

Witness Name: Colin George Turton

Statement No: WITN1574001

Exhibits: WITN1574002

Dated: 1<sup>st</sup> March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN WITNESS STATEMENT OF COLIN GEORGE TURTON

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I, Colin George Turton will say as follows:-

#### Section 1. Introduction

1. My name is Colin George Turton. My date of birth is the [GRO-C] 1958 and I live at [GRO-C], North Somerset [GRO-C] with my wife, Denise Anne Turton. We married on the 9<sup>th</sup> October 1981 and have had four children: Lee, Kerry, Robyn and Jack. I currently work in explosives and am freelance.
2. This witness statement is made in relation to our son, Lee Dean Turton, born on the [GRO-C] 1981, who passed away on the 22<sup>nd</sup> January 1992, at the age of 10, as a result of Human Immunodeficiency Virus (HIV), which he had contracted through contaminated blood products.
3. This witness statement has been prepared without the benefit of access to my son'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 affected

4. Lee was six months old when he was first diagnosed with Haemophilia A in GRO-C 1981. He had problems with his hip, and the doctors originally thought that my wife and I had hurt him. He was kept in hospital for a week, he was tested and it was found that he had a blood disorder. Lee was originally diagnosed with mild Haemophilia; however, following a further test it was found that his Haemophilia was severe.
5. He was originally treated with Cryoprecipitate (Cryo) when he was a baby. He was then treated with Factor VIII, as we were told Cryo was no longer available. He was treated with Factor VIII from around 1981 throughout his life.
6. Between November 1981 and April 1989 we were living in the Bristol area and Lee was treated at the Bristol Children's Hospital (now Bristol Royal Hospital For Children). Lee was treated by Dr David Burman, a Consultant Haematologist until he retired in 1987, Dr Primaves stood in until Dr Hinde and Dr Oakhill were appointed and Lee was treated by them.
7. In April 1989 Lee came under the care of Dr Helena Daly at the Royal Cornwall Hospital (Treliske) as we moved to Cornwall.
8. He also received one treatment from the Torbay Hospital on the 12<sup>th</sup> July 1984. He was treated with Factor VIII, which was produced by BPL.
9. Lee's medical records from the hospital, show that he was treated with other blood products after he was already infected with HIV.
10. Denise and I were never informed about the risks to Lee of being exposed to infection from blood products.

11. Due to the publicity of the Acquired Immune Deficiency Syndrome (AIDS) caused by contaminated blood products I asked Dr Burman about the potential risks of infection to Lee. We were reassured by Dr Burman that the Factor VIII used to treat children was of British origin, not American and therefore it was safe. I cannot recall the exact date of that conversation with Dr Burman but it was prior to Lee's diagnosis.
12. As a direct result of being treated with contaminated blood products Lee contracted HIV.
13. We were told of the diagnosis in August 1985. Lee was only four years old at the time it was just before he started school. We were called into the hospital by Dr Burman. He informed us that Lee was one of two children in the hospital in Bristol who was infected.
14. We were very angry, we felt that Dr Burham was very dismissive of us. We kept asking him questions in the hope that we would get some clarity; however, he kept on repeating that he knew as much as we knew about the situation. In the end he got up and said that if we had further questions we could book a separate appointment to discuss it. He came across as very arrogant and the diagnosis was not given in a good manner. We never saw him again after that appointment.
15. There is now produced and shown to me marked Exhibit 'WITN 002' a copy of the letter from Avon Health Authority to Ross & Co, Solicitors dated the 28<sup>th</sup> November 1997 enclosing a schedule of the Cryo and Factor VIII administered to Lee between 1982 and March 1985. This notes that Lee tested positive for HIV on the 8<sup>th</sup> March 1985 whereas we were not informed of the diagnosis until August 1985.

16. In the meeting with Dr Burman, we also asked him to keep Lee's infection private, because we wanted to first process the information ourselves. We also knew that there was a lot of stigma surrounding HIV and AIDS and we did not want to be subjected to that.
17. We were not given any practical information or explanation from Dr Burham about Lee's infection or how to manage it.
18. I do not believe that we were provided with adequate information at the time.
19. I also believe that information about the virus as well as to how to manage it should have been provided earlier.
20. Denise and I were not happy with the way in which the results of the tests were communicated to us. The doctor was dismissive and arrogant; he showed no remorse, particularly as he had assured us that the blood products used to treat Lee were safe.
21. There was no information provided about the risk of infecting others. Denise was very cross about it, as our daughter, Kerrie, was only two years old at the time and she was at risk as well as Denise who treated Lee whenever he had a bleed.
22. In Lee's medical records we found a letter from Dr Daly to Dr Burman dated the 31<sup>st</sup> May 1985 stating that as Lee was treated at home we are "...at slight risk of contamination, and they obviously ought to wear gloves". We were never told this.

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

23. After Lee died we became aware from his medical records that he was also infected with Hepatitis B (HBV) and Hepatitis C (HCV).

#### **Section 4. Consent**

24. Lee was treated without our consent. We were deceived by Dr Burman as to the origin and safety of the blood products that Lee was treated with; therefore we could not have given our fully-informed consent to his treatment.
25. Lee was also tested without our knowledge, and without our fully-informed consent. For example, we were not aware that he was tested for HIV infection prior to receiving the result of the test. In fact we never knew about him having any blood tests at all.
26. We guessed that Lee had HCV due to the symptoms he displayed but we were never actually given the diagnosis.
27. Lee was obviously tested for HCV and HBV, which became apparent after reading his medical records; however, once again, we were not aware of him being tested.
28. I also believe that Lee might have been tested for research purposes.

#### **Section 5. Impact**

29. As to the physical effects of the illness on Lee, it is fair to say that every aspect of his life was affected by it. He had no energy and was not physically able to do anything.
30. We had first noticed that he was seriously ill in 1988 when Lee was about seven years old. He had bronchitis, a lung infection, rashes and he could not eat properly.

31. In December 1988, Denise and I explained our concerns to Dr Oakhill who sat Lee down and explained to him what he had. This was particularly appropriate as Lee had started taking AZT and had guessed that he had something wrong with him.
32. It was a lot for him to process at only seven, and neither I nor Denise quite understood how he managed mentally, especially as he never received any counselling or other support.
33. Lee's education, as well as his experience at school overall was greatly affected. He continued to attend school on and off. He went to school when he was well enough, but it was rare and he found it hard.
34. Further, Dr Burman did not respect the fact that we had asked him to keep Lee's infection private. He wrote a letter to Lee's GP, Dr GRO-D who then informed Lee's school teacher that Lee was HIV positive and this was disclosed in school.
35. Before Lee was seriously ill, parents did not want Lee to attend the same school as their children. I believe that this might have been how he first became aware that something was wrong with him, as he did not have friends in the infant school, he never had friends at our home, nor was he ever invited round to other children's homes. There were also two teachers at the school who did not want him in their classes.
36. The press even showed up at the school gates wanting to interview us and to take pictures. But we never agreed to talk to them. We wanted to protect Lee. The press interviewed a few parents at the school.
37. It was extremely stressful for all of us and very upsetting to the extent that we made plans to move to Cornwall.

38. Lee was prescribed Azidothymidine (AZT) treatment in December 1988. The treatment became a problem almost instantly, because of its side-effects combined with the symptoms of Lee's illness.
39. I believe he was put on a very high dosage, too high for a young child in my view, and it proved to be toxic to him. The rash he developed as well the difficulties with his vision and the headaches he had were signs that the medication was toxic.
40. To our knowledge, this was the only treatment available at the time. I am not aware as to whether there were better or alternative treatments available at that time that Lee could have received instead.
41. Other physical symptoms of Lee's illness and side-effects of the medication were vision and hearing issues to the extent that he could not see or hear sometimes, he had breathing problems, so he often received oxygen, and he suffered from night sweats. Lee had problems with his liver and had a constantly swollen stomach. He also developed herpes and mouth thrush, which caused him to stop eating.
42. During the last twelve months of his life, Lee was not growing or putting on weight, so he was given growth treatment. He was unable to eat and had lost his appetite so a tube was inserted up his nose which went to his stomach and he was fed liquid food over night. He was also jaundiced. Lee would be awake at night as very frightened and in pain we would take it in turns to sit with him to comfort and reassure him. He was taking different medications for different side effects from illnesses due to HIV.
43. At the time, we felt we needed to keep his illness a secret, in order to protect him. We told some of our relatives about it, such as our respective parents, but we have always tried to keep it as private as possible.

44. At the time we lived in Bristol; however, due to the media intrusion people became aware of Lee's illness and unfortunately there was general hostility towards us from people and we lost friends there.
45. In 1989 we moved to Cornwall, in order to change the environment for Lee and Kerrie, who was only two at the time. We wanted them to enjoy their childhood without people staring at us. Unfortunately, it did not work out in that manner as Lee's health started to deteriorate rapidly.
46. Also Lee's condition put pressure on our marriage and our family. We did not have much of a social life and Kerrie missed out a lot in particular she spent a lot of time at hospital appointments when we took Lee.
47. Moving to Cornwall also affected my career and our financial situation. I used to work as a shot firer (working with explosives) in Bristol. I had to leave my job when we moved and look for a new one in Cornwall. This affected us financially as I had no income while I was looking for a new job.
48. Eventually I found a role as a deputy manager delivering explosives to quarries. I was worked there for two years. Unfortunately, I lost that job because I was taking so much time off to care for Lee. I was unemployed from March 1991 until 1993.
49. I currently do consultancy work for quarries finding work for businesses. Unfortunately, I find that I cannot concentrate on my job as well as I did before and I believe that it is related to the stress caused by Lee's illness and his death.
50. While we were in Cornwall, we felt extremely lonely. Our immediate family lived in Bristol, we felt isolated. We also had nobody to help us. My parents visited now and again but Denise's parents did not visit.



51. Lee died on the 22<sup>nd</sup> January 1992. He was only 10 years old.
52. On the 11<sup>th</sup> January 1992 we were going to Bristol to stay with relatives. During the journey Lee's lip was twitching. When we arrived Lee's lip was still twitching and Denise rang Trelike Hospital. The hospital said that if it became worse to take Lee to Bristol Children's Hospital. The next day Denise found Lee on the floor of the bathroom fitting. He was taken by ambulance to hospital where a computed tomography (CT) scan was undertaken of his head. We later found out he had had a grand mal seizure.
53. Lee really wanted to return home so an ambulance took Lee back to Cornwall. The next day we were called into the hospital when Dr Daly told us that he had a brain infection and was dying and that he had between two and ten days to live. He was prescribed painkillers and he told us he was very scared. He died after eight days.
54. The funeral process was extremely painful for us, as a family. An AIDS nurse from the hospital said that he could not be buried because of his infection. We insisted upon him being buried. He died on the Wednesday and was buried on following Monday, we had only two days to sort out the funeral, but he was buried. We also had a five month old baby to care for. Everything stopped when Lee died.
55. In 1993 we moved from Cornwall to North Somerset, as I had no work at the time, I could not find a job and we could not pay the mortgage. We have moved a couple of times since Lee died so as I could gain employment and obtain a mortgage. We now own our own home.
56. We have become very wary of people, and we find it hard to make friends as we feel that we cannot really trust anybody. Our life remains very private, we do not

have many friends. After Lee died I have told people if prompted that we have three children not four as I cannot bear going through everything.

57. Denise and I are both on antidepressants prescribed by our GP. I also have high blood pressure and I cannot remember things, I feel everything has got to me. I have never been offered any help; no counselling or psychological support. We blame ourselves and each other for what to Lee for not being able to do all the things he wanted to do. We let it happen.

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

58. As a result of his infected status, Lee could not go to a dentist's practice; he received dental treatment at the hospital.

59. Lee was also never able to go to a GP, he was always treated in hospital as the GP would not know how to treat him.

60. No counselling or psychological support was offered to Lee.

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

61. In 1991 Lee received an ex gratia payment of about £21,500. We had only two days to accept the payment and sign a waiver, and if we did not do so then none of the other claimants involved in the litigation would have received any compensation.

62. I believe that this was highly inappropriate, Lee was dying and the last thing that we wanted to do was think about money.

63. We originally intended to put the money in trust for Lee for when he turned 18; however, he died in the January after we had received the payment.

64. We have received a number of payments from the MacFarlane Trust:

- a. In 1988 we received around £1,050 for heating to our house and £135 for a tumble dryer.
- b. In 1991 we received £250 towards bedding as Lee was incontinent.
- c. The Trust had also contributed £750 to a holiday in America that Lee really wanted. However, we were never able to go as Lee was too unwell.

65. We also received an allowance of £25 per week from the MacFarlane Trust. I am not sure when the payments started but all financial assistance stopped when Lee died. We did not even receive any financial assistance for Lee's funeral.

66. I believe we had found out financial support was available from the MacFarlane Trust from a leaflet produced by the Haemophilia Society.

67. I found the application process unnecessarily problematic. Whenever we asked for assistance, we had to wait for a very long time to get a response and then there were meetings to discuss it. All the time our son was dying.

68. The application process took ages and it made us feel like we were begging for money.

69. As a result of the constant obstacles put in our way to prove that we needed assistance, we did not apply for help very often, regardless of the fact that we needed it. Also we had to focus on getting Lee to the hospital and back, and caring for him.

70. I believe that the funds and trusts did not actually understand what was happening and the effect the contaminated blood had on people's lives. It was as if they were playing God, just like the doctors did.

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 do not wish to be called to give oral evidence.

**Statement of Truth**

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

GRO-C

Signed

Colin George Turton

Dated 1st February 2019  
March