Witness Name: Diana Margaret Blake
Statement No: WITN1101001
Exhibits: WITN1101002
Dated: 25th January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF DIANA MARGARET BLAKE

I, Diana Margaret Blake, will say as follows:-

Section 1. Introduction

1. My name is Diana Margaret Blake. My date of birth is GRO-C 1955 and I live at GRO-C with my husband Michael.

2. I make this statement in relation to my son, Stuart Michael Blake (Stuart) who was born on the GRO-C 1978. He died on the on the 29th May 2006 at the age of 27 as a result of infections he contracted from being treated with infected blood products. We also have a daughter, Laura who was born on the GRO-C 1980 and two grandchildren GRO-C 13, and GRO-C 11. Whilst I have had some employment over the years I am now retired.

3. This Witness Statement has been prepared without the benefit of access to Stuart's full medical records.

4. There is now produced and shown to me marked Exhibit 'WITN1101002' a letter from Dr K Rice, Locum Consultant at St Thomas Hospital dated the 21st August 1996 together with the draft Statement of Claim dated 1990 which I will refer to in this statement and provides contemporaneous evidence.

Section 2. How Infected

5. Stuart was diagnosed with severe Haemophilia A in 1979 when he was 13 months' old. He had sustained severe bruising from merely using a baby walker which our GP considered to be unusual. Following a blood test he was diagnosed with a severe blood disorder and referred to Great Ormond Street Hospital (GOSH). We received a letter from Dr Rankin at GOSH dated 10th August 1979 asking us to attend a hospital appointment on 22nd August 1979. We were concerned as to the nature of the diagnosis as we thought it might be leukaemia. However, haemophilia was diagnosed. We did not know there was a family history of haemophilia until Stuart was diagnosed, no-one spoke of it.

6. Following Stuart's diagnosis he was regularly treated with Factor VIII. The product I recall is Armour as well as others. I recall that Factor VIII was in short supply and I was once given a prescription for it which had to be specifically brought in to the hospital for Stuart's use. Later I also learned to inject Stuart at home when he needed Factor VIII which was stored at home.

7. GOSH was Stuart's initial treatment centre but whilst he attended appointments there we also attended the Lister Hospital in Stevenage for treatment even though it was an adult haemophilia centre. It was easier for us to access the Lister Hospital than GOSH.

8. Later, Queen Elizabeth II Hospital (QE2) in Welwyn Garden City became Stuart's treatment centre. However, as there was no specific treatment centre for haemophiliacs at the QE2 Stuart was treated on the Children's Ward under the

care .of the Paediatric doctor, Dr Alison Shurz. I understand that the QE2 Hospital sourced Factor VIII from the Lister Hospital.

9. He also received a one-off treatment in the Poole Hospital on the 28th February 1992.

10. Stuart was treated with Factor VIII from the time he was diagnosed in 1979 until he died on 29th May 2006.

11. I cannot recall any information or advice being provided by any of the hospitals prior to Stuart being treated with blood products about any risk of being exposed to infection from those products.

12. Stuart was infected with Hepatitis C (HCV) and Human Immunodeficiency Virus (HIV) as a result of being treated with infected blood products. Stuart also had viral related Encephalopathy and AIDS related Parkinsons.

13. I recall in 1982 that Stuart was admitted to one of the three hospitals I mention above, but I cannot recall exactly which one, but he was very poorly. Blood tests had been taken and I remember the paediatric doctor referring to non-A, non-B hepatitis. I knew Stuart was unwell but I did not realise that non-A, non-B hepatitis referred to HCV. He was ill for a few weeks but he did recover or at least so it appeared.

14. As a teenager I remember Stuart saying that he had HCV. It was not until then that I realised non-A, non-B hepatitis referred to HCV.

15. With regard to Stuart's HIV diagnosis I remember one of the hospitals' telling me to tell the school that Stuart had a low immune system. However, it was not until 1985 when Stuart was 6 ½ years old that we were told of his diagnosis with HIV. I remember a blood test had been taken a week or two before being told of the diagnosis but we were not told why the blood test was needed. We went to

GOSH and were called into a treatment room. The Consultant told us in a matter of fact detached manner that Stuart had HIV which, in my view, was an inappropriate manner to tell me.

16. I cannot recall exactly now whether at that stage we were given a leaflet concerning HIV but certainly I do not recall being given any information or support or being offered any counselling.

17. Whilst we were told at some point how the infection was transferred I am certain we were not told at the initial appointment. HIV was in the news and it is likely that we knew from news items how HIV was transferred.

Section 3. Other Infections

18. I have not been told that Stuart has received any other infection as a result of being treated with infected blood products.

Section 4. Consent

19. I believe it is likely that Stuart was tested without our knowledge and consent. Certainly when blood was taken for testing we were not given any information as to the purpose of the test. We assumed that it related to Stuart's haemophilia.

Section 5. Impact

20. Stuart was 6 ½ years old when he was diagnosed with HIV. He had bouts of not being very well, he had swollen glands, he suffered from night sweats to the extent that I regularly had to change his bedding, he lost weight, which led to symptoms of anorexia, he had sore throats, a cough, he suffered from stomach problems, shingles and severe diarrhoea.

21. There were times when he was fine but other times he was very unwell. He was hospitalised with shingles when he was 9 or 10 and then again at 18. He needed six months of injections when he had shingles and at 18 he was treated through a drip at home.

22. Unfortunately, HIV affected Stuart's brain and changed his personality. He was very bubbly and he had a great sense of humour however with time he became very aggressive and anxious, he didn't know what he was doing, he couldn't sleep, his sleep was poor, he was frightened of dying, frightened of what was going to happen to him, frightened of not getting married and not having children and was frightened of how people treated him when he had open wounds. The disease totally destroyed him. Towards the end he had no control over his bodily fluids which was very embarrassing for him and he also had AIDS related Parkinsons which affected his brain and his mobility.

23. He also became very depressed and down, and some days he was very angry. HCV also reduced his liver functions from the very early years. He had poor liver function results; but I am not sure whether he developed Cirrhosis.

24. He never worked although he did try to work. As he didn't work he received Attendance and Care Allowances as well as Disability Living Allowance. He was in receipt of the appropriate benefits however, he had to battle for them. He regularly had to fill in application forms to ensure continuation of his benefits.

25. He also received a car through the mobility scheme and was able to drive, because of his disability, from the age of 16.

26. He had huge memory problems which was very noticeable and had a seizure in 2000. This was the first time that it was realised the infection was affecting his brain. It took Stuart some time to recover from the seizure in particular he could not drive for some time. He had another seizure on 24th March 2003 and was admitted to St Thomas'.

27. Towards the end he would collapse at times and I could not pick him up. He was a very tall lad and once a passer-by had to stop and assist. After that he rapidly went downhill. He had no control over his bowel movements and in August 2005 was admitted to the Mildmay Mission Hospital (Mildmay) which is a specific HIV hospital or clinic. He went in for assessment on his cognitive behaviour as well as his overall health decline. Also we, as a family needed respite. I was his day time carer and he also had early morning and evening carers who came in to get him up and put him to bed. He was admitted again in December 2005 for more assessment.

28. The 26th January 2006 was the last time he was at home. He had declined mentally and physically. He was admitted into a local hospice, the Isabel Hospice and was there for 4 months until he died on 29th May 2006. He died of AIDS although his death certificate says he died from bronchopneumonia as well as AIDS and HIV.

29. Stuart's community nurse arranged the place for him at the Hospice. They were not going to take him as he didn't fit the criteria, it only provides palliative care. His community nurse fought until the Hospice took him in. The treatment he received there was amazing.

30. Stuart received treatment through GOSH and he was placed on a trial for azidothymidine (AZT). He was "unique patient number 1" at GOSH, as he was the first child to receive the treatment. He was about 9 or 10 years old at the time when AZT was in liquid form. It is now administered in tablets. We were told there could be side effects but I do not believe that the doctors knew much about the side-effects of AZT on children as only adults had received the treatment.

31. Stuart took it for quite a while and the side effects included diarrhoea and fatigue. He could never describe how he felt.

32. I don't recall any difficulties or obstacles getting treatment for Stuart, when new drugs became available they were given to him.

33. The HIV went into his brain which caused seizures and Parkinson's disease that made him aggressive. Although I don't really know what caused it, the treatment or his condition.

34. As time went on he tried new treatments as they became available. As an adult there were times when he would find it very difficult to take the medication. For example, when he was out with his friends and had to take a number of tablets he chose not to take them as he was too embarrassed. Neither did he feel comfortable hiding in the toilet to take them as he thought that this would make him feel like a drug addict.

35. He lived his life as best he could. He didn't want HIV to define him. He had a small circle of close friends and there were times when he was out with his friends and he would have no control over his bodily fluids so we had to go pick him up. It was awful for him.

36. In 2000 when Stuart was 22, even though he had had a stroke, he was able to buy a flat. He wanted independence while he was still able to do so. However, his memory was very bad and he would forget to shut the front door or he would leave a cigarette burning. I used to go and help him in his flat.

37. I remember he was not treated very well at the QE2 when he was circumcised in 1985 aged 6 ½. His stitches burst and there was a lot of blood so we took him to the QE2. The staff, when treating him, were dressed in gowns from head to foot and they treated him like a leper. The staff called for an ambulance transfer to take him to GOSH. When they finally got an ambulance team willing to take him (many had refused), they came into the room in complete white suits including full head masks. It was like a scene from the film 'E.T.' He was then taken out of

the hospital by the back stairwell. Nobody would touch him on the journey to GOSH so I had to clamp swabs on his penis to stem the bleeding for the whole journey. The way he was treated by the hospital and the ambulance staff stayed with him. The people that gave him the infections did not treat him with respect. He hated hospitals.

38. Another situation I recall was when Stuart had been in contact with chicken pox and had to go to hospital for antivirals to stop the chicken pox and shingles. He was admitted into hospital and placed in a side room in isolation. He was not allowed out of the room so we requested a television for him. He was given an old black and white one that did not work very well. We therefore asked for a better one and in colour. It will stay with me forever when the nurse said "That's all we have. Beggars can't be choosers". It was a disgrace. Stuart was in isolation and he could not mix with other children and his only entertainment was the television.

39. There was also an occasion when he had a seizure and was taken by ambulance to the QE2. When he got to the hospital the staff said that he could not have suffered from a stroke as he was too young. They spoke to us as if we were stupid.

40. I recall another occasion when he was in the Mildmay when Stuart had a nose bleed and blood splattered all over the floor. The staff mopped up blood from the floor with bleach and bleach was splashing Stuart's legs and feet.

41. Another time when we arrived at the Mildmay Stuart had been dressed in soiled clothing, his underpants had just been turned inside out. He was treated very badly. He was in there to be supervised and that included dressing him.

42. When Stuart had a bleed we were made to feel dirty and he was always made to feel like a second class citizen because whenever he was admitted to a hospital

or had an appointment he was always seen in a side or back room. He was always isolated from the other people, which I do not think was right. It made him feel as if he should be ashamed of something that was not his fault.

43. I recall an occasion that we had to tell Stuart's Head Teacher in primary school about his condition. We were approached by him and he asked us whether Stuart had been infected. We could not lie, therefore we confirmed the position. Thankfully, the Head Teacher proved to be very understanding and supportive and did not feel the need to inform anybody else about this.

44. I recall there was a situation in Australia in 2002 when Stuart came to visit us in Perth when we were living there due to Michael's job. The Perth customs officers detained him when he alighted the plane due to the amount of medication he was carrying even though he had letters from hospitals explaining his condition. He was treated like a drug addict and they tore him to pieces. He was visibly shaking due to his Parkinson's and they said this showed guilt. We made a formal complaint about his treatment, he should have been treated with respect but wasn't.

45. He received dental care from GOSH and St Thomas' although an initial assessment was made by our family dentist but he would not treat Stuart due to his HIV and haemophilia. He didn't get enough dental care and had a number of teeth removed. At the end he had a lot of decay partly because he lost the ability to look after himself.

46. Stuart missed a lot of school due to his haemophilia and HIV as he spent a lot of time in hospital away from school, which eventually impacted on his grades. He didn't do well. He lost his enthusiasm for education. He didn't feel that it was necessary so he played golf instead.

47. He obtained some GCSEs but they were all low grades. He focussed on his golf. It was one activity that he was good at and that he felt he could be like his mates.

But he was often in pain with his haemophilia in his knees, elbows and legs. But it was good for him being involved in the golf club although in the end he had no energy for the game. He was a member of Welwyn Garden City Golf Club. We were happy for him to play his golf. Despite his condition he refused to have an electric golf trolley.

48. Stuart's life was regulated by medication but he tried to live life as normally as he could. He loved sport participating and watching. But he was limited due to his haemophilia and could not play cricket, rugby or football. But as I have said he could play golf and he was good at it but it was tiring for him. He had good days and bad days when he was able to play.

49. He had a handicap of 3 and was able to start a Professional Golfers' Association (PGA) apprenticeship which could have lead him to be a professional golfer but it was just too tiring for him. He had a group of golfing friends but he never spoke to them about his HIV or HCV.

50. When his condition allowed him he spent a lot of time at the golf club but some members thought he was a sponger as he did not work but was able to play golf. He got a lot of abuse but the golf club did provide a social life for him even if he couldn't play.

51. He never had any career prospects because of his condition, nor was he ever able to keep a steady job. He had a caring job for a period of time, as well as a job in a shop, but the symptoms caused by his condition made it impossible for him to keep these jobs for long. As Dr K Rice stated in his letter of the 21st August 1996 Stuart's Haemophilia and advanced HIV infection made him "medically not fit for employment".

52. He was frightened of having a girlfriend, if he became serious with a girlfriend he would tell her straight away of his condition. In 2003 he married as he wanted to do what everyone else did. The marriage did not last and he was divorced in

2005. The marriage should never have taken place. She left him quite soon after they were married. He became aggressive particularly when he drank alcohol, she should not have let him drink.

53. Stuart's immediate family knew of his condition including his grandparents and further on as Stuart's condition developed other family members were told. His grandparents were really upset but their understanding of it was limited, they didn't understand it fully but were very supportive. Close friends were not told of his condition which made Stuart feel isolated.

54. We had to be careful with other people's children for example ensuring they did not drink out of the same cups. Stuart knew that if he had cuts his friends could not touch his blood. Stuart always knew he had to be careful.

55. From the day I found out about Stuart's infection I became a different person. I used to be a very active and bubbly person but became overprotective. It was bad enough Stuart being diagnosed with haemophilia but when he was diagnosed with HIV the impact was massive. I became obsessed with cleanliness and emotionally it wore me down. At times I could have driven into a brick wall because I couldn't bear seeing Stuart go downhill.

56. I felt guilty that I could have given him the injection that caused his ill health and that I was the one that has probably killed him. This wore me down emotionally. It took me four years to conceive Stuart and he was taken from us so prematurely.

57. I trained as a hairdresser but there was no opportunity to have a career as I had to look after Stuart. I became his school welfare officer for a time as otherwise he would not have been able to attend school without one and I continued at the school after Stuart left. I have undertaken small jobs, I worked now and again as a carer through an agency and for Marks & Spencer's from time to time but never full time work as I had to be available and take care of Stuart whenever it was

necessary. This continued throughout his life as he never became better. Also my husband had to travel with his job so I would remain at home to care for Stuart.

58. I was in receipt of the carer's and attendance allowances which have helped to pay towards my national insurance contributions so hopefully I will receive a pension but I expect it will be lower than if I had been able to work. I also have no independent finances other than savings which include my inheritance from Stuart.

59. We could not have a huge social life because of it; we did not have friends round to our home as we were always on call for Stuart. If he had a bleed we had to ensure that the right precautions were taken.

60. I had to be careful when friends came to the house, they did not know of Stuart's condition, it was stressful keeping it a big secret until later on.

61. Not one day goes by without thinking of Stuart and how it has had an impact on us as a family. I think about what we have missed out on, I have not been able to see his children as grandchildren. It has destroyed the person I was. I am physically worn down.

62. A short time after he died I became very poorly and started having pains in my head and neck, I could not taste food or drink everything tasted disgusting. I was told that I had a form of the shingles virus, (a type of Bells Palsy) which left me with Trigeminal Neuralgia, the virus had affected my head. I lost three and a half stone. My body was just worn out. I had not had time to be poorly when Stuart was alive and my body reacted after his death.

63. The stigma attached to Stuart's condition was awful. We tried to be as normal as possible but it was dreadful being grouped with drug addicts and gay people although I've never been angry with those people.

64. I have always been conscious not to tell people of Stuart's illness for his sake as it was not my decision to make, it was not up to me who knew of Stuart's condition.

65. My cousin is a nurse and I told her of Stuart's condition particularly as the children, when they were younger played together. It totally knocked her for six and I could tell that she became very cautious when the children were playing. I could sense she was watching them all the time. She couldn't relax.

66. It affected my brother too. Stuart and he were close. My brother too was dying and Stuart would spend time talking to him.

Section 6. Treatment/Care/Support

67. We did not get any support from the hospitals. However, about a year before Stuart died we did attend a mental health care unit to talk over our feelings but it was offered too late.

68. Also families in a similar situation to us came together with a couple of nurses from GOSH to create our own support group. We would take it in turns to host the group at our respective homes. This was for parents. I recall that on one occasion we did use a room at GOSH. The support group was initiated as families would often meet at clinic appointments. Within a year of the support group starting a boy died and I would have thought that the hospital would have assisted in supporting us. But they didn't, nothing was offered.

69. It was emotionally very tough as you saw friends die. Towards the end Stuart had his own community nurse and she was amazing.

Section 7. Financial Assistance

70. I expect we found out about the Trusts and Funds via the hospitals or probably the Haemophiliac Society of which we were members though I am not sure when we found out about them.

71. The first payment Stuart received was in 1991 as a result of the litigation. I recall that we had to sign a waiver letter in order for everybody involved in the litigation to receive their payments, which I strongly believe was a form of blackmail.

72. He also received £20,000 from the Skipton Fund as a result of his HCV. Stuart used the money as the deposit on his flat. The flat was bought with a mortgage and his benefits paid the mortgage repayments.

73. Stuart also received some regular payments from the MacFarlane Trust, once he moved to live independently; however, I am not aware of the amount that he was paid. In addition he received winter fuel allowance every year.

74. An application was made to the MacFarlane Trust for a wheelchair which Stuart received in the sum of £421.23 as well as a computer which the family benefited from.

75. There were also a few weekend trips funded for Stuart and a few other infected people. It was meant to be a form of a therapy. I do not know how many of them Stuart went on; however, I recall that there were at least two, including one to Brighton. I am also not aware where the financial assistance came from to fund those trips.

76. I recall that Stuart was meant to pay for his prescriptions once he became an adult; however, the hospital found ways round it so that he received free prescriptions.

77. We were not aware of how much money was available to us and what items could be funded. It was all a mystery, there was no information widely available therefore we hardly applied for funding. Stuart felt that the payments he received were an insult to him.

78. The Trust also paid towards the cost of Stuart's funeral, I believe it was about £2,000 but I'm not sure. My husband, our daughter and I were also offered a bereavement weekend as a family, which were paid for by the Trust; however, we were not provided with the information right away. I believe that we might have been told about it at some point by a nurse.

79. I was very disappointed with the way in which the MacFarlane Trust/Skipton Fund was arranged, as children received smaller payments than adults. I do not believe that is right, as it indicates an assumption that either a child is worth less than an adult, or that a child will not live for much longer so they do not need as much money.

80. I believe that the application process for financial assistance was not particularly difficult. The main difficulty was finding out about the various things that could be applied for.

Section 8. Other Issues

81. I am disappointed that some of Stuart's records have been destroyed though we have managed to acquire some records. It should not have happened. I want the Inquiry to find out what happened to those records and to locate them. As Stuart was the subject of the trial for AZT and had the unique patient reference

number as 1, I doubt that the records have been destroyed as they would be important to the hospital.

Anonymity, Disclosure and Redaction

82. I confirm I do not wish to have anonymity and that I understand the statement will be published and disclosed as part of the Inquiry.

83. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

I believe that the facts stated in this Witness Statement are true.

Signed.. GRO-C ....

Diana Margaret Blake

Dated: 25th January 2019.