Witness Name: GRO-B
Statement No: WITN0637001
Exhibits: 1
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on GRO-B and live at GRO-B GRO-B. I have GRO-B GRO-B living with me, and I also have a GRO-B who has left home. I work as a GRO-B

2. I make this statement as the widow of GRO-B: H, who was infected with Hepatitis C as a result of receiving contaminated blood products and who died on GRO-B at the age of GRO-B

3. **This witness statement has been prepared without the benefit of access to my late husband's full medical records.**

Section 2. How Affected

4. H was diagnosed as a Haemophiliac at the Singleton Hospital Swansea (SH) in 1982 when he was about GRO-B years old after he injured himself playing football. He was treated at the Haemophiliac Centre at SH under the care of

Dr Ishnall and then Dr Chinla where he was treated with Factor VIII concentrate.

5. When I met H in about GRO-B he told me he was a Haemophiliac. I believe no information as to the possible risk of infection was ever given to H before he was given Factor VIII; they just gave the factor to him without explaining any risks.

6. H was told that he was Hepatitis C positive in or about July 2005. I remember this because we had booked to go on a holiday to Florida in the USA in August of that year through a friend who had a travel agency in GRO-B. H had to phone the insurance company to inform them about his Hepatitis C infection.

7. I was not with him when he was told he had Hepatitis C; although after his diagnoses I made sure that I went to most of his further appointments.

8. As far as I am aware, no information or advice about how to manage the infection was given to H when he was told he was Hepatitis C positive. He was only told that there was a risk I might have contracted it as I was his partner. As a result I was tested for Hepatitis C. Fortunately the test came back negative. I was given no information or advice to help me understand the consequences of H's infection. I feel that detailed information should have been provided to both of us, and we should have also been given any information and advice in writing and at an earlier stage.

9. My sister GRO-B was a GRO-B at SH working in the GRO-B department for about two years. She was present at many consultations when patients were told by the consultants they had Hepatitis C and she informed me that the doctors such as Dr Chinlai, when telling patients they had Hepatitis C, would provide them with very little information and they considered that 90% of their patients developed Hepatitis C, because of drug or alcohol abuse and the other 10% accidently.

10 H was shocked when he found out that he had been infected with Hepatitis C. The doctor said it was because he was a Haemophiliac, but that made no sense; no mention was made that it was because he had received contaminated blood products.

11. He was told he had Hepatitis C in the medical, very matter of fact way. We received no letter confirming his diagnosis and no compassion, empathy or understanding of the circumstances.

12. My view from when H was having treatment was that it was always just assumed that he was an alcoholic; people were very judgemental.

Section 3. Other Infections

13. I also believe H may have been infected with vCJD as a result of being given contaminated blood products as I recall him receiving a letter from the NHS saying he could be at risk of being infected with vCJD.

Section 4. Consent

14. I believe H was tested without his knowledge or consent as he was not told he was being tested for Hepatitis C

15. Whilst I am not sure, it is definitely plausible that they would want to test him for research purposes.

Section 5. Impact of the Infection

16. Before his infection with Hepatitis C H was a loving, caring man who was also very outgoing, and who was always there for his family and attended social events; he was a *'hands on'* father. This infection changed him completely. He became a withdrawn introvert and was depressed. H lost his spark. Everything was taken away from him.

17. After his diagnosis, H was in a state of shock. He was normally a decisive man but suddenly he just did not know which way to turn. He was so worried about having an intimate relationship with me; he was also very worried and concerned about the stigma surrounding his infection. H became a shadow of his former self with the weight of the world on his shoulders.

18 H went through gradual changes. In September GRO-B He had gastric problems; namely a blockage and a strangulated hernia, which was originally Dr Mark Ritchie mis-diagnosed as gastroenteritis. Later, H had a fall and his bowels opened and I noticed that his stool was all bloody and black.

19. At this time H was taken to Morritson Hospital Swansea. When we got there the doctor just wanted to send him home, even though I was adamant that H was dehydrated and there was something seriously wrong, the doctor just would not listen.

20. I then took H to the A&E department of Morriston Hospital Swansea (MHS) and I made him wait to be seen. As he could not have a scan at that time they took him onto a Ward. H should never have been sent home by the doctors at the hospital. He was weak and ill-equipped to be going home. It was a dangerous discharge. The A and E department kept H in overnight, and kept him in a ward to await further tests.

21. The next morning I received a call from a nurse at MHS who informed me that H was very ill; life threatening sick. I arrived in about five minutes and sat in the room. The clinician made me feel H's stomach and explained that he had a hernia. I told him to get H in to surgery, which they eventually did. From my recollection, I do not think that they needed to use any blood products as there was not enough bleeding that it was required.

22. My daughter knew her father was ill but my sons did not. The surgery lasted for three hours and then H was in ITU for 3 days under the care of Dr Roger Morgan who explained that H had suffered a blockage and a

strangulated hernia. If I had accepted the original diagnosis H could have died.

23. After his operation, H wanted to come out of hospital for Christmas. He stayed in hospital for a week following his operation and then came back home on Christmas Eve.

24. The doctor had said that the surgery itself went well, but the symptoms that H was still suffering from were as a result of his other problems and conditions that he already had. H never truly recovered after this. He had liver failure and cirrhosis. Dr Lucy Noonan Croft came round to visit H on her own accord to check up H after he came out of hospital. I was asked to leave the room while they spoke.

25. I spoke to H afterwards and he said that he did not want to go back into hospital, he just wanted to be left alone and have some time to reflect; I think he was in denial. He refused carers and only wanted me to look after him. I was not working then so I was able to care for him.

26. In or about GRO-B H started on Interferon and Ribavirin treatment. The nurse taught him how to administer the Interferon injection himself. I did it for him once when he could not, but other than that H would administer the injections himself. Unfortunately the treatment did not work. H was told this was because he was overweight.

27. H lost four stone and tried the same treatment again two years later in GRO-B but it still did not work. These were the only two treatments he had for his Hepatitis C infection.

28. Whilst H was being treated with Interferon/Ribavirin he suffered from tiredness, diarrhoea, nausea, headaches, lack of energy and found it difficult to concentrate. He had severe mood swings, depression, anxiety and fatigue. H lost a lot of weight too although his stomach was still big from ascites.

29. There was a long time between the diagnosis of H's Hepatitis C and his eventual treatment, although he had liver function tests during this time. H developed cellulitis on his legs as a result of his liver disease and was in hospital for three months from GRO-B to GRO-B. He was told he had Esophageal varices in his throat, and would bleed from them. The worry was that he would bleed to death like this. Eventually H was sent home with 21 different types of medication, which was eventually reduced down to 11 types.

30. H fell several times at home and our sons would help him up. I tried to make him start sleeping downstairs, but he refused. His legs would weep with water from his cellulitis and so I slept on the sofa for about three months.

31. I remember when H was in hospital an Occupational therapist, nurse and physiotherapist spoke to him but they did not even come and look at his house before they sent him home. If they had, they would have seen the house had stairs which he could not climb. He could not walk and the bathroom was upstairs.

32. H's legs would weep liquid. He should have been ordered a hospital bed from when he left the hospital. It would have saved an enormous amount of work and stress if the Occupational therapist had used some kind of forward thinking of the situation and attended the house and carried out a proper assessment.

33. The Occupational therapist would ask me what supplies I needed. I did not know. I thought he should have been telling me as he was the Occupational therapist and should know what was needed.

34. In GRO-B we had an appointment at QEH where H was to be assessed for a transplant. Transport was arranged by the ambulance service who knew of H's problems. Unfortunately an ordinary car came to pick H and me up. The car was small and with H's physical condition, he required more space for his legs. The driver started getting angry and said

that he was going to be late. The stress caused H to have an anxiety attack so he got out of the car. The driver just left us there and then H collapsed in the street.

35. This was an ill equipped and inadequate service to transport H There should have also been a paramedic on board too. One mistake is forgivable but multiple mistakes are unacceptable.

36. After explaining to the hospital what had happened, a further appointment was arranged at QEH in GRO-B. Once we got there and saw the consultant that would carry out the transplant, I explained that I had all H's documents and that he was on beta-blockers. She agreed that H could be considered for a transplant and that his genetics be tested to find a compatible match. We received a letter in GRO-B asking H to have some initial tests and checks which would be required before a transplant could go ahead, but by this point H had already passed away.

37. H died in my front room in front of me and my eldest son. I have suffered from PTSD after witnessing this. It has also had a big impact on my son. He now suffers from serious anxiety issues and he does not go out anymore; he does not believe that people understand him or his position and he has become very withdrawn.

38. I have flashbacks of the moment H died. I remember H was in the bed and my son was standing up. I said not to worry. H was shaking and so I put him in the recovery position and called the ambulance service, the operator said to lift H off the bed and perform resuscitation on him. H had toxins going to the brain from his liver.

39. My youngest son was working but was on anti-depressants after losing his father like this. My GRO-B also gets depressed but she has never been on medication; she is resentful of what happened.

40. My grandchilden have missed out on having a grandfather. H saw one his grandchild, but died two days after her first birthday.

41 H was a chef and he could not work after he became ill; he stopped working in GRO-B after his surgery. He went back to work for a short period of time but he could not manage it.

42. His workplace wanted to know why he was off work so often and the head office said they would get his medical records and check. H did not want this and so he effectively took long term sick leave.

43 H's illness had a catastrophic financial effect on us. We were not able to go on holidays or take out travel insurance. Our last proper holiday was in 2005 when we went to Florida.

44. The last holiday we had as a family was to North Wales in 2012. H found it difficult and he was tired but he made the most of it for the kids.

45. We were also unable to take out any life insurance for H because his condition became too advanced, and we were refused. Financially, I was left with nothing because I had nothing to fall back on. The mortgage was already in arrears prior to H's death because I just couldn't maintain it. We were struggling with benefits, and they did not cover the mortgage. The mortgage lenders were understanding and reduced the amount but after he passed away I had to play catch up but I didn't have the financial stability to do so, and I was grieving for the loss of my husband.

46. I eventually manged to get some help from my siblings, and my big brother who didn't want me to be homeless. He knew how it was to lose a partner, and knew what I was going through. Thankfully I still live in the house I shared with H.

47 H was also refused disability benefits by a panel, even though he could hardly walk.

48. After H passed away, I lived off benefits because I couldn't face going back to work. I lost my mother eight months before I lost H I couldn't go to public places, or be around people. I would have terrible panic attacks, which I still get to this day. I never got the chance to grieve for my mother properly before I had to start grieving the loss of my husband.

49. In February 2017 I had to start working again, because I was financially unable to go on without a job. Having financial security has always been important to me. I had to bite the bullet, and try to fight my anxiety. I would just focus on getting out of the house and on other people. I didn't want my mind to be racing around, thinking about everything I have lost. Had H not been infected I would not have to work the amount that I do, or worry about money in the same way.

Section 6. Treatment/care/support

50. I believe a liver transplant should have been offered and H's position assessed much earlier. The specialists only came to SH once every six months and so the possibility of a transplant was not properly assessed at the earliest possible stage which might have saved H's life.

51. One appointment was made for my husband at MHSI with a psychologist but he could not make it due to his condition. They never followed up with another appointment or any other offer of counselling

52. No counselling or support was ever offered or made available to me and I therefore had to have sessions privately. I suffer from severe anxiety and PTSD, and have to rely on medication to get through the day. I have had to increase the medication because I just couldn't handle everything going on in my personal and work life.

Section 7. Financial Assistance

53. I received money from the Skipton Fund in the form of a Stage 1 lump sum payment of £20,000 and then a Stage 2 lump sum payment of £50,000.

54. I found out about the Skipton Fund from a clinician in SH. The application process was dealt with by H.

55. I used to receive a payment from the Caxton Fund on a monthly basis, but this was superseded by the Velindre Trust.

56. The Velindre Trust sent me a payment of £34,850 in November 2017, which I assumed to be a bereavement payment. About a week later they sent me another payment of £34,850 in December 2017. The payments turned up out of the blue, I never received any letters or correspondence about receiving the payments. I had no idea it was coming, it just turned up in my bank account. I assumed it was like the Skipton Fund, with two stages of payments. I was given no further information about the payments at this time.

57. I assumed that the two payments were meant to be sent. I therefore used the money to settle my debts, such as repaying my mortgage, and I also put £13,000 in a savings bond. I also gave my children some money to help with their futures, and my grandchildren. They had lost their father too, and it didn't feel like the money belonged to just me. I have always looked out for others, and now I have to rely on people because of the mess I am left in.

58. To my recollection, a few weeks later, the Velindre Trust contacted me to say that the second payment was a mistake as they had duplicated the payment.

59. I had already put £13,000 away in a savings bond to fall back on, but I paid this money back when they requested it. The rest of the money that I had been sent had already been used to pay my mortgage and so I could not get this back, and I had given money to relatives. My children had used this money to pay off their own debts, and I had no way of getting it back.

60. I offered to make payments out of my pay on a monthly basis but they refused my offer. From February 2019, they started taking £300 a month in order to repay my debt, however they constantly send me letters threatening to put a charge on my house. Most recently, the credit management company have sent me a letter saying they have advised the Velindre Trust to start legal proceedings against me, Exhibit WITN0637002.

61. This is a huge financial strain for me. Initially I was sent through an expenditure form, to fill out all of my monthly income and outgoings. On this form, I suggested that I could afford to pay £300 per month. They did not accept my offer, they wanted more, however they did start to take the £300 per month anyway. After paying this debt back, and all my bills I essentially work for nothing every month. I have no spare money and I struggle to pay for heating in the winter. Over the winter months I get set back with my bills because I have to use more hot water and I have to have my heating on. I spend the whole winter period stressed about paying the bills at the end of the month.

62. I have received no other money, grants or other financial support from anywhere.

63. I do not feel that the amounts paid are sufficient and they do not reflect the appropriate compensation for the damage that was done. A large lump sum payment would be better than the 'drip feeding' of payments that we were given.

Section 8. Other Issues

64. I just want justice; anything after that is a bonus. I want the people that were involved and responsible for this to be held accountable.

65. I am very stressed about the costs over Christmas. I don't think I am even going to be able to have a Christmas this year. I don't know how I am going to buy my children or grandchildren presents. I sometimes think about pawning

my jewelry but it's just something I will have to buy back in the future if I can afford to. I can't bear to lose my engagement and wedding ring but I am considering having to pawn them in order to have Christmas with my family.

66. This time of year is supposed to be for family, and I cannot have that. It's a struggle to even live. It's an ongoing thing, that doesn't get any better. Things just keep getting worse. It feels like I just can't seem to get out of the hole I am in.

67. All I want is for my children to be happy, but they won't ever be okay. There is nothing I can do to help them. I have nothing left anymore. I have to be the mother and father to my kids, and I just don't know how much longer I can do this.

68. I have heart palpitations and every time I get a threatening letter through the post from the Velindre Trust it throws me into a panic. The CCI management company threatens me, and I have nothing left to give them.

69. The house that I live in is the house H and I bought together. We have always lived there. We built this house together; we skimped and saved for this house when we were first married. I have never lived anywhere else. This is where H died and I know his spirit is still here. All our memories and our family are in this house and I can't lose it.

70. The NHS already took my husband from me, they have run me bankrupt and now they want to take my house from me and leave me with nothing left.

Anonymity

71. I wish to remain anonymous.

72. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-B

Dated 19/12/2019