't leave.

88 D1 still suffers with wide ranging side effects resulting from both her HCV and the treatment she has received to clear her it. This includes chronic fatigue syndrome ("ME"), and Fibromyalgia, a condition that causes widespread pain and extreme tiredness. She also suffers with insomnia, which is most likely brought on by the above.

89. From the point at which D1 started her treatment with Interferon, the quality of her eyesight has slowly deteriorated. Some days, she can barely see

in front of her. We have since found out that in a small number of patients, it is a side effect of Interferon to cause visual impairment.

90. She also experiences brain fog. Myself, my husband, and my daughter GRO-B see D1 as a regular occurrence. When we have conversations with her, sometimes, she will completely 'zone out'. After a short while, she will come around, and will not remember anything about the conversation we had just conducted. We have recently found out that this is also a side effect of HCV.

91. D1 also suffers with arthritis, a weak bowel, and bad migraines. This causes her to have a constant low mood. She was finally able to clear her HCV, but due to the side effects she experiences, she is constantly reminded of a terrible period in her life. She has to rely on her family for support, to help her try and lead some kind of a normal life.

Impact

92. When I found out about D1 HCV in 1993, I was absolutely devastated. I gave my daughter Von Willebrand's Disease and that was a hard-enough pill to swallow. To be told that she got her infection from contaminated blood she had received as a result of her Von Willebrand's, well this was incomprehensible.

93. If I could have taken it away I would rather it was me. I have been given so much more treatment than D1 over the years, so if anyone was to get an infection, then it should have been me. My heart is broken and to this day and I am racked by guilt at how things have turned out.

94. Whilst D1 has now cleared her HCV, I worry about her all the time, and I am always on edge. When I see her, I always say "you look a bit yellow around the eyes, are you okay?" As mentioned I always have a constant fear that it could return, and due to my age, I might not be there to help her in the future. This is something that always plays on my mind.

95. My GRO-C suffers with Atrial Fibrillation, a heart condition which we have been told is stress related, and we believe was bought on by anxiety relating to D1 infection.

96. It is my family's firm belief that D1 HCV caused marital problems for herself and her first husband D1 was diagnosed with her infection just after she got married to her husband. After this point, he started to become a horrible person, who would do and say the most spiteful things. This was particularly prevalent during her first course of treatment.

97. Luckily D1 husband finally left her family home. Not long thereafter, they divorced, so D1 and GRO-B her son moved closer to her family in GRO-B Northern Ireland, so that we could more easily provide her with assistance.

98. D1 remarried to her current husband GRO-B in 2010.

99. Alongside this, due to the side effects D1 HCV had caused, she had to take a number of days off work as she was so tired. Her persistent ill-health meant she had to give up work in the end. She lost valuable earnings as she was a qualified book binder, with good promotional prospects.

100. It was not only D1 who suffered financially as a result of her infection. I was previously a child minder between 1977 and 1985 approximately. As I had to devote a lot of time to D1 after the point at which we believe she was infected in 1983, I had to give up work. I lost a substantial income for my family, as I knew that D1 came first and I needed to devote my time to caring for her.

101. When D1 was newly diagnosed and then when going through her two courses of treatment, myself, my husband, and my daughter GRO-B lived a twenty-mile round trip away from D1 home. Due to her ill-health, she was unable to carry out a number of daily tasks and look after GRO-B Myself, my husband, and GRO-B used to travel the twenty-mile round trip daily to assist her incurring a large amount of money in petrol costs.

102. As she had to give up work, D1 was financially unable to keep up with her regular payments. I recall having to cover finance payments for her car.

103. When D1 moved back to GRO-B to be near her family, she had to sell her family home in GRO-B Northern Ireland. However, myself and my husband had to give her over £18,000 for her to be able to buy the new house. This was a great financial outlay for us both at our time of life.

Stigma:

104. After D1 was newly diagnosed in 1993, her first husband had broadcast to a number of people in her village of GRO-B that D1 was infected with HCV. Also, that she was a drug addict, alcoholic, and had liver problems. Naturally, as this was a tight community, these rumours were passed on like Chinese whispers, spreading around the village like wildfire, until everyone knew.

105. People treated D1 differently from that point on. My daughter GRO-B D1 and myself used to take trips to the local shops in GRO-B People used to deliberately look away, or walk around us, staying away purposefully from D1 when they passed us in the street. When we entered the shop, and carried out our normal shop, we would place things on the counter to pay for them. However, when she had gone to pay, instead of being handed the change, they would place it on the counter top so they did not have to touch her. She, well in fact all of us, felt shunned in our own community.

106. Before this, she was a very popular person and everyone loved her. I can only assume that her infection had cost her a lot of close friendships, due to the stigma which was attached to HCV around that time. She was not a dirty person. She was not a drug addict, nor an alcoholic. She was infected as a result of being given contaminated blood. Factors which were out of her control. However, no one ever stuck around so that we could explain this.

Section 6. Treatment/Care/Support

107. D1 did face difficulties in obtaining dental treatment. As we both had Von Willebrand's Disease, we received dental treatment at the hospital. Therefore, they were aware of her infective status. D1 was always kept until the end of the list and had to go into a room covered in plastic from top to bottom. This always made her very upset and she would cry a lot saying; "why me? I did nothing wrong" This broke my heart.

108. On the other hand, D1 did face difficulties in obtaining treatment, care and support as a result of her HCV, whilst giving birth to her two sons.

109. In GRO-B 1995, D1 was admitted to the Royal Victoria Hospital, Belfast, as she was due to give birth to her first son GRO-B From the moment we stepped into the hospital, we were treated appallingly.

110. Instead of being placed onto the main maternity ward, she was placed into her own separate room in the corner, which had its own bathroom. On the outside of her door, there was a large yellow sign which stated "Hazardous" in big bold letters. This meant that everyone who was sitting outside of her room when we visited would stare at us, sometimes with a look of disgust. It was a most unpleasant experience.

111. In GRO-B 1995, D1 gave birth to her son GRO-B During the procedure, she was surrounded by nurses who were dressed in plastic gowns head to toe, with gloves, and masks. This was unnecessary and made D1 feel so uncomfortable at such a crucial and stressful time for her.

112. After this, GRO-B was placed into the corridor outside of the nursery. When he would cry, D1 would have to ask for the nurse to bring GRO-B into the room, as otherwise, he was ignored by all the nurses.

113. D1 was also not allowed to leave her room. She was also not allowed to mix with anyone, or eat with the other new mothers who were on the ward. This made her feel isolated and sad. My mother and myself spent a lot of

time visiting her, as without seeing us, she was left in the room by herself with no other social interaction.

114. All of D1 belongings such as clothing and towels, and GRO-B nappies, bottles and baby clothes were placed into large yellow hazardous bags, which the nurses had placed at the end of her bed. We thought that the nurses were going to throw them away, so we took them home to be washed and returned.

115. D1 was treated in much the same way during her second birth in 2011. Again, she was placed into a private room with a private bathroom. Whilst she did not have the yellow sign which stated "Hazardous" posted on the outside of her door, this was the only thing that was different about her experience.

116. When D1 was giving birth to GRO-B and afterwards, the nurses put on a gown and mask to attend to her. This time GRO-B was in D1 room. They did not take GRO-B into the nursery at any time, he was treated so differently D1 could not relax. She was uptight the whole time.

117. When D1 needed assistance such as bathing or medical needs, the nurses and carers who were in charge of her care were always reluctant to help her.

118. I did not question the nurses at the time, as I did not want to upset D1 by causing a fuss.

119. The way in which D1 was treated during both of her sons' births was disgraceful and unjust. You are meant to be cared for whilst in hospital but this was not the case.

120. As far as I am aware, D1 was not offered any counselling or psychological support as a result of her HCV diagnosis or during treatment. Nor in relation to her possible infection with vCJD. Instead, she was offered reflexology, a type of massage where pressure would be applied to her feet,

hands, and ears, based on a theory that these body parts are connected to certain organs and body systems.

121. I was not offered any counselling or psychological support as a result of D1 diagnosis nor have I ever been offered it in relation to my condition or possible exposure to vCJD.

Section 7. Financial Assistance

122. I was made aware by D1 hat she had received £20,000 in financial assistance from the Skipton Fund.

123. 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 D1 had gone through to obtain her financial assistance, other than that she received a lump sum payment.

124. When D1 applied for financial assistance, there was a precondition imposed on the making of her application. In 1994, we had started a private case, using solicitors, against Royal Victoria Hospital. We struggled to gain access to her medical records. This was because Dr Mayne initially would not provide D1 with access. Eventually we got hold of them and they went to the Solicitors. They were never returned and the company is now closed. We had to drop the case so that we could gain access to her financial assistance from the Skipton Fund. I am not aware who imposed the condition only that dropping the action was the only way she could access the Skipton pay-out and she was desperate at the time.

Section 8. Other Issues

125. 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 ("IBI").

126. Recently, around 9 years ago in 2012, I was told that I no longer had Von Willebrand's disease by Dr Gary Benson. Also, that my sister, and both of my daughters GRO-B and D1 had grown out of their disease. This was all within one year of one another. We were all discharged by the Haemophilia Clinic at Royal Victoria Hospital, Belfast.

127. This fact, makes me wonder whether we had Von Willebrand's to begin with. Were we wrongly diagnosed? Were we given blood for no reason due to our wrong diagnosis? Due to my bleeds I think not, but it does make you question everything.

128. Two years ago, I had a tooth taken out by the dentist. The dentist needed confirmation from Dr Gary Benson that I no longer had Von Willebrand's Disease in order to carry out the operation without the assistance of blood products. A short while after, Dr Gary Benson sent correspondence to my dentist which confirmed that they could go ahead with the operation as planned.

129. After the operation, I returned home. However, due to the amount of blood which I was still losing from the area where my tooth was extracted, I sat up all night bleeding. I did not want to go to the hospital to get blood as treatment so I persevered. By the morning my bleeding had subsided. For this reason, I believe that I have not outgrown by Von Willebrand's Disease as I was told.

130. I am absolutely devastated that when D1 was told by Dr Mayne about her HCV in 1993, that it was made in such a heartless manner. She told us life changing news in such a blasé way, as if it was not a big deal.

131. We had to find out by ourselves what impact D1 HCV would have on her body, by going to Haemophilia Conferences, asking relevant questions, and carrying out our own research. I found out more information from people who were already diagnosed with HCV, than I did from the medical profession.

132. In 1996, we were asked by the Haemophilia Society to send letters to our MP's, to ask if they would raise the perspective of people suffering with HCV. The replies we received were really disheartening. Out of approximately

ten letters sent, we received four responses and none of them really appeared to understand what HCV was. One actually asked what vaccination she had been given, that was the level of ignorance about the condition.

133. All in all, due to the treatment my daughter received from the National Health Service ("NHS"), which caused her HCV, I have lost trust in the overall health system in the United Kingdom.

134. Everything I am now told by the doctors, I second guess. Myself, my daughters GRO-B and D1 and my granddaughter all refuse to accept treatment of blood or blood products because of what happened to D1 We know that technologies have developed since 1983, so there is less of a risk, but then again, we did not think contaminated blood would be possible back them. You can never be too safe.

135. I have told Dr Frank Jones that I wish for my refusal of blood or blood products to be put on my medical records. He told me that "if I were to get a head problem, then I would have to have it." I agreed. Unless it was life-threatening, then this is the only time I would receive blood. I am sure that there are other people out there like us.

136. The Contaminated Blood Scandal should never have been allowed to happen. It is completely ridiculous that our Government put money and profit over people's lives. Who thought it would be safe to get blood from prisoners and drug users in the United States of America, and pay them for their donation? Then, use this blood to treat patients of all ages freely in the NHS.

137. All our friends infected with either HCV or HIV, with whom we became close through the Haemophilia Society are dead. It was heart breaking to listen to their stories. I just hope nothing like this happens again in the future. So much pain and suffering. I wish to give them a voice, and speak out on their behalf. They fought hard to get the truth about HCV to Northern Ireland. I feel they were kept in the dark and not told the truth until it was too late.

138. I feel that society had a right to inform and be informed about the risks of HCV in treatment with blood.

139. I do not hold grudges against the doctors who were in charge of D1 care. It must have been a hard time for them too, not knowing what was making their patients sick. Then, when they were made aware of the presence of HCV, the guilt must have been irreconcilable that they had a hand in giving patients the blood or blood product that infected them.

140. My daughter is the loveliest person to walk on this planet. She has a heart of gold, and everyone who knows the real D1 has no bad words to say about her. She now has a wasted life. Whilst she is PCR negative for HCV, she is surrounded by constant reminders of her past through the suffering she endures to this day.

141. Contaminated blood has far reaching consequences. It is not only the person it infects to suffers, but the persons around them. Why my D1?

142. I wish to thank Sir Brian Langstaff for bringing the Infected Blood Inquiry to Northern Ireland to help prove the truth about what went wrong all those years ago. You have allowed for us to have our voice heard. This is something I have tried to do for many years. I am forever grateful.

Statement of Truth

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

Signed GRO-B

Dated 23-6-2021

Table of Exhibits:

Date	Notes/ Description	Exhibit number
10 July 1972	Letter from Dr Elizabeth E Mayne, Senior Registrar, Department of Haematology, Royal Victoria Hospital to Mrs GRO-B GRO-B	**WITN3544002**
22 January 1991	Letter from Dr Elizabeth E Mayne, Consultant Haematologist, Department of Haematology, Eastern Health and Social Service Board, Royal Victoria Hospital, to Mrs GRO-B entitled "to whom it may concern for medical consultation."	**WITN3544003**
Undated	Programme, from Northern Ireland Haemophilia Society, entitled "Northern Ireland Haemophilia Weekend."	**WITN3544004**
27 February 1998	Letter from Northern Ireland Haemophilia Comprehensive Care Centre, Royal Hospitals, to all patients attending the Northern Ireland Comprehensive Care Centre.	**WITN3544005**
December 1997	Letter from Tony Wilson, Chief Executive, The Haemophilia Society, to Member, entitled "Recombinant/Blood Products and New Variant. CJD."	**WITN3544006**
Undated	Letter from Dr Christopher A Ludlam, Chairman, United Kingdom Haemophilia Centre Director's Organisation, entitled	**WITN3544006**

	“New Variant CJD and the Treatment of Haemophilia.”	
24 January 1986	Letter from Dr Elisabeth E Mayne, Consultant Haematologist, Department of Haematology, Royal Victoria Hospital, to Mrs GRO-B	**WITN3544007**