Witness Name: GRO-B
Statement No: WITN1284001
Exhibits:0
Dated: March 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, DOB GRO-B and I live at GRO-B GRO-B

2. My first husband, GRO-B: H1, DOB GRO-B, died on GRO-B after being infected with HIV, Hepatitis A, Hepatitis B and Hepatitis C through contaminated blood products.

3. My second husband, GRO-B: H2, DOB GRO-B died on GRO-B after being infected with Hepatitis C through contaminated blood products and was also told that he may have been exposed to vCJD.

4. This witness statement has been prepared without the benefit of access to my husbands' full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. H1 had severe Haemophilia A and was disabled as he grew up before treatment became available. He was in his 20's when whole plasma was used to treat his bleeds. He then moved on to cryoprecipitate.

6. In 1974 we took our three young children on holiday to GRO-B and, following a bleed, he was treated with Factor VIII concentrate for the first time at the local hospital. During that night he began to feel very unwell. He developed a fever, was shivering, had a severe headache and abdominal discomfort. As I didn't drive, we vacated our holiday accommodation in the middle of the night to get home as soon as possible. We were certain that the new treatment had caused his rapid onset illness.

7. We were shocked to learn that H1 had been infected with Hepatitis B and we were instructed that he must have complete bed rest until all of his symptoms had disappeared, which ended up being 13 weeks. During this time he suffered muscle weakness and consequently had more bleeds. We were also told to isolate him from the children and sterilise all utensils. To make matters worse, our youngest daughter aged just five months developed whooping cough, and our other two daughters had chickenpox.

8. In 1976, the consultant at our Haemophilia Centre told us that cryoprecipitate was being phased out and was no longer available. When we collected the next 'home treatment', it was Factor VIII concentrate. As he walked down the hospital corridor, the consultant turned and said 'don't blame me if you go yellow'. At that point, we assumed he was telling us that my husband's liver may still be recovering from Hepatitis B. Now, I firmly believe that the consultant was already aware that the concentrate was probably contaminated, as others had already commenced this new treatment prior to us.

9. Within a few hours of administering the new concentrate, my husband became acutely ill with abdominal pain and severe jaundice. We soon learned that a number of friends and relatives with haemophilia were also ill. He was ill for three weeks with what was diagnosed with Non A Non B (NANB) Hepatitis, later to be known as Hepatitis C.

10. My husband was told at the Haemophilia clinic that his liver would regenerate. We could not believe what was happening and I felt guilty because I administered all his intravenous treatment; it had passed through my own hands! He became a changed character with mood swings, impatience and severe panic attacks. We were very much in love and we couldn't have been any happier in spite of the many difficulties, but he changed dramatically following two severe episodes of Hepatitis one after the other.

11. We first heard about the risk of HIV in the news after a haemophiliac was infected in 1983. We immediately phoned up the Blood Transfusion Centre in GRO-C and arranged an appointment to see if it was safe to continue to using Factor VIII concentrate. We were told in no uncertain terms that there was nothing to worry about it and H1 should continue to have treatment. We left reassured, but shortly after, the consultant called his patients in for blood tests. This set alarm bells ringing and we dreaded the results at the next six monthly check up. At the following check up, H1 was told by Dr Ian Franklin 'of course you know you are HIV positive.'

12. Dr Franklin told us that we should have safe sex and we should not have more children. He also told us that the virus could be caught through kissing and that we shouldn't tell anyone about the infection. We left the clinic so traumatised that we couldn't speak about it on the journey home; in fact we didn't speak about it until bedtime when the children were asleep. We both broke down and cried in each other's arms.

13. One by one our friends and relatives made contact with each other. We knew many haemophiliacs as we were committee members of our local group. To our horror, most of them were infected with NANB Hepatitis, HIV or both.

There were therefore discussions in the waiting room whenever we went to the haemophilia centre. Shortly after, we received a letter telling us not to talk about it in the clinic waiting room.

14. When I asked about the risk to me, they said 'maybe we should test you as well'. It took me six months to get my results back which was an extremely frightening time and we were in constant fear that our three young children would be orphaned. Fortunately, my results came back negative.

15. I do not have any first hand information as to my second husband's infection, but he was not informed of his Hepatitis C diagnosis until 1993.

Section 3. Other Infections

16. I am not aware of what other infections that H1 may have been exposed to.

17. A few years ago, my second husband received a letter from the haemophilia unit informing him that he had been exposed to vCJD. We were told it was important for us to inform everyone who gave him any type of treatment including the GP and his dentist.

Section 4. Consent

18. We were aware that H1 was being tested for HIV as we had raised our concerns regarding the virus to the hospital and were later called in for tests.

19. I do not have any first hand knowledge of the tests that H2 consented to or had knowledge of.

Section 5. Impact of the Infection

Impact on H1

20. After H1's Hepatitis B infection, he became dependent on me and suffered with severe panic attacks and depression. I had to run to the shops with my youngest daughter in her pram as he thought he was going to die.

21. We received no help or any other advice and it took him 18 months before he felt able to cope. He was never able to work again. Our income was so little that we only had fruit if there was enough money at the end of each week.

22. We didn't tell the children about H1's HIV infection immediately because we were ill-equipped with information and Dr Franklin told us not to. They were already teenagers but we felt that they had to be told soon, which they were. They did know about his Hepatitis infections but they didn't know what the implications were for his health. Eventually, when our children were a bit older and witnessed their father's deterioration, we decided to put them in the picture. Unfortunately, because so many of our neighbours knew that H1 had haemophilia, a rumour went round the neighbourhood that there was a deadly disease going round.

23. When I took my daughter to the dentist there was a form to fill out if someone in the family had HIV. When the dentist went to examine my daughter, he said to her 'I'm clean'. This was absolutely humiliating and he did not apologise when confronted. After this, H1 would not tell anyone that he even had haemophilia, just that he had arthritis.

24. As the years went by, my husband's health deteriorated and with it, his mental health too. He became violent towards me. Sometimes in the middle of the night while I slept he beat me on the head and attacked me with his walking stick. He hallucinated at times and on one occasion I had to call the GP out as I feared for my life and that of my children. The GP would not listen to my

pleas that H1 must not be given intramuscular injections and injected him anyway. This caused him to have a massive bleed.

25. H1 was far from cooperative and it was a very difficult time. The virus was affecting his brain. My daughters had to have time off school as they were so traumatised to see the change to their Dad. I was sworn to secrecy by my husband not to tell them about this at the hospital. All I wanted to do was to be there for him and help him through this dreadful time. I loved him so dearly and he was pushing me away. His GP prescribed him valium for many years and he became addicted.

26. H1 was prescribed a lot of medication including AZT, with which he had dreadful side effects. Some of the drugs interacted with his treatment for Hepatitis C. He was retaining immense amounts of fluid in his abdomen and limbs, and suffered side effects from the drugs used to alleviate other symptoms. In 1990, he suffered a massive stomach haemorrhage from bleeding varices in his stomach and oesophagus. He was in a coma for a few days.

27. While he was being nursed in a side ward, I arrived in time to witness his door wide open with several doctors trying to catheterise him. He was totally naked and visible to all passing visitors. They offered no privacy or dignity whatsoever. In spite of this, he went on to survive another four years with more internal bleeding episodes and appointments every few days. He slept most of the day but never revealed how ill he was to his consultant.

28. During his final years we moved to a bungalow with my own mother, to whom I became a carer. I was already a full time carer to my husband for many years but could only claim one very small carers allowance. I was by his side in hospital continuously for several days until his death. He died at a weekend when his consultant was off duty and had instructed 'nil by mouth'. Nevertheless, he woke up very bright and hungry and could smell the dinners being served. He asked for food but was refused it. It was to be his final request and it was denied. The nurse in charge asked me if he was in any pain and I said that he was comfortable thank you. She then returned with a

syringe of morphine and said it would settle him, before going off duty. My husband died within minutes and yellow tears ran down his cheeks.

29. The doctor on duty wrote out the forms certifying the time and cause of death. He failed to report Hepatitis B and told me it was in my best interest not to record his HIV status. It stated that he had liver cirrhosis, liver cancer, hepatic encephalopathy and Hepatitis C. I was allowed to see him very briefly before he was put into a sealed body bag and transported up the motorway to the funeral directors, where again, I was told I could not see him.

30. This has had a tremendous impact on my life and that of my family. I am in a permanent state of grief and anger and I am tormented by the memories that will never leave me. My dearest husband suffered mercilessly at the hands of the NHS and the perpetrators who allowed it to happen. I want justice.

31. My daughters have been shielded from some of the facts but are equally distraught having witnessed their Dad becoming ill during their early years, and this has impacted on all our lives both then and now. Our grandchildren missed him so much and he was unaware that he was to have one more granddaughter and five great grandchildren that he would never meet.

32. My husband was a very private man and I pray he will forgive me for telling the story that he would not tell during his living years.

Impact on H2

33. Some months after the loss of my first dear husband, I received a phone call from the mother of a haemophiliac whom I had known for over 20 years and was a close friend of ours. He had been rushed to hospital with detached retinas and was told he may lose his sight. She needed support as he needed surgery in an eye hospital unfamiliar with the care of a haemophiliac. His surgery was successful and I visited him daily to help with his post op care at home. He too was disabled and was a successful chartered accountant and a magistrate. When he had fully recovered, we continued to see each other and

fell in love. We were married two and a half years later, both in our fifties and blissfully happy.

34. He was in excellent health despite being Hepatitis C positive. He was not told until 1993, one year before we got together. He was monitored at the haemophilia unit every six months.

35. When he told his dentist that he had been exposed to vCJD, she said she would no longer be able to treat him until she had sought advice. We were later humiliated in front of other patients when she said she would offer him treatment if he provided his own equipment. Later on, she reneged and offered him treatment as the last patient of the day, so that she could double sterilise all of the equipment.

36. In 2010, the haemophilia consultant noted that he had some liver inflammation and suggested he be referred to the liver specialist.

37. In 2015 the liver specialist recommended a three month course of treatment to eradicate the Hepatitis virus, with minimal side effects, and stated that H2 was a perfect candidate as he was completely asymptomatic although he had a degree of cirrhosis which we were told may be reversed.

38. He underwent numerous tests and the medical staff answered the many questions that we had compiled in order to satisfy all our concerns. If successful, he could live to have a normal lifespan for a man of his age; he was 61 years old at that time.

39. After a great deal of deliberation, my husband began his course of treatment, knowing that he was in safe hands and that two specialist nurses and a doctor were monitoring him frequently and could be contacted if needed. The chance of a successful outcome was 95%, but what happened next was truly appalling.

40. On the second day he reported some side effects and was advised to give it a few more days. On the fifth day he suddenly became very weak and jaundiced, having vomited excessively. Not one of the team overseeing his care was available and each phone number was unavailable over the weekend. In desperation, a neighbour offered to take him to the specialist hospital. He collapsed in our drive with his legs buckled under the car. He had no strength to support himself. I dialed 999 and stressed the importance of him attending the hospital caring for both his haemophilia and his new drugs therapy. My pleas were in vain and he was taken to our local hospital who knew nothing about his haemophilia or condition. It was eight hours before my husband's doctor made contact with the local hospital, by which time he was diagnosed with bilateral pneumonia.

41. He was taken to an acute medical ward and the following day he was told he would not leave hospital again. He was alone at the time. He had non stop hiccups, high oxygen therapy, an assortment of drugs and intravenous fluids in both arms. His condition deteriorated, he was transferred to a high dependency unit and finally transferred by escort to another hospital's intensive care unit. He was catheterised, intubated, had a nasogastric tube fitted as he was bleeding internally, and he was given drugs that interacted with his medication. His liver specialist had failed to give the necessary information and within a few hours, he went into multi organ failure and was put on life support.

42. I was by his side when he died the following morning. His dedicated team had failed to support him following an adverse reaction to his new drug therapy. He was severely jaundiced, bruised and swollen, and was having fits. He had suffered hallucinations during his stay in hospital and for much of the time, he was unable to converse with me. He was unrecognisable. I was by his side when he died and I had to leave the hospital and never see my husband again.

43. His post mortem revealed that he had four stone of excess fluid in his abdomen and limbs. The funeral director advised strongly that I would be too

traumatised if I were to see him, as fluid was still leaking through his skin and saturating his new suit that I had provided. One year later, the Coroner stated the cause of death was 'a result of a drug's trial intended to resolve the previous damage caused by intravenous blood transfusions'. GRO-D GRO-D GRO-D

44. My daughters and granddaughters all supported me during this appalling fortnight. None of us will ever forget the devastating events that lead to my husband's death. We all miss him beyond measure. He should still be here with me so that we could grow old together.

45. This has had so much impact on my life in so many ways, as we were totally unprepared for this sudden dramatic outcome. My husband's interim death certificate would not allow me access to his very small pension. Our savings were locked in and I was unable to get any financial help. My state pension was very small as I had been a carer to three people dating back many years. I had meetings at the three hospitals and the ambulance service to gain all the information I needed and answers to why this had been allowed to happen. This was very traumatic and I requested the help of an advocate. Probate was very lengthy and I spent 12 months liaising with the Coroner leading up to the inquest. I had to learn rapidly how to use the internet, a mobile phone and public transport which I hadn't used for 50 years. I was, and still am, constantly under a great deal of pressure.

46. My husband's motability car was taken back within a week and I had to sell his brand new electric scooter and his wheelchair to release funds. I cancelled all my warranty agreements and TV provider. I was now living very frugally.

47. There are constant reminders that fill me with grief and anger over events that should never have happened. During the probate period when all our assets were frozen, I received two letters from credit card companies addressed to my husband, stating that if he didn't clear his balance, they would take action against him, in spite of previous confirmation that they had already been notified of his death by my solicitor. Four months after his death, our own GP

sent him a letter requesting him to attend for his annual checkup. I received apologies but one year later, I received another letter inviting him to participate in a bowel cancer test.

Section 6. Treatment/care/support

48. One of the social workers visited me and took me out to help me take my mind off everything, although I was never actually offered counselling. I arranged some counselling recently but I had to stop it because I found it too difficult.

Section 7. Financial Assistance

49. After H1's HIV diagnosis, we were informed by the hospital consultant that we were now entitled to an additional supplement to our income to provide extra money for a healthy diet for H1, and that we should apply to our local DHSS. My husband was initially refused so a representative from the national Haemophliliac Society accompanied me to the appeal. My husband was too ill to attend. I was initially refused at the appeal hearing as they said we 'might spend it on champagne and caviar'. I broke down and he was ordered to apologise, and the supplement was granted.

50. My husband was a party to the 1991 litigation through my local solicitor who acted as an intermediary. We were told that absolutely everyone had to agree to the settlement or nobody would receive anything. He therefore had no option than to sign the waiver. As we were a family with three children we received the full amount.

51. After H1 died I received a small weekly supplement from the MacFarlane Trust. This was later reduced and then stopped completely when I remarried two and a half years later.

52. GRO-B

53. GRO-B

54. To start with the support schemes were quite good, but after my second husband died unexpectedly I had to go through probate and all of my assets were frozen; during this time the Caxton Foundation completely cut us off and I couldn't go to DSS because I had savings even though I couldn't access them.

55. I went almost 3 years without any financial assistance before I was supported by the EIBSS. I haven't had any problems with EIBSS and I have found them quite good to deal with. I now receive monthly payments from EIBSS.

Section 8. Other Issues

56. I would like the Inquiry to look into the lack of joined-up care between hospitals. When H2 fell ill after starting his treatment the ambulance crew said they were unable to take him to the Queen Elizabeth Hospital. This was despite him having a special card with the information of the drug's trial, a Haemophilia card and an SOS Talisman around his wrist, all stating that he should be taken to the Queen Elizabeth. Instead he was taken to GRO-B GRO-B where he was given oxygen and told he would be fine in a few days. This decision contributed to his death.

57. It has been a great privilege to share my life with two very special people, but my struggle goes on as I am consumed with grief. I was married for 28 years and 19 years respectively and was devoted to both. Now I seek justice. Allow me that.

Anonymity

58. I would like to apply for anonymity as I have named several doctors and I fear there may be consequences of doing so.

59. I do not want 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 21/03/2019