Witness Name: Sandra Margaret Capelin
Statement No: WITN3811001
Exhibits: **Nil**
Dated: 08 Jan 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SANDRA MARGARET CAPELIN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 03 October 2019.

I, Sandra Margaret Capelin, will say as follows: -

Section 1. Introduction

1. My name is Sandra Margaret Capelin. My date of birth is GRO-C 1947. I live in Cornwall, my full address is known to the Inquiry.

2. I am the mother of Gary Philip Capelin (**W0952**), and I am married to my husband Philip Capelin (born GRO-C 1948). I am providing this statement to the Inquiry with the assistance of my husband.

3. I intend to speak about our son, Gary, and his infections with hepatitis A, B, and C. In particular, the nature of his illness, how the illness

affected him, the treatment received and the impact it had on him and our lives together.

4. I am not legally represented and I am happy for the inquiry investigators to assist me with my statement.

Section 2. How Affected

5. My husband and I met in 1966, and we married soon after in GRO-C Sussex, on 07 June 1969. Our first child, Gary, was born on GRO-C 1970.

6. I trained as a registered sick children's nurse (RSCN) at Queen Mary's Hospital for Sick Children from 1965 to 1969. I have a masters degree, M.ED. I worked briefly on the children's ward at Worthing Hospital, following which I worked for the Plymouth Hospitals Trust as a RSCN. My husband worked as a carpenter and kitchen fitter, he also worked with adults with learning disabilities teaching them woodwork and independent living skills.

7. Gary's haemophilia was evident to me from birth. His umbilicus was slow to heal after birth, and his belly button looked overly large. The doctors were unsure why it was slow to heal, and this went undiagnosed.

8. Gary was a placid baby. He was easy to care for, gaining a pound a week while he slept and grew. He was a 'dream baby'. Our second child, Rachel, was born around 20 months after Gary.

9. Gary's health was fine for the first 6 months, but he soon began to develop a lot of ear infections. He was on antibiotics almost every other week, suffering 9 perforations in all. Aside from this, he appeared healthy.

10. As a toddler Gary began to show signs of bruising easily. After we had a kitchen extension, Gary would trip over the new fittings, often hitting his head on the side of the counter. One time, he had a big haematoma, and we took him to A&E with the head injury. This was a regular occurrence.

11. At the A&E department, the nurse who attended to Gary did not seem convinced by our explanation of his injuries. The nurse said that our story did not correspond with Gary's bruising. As a qualified paediatric nurse, I was aware of exactly what forms they were filling in. I began to feel that the doctors and nurses thought that we were mistreating Gary. Though the social services did not get involved, we certainly felt that we were on their radar.

12. This continued on every further occasion when Gary had an accident. Whenever he had a bump on the head with another child, the teachers and cub leaders asked me why his injuries were so much worse than the other children's. I asked the hospital and my GP repeatedly to do blood tests, but they claimed that they would not use needles on children unnecessarily.

13. Gary was a late developer, so aged 11 we took him to the orthodontist at St Richard's Hospital, Chichester, who advised that Gary needed several baby teeth removed. The initial procedure was carried out by our local dentist, Joyce Leonard. On the first occasion, he had three teeth removed.

14. After having these removed, Gary was unable to speak. He tried to move his mouth but this would just cause him to bleed from his mouth. We put him to bed with soup and told him to rest. That evening, I phoned our local GP, Dr GRO-D in GRO-C, who asked us to bring Gary down to see him. I refused to do so, knowing that this could lead him to start bleeding again. Dr GRO-D replied that 'if he has stopped bleeding, he is not haemorrhaging'. He refused to attend Gary.

15. The next morning, Gary's mouth was full of a gelatinous clot of blood. I inserted my finger to try and remove it, thankfully without causing it to start bleeding again. His bed, pillows, mattress and sheets were drenched in blood. The scene was horrific. Normally this would have required a whole new bed, but we could not afford this at the time. We hosed it down and let it dry out.

16. I phoned Dr GRO-D again that morning to inform him of how bad Gary was. He appeared to be totally unconcerned. He did not appear that he wanted to see Gary, and again refused to undertake any form of testing to determine what the cause was.

17. 10 days after the first set were extracted, we went back with Gary to the dentist for the second set of teeth to be removed. Dr Joyce Leonard informed us that she would not treat Gary unless his GP undertook clotting times tests. Though she did remove the set of 3 baby teeth on this occasion, Dr Leonard was the catalyst to getting Gary tested for haemophilia.

18. I believe that we went to Worthing Hospital for the clotting times to be tested. I remember driving Gary to the appointment, where he was diagnosed with haemophilia B, 3% Factor IX, at the age of 11. This was his first year of senior school, and clearly he should have been diagnosed much sooner. Having informed Dr GRO-D of the results, he replied 'well now you know what it is'. He did not express a shred of remorse, nor any apology whatsoever.

19. After his diagnosis, Gary was referred to Dr Savage at St Thomas' Hospital in London. Dr Savage would see him for annual check-ups, whilst Dr GRO-D or Dr GRO-D continued to see him at Worthing Hospital when required.

20. Dr's GRO-D and GRO-D always advised us to ask for them when Gary was taken to the hospital. The staff at the hospital would often panic

when we had to take Gary in, they would always try and admit him and panic, this did not help the situation.

21. Gary would receive Factor IX products at Worthing Hospital as and when required. We were not told the name of these products, nor were we informed of the origin of the blood used to make the Factor IX products. We were certainly not told of any risk of infection from the Factor IX products.

22. I told the school of Gary's diagnosis with haemophilia, informing them that he should be treated completely normally unless he incurred an especially bad accident. Soon afterwards, Gary returned from school and told me that the whole school had been called to an assembly and told that they should not hit Gary as this would kill him. I tried to reassure him, and said that he was exactly the same person as he was before.

23. After this incident, I contacted the school and told them that he had Christmas disease but this only led them to panic in case he was infectious. I then tried calling it Factor IX deficiency. This seemed to calm things down, though they continued to describe him as a 'bleeder'. At the end of his first year of senior school, the teachers refused to take Gary to Thorpe Pork with the rest of his year group. I argued strongly against this decision, and eventually they allowed him to go if his Dad would accompany him. Phil took a day off work to go along with him, and upon arriving, let him go off and enjoy himself.

24. Gary was suffering lots of bullying at school. As a small and cheerful boy, his haemophilia made him a target for the bullies. He kept a lot to himself, and eventually he began to stop attending school. GRO-C GRO-C GRO-C. Gary, aged 14 or 15, had begged me not to intervene in this matter.

25. On one occasion, Gary injured his leg quite badly. I am not aware of the full circumstances of this. He was initially treated at Southlands Hospital in Shoreham, then was transferred to St Thomas' Hospital where he stayed for 3 months. From February to May of that year, which I believe was 1981, Gary was treated for the swelling of his leg. He was administered daily Factor IX and received physiotherapy for his rehabilitation.

26. During this treatment, I believe that Gary was seen by some sort of psychologist at the hospital. I remember that he asked Gary to draw a picture of breakfast time in our house. Gary drew a picture of him and his sister throwing cornflakes at each other whilst my back was turned. I know this could not have possibly been true.

27. I believe that Gary did not want to come home, because of the bullying he was suffering at school. The doctors thought that something was going on at home because of this, though all I wanted was normality and stability for Gary after all he had endured.

28. After this treatment, the school had an open evening, which Gary urged me not to go to. I insisted that we went as his parents. The teachers said that they thought Gary had left the school. This led us to address this with Gary and to demand he tell us what was going on.

29. As Gary had been badly let down by the school, and because of all the bullying he had experienced, we decided to pay for him to be tutored so his education would not suffer. His English teacher, Mr Middleton, agreed to tutor him, whilst we found a tutor for maths, history and art. Phil taught Gary woodwork at home.

30. At a routine annual check-up at St Thomas' Hospital in 1986, when Gary was age 15, Dr Savage informed us that Gary had been diagnosed with hepatitis B virus ('HBV'). Dr Savage said that he was sorry to have to inform us that Gary had HBV, and that he had been carrying the virus for 2 years. He also said that there was nothing we

can do, and that he could be dead within 10 years from cirrhosis of the liver and/or cancer.

31. This news was broken to us in a very matter-of-fact manner. We were told face-to-face in a clinical and cold statement. Dr Savage did not advise us as to how Gary had contracted the virus, nor did he give us any information about managing the illness. As a paediatric nurse, I did tell Gary and his sister not to share toothbrushes and cups, for example, though this did not come from the consultant himself.

32. I implicitly trusted the NHS as a nurse at that time. I did not know how devious and untrustworthy they could be. I simply thought that it was bad luck, and there was nothing we could do. As a family the news was devastating. As a mother to hear that about her only son was almost to much to bare.

33. Around June 1986, we received a phone call from the Royal Free Hospital. The caller, who was associated with Dr GRO-D, described a new 'wonder drug' called interferon which could be used to clear Gary's HBV infection. Gary was just coming up to sitting his GCE exams, so I agreed with the Royal Free that he would consider the treatment once he had completed his exams.

34. We had to pay the school so Gary could use the premises to sit his exams. Gary achieved a pass in all his GCEs, which got him an interview at Chichester College. He was accepted, and he went on to attend drama school there. We were very proud of him for achieving this.

35. Having sat and passed his GCE exams, Gary went in to the Royal Free Hospital in London to begin the interferon treatment under Dr GRO-D GRO- From the very start, Gary was appalled at the way he was treated. He was put in isolation on a hepatology ward, where he would regularly witness dead bodies being wheeled past him. This was awful

for a 15 year old boy to see. I remember that he said he felt like a Tetley tea bag whilst in the hospital. He had constant blood tests.

36. The first dose of interferon set the tone for what was to come. The interferon was administered intravenously, with 1ml administered per minute up to 12mls in total, with 3ml of flush water. This would take 15 minutes to administer in entirety. Gary's temperature would increase dramatically for the first hour. Then, almost exactly on the hour, he would have a terrible fit and shakes. After another hour, his temperature would gradually reduce, and his breathing would begin to return to normal. Altogether this ordeal would last for 4 hours and it became a regular pattern.

37. Gary received the interferon treatment every day at around midday for 10 days whilst in the Royal Free Hospital. Then, he was allowed to be treated at home as I was a qualified nurse. At first, the GP had to administer the interferon to Gary.

38. Throughout all this treatment, I strived to make life as normal for Gary as possible. Despite the awful effects of the treatment, I wanted Gary to be able to see his friends in the day, have meals at a regular time, and for the treatment to restrict him as little as possible. The GP surgery could offer two times, one at 9am, which would ruin the entire day for Gary, or at 6pm, which would interrupt his daily schedule just as much.

39. I decided to administer the treatment myself, doing so daily at 8pm so as to ensure Gary had a daily routine. I administered the interferon to Gary, knowing that if I gave it to him too fast it could kill him. I was also aware of the suffering he would have to endure after each treatment. This was the scariest thing I have ever done. I get very emotional when I think about this. Sometimes Gary would ask his Dad to lie on his stomach during the fits in order to stop the nausea.

40. Gary preferred me to administer the interferon to him at home, and he felt life became a bit less interrupted. This treatment continued for 3 days a week for 3 months, and we would not know if it had been successful in clearing the HBV for 5 years.

41. We were warned that the interferon treatment could change his character and cause some hair loss. This began almost immediately after the treatment ended. Before, Gary had long, thick hair. He combed it regularly, and after the treatment it would come out by the handful. His hair became thinner and thinner.

42. Gary had frequent check-ups at the Royal Free, possibly monthly, after the treatment had ended, though these became less regular. After 5 years we were told that Gary had cleared the HBV infection.

43. Around this time, Phil, Rachel and I went to Worthing Hospital to have the HBV vaccination. I believe that we were advised to do so by Dr Savage or GRO-D. We expected to be there briefly to receive an injection and then leave. Instead, we were put on a ward and had to lay on a bed for half an hour to check to make sure there was no reaction.

44. We began to notice that Gary's character had changed soon after the treatment had ended. Before the interferon treatment, Gary was a jovial and optimistic person. After the treatment, Gary's mood dipped. He was quieter and more subdued. He also adopted an attitude of 'If I am going to die then I will live life my way' and took unnecessary risks to augment his life.

45. Gary did not show immediate signs of severe depressive episodes, like he did later in life. He did not cry or appear like breaking down. Instead, he appeared like he had completely dipped, and I believe this was the start of depression throughout the rest of his life, caused by the interferon.

46. After this treatment, Gary studied drama at Chichester College for 3 years. He was also a drummer in a band, making enough money to

survive when living in Chichester and Brighton. He then went to the Academy of Live and Recorded Arts in Wandsworth for a further 3 years of study.

47. Whilst Gary carried on with his life, Phil and I had moved down to Cornwall. One day, around 18 months after having been given the all-clear from HBV, Gary phoned us to tell us that he had been diagnosed with hepatitis C virus ('HCV') infection. He was devastated and completely heart-broken.

48. On hearing the news, I felt devastated. My husband, Phil, was extremely angry. After all that Gary had endured, he was thoroughly annoyed that his son had to suffer more health problems through no fault of his own.

49. Shortly after after being told of his HCV infection, Gary was then informed that he did not in fact have HCV, but rather antigens to HCV. This suggested that he had the virus previously, and that the interferon must have cleared it. I was extremely angry at this news, and was disgusted that he had been put through all this stress. This anger extended to the system as a whole, for how the matter had been dealt with and communicated to Gary.

50. Recently Gary was also told by the hospital that he had never been treated for HBV and that they had no records of him receiving Interferon. I find this deplorable, of course they should have records, he was the first child in the UK to receive Interferon. Why are they hiding this?

51. I have been asked if I had ever been infected with Hepatitis, the answer is yes. I noticed that my eyes had begun to go yellow and I appeared jaundiced. Then, whilst at work, I started to feel excruciating abdominal pain. I knew that I had somehow contracted HBV, most likely from a needlestick injury when administering interferon or Factor

IX to Gary. I eventually got over it and did not receive any treatment. I have not been tested for HBV since this episode.

52. I believe that Gary is now clear of all hepatitis virus infections. I understand that he still has regular check-ups as regards his haemophilia.

Section 3. Other Infections

53. I believe that Gary was informed that he had antigens to hepatitis A, in conjunction with his HBV and HCV diagnoses, suggesting that he had at some time contracted hepatitis A.

54. I understand that Gary was exposed to vCJD from his treatment with Factor IX infected blood products.

Section 4. Consent

55. I believe that I consented to, and Gary consented to, his being treated with Factor IX in respect of his haemophilia B. I was not informed of any risk of infection as a consequence of receiving Factor IX blood products.

56. I did not consent to Gary being tested for HBV. To the best of my knowledge, Gary did not consent to being tested for HBV. I believe that Gary was tested for HBV without his or my consent for two years prior to him being diagnosed HBV positive. Dr Savage, when informing Gary of his diagnosis, said that he had been found HBV positive two years previously. They kept this from us for two years which I find deplorable.

57. I understand that Gary was tested for HIV around the same time that he was tested for HBV, though I was not informed of, and did not consent to, him being tested for HIV.

58. I believe that Gary was used as a guinea pig by being treated with interferon for his HBV infection. Dr GRO-D told us that Gary would be the first child, after a man in Scotland previously, to receive interferon treatment. We were not informed of the potentially severe side-effects from the treatment, primarily because this was a new treatment being used on a child for the first time.

59. I do not believe that Gary, Phil and I, were given adequate information in respect of managing Gary's infection with HBV. We were given no information as to how the virus may have been contracted, how to manage the virus and how to prevent others from contracting it.

60. I believe that I would have been aware of the risk of contracting HBV by administering interferon to Gary. I do not recall if I was made aware of the risks, though I would have been aware as a paediatric nurse.

Section 5. Impact

61. Gary's infections and treatment have had a massive impact on his life. I believe that Gary's mental health has suffered dramatically as a result of all this trauma. He always had a relaxed and laid-back attitude to life. He was an extroverted person with a great sense of humour, with everyone finding him fun to be around. Since his diagnosis with HBV, this side of his character was lost.

62. The interferon has taken a devastating toll on Gary. His depression can be traced back to this treatment, and his character has changed as a result. He has shown signs of GRO-C, GRO-C and PTSD. He is often angry and introverted, and we feel we have lost the son that we used to have. He has highs and lows, when he is on a high he has previously gone on massive spending sprees.

63. Gary's infections and illnesses have had a detrimental impact on his relationship with his sister. His sister would have liked him to be there for her, as he used to be her protector during their childhoods. Rachel,

GRO-C was unable to understand why her brother was not there for her during her divorce. Gary's depression meant he could not perform that duty at that time.

64. When Gary found out what was happening to him, he put a bubble around him and would not let anyone in. Since talking to the Inquiry investigators, which was the first time he has ever opened up about his experiences, he has started to become better at talking to us. He has begun to open up a bit more.

65. Although Gary has always dealt with things in his own way, the process of talking to the Inquiry, for the first time, has helped him a lot. He has begun to discuss things and get things off his chest. We have both noticed that his attitude has changed, he is more relaxed, and he is able to talk to us.

66. Gary no longer goes for orthodontic treatment due to his previous experiences. When he had a recessive mandible, the orthodontist was treating Gary with a brace. He explained that he could fracture Gary's jaw in order to pull it forward. However, when he was told that Gary was HBV positive, the orthodontist told him that he could no longer treat him. I cannot remember this mans name.

67. On our last visit to the orthodontist, he resembled something out of a sci-fi movie. He appeared excessively masked, dressed head to toe so as to prevent him from contracting the HBV infection. He then simply removed the brace and discharged Gary. Gary was extremely embarrassed by this, and has chosen not to seek dental treatment since.

68. Phil used to say to me that he felt the medical profession saw me as a 'fussy neurotic mother' whenever I questioned what the best treatment was for our son. I shared this feeling because of how I was treated by not only medical professionals but also the educational authorities, who I felt all had it in for me at one stage. I also felt at risk of being referred

to social services. Despite this, I would always do everything within my power to help Gary.

69. Witnessing our son go through such extraordinary suffering and pain during his treatment with interferon was traumatic for both of us. When administering the interferon to Gary at home, I knew that one mistake could kill my son. This was extremely traumatic, and still impacts me to this day.

70. GRO-C GRO-C I consider myself to be a strong woman, and I very rarely cry. GRO-C GRO-C GRO-C. I believe this shows how Gary's illness and the trauma has manifested itself on myself and Phil.

71. I have written and published a book that aims to inspire people to fight for their children to get the best medical treatment they need and deserve. GRO-C GRO-C. GRO-C GRO-C I feel strongly about this issue.

72. Phil and I have never spoken to anyone about this whole traumatic experience until now. We have not confided in friends or close family, choosing instead to deal and cope with it ourselves as a family. No one has ever understood what it has been like for us to deal with.

Section 6. Treatment/Care/Support

73. To the best of my knowledge, Gary has not been offered counselling or psychological support in consequence of his infection with HAV, HBV, and HCV, or for the effects of his treatment with interferon. We have never been offered any counselling.

Section 7. Financial Assistance

74. I believe that Gary applied for financial assistance from the Skipton Fund, for which he was told that he is not eligible.

75. My husband and I have not applied for, or received, any form of financial assistance as a result of Gary's infections from infected blood products. In fact we lost a lot of money due to the fact that I had to stop working to care for Gary.

Section 8. Other Issues

76. We both want the truth to come out and for this Inquiry to find out what went wrong. It is not about compensation or benefitting us. It must be ensured that this cannot happen again.

Statement of Truth

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

Signed GRO-C

Dated 8. 2. 2020