

Witness Name: Craig Tansley

Statement No: WITN1555001

Exhibits: 0

Dated: 28 March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF CRAIG TANSLEY

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I, Craig Tansley will say as follows:-

#### Section 1. Introduction

1. My name is Craig Tansley. My date of birth is the **GRO-C** 1965 and I live at **GRO-C** with my wife, Louise Tansley (Louise). We have two adult children, Lewis and Elisabeth and I am employed by Derby College as an assessor, I teach and assess qualifications.
2. This statement is made in relation to my brother-in-law, (Louise's brother) Simon John Campion (Simon) who was born on the **GRO-C** 1969 and sadly passed away on the 27<sup>th</sup> July 1996 at the age of 27. He was treated with contaminated blood products and as a result contracted Human Immunodeficiency Virus (HIV), Hepatitis B (HBV) and Hepatitis C (HCV). He died of Acquired Immune Deficiency Syndrome (AIDS) with complications relating to Pneumonia. I am the personal representative of Simon's Estate.
3. This witness statement has been made with the benefit of partial access to

Simon's medical records.

## **Section 2. How affected**

3. Simon was diagnosed with severe Haemophilia A when he was three months old by Dr Arthur at the Derbyshire Children's Hospital.
4. Simon was treated with blood products from when he was six months old until he died. The brands of Factor VIII which he received that I am aware of from the records I have seen from the National Haemophilia Database were BPL and Koate. Also Alpha viii, Profilate, BPLviii, Replanate, Profilate, Oxford viii, Cryoprecipitate and Kryobulin
5. Also Simon's medical records which I have from 3<sup>rd</sup> July 1981 to 25<sup>th</sup> June 1986 show that he received Antihaemophiliac (270) batch numbers HLB2852, HL2770, HL2849, HLA2929, HL2938, NLA2960, NC8413 and dried Factor VIII, batch numbers V36504, U26512, NC8339, NC8368, NC8292, WC8292, HLA3036, HLA3069, HLB3094, HLB3105, HLA3116, HLB3121, HLA3129, HLB3168, IU290, IU270, IU830, AB0650, IV850, A60900, A61010, NO8Y327T and NO8Y3349.
6. Simon received most of his treatment from the Derbyshire Royal Infirmary. Further, I am aware that he was treated by Dr Winfield when he was very young then Dr Mitchell and later by Dr A McKernan.
7. As far as I am aware from Simon's mother, they were never informed or advised of any risks of being exposed to infection from being treated with blood products. His mother started becoming aware of the risks associated with blood products from reports she had seen in the press at the time.
8. Simon was diagnosed with HIV when he was about 15 years old. His medical records show two different dates for his diagnosis being the 5<sup>th</sup> February 1985

and the 15<sup>th</sup> December 1985.

9. Dr Mitchell telephoned requesting Simon and his parents go and see her at the Derbyshire Royal Infirmary. At the meeting they were told that GRO-C  
GRO-C Simon had to have further tests undertaken. More blood samples were taken and soon afterwards the hospital telephoned again requesting they attend another consultation, Simon was told at this consultation that he had contracted HIV.
10. The family were then invited for a group meeting at the hospital. When Simon, his parents and Louise arrived there were also many other families in attendance as well as academics, doctors and dentists, it was apparently very unnerving for the family. However, tea and cake were available and the atmosphere seemed to be relaxed. This meeting descended into some professionals refusing to treat people with HIV or arguing over the process and procedure. The family felt belittled and talked over because the indicative medical content was beyond their understanding.
11. Louise and her mother do not recall whether there was much practical information provided at that meeting. But they were certainly advised to go forward with their lives and not to tell anybody about the infection due to the stigma associated with the infection.
12. At that point Simon and his family did not know how his life would be affected by his illness. They were all in shock and at that time people did not question doctors. Nobody seemed to understand what had happened and no explanation was given. Even the doctors seemed not to know appropriate ways forward or what patients should expect.
13. I do not consider the way in which the families were advised regarding the treatment of the infection was appropriate. Louise recalls the way in which the

meeting was handled was very vague. No adequate information about the virus was provided, indeed, adequate information has never been provided to Simon and his family.

14. Certainly more information should have been provided and it should have been provided a lot earlier. It is clear that doctors knew of the risks associated with the blood products from America and they were very aware of the risks associated with the virus. It seems that they had a lot of information but they did not want to provide it to the public.

15. Simon and his family gained most of the information about HIV from the media. There was not a lot of useful information other than what not to do, such as warning about infection from toilet seats and shaking hands. There was a lot of scaremongering, but no information about the risks of being infected from needles when administering Factor VIII to Simon or to wear gloves when doing so.

16. About ten days before Simon died the medical staff at the Sue Ryder Care Home where he died, revealed he had HCV as well.

17. When Simon's medical records were obtained in 2018 it was also discovered that he had contracted HBV. His medical records contained a letter from the Leicester Royal Infirmary confirming the HBV infection, and also Cytomegalovirus (CMV).

### **Section 3. Other Infections**

18. I am not aware of any other infections that Simon might have contracted as a result of being treated with contaminated blood products.

### **Section 4. Consent**

19. There was never adequate information provided to Simon or his family about the

tests that were performed on him. For example he had a lumbar puncture but it was not explained why.

20. I believe that if Louise and her family knew then what they know now, they would have asked more questions to better understand what was happening.

21. Simon's mother does not understand complex terminology, so she simply would not have known what to ask the doctors.

### **Section 5. Impact**

22. Physically Simon was generally in good health from his diagnosis to about 1993. However, by 1993/early 1994 he started to suffer from recurring infections, such as thrush, shingles and chest infections, as well chronic sinusitis and a persistent cough. He also had low muscle power and muscle wasting. He had fixed flexion deformity (clasp knife), meaning that he was not able to fully extend his knees.

23. Simon also suffered from constant diarrhoea and a loss of bladder control, which caused him to have to wear nappies.

24. He also had poor mobility and he had to have regular MRI scans as his brain was slowly failing to function which caused his motor skills to slow down.

25. In about 1993 when Simon was around 24 years old, he started to lose his ability to walk. He had constant infections and shingles attacked his spinal cord which caused him to lose control over his legs and bladder. CMV could have caused this as well. It was very difficult for him. When he lost bladder control he had to have help to be cleaned up which caused him distress as he hated the loss of dignity.

26. Overall, Simon was a very positive and happy person. However, towards the end of his life he became very angry and frustrated with what had happened to him.

On occasions the anger would break through; however, he never really wanted to discuss it with us. He was very private and he tried to remain positive for others.

27. I believe that he accepted what was unfortunately eventually going to happen to him.

28. Due to his physical inabilities, such as loss of the ability to use his lower limbs, inability to work and loss of bladder control, he became very angry and upset. As I have said he was a very private person and independent, so having people assist him with everyday tasks, including washing him was very difficult for him.

29. Simon was treated with Azidothymidine (AZT), which started in January 1990. However, it proved to be toxic for him, so the doctors decided to stop it in January 1993.

30. AZT had awful side-effects for Simon. He was constantly vomiting, he had diarrhoea and it generally made the quality of his life very poor. He also became very anxious around that time.

31. In November 1993 he was treated with Didanosine until May 1995 and from July 1995 he was treated with Dideoxycytidine (ddC). However by this stage he had serious neurological problems. He soon developed a spinal infection and relied on his wheelchair. He died soon afterwards at the Sue Ryder Care Home on the 27<sup>th</sup> July 1996 at the age of 27.

32. I do believe that more could have been done about the treatment Simon received. During the early 1990's a new generation of drugs started to become available. I believe that someone should have discussed his options with him and give him a chance to try other drugs.

33. When I met Louise in 1988/89, I slowly learnt about Simon's condition. I got to

know the family and how much they were struggling because of it. I was very annoyed by everything that I was seeing and the lack of support.

34. I contacted the Terence Higgins Trust to ask where the family could seek help. I was put in touch with Jenny Deakin (Jenny), who was a personal case worker at the Leicester AIDS Support Service. She gave us a lot of information about where to access care and support. She helped us to apply for grants and funding to make the house more suitable for Simon.

35. She also told us about the MacFarlane Trust and how to access support and also how to get Simon disability living allowance, as well as a carers' allowance for his father through the DHSS.

36. Jenny suggested Simon be admitted to the hospital for his final days. She provided excellent help as did Simon's GP and district nurses. Other than that, there was not much support from other doctors at the time and the family were left to get on with it.

37. Simon's father was his carer after he was made redundant from work. He did some casual work, but he mainly cared for Simon after he was made redundant. Simon's mother worked part-time. Until a stair lift was installed Simon's father had to carry him up and downstairs. Applications for grants to modify the house were made; however, unfortunately Simon died as the works were completed so never saw or used the facilities.

38.

**GRO-D**

**GRO-D** He blamed himself for Simon's condition as he had administered Factor VIII to him.

39. Simon's father was also angry, he was overcome by grief, he could not cope with what had happened. GRO-D

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GRO-D

41.

GRO-D

42. Simon's mother is socially withdrawn, she is not able to communicate about what has happened. GRO-D has just tried to live her life. Having kept the situation to herself and within the family, she now wants to be open and honest. GRO-C

GRO-C

43. Our children have always known of Simon's status as there are still potential issues for their own health. Also, our son, Lewis, looks like Simon. When Simon was ill our children were farmed out to others while Louise and I were in hospital or the hospice with Simon and subsequently were not supported as they should have been at the ages of 1 and 4.

44. Simon's illness and his passing as a result of it have been extremely difficult for me as well. He was my best friend and I was closer to him at that time than I am



to my own brother.

45. We were both practically-minded and we shared a lot of good memories. We enjoyed mechanics, and we had spent hours on projects in the shed, for example tinkering with an old hand rotavator and spraying his Landrover.

46. I miss his companionship and I feel he missed out on so much. I know that he adored his niece and his nephew and would be proud of the way they have developed. We all would have had great family time together. Also, Simon would have loved to have had children of his own (a deep regret).

47. Simon's education was affected by his illness. Originally, he missed a lot of school before he was diagnosed with HIV due to his Haemophilia. He was diagnosed with HIV when he was around 15 and this was when he really started to fail at school. He was not able to focus on his studies. However, vocationally Simon was good.

48. School was not a positive experience for Simon. He had some friends there, but he never really socialised with them outside of school. He had a lot of time off school because of his illness, he would often leave school early, and he did not have playground breaks, therefore had no opportunity to mix with other children. His parents were very protective of him, which made things ever harder for him.

49. Simon had little interaction outside the family unit and spent time with the animals on his uncle's farm. When Simon left school, he had a period of work experience at an upholstery factory which later led to a job. He met a young lady there who he got on well with. They became very close. Simon's mother said that he should explain his condition to her, which he did after a few months. She confided in her parents and it got back to Simon's employer and resulted in Simon being dismissed from his job. This ended the relationship with the young lady after his dismissal.

50. The employer was [GRO-D] in Coalville which upholstered furniture. The company knew Simon had Haemophilia and must have put 'two and two together' and questioned him on his so called 'failing performance at work'. As a result, Simon was dismissed as he was not ready to reveal his HIV status.

51. He had a great sense of vocation and set up his own workshop, where he would undertake little jobs for people, such as upholstering settees and other pieces of furniture.

#### **Section 6. Treatment/Care/Support**

52. I do not believe that Simon was treated fairly at hospitals due to the prejudice associated with HIV. At Leicester Royal Infirmary he was always treated in isolation, he felt like a leper, he was always placed in a private room, medical staff always wore gowns and masks, and nobody would want to pick up his bed pans or used plates and crockery so as not to be responsible for them or even to touch them.

53. There was also an occasion when a dentist Mr [GRO-D] refused to treat him because of Simon's HIV status. He had to go to hospital to receive dental treatment.

54. When Simon started losing control of his legs he needed a wheelchair. Two Health Authorities (Derby and Leicester) disagreed over who should be responsible for financing it. After waiting for a significant amount of time without a resolution, the Red Cross stepped in and provided him with a wheelchair.

55. Overall, I believe that care was not really an issue. The issue was the lack of information and support. I feel the Haemophilia Society was not supportive in terms of information and on-going support and could have been much more

proactive.

56. I came across a letter in Simon's medical records stating that he was offered counselling; however, in fact counselling was never offered to any of us.

57. The only time any support became available was when Jenny became involved. She took a lot of time to explain things to us and support us.

### **Section 7. Financial Assistance**

58. The family also struggled financially and were not made aware of any trusts or funds available until they were introduced to Jenny and certainly when Simon's dad lost the care allowance the family lived on his mum's part time wage.

59. I managed to apply for and get about £40 per week from the MacFarlane Trust for Simon and also a disability care allowance and it started about December 1992.

60. Simon's father received a carer's allowance which was over £40 per week as he was Simon's carer and as result he did not work.

61. What really upsets me is the fact that we were not aware of Simon's Hepatitis. His family home was not suited to his needs and it desperately needed some adjustments to be made. If it was known that he had Hepatitis an application could have been made to the Skipton Fund to make the adjustments needed.

62. Simon also received an ex gratia payment of £23,000 and as a condition of the payment he received he had to sign an indemnity form.

63. After Simon's death, his family received £1,000 towards funeral expenses. No one had to apply for it. We also received a small sum from the MacFarlane Trust after Simon died as back payments that were due to him.

64. We were very grateful for Jenny's help and support, even after Simon died she continued to take us in hand inviting us to a barbecue for example, she was the only one who understood our situation. [GRO-D]

[GRO-D]

65. We also received a very sensitive letter of condolence from the MacFarlane Trust after Simon died. But again ongoing information would have been helpful, we were just cut adrift.

### **Section 8. Other Issues**

66. I have encountered many problems obtaining Simon's medical records. I have tried to access them via a variety of means.

67. However, I have been unable to obtain any records, other than blood test results, from the Derbyshire Royal Infirmary. I have received several versions of events for example, I was informed that they were destroyed in 1995; however, I do not believe that this is true as this would be a year before Simon died.

68. I have asked for a proof of destruction which I have never received. I have asked where they were sent to, and then I was told that there was a fire which destroyed them. They have now ceased to communicate with me.

69. In contrast the Leicester Royal Infirmary proved to be very helpful. I only had to send one email requesting Simon's records and they provided me with full disclosure of the documents available, including the meals he had been given.

70. The UK Haemophilia Centre Doctors' Association have also disclosed notes, although NHS England have been less than helpful in providing records despite the direction from the Chair of the Inquiry, Sir Brian Langstaff.

**Anonymity, disclosure and redaction**

71. 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.

72. I 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

Craig Tansley ✓

Dated: 28 March, 2019