Witness Name: Meg Yvonne Parsons
Statement No: WITN1460001
Exhibits: WITN1460002 - 4
Dated: 12 April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF MEG YVONNE PARSONS

I, Meg Yvonne Parsons will say as follows:-

Section 1. Introduction

1. My name is Meg Yvonne Parsons. My date of birth is the GRO-C 1972 and I live at GRO-C with my husband, Kevin John Parsons. We have been married for 18 years and have two sons, GRO-C (16) and GRO-C (13). I work in a College supporting students with specific learning difficulties.

2. This statement has been made in relation to my brother, Robert Peter Gibbs, (Robert) born on the GRO-C 1970. He passed away on the 28th July 1991 at the age of 21, as a result of AIDS caused by Human Immunodeficiency Virus (HIV), which he contracted through being treated with infected blood products.

3. Robert was the son of Peter John Gibbs and Helen Joyce Hirsch as well as an older brother to Elizabeth Helen Gardiner, (Liz) my twin sister. Our family resided in Bristol from 1970 until 1978, and then in Sidmouth, Devon from 1978 until 1991.

4. This witness statement has been prepared without the benefit of access to my brother's full medical records.

Section 2. How affected

5. Robert was born with moderate-severe Haemophilia A. He was approximately one year old when he was diagnosed with the condition; I do not know the exact date. He had a bleed to his mouth and lip and was taken to hospital.

6. Robert's haemophilia diagnosis was a surprise to my parents, as they weren't aware of haemophilia being in our family.

7. As a result of Robert's condition he was treated with Cryoprecipitate from when he was first diagnosed until around 1975/1976. He was then treated with Factor VIII. He was treated both at home and in hospital.

8. There is now produced and shown to me marked Exhibit 'WITN1460002' Robert's Hospital Treatment Record including the relevant information concerning the products that he was treated with, such as the batch numbers and dates. As can be seen he was treated with Armour, NHS Lister, Alpha and Profilate. His records suggest that he was treated with both, heat-treated and not heat-treated blood products.

9. Between 1971 and 1978, Robert was treated by Dr. Beryl Corner at the Bristol Children's Hospital. Between 1978 and 1991 he was treated at the Royal Devon and Exeter Hospital (Exeter). From about 1985 till he died (1991) he was treated by Dr Richard Lee (Dr Lee) (now retired) but I cannot recall the previous consultant's name.

10. My parents were not informed about any risks involved in being treated with blood products.

11. There is now produced and shown to me marked Exhibit 'WITN1460003' a copy of a letter from Dr. G. L. Scott to Dr. Whitfield dated 26th March 1975, (copied to Dr. Beryl D. Corner, Consultant, of the Bristol Royal Hospital for Sick Children) together with the letter in reply from Dr. Corner, dated 2nd April 1975. Dr. Scott states that Factor VIII had a reputation of having "almost magical purposes". Dr Corner states in reply "I think it is most unfortunate that factor 8 has received this publicity because... parents consider that it is vastly superior to cryoprecipitate and unless their children are getting it, they are not having the best treatment."

12. As a result of being treated with contaminated blood products, Robert was infected with HIV.

13. In 1985, Dr Lee explained verbally to Robert and my mother about the need for Robert to be taken to test for the infection of HIV, as there was a risk that he had contracted HIV from his Factor VIII treatment.

14. At a further appointment Robert and my mother were told by Dr Lee that he was HIV positive. Robert was approximately 14-15 years old, however my mother cannot remember the date of the appointment and has no record of it. My twin sister Liz, and myself were approximately 12-13 years old at the time. Following the appointment they returned home and told myself, my sister and my Dad of the devastating diagnosis. This was out of the blue and completely shocking for us all, it was very difficult for us to absorb.

15. Robert and my mother were told of the diagnosis by Dr Lee apparently with sensitivity. They had a good relationship with Dr Lee and respected him. My mother believes that he had a lot of sympathy for the situation and the diagnosis/information was communicated in a sensitive manner.

16. My mother cannot remember being given any information to understand and manage the infection at the initial meeting with Dr Lee. However they were told by Dr Lee that HIV could be spread through bodily fluids, i.e. blood: open wounds and cuts as well as sex.

17. Personally no one gave me any information, or made me aware of the risks apart from my mother telling us to be careful. The only information that we had about HIV and AIDS at the time of Robert's diagnosis came from the media, including the shocking tombstone advertisement on TV, as well as some information at school, which was minimal.

18. As a child I was really confused and worried that I might catch AIDS. At times we helped Robert with his injections, we had close physical contact with him. Potentially it was dangerous.

19. I recall one occasion where Liz and I were put at risk of infection. We were walking to school and saw a crowd of people ahead of us. Robert had fallen off his bike and he was bleeding heavily. At the time nobody knew that he had HIV, therefore his school friends did not know of the risks. Liz and I tried to stop the bleeding, we had blood on our hands and tried to prevent others from having any contact with his blood. We took him to the local hospital.

20. We were at risk on a daily basis. On family day trips and holidays we often drank from the same drinks bottle and used the same toothpaste. We could have been infected as Robert suffered from bleeding gums.

21. During the last couple of weeks of Robert's life, due to our broken family's situation, my sister Liz and I nursed him at home, we were given no guidance regarding the risk of HIV infection. We were aged 18 and followed our common sense.

Section 3. Other Infections

22. I believe that it was highly likely that Robert also contracted Hepatitis C (HCV) as a result of being treated with contaminated blood products. Robert's medical records have been destroyed so we have no firm evidence of this.

23. I was made aware through the Tainted Blood campaign/support group that Robert's estate might be eligible for payment/s from the Skipton Fund. I had not been aware that we were eligible for this, I found the information online and applied for the Stage One payment.

24. Dr Coppell, a Haematology Consultant at the Royal Devon & Exeter Hospital (Wonford) completed the Skipton Stage 1 application form, and sent the form directly to the Skipton Fund; I didn't get the opportunity to read it. I haven't been able to access any hospital notes that indicate that Robert was infected with Hepatitis C.

25. We received the Stage One payment from the Skipton Fund; this to me is an indication that Robert must also have contracted Hepatitis C, or that there was a high probability that he had from contaminated blood products.

26. I am not aware of any other infections that Robert had as a result of being given contaminated blood.

Section 4. Consent

27. Robert had regular check-ups at the Haemophilia Centre, I believe quarterly, when blood samples were taken. We did not know what he was being tested for; to our knowledge they were regular blood tests relating to his Haemophilia.

28. Robert was a child so he was tested for HIV with my mother's consent.

Section 5. Impact

29. For Robert the diagnosis was a life sentence, with no life prolonging medication available. He had been tragically infected as a young child with HIV by his Factor VIII treatment.

30. Mentally the diagnosis was very difficult for him to comprehend at the age of 14-15. It was difficult for him to take on board the fact that he would never be able to lead a full life.

31. The hardest thing was that we did not talk about Robert having HIV/AIDS amongst our immediate family, therefore there was a severe lack of family support for Robert, myself and my sister. The result of this was that we didn't now how each other were feeling.

32. Physically the effects of having HIV/AIDS were devastating. At the time of his death he was a mere shadow of his former self. He was nothing more than a skeleton.

33. When Robert was diagnosed with HIV at the age of 14-15 he requested that Dr Lee was always honest with him. He did not want anything kept from him, and Dr Lee respected this request.

34. At the age of 17 Robert was diagnosed with cancer of the lymph system after discovering a small lump in his neck. Dr Lee told Robert that the cancer was a sign of the HIV developing into AIDS. This was a devastating blow for Robert and he was obviously very shocked to have cancer, but even more shocked to know that his life was going to be so short. He had an operation to remove the

lump and had a course of chemotherapy. Robert never regained his full strength after having cancer and his health from then on deteriorated.

35. At the age of seventeen Robert was in his prime; an intelligent, well built, handsome young man, but the chemotherapy hit him hard. He lost weight, lost his hair and struggled to continue with his A Levels at school.

36. He continued to lose weight, and had several stays in hospital. He deteriorated very quickly in the months leading up to his death. He had a persistent cough and he was very weak. He spent the weeks leading up to his death in hospital, where his body could not cope with the AIDS associated infections.

37. Our parents divorced three months before Robert's death, the situation had already ripped my immediate family apart. My father bought a small house in Exeter for the three of us to live in to give us some stability at this devastating time, my father had his own house so he wasn't residing there. Robert decided that he wanted to die there rather than in hospital, or due to the current family circumstances at our family home in Sidmouth. Two weeks before his death he left hospital and he was brought to our new home by ambulance.

38. My sister Liz and I nursed and cared for Robert for the last two weeks of his life. He was skeletal; he had a collapsed lung, and was losing control of his bodily functions. We nursed him day and night, we were only 18 years old. We had support from our father, GRO-D
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GRO-D she had shown nothing but devotion and commitment to caring for Robert. I believe the tragic circumstances, and Robert's deterioration affected her mental health.

39. Shortly before Robert's death he requested that someone talk to myself and Liz. We were both in denial that he was going to die, and we were too preoccupied with busying ourselves to accept what was going on. Even up until that time, when Robert's death was imminent, no one had approached me to talk or ask how I was, this included close family, family friends or any health professionals.

40. On Robert's request a healthcare professional visited us at home two days before Robert's death. She told us that death was imminent and that we should prepare ourselves for it. We had been strong up until then, but we found this news devastating and at this point we crumbled and the reality of the situation kicked in. We were only 18, we were the ones nursing him, GRO-D GRO-D I believe that the trauma that my sister and myself went through has stayed with us for all of our adult lives.

41. The next day Robert told me to stop busying myself and to come and hold his hand; he was at peace and knew that he was fading away. Tragically he died on the 28th July 1991, at the age of 21. It was GRO-C before my sister and my 19th birthday, and since then I have struggled to feel the joy of celebrating my birthday, it's too close to the anniversary of Robert's death.

42. There were a number of things which Robert wanted to do as a young man. Once his chemotherapy ended and he was recovering from it he decided he wanted to move out from our family home and do fun things with his friends. Rob moved out of the family home into some digs in Exeter with some friends so as he could be independent.

43. He did outstandingly at school, despite having a considerable amount of time off as a result of his haemophilia. He achieved 9 O Levels and proceeded to study 3 A Levels. Robert lost motivation during his second year at sixth form when he was diagnosed with cancer, he was also not well enough to continue with his studies. He was really bright and he could have gone onto study at university if

his health had not been deteriorating due to having AIDS. Robert knew that his life was going to be really short and he decided to give up studying for his A Levels as he believed that continuing with his education was a waste of his time.

44. Once he has recovered from the chemotherapy he got a job at Barclays Bank in Seaton, Devon. He only stayed in the job for 3 or 4 months, due to associated health problems. I do not know if his employer knew about his HIV status, I presume that they didn't.

45. Robert was lucky to have some really close friends, which gave him the chance to be as normal a teenager/young man as he could. He was determined to live as normal a life as possible and he did not want to stand out as being different to his friends. He risked telling his closest group of friends about his HIV status, fortunately they kept it to themselves and proved to be very supportive of Robert right up until his death. He was lucky to have such trustworthy and supportive friends.

46. Robert smoked cannabis with his friends, he found it therapeutic and it helped with his physical symptoms.

47. Robert felt that due to the risk of passing on HIV, he was unable to hold down a relationship. He only had one girlfriend; however he decided to end the relationship, because he was not prepared to tell her about his illness. He knew that there was a risk of him infecting her. He was frustrated that during his lifetime he felt unable to have a physical relationship with a girl, this was something that he would have really liked to experience.

48. Robert passed his driving test, and had a love for cars. He owned a red Peugeot 206, complete with spoilers, leather steering wheel and a set of very loud speakers. He loved that car. As a family we gathered strength and inspiration from Robert, and how he chose to live his life.

49. Life went on with our parents doing their best to make as many happy memories as they could, and we went on several family holidays together.

50. Robert was laid back personality and he had a love for music. He had a big record collection and his favourite artist was Bob Marley. He was always playing music in his room, and I am sure he used music as a way to escape the uncertain and scary situation he was in. He requested several Bob Marley songs to be played at his funeral.

51. In 1990, the year before he died, our mother took Robert on holiday to Jamaica. He visited his idol Bob Marley's birthplace. Despite being fairly unwell, this was a very special holiday for them both.

52. Soon after this holiday our mother took him to the Hypocrates Health Institute in Florida. It had been recommended to her, and it promoted eating and lifestyle changes which could possibly prolong the life of someone with HIV. They were clasping at straws, but my parents would have done anything to improve his situation.

53. At around the age of 17 when Robert started to experience AIDS related symptoms, Robert was prescribed Retrovir (AZT) by his Consultant Dr Lee. This drug caused him to have a persistent cough, feel sick and he was told the drug was causing him to lose weight.

54. To my knowledge, Robert's infected status did not impact on his other medical treatment. During his final stay in hospital he was given his own room, he was never put in isolation.

55. We all individually struggled to comprehend the reality of what lay ahead. Robert had been given a life sentence, and due to the stigma associated with AIDS we

spent our childhood having to keep the worst secret imaginable. We lived in GRO-C, a small seaside town in Devon. If the local community found out that he had AIDS we risked alienating ourselves, bullying and probably having to move out of the area.

56. As a child I did not feel able to talk to friends, teachers or other family members about Robert's HIV/AIDS status, and no one ever spoke to me. This had a colossal impact on me, and unfortunately as a family, as referred to above, we did not support each other. I believe that the reality of what was happening made it too painful. In the 1980's AIDS was seen as disease associated with the gay community, there were petrifying adverts on TV and a feeling of fear associated with the disease. We had to put up with friends (including adults) joking about AIDS and we did not feel able to defend our situation. This left us feeling unsupported individually and isolated as a family.

57. Our family were not offered any support or counselling.

58. My parents did not discuss Robert's illness with me when as I was growing up, it was too painful. They also did not support me in offering guidance in what I was going to do in the future. We were all aware that Robert would not have the same opportunities, so I believe that speaking about my future seemed insensitive. As a result of this, my parents did not discuss or show any particular interest in my future plans.

59. Robert had a good relationship with both our parents, but especially with my mother. She had cared for him with his severe haemophilia since he was a baby. She administered his Factor VIII injections from a very young age, and took him to all his hospital appointments. He had a fair amount of time off school with his bleeds, and my mother did not work as she needed to be on hand to look after and to care for him.

60. Robert's illness affected mine and my sister Liz's relationship with our mother as children and in our adult lives. As children we felt that her attention was taken up with Robert, this had a great effect on us.

61. Our father was and still is supportive, he tried to help us as much as he could. In 1993, two years after Robert's death he started a new life in Thailand.

62. Lacking parental guidance as a direct effect of Robert's illness forced me and my sister to become independent and to make our own decisions from a young age.

63. Robert's illness affected my parent's relationship. By the summer of 1990, our parents' marriage had fallen apart, and when our mother was on holiday with Robert in 1990 she met Tom, an American, who later became her second husband. GRO-D.

64. In the Spring of 1991 (three months before Robert's death) my parents divorced.

65. After Robert died, our already broken family went our separate ways. In October 1991, two months after Robert's death my mother moved to Florida. GRO-D GRO-D GRO-D I believe that Robert's illness affected her mental health

66. GRO-D GRO-D

67. This was devastating on Liz and I, our brother passed away GRO-D GRO-D

68. After 17 years of living in America, she returned to the UK.

69. For as long as I can remember my mother has been GRO-C GRO-C The implications of this have resulted in profound consequences for us all. I believe that Robert being infected with HIV by infected blood products contributed to her problems.

70. My mother is emotionally fragile and she currently is not in good health. I believe that her fragile mental state stems directly from Robert's HIV infection and his death. My broken relationship with my mother still causes me pain. GRO-D GRO-D

71. Dad moved to Thailand in 1993, and is still very happy in his life out there.

72. My twin sister Liz started at Southampton University in October 1991. She achieved a 2:1 degree in English and History and is a primary school teacher.

73. I returned to Bournemouth University in October 1991. Liz and I were living close and we were a great support and comfort to each other.

74. My sister and myself did not just suffer the loss of our brother, we also suffered the loss of our parents as they both moved abroad. My sister is and always has been my brick and she has been the main source of support for me.

75. My own children have reached the ages that Robert was infected (approximately 10 years old) and the ages when he was told about his infection (14/15), it breaks my heart to know that his life was taken away from him. As our eldest children approach 17 this year, it is unfathomable that this is the age that Robert was told he had full blown AIDS. When adult life should have been beginning, his childhood and life were snatched away.

76. This is the impact of the contaminated blood, it has ripped our family apart and has given us a burden of grief which still lies heavily on our hearts. Re-telling the

events now for the Inquiry opens these wounds and makes the burden weigh heavy on us.

77. The impact of Robert being infected by HIV as a child has deeply affected my childhood and adult life, I continue to be traumatised by the events and circumstances of the past.

78. There is now produced and shown to me marked Exhibit 'WITN1460003' thoughts and memories I have written about this tragedy called 'Emptying My Head of Some Thoughts and Memories'.

Section 6. Treatment/Care/Support

79. No counselling or support was ever offered to Robert or to myself or my family. I believe that this was an absolute disgrace. The only health professional Robert ever talked to was his consultant Dr Lee.

80. After Robert's death my immediate family were broken, and we were left to find our own way to grieve and deal with what had been a devastatingly traumatic time.

Section 7. Financial Assistance

81. Robert received approximately £20,000 from the MacFarlane Trust in about 1989/1990.

82. I believe that Robert found out about the MacFarlane Trust from Dr Lee or the Haemophilia Society; however, I am not aware as to the application process or any pre-conditions imposed.

83. I understand from my Dad that as a result of the 1991 litigation Robert received an ex gratia payment of £40,000 from the government.

84. After Robert died, as referred to above, our parents received around £20,000 from the Skipton Fund in January 2017.

Section 8. Other Issues

85. The burden put on entire families as a result of people being infected with those horrible diseases will never go away. However, this is now the opportunity to investigate the tragedy and hopefully bring some closure, if the government admits that this was a terrible thing to happen and that it should have never taken place. It is unlikely that families would have agreed to treat people with contaminated blood products, particularly to treat young children like my brother, knowing about the risks involved.

86. I am left wondering whether Haemophiliacs were simply seen as less important, and why the government at the time agreed to import Factor VIII from the USA when they knew the risks. I blame them for infecting my brother with HIV as a child, for my brother's suffering and for his unnecessary death. I blame them for the trauma this has inflicted on myself and my family. I welcome this inquiry to investigate why this was ever allowed to happen.

Anonymity, disclosure and redaction

87. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

88. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed GRO-C ....

Meg Yvonne Parsons

Dated: 12 April, 2019