Witness Name: Louise Marsden
Statement No: WITN1371001
Exhibits: 1
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISE MARSDEN

I, Louise Marsden will say as follows:-

Section 1. Introduction

1. My name is Louise Marsden. My address is GRO-C GRO-C County Antrim GRO-C. My date of birth is GRO-C 1960. I live with my husband Trevor and our foster daughter Kirsty, who is 22. GRO-C She has lived with us since she was 12.

2. We have four adult children, Nicola Christie, Lucy Larkham, Rachael Garrett and Samuel Marsden.

Section 2. How affected

3. I make this statement in relation to my husband, William Trevor Marsden who was infected with Hepatitis C as a result of receiving contaminated blood products. He has given a statement to the Inquiry. His witness number is WITN1372001.

4. This witness statement has been prepared without the benefit of access to my husband's full medical records. If and in so far as we have been provided with limited records, the relevant entries are set out as exhibits to Trevor's witness statement.

5. My husband suffers from Haemophilia B. His Haemophilia has been diagnosed as severe.

6. There are details of some of the blood products Trevor received in his medical records. He received Factor IX Concentrate.

7. As far as I am aware, my husband was infected with Hepatitis C as a result of being given Factor IX at the Haemophilia Centre in the Royal Victoria Hospital (The Royal) in Belfast.

8. The Haemophilia Centre was relocated to the City Hospital in Belfast, which is where Trevor is treated now. It is still the same Centre, just in a different location.

9. When Trevor was a child, he was treated at the Royal Victoria Hospital, initially in the children's department under the care of Dr Jones. When he turned 18, Trevor was treated in the adult department under the care of Dr Elizabeth Mayne. After Dr Mayne left the hospital, there was another female Consultant who was hardly ever at the Centre, so there was a significant amount of time when Trevor was without a Consultant. The female Consultant who replaced Dr Mayne then moved to Canada.

10. Dr Gary Benson, who is now Trevor's Consultant, later joined the Haemophilia Centre from Southern Ireland. I believe that Dr Benson was brought in as he was from Southern Ireland, which had dealt with the contaminated blood issue in a robust and timely manner, unlike the UK.

11. I do not know when Trevor was infected with Hepatitis C. Dr Mayne told me that Trevor was infected in 1976, when he was treated in hospital for a sprained ankle with factor IX concentrate and a blood transfusion. I asked Dr

Mayne how she could be so sure about this, to which she replied that they had conducted a retrospective test. She explained that they had kept all of Trevor's blood samples and they had tested them until they found one that was clear of Hepatitis C. This predates the time that I knew Trevor.

12. In late 1976, Trevor was admitted to Purdysburn Hospital, commonly known as the fever hospital, as he became jaundice. We believe that was the first significant sign of Trevor's Hepatitis C infection.

13. I refer to Trevor's statement as to the extent of any information or advice he was given before receiving blood products about the risk of being exposed to infection. From what he has told me, he was never given any advice about the risk of being exposed to infection.

14. As a result of receiving contaminated blood products Trevor was infected with Hepatitis C.

15. In 1996, Trevor received a letter from his Consultant, Dr Mayne, which said that she had not seen him in a while, so he should go into the hospital for a review. This was new to us, as Trevor had never been called in for a review before. Trevor went alone to the appointment. He told me that Dr Mayne and Dr Orla McNulty were both in the appointment and they informed him that he had Hepatitis C.

16. Had I known that Trevor was going to be told this; I most certainly would not have let him go to the appointment on his own. Neither I nor Trevor had heard of Hepatitis C and what they told him put him in a state of shock. On his way home from the hospital, Trevor stopped midway at his maternal grandparent's house. From there, he phoned me at work to tell me what he had been told at his appointment about his Hepatitis C infection. He said that his head was spinning.

17. Trevor had no idea what the virus was. He was confused and shocked. From work, I went onto the dial up internet. The only information I could find about Hepatitis C was from the British Liver Foundation. The website provided very limited information about Hepatitis C. It did say that Hepatitis C could lead to

cirrhosis of the liver and ultimately death, if a liver transplant wasn't received. That was traumatic to read. It was like being hit by a juggernaut. Due to our lack of understanding, we started imagining the worst case scenario.

18. I do not think that adequate information was given to Trevor and me to understand and manage his Hepatitis C infection.

19. I strongly believe that Trevor should have been told about his Hepatitis C infection earlier. In Trevor's hospital records, which we obtained in 2017, I found a clinic note which said that at his next appointment, Trevor should be tested for Hepatitis B and C. This is exhibited to Trevor's witness statement. I have also seen a test result dated 1991, which confirmed his Hepatitis C diagnosis. When Trevor was told that he had tested positive for Hepatitis C in 1996, Dr Mayne didn't tell Trevor about the 1991 test.

20. In 1997, Trevor and I attended a consultation with Dr Mayne. My overriding feeling from that meeting was one of being patronised. I asked her several questions to which she provided no answers. She simply stated that what I was asking was for more information than I needed to know and that I shouldn't worry about it. She offered to test me for Hepatitis C, but at the same time told me that I did not have the virus. Why was there a need to test me then? I did have the test in 1997 and I tested negative. I exhibit my Hepatitis C test result dated 25 February 1997 at WITN1371002.

21. I strongly believe that Trevor should not have been seen by himself when he was told about his Hepatitis C infection. The manner in which he was told was criminal. The doctors were dropping a bombshell on Trevor's life and they didn't consider the consequences. I know from speaking to Trevor how distressed he was after the appointment. There was a complete lack of empathy from Dr Mayne.

22. Initially in 1996, no information about the risk of transmitting his Hepatitis C infection was provided to Trevor. In later consultations, as a spouse, I asked Dr Mayne if I could be infected with Hepatitis C by having unprotected sexual

intercourse with Trevor, to which she answered no. I later found out that this was incorrect.

23. I don't feel that we were fully informed about the implications of Trevor's Hepatitis C infection and the risk of transmission until he was on his second course of treatment in 2006. There was no openness or transparency in giving infected people and their family's information.

24. Some information came through the Haemophilia Society who tried organising information sessions, but we were separated from events on the mainland. Things happening on the mainland didn't reach Ireland. We were invited to information sessions, but there were cost implications and no assistance was given for travel or overnight stays. We therefore couldn't afford to attend these sessions in England.

25. Shortly after Trevor's diagnosis, we attended a meeting facilitated by the Haemophilia Society at which Dr Mayne used an analogy to describe the risk of transmitting Hepatitis C. I had brought up the topic again and asked her how Hepatitis C could be transmitted. She said that if she put a drop of blood on a work surface which was infected with HIV and another which was infected with Hepatitis C and she bleached and wiped away the HIV, that would sterilise the surface of HIV and there would be no risk of transmitting the infection. However, she said that Hepatitis C was a clever virus and the infection would not be killed simply by bleaching the surface, so the risk of transmitting the infection remained. She implied that the smallest bit of blood or bodily fluids could transmit the infection to others. That was shocking, particularly as we were living in a family unit with four young children.

26. In 1983, Dr Mayne called an open meeting for Haemophiliacs at the hospital and she announced that everyone there would be tested for HIV. She gave the Haemophiliacs present the choice of whether they wanted to know the result of their HIV test. I found that bizarre. Nevertheless I put up my hand indicating that Trevor wanted to know his HIV test result. Dr Mayne told the

nurse to mark down that Trevor didn't want to know, but that Mrs Marsden did. I felt patronised and belittled by that. Trevor's HIV test result was negative.

Section 3. Other Infections

27. In 2001, Trevor received a letter from Dr Jones, his childhood Consultant, about vCJD. He was informed that he may have received blood products from a patient who donated blood and had subsequently died of vCJD. In the letter, Trevor was asked if he was identified as a patient who had received such products, did he want to know? Trevor returned the form indicating that he did want to know. I thought it was a strange way of telling someone. It was a repeat of the HIV meeting.

28. Subsequent to the letter from Dr Jones, Trevor was invited to Birmingham for a meeting about vCJD. All expenses were paid and he was allowed to take a family member with him. Trevor didn't want to go to the meeting, but I convinced him to go.

29. It was set out like a conference. We flew to Birmingham and back to Ireland on the same day. We were placed at small round tables with two clinicians. We were told that the reason for the invite was that Trevor had received blood products from someone who had died from vCJD. I assumed that the clinicians were there in case someone had a breakdown. This was very similar to the meeting regarding HIV.

30. At the vCJD meeting I stood and spoke. I said that the elephant in the room was the anger that the Haemophilia community, the infected and the affected feel. Following this meeting, we did not hear a word from anyone. There was no follow up consultation and nobody has been in touch to see how we are coping living with the possibility that Trevor may develop vCJD.

31. When we went for the HIV meeting in 1983, the hospital/clinicians reassured everyone that they were there to look after us, and that they would ensure that that kind of meeting would never happen again nor would such a threat arise again, yet we were back in that situation again with vCJD.

32. In the course of Trevor's medical records being reviewed by our Solicitor in order for her to prepare Trevor's statement for the Public Inquiry, she has identified that Trevor tested positive for Parvovirus and CMV in 1996. She also found reference in Trevor's records to evidence of past infection with Hepatitis A and B. This was a huge shock to us both. We were never informed of these further infections by Trevor's Consultants.

33. We didn't think that Trevor would be found to have any further infections. We thought we knew everything there was to know. We plan to make an appointment to see Trevor's Consultant to discuss these infections with him.

Section 4. Consent

34. In 1983, at the HIV meeting, Trevor and the other Haemophiliacs were, without having been asked for their consent, told that they would all be tested for HIV. We had had Nicola in 1982 so we were both extremely concerned that Trevor was infected with HIV and that it may have been passed to her. The misinformation and hysteria was awful.

35. I believe that Trevor was tested for Hepatitis B and C in 1991, although he was not told about his Hepatitis C infection until 1996. He did not know about or consent to the Hepatitis C test. Trevor was therefore obviously tested without his knowledge, consent and without being given adequate or full information. In addition to this, the retrospective tests referred to in Paragraph 11 above were also carried out without his knowledge or consent.

Section 5. Impact of the Infection

36. I first met Trevor in 1976. We started going out in 1979. He was 17 at the time. He was lean and six foot tall. He rode horses and motorbikes to bring his cattle in. He would wake up at 5.30am every morning and go to bed at 11pm, sometimes later, as he worked so hard on the farm. He was a workaholic and

fit and healthy. If he wanted to do something, as long as he put his mind to it, he could do it. Things changed dramatically in 1990.

37. In 1990, Trevor began to feel very lethargic and unwell. He was struggling to overcome his tiredness and his ability to work on the farm was being affected. The changes in his physical and mental health were obvious. Our financial situation began to deteriorate as Trevor was unable to work as much as he normally did. Trevor could not produce the income he was once able to. I therefore returned to work to help alleviate the financial pressure we were under.

38. In 1991, when unknown to us, Trevor had tested positive for Hepatitis C, I became pregnant with Sam. Due to our financial struggles, I considered having an abortion. I did not know how we would cope with another child financially, but I went through with the pregnancy whilst working.

39. Between 1990 and 1992 I worked for Legal and General. In January 1993, I joined a law firm called Towry Law.

40. Between 1993 and 1994, whilst I was working at Towry Law, Trevor would phone me at work to ask me about things he had forgotten. I noticed that Trevor was suffering from memory loss and would constantly need prompting if there was something that needed to be done. His regular phone calls became an issue for me at work. At the time there were no mobile phones and all calls to work came through reception. The frequency of Trevor's calls was clocked and my boss accused me of running the farm business from the office. Because of this, in 1994 I was made redundant. I was distraught about this.

41. I managed to get another job in financial services in Ballymena, 26 miles away.

42. Things between Trevor and I were difficult at that time. In conjunction with this, my parents also came to live with us. My father died in 1989. My mother benefitted from a small pension which I viewed as a godsend at first.

Unfortunately, tensions arose and my relationship with her went downhill when Trevor and I started arguing.

43. My in-laws had been against our marriage, so my relationship with them was stale. They assigned a third of their farm to Trevor. Trevor was therefore unable to control the entire farm business, as his parents owned the remainder of the land in their names.

44. Trevor purchased a hundred acre farm having borrowed money from the bank at a high interest rate. After Trevor bought the new farm, he struggled with its upkeep. My mother witnessed many arguments between us about it. At that time, my relationship with Trevor was breaking down.

45. The tensions in our relationship were not helped by the fact that Trevor had made a lot of decisions without me. He sold his uncle the purchased farm for no consideration. He also sold the same uncle some machinery. He should have walked away from that deal with money, but he completed the contract without discussing it with me. I only discovered the sale after it was complete. Trevor was not thinking rationally in making these decisions.

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47. Thankfully, my children did not turn against me, but Trevor was fragile and he started believing what other people were saying, that I was his enemy. Trevor thought that if he went back to being a single man everything would be alright, as his health was okay when he was single. He was in denial about his Hepatitis C and he still had faith in Dr Mayne and he thought that she would call one day and say it was all a mistake and that he did not have Hepatitis C. Trevor's cognitive ability was totally impaired.

48. In the late 1990s, as is stated in his medical records, Trevor was not sleeping. He told me that at night he was stood over me watching me sleep, imagining that I was in a coffin. I went to our doctor who said to take Trevor to Muckamore Abbey Hospital for a mental health assessment. However, Trevor

refused to go to the hospital for an assessment. I felt desperate and isolated. My sounding board and rock was my friend Laura who kept me on the straight and narrow. She said that she thought that I had to decide whether I wanted to keep my family together and stand strong, or if I wanted to cave in. I chose to stay and fight to maintain my family.

49. In 1996, when Trevor was first told about his Hepatitis C infection it was like he was pushed over the edge of a cliff. Our relationship deteriorated GRO-C GRO-C He was depressed, lethargic, confused, and had chest pain and paranoia. Some of that was expressed to our children, mainly Lucy and Nicola who were old enough to understand what was happening, although Rachael and Sam were also exposed to this.

50. Trevor and I were fighting like cat and dog. Trevor's parents and siblings became aware of the tensions in our household, but at that point, none of them knew that Trevor had been diagnosed with Hepatitis C or were aware of his mental and physical symptoms. I felt his family blamed me for the problems we were having.

51. Trevor and I hardly knew anything about the Hepatitis C infection at that time. Trevor and I were careful about the conversations we had at home in case the children overheard.

52. At the time, Sam was only 4 and Rachel was 7. Under the belief that the risk of transmission was high, we had to ensure that Trevor's shaver was kept away from the children and that our teenage daughters, Nicola and Lucy, did not accidentally use his razors to shave their legs. We had told the children not to use his toothbrush. I had to effectively isolate Trevor in order to minimise the risks to the rest of the family and it was all because of the analogy used by Dr Mayne. I used to bleach Trevor's toothbrush everyday, despite Dr Mayne's advice. I felt I had to do something. I was paranoid. Our family life suddenly flipped from one day doing normal things to not doing normal things.

53. I am better educated now and I know that the risks weren't nearly as serious, but at the time my priority was my children. When Trevor was experiencing the symptoms of Hepatitis C, my overriding thoughts were about their safety. I was primarily concerned that they could get infected and I had to do my best to ensure that they knew not to do certain things which could put them at risk without telling them why. This caused them obvious confusion and my children asked questions about why their father's toothbrush could not be near theirs.

54. At that time, Trevor and I decided not to tell the children about his Hepatitis C infection. Firstly, because we didn't know much about it ourselves and were not in a position to explain it to them and secondly, we didn't know the impact it would have on their lives. We wanted to protect them, especially socially and emotionally.

55. Trevor first received treatment in the late 1990s. The hospital described the treatment as being akin to insulin for diabetics. They gave him a pen and said that he just had to lift his jumper, put the pen in his liver area and click it in and then take some tablets. At no point was he warned about the side effects of the treatment that were to follow. Trevor was told to inject himself on alternate days and was told that if anything untoward happened, he should call Ward 22 at the Royal hospital. This was a clinical trial involving Interferon and Ribavirin that was supposed to last six months.

56. The first time Trevor injected himself, he said he was not feeling well and decided to take a bath. Once Trevor was in the bath, he was unable to get out. My daughters had to help me get Trevor out of the bath and into bed, as I wouldn't have been able to lift him by myself. The last thing Trevor needed was to have his teenage daughters seeing him naked and having to help him get into bed, but that was how weak the treatment made him.

57. Even when Trevor was in bed and wrapped in a duvet, Trevor was shivering in a manner that I can only describe as an epileptic fit. It was terrifying and no matter what I did, he couldn't get warm. I was running up and down the hall

shouting at my children to prepare hot water bottles, which I was packing around Trevor. My children were in meltdown, crying and hysterical asking what was wrong with their Dad and if he would die. I had no answer for them.

58. I was torn between comforting my children and caring for my husband. I phoned Ward 22 at the hospital, only to have the nurse tell me that it was simply flu like symptoms, a common side effect of the treatment. She told me to give Trevor paracetamol.

59. I left Nicola and Lucy to care for Rachel and Sam. Trevor could barely lift his head off his pillow to have a sip of water, so I had to stay by his side.

60. Trevor lost all of his confidence due to the degradation and embarrassment he felt as a result of his treatment.

61. Aside from Trevor and me, nobody knew that when Trevor was undergoing his first course of treatment in the late 1990s, Trevor was suicidal. He attempted suicide GRO-C

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GRO-C he would refuse to go to hospital or seek help, as to him, that was an admission of failure and others would find out the impact the Hepatitis C was having on his life.

63. His attitude was that he was going to die anyway, so what did it matter if he died then or later. He took a lot of risks. I honestly do not know how he survived.

64. As the side effects of each injection and set of tablets began to wear off, he knew he had to have another injection and go through it all over again. Trevor could not cope and there was no solution for him. He must have been on the treatment for two or three months before giving up, as he was unable to take anymore. The hospital reassured us that Trevor would have a second chance at the treatment.

65. To everyone else, Trevor was fine and all our issues stemmed from marital feuds. Only those at home knew the truth. Whenever anyone asked Trevor how he was doing, he would say that he was fine. He is the same today. On the surface it seemed like he was coping, but he was not.

66. I wanted Trevor to attend counselling, but he didn't want to go as he believed there was nothing wrong with him. I tried my best to keep our relationship alive and to maintain the intimacy and dynamic, GRO-C GRO-C so that another issue we had to overcome.

67. I was terrified as Trevor was ill with Hepatitis C and his treatment had failed. I had four children and I had no idea what our future held. I knew from seeing Trevor's condition that I couldn't go through what he was going through. As a bare minimum, my children needed one parent and in order to look after Trevor, I had to be healthy, as there would have been nobody to help me if I became unwell.

68. We tried to live as normal a life as we possibly could. However, my daughters had to take time off school to help me at home. I wrote notes to their teachers saying that they were sick and I told my work that I was sick. My sickness absence resulted in me being given a disciplinary.

69. Meanwhile Trevor was still concealing the truth about his Hepatitis C from his parents.

70. In the early 2000s I clawed back my family and my relationship. This caused a rift between me and my sister. In 1999, I had to ask my mother to leave our house as she was not helping the situation with Trevor. My sister was furious, but I did what I needed to improve the situation at home.

71. I also made changes to our lifestyle, particularly our diet, ensuring that we ate healthily and well. Our social life was practically non existent.

72. After my mother left the house things improved between Trevor and I. Credit must also be paid to Nicola and Lucy who bore the brunt of helping me care for Trevor.

73. The further medical complications Trevor has from Hepatitis C include cirrhosis of the liver. Trevor's memory has been badly impacted and he was diagnosed with Alzheimer's at a relatively young age. If you give Trevor too much information or ask him for too much, he gets easily confused and that gives him anxiety. Although he was prescribed medication for his Alzheimer's, he refuses to take it.

74. In 2006, Trevor once again braved the Interferon and Ribavirin treatment. This was now Pegylated Interferon which, at the time was new. We had considerable difficulty getting Trevor a second round of treatment, as we were initially told that the drug would not be given to people who had already had a course of treatment which had been unsuccessful. We were told this was because Pegylated interferon was a costly treatment. Eventually Trevor was given a second round of treatment.

75. Trying to get Trevor to remain on the second course of treatment was an absolute nightmare. As with the first course, he had awful side effects. This time his hair also fell out. His mood swings meant that he was angry, frustrated and depressed.

76. The treatment reduced Trevor's white blood cell count, so he had to take Neupogen to strip the white blood cells from his bone marrow in order to maintain a reasonable immunity level.

77. During the second round of treatment, Trevor and our family were in a better place. However, Trevor still wanted to come off the treatment early, as a year was a very long time to be on it and again he had to inject himself every other day. I had arguments with Trevor about staying on the treatment. Rachel once told her father that he had to stay on the treatment, as he had to walk her down the aisle one day. Trevor pulled through and the treatment was successful. He was told that he had "cleared" Hepatitis C in 2007.

78. In the 1990s, Collette McAfee, a nurse at the Haemophilia Centre informed us that there was no treatment for Hepatitis C. I do not know if there were other

treatments that ought to have been offered to Trevor as I do not know what was else was available. I believe that at some point, some form of counselling or support should have been given to Trevor to help him through the treatment.

79. If Trevor required dental care, he would have to go to the School of Dentistry based in the Royal hospital. Before Trevor went into the dentist's room, everything was covered in plastic, including the chair. All the equipment used on Trevor would be destroyed following his appointments. Some of his other hospital care was also poor. Once, I accompanied Trevor to an appointment, only to be told that the consultant had gone out to play golf. When Trevor broke his leg in three places, instead of caging it, they put him in a plaster. Because it was not caged, he now has an issue with his mobility.

80. Trevor was only told in 2006 that because of his Hepatitis C there were certain things that he could not eat. He had been eating the food he was told not to eat for years with his Hepatitis C. If he ate a cream bun, he felt like someone had kicked him in the liver. We had to tone his diet down completely as what he ate affected his brain.

81. Trevor has never been a massive drinker, but if we went out for a meal and someone offered him a glass of wine, as his wife, I would intervene and stop Trevor before he accepted it. People saw me as a controlling wife. Trevor could probably manage a glass of white wine, but any more would put him on edge. If he had a glass of red wine, within an hour he would have terrible stomach pain.

82. There are things Trevor would have loved to have done in his life and would have been capable of doing but for his Hepatitis C infection. He would have loved to pursue his interests of motorcycling, horse riding and hunting more than he has been able to.

83. Much of Trevor's social life revolved around the farm. Had Trevor not been infected with Hepatitis C, he would have been able to keep up with its maintenance and I believe that we would have had more opportunities to

expand and diversify on the farm. Financially we would have been much better off.

84. I was born in December. When my children were younger, when I got birthday presents I gave them to my children for Christmas or I returned them in exchange for money. I borrowed money from my sister as things got that bad. Trevor found out and we argued about it. There was a lot I could not discuss with Trevor, which I should have been able to without worrying what his reaction would be.

85. Trevor's head was in the clouds and he was unable to think things through with a rational mind due to his cognitive difficulties. Before I shared something with him, I would wonder whether he would understand what I was saying or how many times I would need to repeat it in order for him to understand.

86. In 1983, when Trevor was tested for HIV, it was the sliding door moment in terms of his attitude to his Haemophilia. At that point, he stopped telling people about it. He was very aware of the stigma associated with Haemophilia. As parents, we also restricted the information we gave our children, as we were afraid of the impact any possible stigma would have on them. It was a terrible way to live, especially considering we lived in a small community.

87. Trevor and I are asset rich, but income poor. Our home is in a state of disrepair. There is mould on the ceiling, and cracks in the walls. We cannot afford renovations. We are currently living on benefits and the small bit of assistance we receive from the funds. GRO-C
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88. Over the years, we have received numerous repossession orders due to mortgage arrears and we have a considerable amount of debt. We took out a mortgage with GE (later sold to Engage Credit in 2012) to consolidate previous debts.

89. I used to work in financial services and there was a requirement for employees not so have too much debt or County Court judgements in their name. I could not fulfil that requirement and so it got a point where I was no longer able to work in that field.

90. The money we acquire from selling land goes mostly toward clearing our debts. I estimate our total debt is around £60,000. We make monthly payment towards this of £750.

91. Trevor is unaware of the level of debt we are in and if I told him, it would only add to his stress levels. I have therefore shouldered the entire financial burden. We have accumulated £10,000 in fees alone.

92. Thankfully, my children have succeeded in their lives and have done extremely well for themselves. All three of my daughters live close by and I sometimes wonder whether they have limited their career choices by not moving too far away from their Dad due to his health.

93. At one point Rachael's husband talked about them moving to Canada where his family live. He thought it would be lucrative for them to move there. I think they didn't go because of Trevor's health.

94. My children are extremely supportive of us. If Trevor is in hospital, they walk over broken glass to see him and they call us all the time to check on how we are.

95. My children grew up caring for their Dad and as a result they are incredibly protective of him. This can be burdensome on me sometimes. If anything is wrong with Trevor, they ask me what my plan is and expect that I will have a solution.

96. In spite of the medical professionals, and those who took advantage of us, the Marsden's survived. I do not know how we did it. I think of all the moments where a bit of practical help and support would have gone an awfully long way. I tried my best to control everything for Trevor so that there was the least impact on him in every aspect of his life. I do not feel that anybody helped us.

97. I suffer from anxiety and insomnia due to stress I have been under over the years. I developed a broken sleeping pattern. I occasionally take sleeping tablets and anti-depressants now; however I am not keen on medication, so I only take them when I really need them.

98. At times, I have also been unable to eat. I have always tried to stay physically healthy, as I cannot afford to be sick, as I need to look after Trevor.

99. Trevor's brother eventually found out about Trevor's Hepatitis C. Trevor also told his parents, but by then, Trevor didn't need their help or support. Trevor only told his parents about the risk of him having vCJD in 2018, eight years after he found out.

100. The looming threat of vCJD has made things very difficult for Trevor. Our faith in the medical profession has been shattered by everything that has happened to Trevor.

101. Trevor now refuses to see a doctor. They lied to him when they told him he may have HIV in 1983, they failed to inform him of his positive Hepatitis C test in 1991, and they lied about treatment. We have no interpersonal relationship with our doctors. Trevor is cautious about what else doctors could be hiding from him.

102. As a family, we feel very angry about how the contaminated blood scandal has been dealt with, particularly the time it has taken for us to be heard. If there is to be some form of compensation paid out, at the very least, we would be able to free ourselves of debt. We do not have life insurance to help our children if we died tomorrow and our debts are not their responsibility. Trevor and I did not envisage this sort of life. We have no mass of money to do the things that, at our age, we would have wanted to do. We wanted a comfortable life.

Section 6. Treatment/care/support

103. In 1999, I sought counselling for myself, which I paid for privately. That was a difficult thing to do, because we had very little disposable income.

104. After his diagnosis of Hepatitis C, we were told that because it affects the liver that there would be joint clinics for all the haemophiliacs with a Haematologist and Hepatologist present. I went with Trevor to one of these clinics with the understanding that the clinics would be a regular thing, but that was the only time Trevor was ever invited to a joint clinic.

105. It has certainly never felt that anybody was willing to help us.

106. There have also been inconsistencies between different tiers of the medical profession. Dr Mayne once prescribed Trevor some evening Primrose Oil, and the GP practice called me to say that they could no long prescribe that to him any more.

107. No support was ever offered to my husband or our family in consequence of what happened. We struggled and even the smallest bit of support would have helped.

Section 7. Financial Assistance

108. I found out about financial assistance through the Haemophilia Society.

109. Trevor entrusts his finances to me. I completed all the applications for financial assistance.

110. In order to apply for assistance from the Skipton Fund, we had to have their application form completed by the Haemophilia Centre to confirm Trevor's Hepatitis C diagnosis, how he had contracted the infection and the severity of his infection. Trevor was paid a £20,000 lump sum from the Skipton fund.

111. In March 2019, I received an email from the Caxton Fund stating that Trevor and I would collectively receive £341 per month. We were told that those in

Northern Ireland would receive their payments from a government department.

112. We were told that if we wanted to apply for ad hoc grants, they would be discretionary and means tested.

113. When applying to the Caxton Fund for the monthly payments there was a lot of paperwork involved. We had to justify how the money we were claiming would help us. Trevor gets cold easily, so I applied for thermal underwear for him. I had to justify this and describe to them exactly how such items would help him. It was ridiculous. I practically had to write an essay. Getting financial assistance should be straightforward and simple, and not like a job application.

114. Because of the difficulties involved in applying for financial assistance, we have never applied to the Business Services Organisation who runs the Infected Blood Payment Scheme for Northern Ireland. Everyone has their self respect.

115. My view of the various trusts is that they are unhelpful and purposeless. I believe that there are an awful lot of people who have unreasonably benefitted from the funds, whilst there are those who have suffered who have received next to nothing. I feel that the Haemophilia Society was commended, whilst people like the Marsden's were involved, but not helped.

Section 8. Other Issues

116. Trevor cannot obtain life insurance due to his health conditions. Our house is also currently uninsured.

117. God knows how many people who were infected will be dead by the end of the Inquiry. Some we know, some we don't. I empathise with them and their families and I feel their pain.

118. The use of contaminated blood should never have been authorised. People made decisions based on money and believed that the haemophiliacs were seen as a perfect control group. They were the perfect candidates; they were compliant, they paid their clinicians regular visits, anything that could have happened to them would not alter the fact that they were already living with a condition which impacted every aspect of their life. I feel there was an attitude that, in any case, Haemophiliacs life expectancy wasn't that high. I don't think anybody thought Trevor would survive as long as he has.

119. I am distraught that the UK, the mother of all Parliaments, has failed to protect their nationals and has been so incompetent in dealing with this issue, whilst Southern Ireland dealt with it more robustly. They had their tribunal, and paid out their compensation as did other countries around the world.

120. Trevor is good friends with Samuel Wilson who happens to be our local representative for the Democratic Unionist Party, whom Theresa May had to form a coalition with to gain a majority in Parliament. When the Public Inquiry was finally announced, I knew that Samuel would have played a part in the Public Inquiry being announced. I am ever so grateful to Samuel, as I know that the Conservative Party would not have done it.

Anonymity

121. I do not wish to be anonymous and I wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed……………………………………………

Dated……………………………………………

Signed. GRO-C

Dated. 11/4/19