

Witness Name: Karen Jacqueline Allen

Statement No: WITN1622001

Exhibits: 0

Dated: March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF KAREN JACQUELINE ALLEN

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I, Karen Jacqueline Allen will say as follows:-

#### Section 1. Introduction

1. My name is Karen Jacqueline Allen, DOB GRO-C 1957 and I live at GRO-C  
GRO-C Somerset, GRO-C.
2. My husband, Derek Charles Allen, DOB GRO-C 1957, died in February 1990 after being infected with HIV and Hepatitis C through contaminated blood products.
3. 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 Affected**

4. I met Derek in 1979 and we married in August 1981. Derek had been diagnosed with Haemophilia A from birth and had two brothers who passed away as a result of haemophilia.
5. Derek was on Factor VIII home treatment and would always administer it himself; he wouldn't let me do it. We had to keep the product in our fridge and we would administer it virtually daily. I remember they were Bayer products.
6. Derek worked for the taxi firm that his brother owned. There were times when Derek couldn't drive due to having bleeds which occasionally made it difficult for us financially. We didn't have an awful lot of money in the 1980s and our son, David, came along quickly.
7. Derek initially struggled to bond with our son and he became jealous of the time that I devoted to him. However, when our son was slightly older (about 18 months old) Derek grew out of his jealousy and we started to discuss having another child.
8. There was a lot in the media at this time about the HIV virus and AIDS, but Derek seemed to think that if he had HIV the doctors would have told him. I was more worried and I wanted reassurance, so I called the hospital to ask if it would be safe for us to have another baby. I was told that they wanted me to go in for tests. I already had one child so I knew that the tests they were proposing were not fertility tests. I knew exactly what was happening; it said it all. My gut feeling was that they knew Derek had HIV and they wanted to test me to see if I had it too. I said "that's not happening" and put the phone down.
9. I was absolutely stunned and sat on the stairs for a long time after that phone call. All of your dreams go at that point. We were denied more children and our son was denied brothers and sisters.
10. This news had a huge impact on our marriage. Our sex life stopped as I didn't want to put myself at risk. I spent a long time thinking 'what if I do have the

disease?' and 'what will happen to our son if I do?'. This worry affected our relationship and came between us, and we ultimately separated not long after.

11. I didn't talk to anyone about my conversation with the hospital, including Derek, and I am glad I didn't. I didn't feel it was my business to tell him my suspicions and by not telling him about the infection he had another 3 years without worry. I have never regretted my decision.
12. Derek went to a routine clinic appointment at St Thomas' in 1986 where he found about his infection. A support worker was planning on telling Derek but before they got the chance to tell him, Derek saw in his medical notes that he had been infected with HIV. He also saw the date he had been infected. He wasn't given any information about the prognosis or routes of transmission; there was nothing. I was absolutely appalled by the way in which Derek was treated and told about his diagnosis. There was no consultant present when he was told.
13. When Derek told me about his infection I told him that I had thought that might have been the case and explained the phone call I had with the hospital 3 years earlier. He didn't say anything about the phone call but he did tell me that he also saw in his notes that I had tested negative for HIV, unbeknownst to me.
14. I went to my GP to be tested for HIV because I was still worried about something happening to me and leaving David on his own. I told them that I already had a negative test. They tried four times to take blood from one arm and then three times in the other, but when they failed every time I told them to stop trying as seven times was enough. I left without being tested again.
15. The doctors believe that Derek had also been infected with Hepatitis C as he was having seizures just before he died. However, when I tried to access his medical records from St Thomas' they were conveniently unable to locate his file.

16. To my knowledge I have never been tested for Hepatitis C and I do not believe that I was ever asked if I wanted to be tested.

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

17. Derek may have also been infected with Hepatitis B but I am not aware of what other infections he may have been exposed to.

### **Section 4. Consent**

18. I was tested for HIV without my consent. I had no knowledge that I had ever been tested and it is therefore clear that I was tested without my consent. I also don't know why my personal test results were in Derek's medical records.

19. I believe that Derek has been tested for the purposes of research. When I attended the Inquiry meeting last summer I heard about a letter written at the relevant time that stated it was cheaper to test on haemophiliacs than chimpanzees. I found the meeting very difficult.

### **Section 5. Impact of the Infection**

20. When Derek and I separated I moved to my sister's house for 12 weeks before moving back to Saffron Walden to allow Derek to continue having a relationship with our son. Derek saw him every week and they had a good relationship.

21. Derek came to pick up David one day and he looked a bit gaunt. He didn't look himself and he had lost a lot of weight. It dawned on me that he had gone from having the HIV virus to having full blown AIDS. I realised he didn't have a lot of time left and I started to worry what I was going to tell my son and how I was going to prepare him.

22. The nurses caring for Derek would wear Hazmat suits. Derek never lost his sense of humour and would laugh because he found it funny.

which I think was really important. When David finished school I got a job in a factory, before working with adults with disabilities and later teaching English as a foreign language.

31. After his father's death, David started to struggle in school. I received a call one day from his teacher telling me that he had become very quiet.

32. I did not tell David about his father's infection until he was around 18 years old and had left school because I didn't want him to get bullied or have any problems at school. I initially just told him what it said on the death certificate; that his father had got sick and died of pneumonia.

33. When I finally told David he was stunned but when I explained everything he agreed that it was best that he wasn't told when he was younger. Finding out the truth about his father made David really angry, especially as more information came out.

34. David told me recently that he remembers me being depressed for most of his childhood, and looking back this is probably accurate, although it was very difficult to hear.

35. Fortunately, David has managed to come through everything; he got married last year and is now expecting a baby.

#### **Section 6. Treatment/care/support**

36. I am not sure if Derek was offered any counselling or support.

37. There was a lovely lady named Liz who was in charge of the support of the widows from the MacFarlane Trust. Liz was lovely and made sure that we got everything that we needed. She offered counselling to me and my son but neither of us were ready to talk. However, they got rid of her with no warning and replaced her with civil servants; she wasn't even able to say goodbye.

## **Section 7. Financial Assistance**

38. We received £20,000 from the MacFarlane Trust after Derek's death and his girlfriend was able to come after us and take £7,000 of it. It wasn't right. She had already emptied his bank accounts and taken his house and now she wanted to take food out of my son's mouth.

39. We received a second payment of £44,000 in 1992 and fortunately she wasn't entitled to any of this money.

40. The EIBSS are not as communicative as the MacFarlane Trust were and I had difficulties filling in the forms for them as they failed to make it clear that they had to be completed online. However, they do give me more money than I received from the MacFarlane Trust as well as a winter fuel allowance that I never previously received.

## **Section 8. Other Issues**

41. I want to see the children of the infected who are now adults given a good explanation, and the inheritance they were denied. This is for David and all of the other children.

## **Anonymity**

42. I do not wish to remain anonymous.

43. I don't know whether I would be able to give oral evidence to the Inquiry without breaking down.

**Statement of Truth**

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

Signed... 

**GRO-C**

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Dated... 29<sup>th</sup> June 2019 .....