Witness Name: GRO-B

Statement No:WITN1403001

Exhibits:WITN1403002

Dated: February 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. I am a widow and live alone.

2. I make this statement in relation to my husband GRO-B: H (date of birth GRO-B who died on GRO-B at the age of GRO-B after being infected with HIV via contaminated blood products.

3. H and I met in GRO-B and we married in GRO-B. We have two daughters together.

4. This witness statement has been prepared without the benefit of access to my late husband's 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 infected

5. H suffered from severe haemophilia A. He suffered from joint bleeds and was affected by his condition throughout his life and our relationship.

6. H had a longstanding issue with growths of cysts on/in his joints which required specialist review and treatment including surgery in 1984.

7. H received most of his care from the Royal Liverpool Hospital. His treating physicians included but are not limited to; Dr Carty, Professor Robert Owen, Mr Shatwell, Mr Alistair Turner, Dr Van Dettel, Dr J Kelly, Dr Bartzokas, Dr Robinson, Dr Mackie, Dr Galloway, Professor Duffy and Dr McVerry.

8. H was self-administering Factor VIII at home from around 1983. He received numerous blood transfusions in 1984-1985 following surgery, and was also given up to eight doses of Factor VIII each day.

9. H was not to my knowledge given any information relating to the risks associated with the use of Factor VIII or any associated risks of infections, and neither was I.

10. Whilst I have no specific dates or treatment batch information relating to H's infection with HIV, it is clear H first displayed clear indications of a suppressed immune system and a rapid decline in his health from 1984 onwards.

11. H underwent surgery at the Royal Liverpool in 1984 after which his health started to deteriorate rapidly H was moved to a side room on his own and we were told that he had contracted a virus that they suspected to be Salmonella H was vomiting, becoming delirious and losing weight rapidly. I was made to wear protective clothing when I visited him.

12. H was sent home for a short period with a district nurse in attendance; however she only attended on two occasions before refusing to come back.

She asked me whether the hospital had informed me what H was suffering with.

13. The first discussion that we had with a doctor regarding the possibility of HIV infection was with a junior doctor at the Liverpool Royal Hospital in October 1985. This was long after I had suspected H had been infected and I had repeatedly asked medical professionals to test H and offer him some form of targeted treatment.

14. The junior doctor confirmed that he believed H was suffering with AIDS; however this was never confirmed by R McVerry who was the consultant overseeing H's care at the time. Dr McVerry simply dismissed my concerns.

15. I had blood taken twice to be tested. I was never informed this was due to any risk of HIV but was told this was to test for Salmonella. I recall asking why our daughters were not being tested as we all ate the same food at home, but I was reassured this wasn't necessary as it was me who was in closest contact with H

16. The only information I was getting was from the media coverage. I read about symptoms of HIV/AIDS in the news and I thought that they were very similar to the symptoms that H was suffering from.

17. When I raised my concerns with Dr McVerry that H was suffering from the symptoms of AIDS, he advised me that H's symptoms could be explained by numerous viruses or infections. He denied it was AIDS and he told me not to be neurotic. In one such meeting with Dr McVerry, when I was frantically explaining how concerned I was for my husband's health, he was swinging around in a swivel chair whilst eating a KitKat. This shows the kind of treatment I received from Dr McVerry.

18. Without confirmation of infection from the staff treating H, I sought desperate measures for a firm diagnosis and treatment options. On

19.10.1985 I travelled independently from Merseyside to St. Mary's Hospital in London to attempt to speak to Professor Pinching; an AIDS specialist. I did not tell H that I was going as he was hallucinating at this stage and was in no fit state to take anything in.

19. Unfortunately, Professor Pinching was unavailable as he was out of the UK at the time but the staff at the hospital facilitated a telephone conversation with him. During this discussion, Professor Pinching agreed that H 's symptoms and history were likely to be associated with a HIV infection and he agreed he would discuss H s case with Dr McVerry.

20. Professor Pinching also implied a lack of clear diagnosis and open discussion with myself and H could be because the hospital did not want to fuel the hysteria of AIDS, which was rife at the time.

21. After my consultation with Professor Pinching, Dr McVerry told me not to question his standing or undermine his opinions, as he was my husband's treating consultant; the clear implication was that he knew best.

22. H himself suspected he had something very serious and although he once asked me if I believed he had HIV/AIDS (after we saw news coverage of Rock Hudson's death on TV) I reassured him at the time that staff had not indicated this was the case despite my own belief that he was right.

23. From January 1985 H 's medical records show that his sample bags sent for testing were labelled as 'high risk'. They also show that he was first tested for HTLV III in January 1985. There were also tests sent in June 1985 to the hospital for tropical diseases in London where he was tested for pneumocystis. Again, neither of us was warned that H may be suffering from HIV or any potentially infectious disease.

24. H died in GRO-B 1985. The first official confirmation of H having AIDS/HIV was after his death when I saw it listed on the death certificate.

Section 3. Other Infections

25. I am not aware of any other infections that H may have been exposed to but, given what I now know; it is likely he was exposed to hepatitis.

Section 4. Consent

26. We had no knowledge that H had been tested for HIV and therefore could not have consented to these tests.

Section 5. Impact of the Infection

27. H was treated terribly whilst he was in the Royal Liverpool Hospital receiving treatment. It was largely left to me to change his clothing and bedding as the nurses appeared to not want to go in his room. On occasions when I was not present, food and drink was left on a trolley outside of his room and H was left unchanged lying in a dirty bed in his own faeces and body fluids with blood all over the floor.

28. There was also one occasion when H fell out of bed because the nurse had not put the cot sides up. I believe the hospital could and should have done more. I have even found someone else's medical records mixed up with H's.

29. One night I stayed overnight in the hospital with H The nurses had asked me to bring in photos of the girls, and when I showed these pictures to the nurses they ran off crying. In hindsight, I suspect they knew about H's infection and had the reaction because they knew he was going to die.

30. In October 1985, H was sent home with no visiting health care and I was left alone to care for him. His health at this time was rapidly declining and he was in acute mental and physical distress. This was traumatic for both me and

the children to witness. This is particularly concerning as I was caring for him and he was interacting with our daughters without us knowing that H had been infected with HIV, despite the fact his results show he had tested positive much earlier than this.

31. I was given no information in relation to risks of infection for me or our children and was left to care for H at home without any support and at the time he was suffering from diarrhoea, vomiting blood and was literally dying in front of me.

32. Due to the poor care he was receiving, for two years I practically lived at the Royal Liverpool Hospital on and off. Eventually, I had no choice but to split up our two daughters and send them to live with separate relatives so that I could look after H. As a result they missed out on having both a mother and father during H's illness.

33. I observed H deteriorate and waste away in front of my eyes slowly and surely over several years, and he changed both inside and outside from the loving husband and father to someone who was depressed, withdrawn and with little interest in life or people. This was heart breaking and so very out of character for him.

34 H suffered from depression, low moods, confusion and severe headaches. He was assessed by a neurologist in 1985 and diagnosed as having encephalopathy. He lost weight, often suffered from fevers and feelings of generally being unwell, which was noticeable from 1983 onwards. He had nausea, sore throats, night sweats and joint pains.

35. He was tested and found to have contracted Salmonella and *Clostridium Dfficile* in Liverpool Royal Hospital in 1985 and he was constantly in and out of the hospital for the last 18 months of his life, declining in health with each visit.

36. His records indicate he had *Cytomegalovirus* and he also had a clear presence of *Pneumocystis* in June 1985, as the Liverpool Royal sent samples to a hospital in London to be tested for tropical diseases.

37. H had little contact with friends and family during the latter stages of his life, particularly when he was in hospital and being barrier nursed, as contact was restricted. This sense of isolation and being excluded from his much-cherished family-life brought about a clear deterioration in his mental state and emotional wellbeing. H was a social person who enjoyed company and thrived when caring for his children; without this he had no sense of purpose and was lost, emotional and distressed. This was made worse by the fact he was never told about his infection and therefore could not understand his illness or prognosis.

38. On 18.10.1985 I sought support from our local GP who wrote urgently to the Royal Liverpool to re-admit H as an inpatient. I have a copy of the GP letter which indicates H's decline and symptoms of confusion, and that he was vomiting blood at home. This letter also mentions my suspicions about H's virus, to which the GP added 'we all know which one'. There is now shown to me marked **WITN1403002** a copy of this letter.

39. H was readmitted to the Liverpool Royal Hospital at this time and he died GRO-B later.

40. The morning H passed away I was very unwell and my muscles were so weak. I actually urinated myself as my muscles gave way. I was supported by my father who was amazing and incredibly supportive.

41. My dad was so helpful in arranging H's funeral, as I wasn't in a fit state to do so. My GP had given me medication to sedate me and I was so heavily sedated that I barely even remember the funeral. My father later informed me that the undertaker told him that was the first time in his career he had been made to wear protective clothing. He said H had to be put into a body bag

and then the coffin could not be reopened; I was devastated mentally and emotionally.

42. I took H 's death extremely hard. I had to move out from my daughters for a period of time as I struggled to come to terms with everything. I was in a very bad way; I couldn't get up, washed or dressed and started drinking as a coping mechanism. Fortunately, my doctor told me to pull myself together or I would lose the girls into care otherwise. He said he would visit me in a few days by which stage he wanted to see me in a much better state. This was a turning point for me as I didn't want to lose the girls.

43. The stigma surrounding haemophiliacs and AIDS was terrible. I was asked in the local village shop if I had AIDS and the girls were asked the same thing at school. They often came home crying. To protect myself and my daughters I just told people that H had died of leukaemia.

44. My sister had to break the news to my daughters that their daddy had passed away.

45. H 's ill health and death devastated my daughters. They had to be separated and live with different family members whilst I cared for H. I remember on one occasion GRO-B wrote me a letter begging me to let her come home, but I simply couldn't let them see him in such a bad way as it would have upset them too much.

46. My eldest daughter GRO-B, recently told me that she hated me at the time as she didn't understand why she had had to change schools at that time. This has made me feel so guilty.

47. I couldn't work as I had to care for H, and as a result we really struggled financially. I often went without food to make sure I could feed my daughters, although they did not understand why I couldn't send them on school trips like the rest of their school friends. I have had to work all of my life to put my girls through their education.

48. I live every month out of my overdraft, and have been living that way for around three years now. I had to sell my house as it was too expensive to maintain the property and I could no longer afford to live there.

49. Our lives were absolutely shattered by H's tragic death. If I had known the truth and the full circumstances around H's illness, I believe I would have been able to plan our lives and cope slightly better. However, I was robbed of the opportunity to do this as the truth was hidden from me for so long, which also put my family at unnecessary risk.

50. I have a grandson who is a severe haemophiliac which causes all of the memories to come flooding back, and I just have to hope that history never repeats itself.

51. H passed away 34 years ago and I still visit his grave every week.

Section 6. Treatment/care/support

52. Neither myself, H nor the children received any support either medically or psychologically at the time, nor have we ever been offered specialist psychological support since his death; we have had to seek this ourselves via campaign groups and social media after decades.

Section 7. Financial Assistance

53. I received the £20,000 Stage One Payment from the Skipton Fund. I was refused the Stage Two Payment that other widows were receiving as they had run tests which were 'inconclusive' as to whether H had suffered from cirrhosis.

54. I found out about the MacFarlane Trust in 2012 through the NHS.

55. I currently get monthly payments from EIBSS. From June 2013 I was means tested and received payments of £83 per month. It later went to £250, however because I was working and did overtime they often cut my payments. I went to my MP over the matter who argued as to how ridiculous it was that I had payments deducted from me because I worked overtime. Now that I am not working I receive £833 per month.

56. At one stage I urgently needed a new front door as it broken and was causing my hall to get wet. This would have cost me around £700. I went to the MacFarlane Trust who refused to pay. I then went to my local MP, Dave Watts. We went for a meeting in Parliament at which Anne Soubry was also present. When I told her about my situation she was disgusted. She told Dave to write another letter but this time to include her name in it. The award was finally paid a few weeks later, but I never should have had to go to Parliament in the first place. I think a lot of politicians are reluctant to help us as often when an MP speaks up for us, they are conveniently moved into a different position.

57. I previously applied for a grant for a pair of glasses and dental treatment. James from EIBSS told me to send in a receipt for the glasses and they would reimburse me. I phone him back a few weeks later and he apologised and said they had been put in the wrong tray. He then said they would be sending out a letter telling me to try and apply to the NHS helpline for reimbursement as they were unable to help widows with such matters. In the end I had to rely on a family member to lend me the money for the glasses, and I have still been unable to afford the dental work.

58. A few years ago I also applied for a grant for a downstairs bathroom as I have arthritis and they had sent me a letter stating they had excess money so I could apply for additional grants. I had to send them three bank statements, three different builders' quotes, the costs of all of my bills, groceries, credit cards, travel, earnings, pensions, mortgages and much more. It was absolutely ridiculous. They eventually installed a downstairs shower but I had to sell the house shortly after as I couldn't afford to stay there.

59. My boiler is broken at the moment but I would rather go without heating than have to go through the lengthy process with EIBSS only to be denied. Similarly, I have lost all of my teeth at the side of my mouth and I cannot afford the £450 required for dental treatment, but I know that EIBSS will just put me through unnecessary stress before refusing my application.

60. I feel I have had to beg for every bit of financial help I have received.

61. They have also done a terrible job of informing people about the financial assistance available to them. Not many widows even know that the Honeywell Trust exists. I was sent to them by the MacFarlane Trust and encouraged to apply for further education or driving lessons; I'm 66 years old, what do I want with those! I was only told about them by a lady who worked for the MacFarlane Trust who was extremely helpful and nice to everyone.

62. In any event, the Government has opened all of these Trusts for us but has now sent all of the money from the MacFarlane Trust to the Terrence Higgins Trust. I don't understand what the money is doing there or what the Terrence Higgins Trust is doing to support us.

Section 8. Other Issues

63. I don't understand why the Government is making us go through all of this. They are spending millions of pounds on an Inquiry when they could have just held their hands up and made sure that everyone affected was provided for from the beginning.

Anonymity

64. I wish to remain anonymous.

65. I would be happy to give oral evidence to the Inquiry if they considered it would be helpful.

Statement of Truth

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

Signed.. GRO-B ....

Dated 26 02- 2019