

Witness Name: LYNDA MAULE

Statement No: WITN3517001

Exhibits: 0

Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LYNDA MAULE

I, LYNDA MAULE will say as follows:-

Section 1. Introduction

1. My name is Lynda Maule. I was born on GRO-C 1962. I live alone at GRO-C
GRO-C I have two children and 3 grandchildren. I work at a university as a facilities operator.
2. I make this statement on behalf of Paul Alan Slater and Kevin Mark Slater.
3. Paul Alan Slater was born on GRO-C 1961. Paul and I were in a relationship for 5 years, from 1978 or 1979. Our daughter Rachel was born in 1980. Paul passed away from AIDS on 4 August 1991, aged 31. He was infected with Human Immunodeficiency Virus (HIV), Hepatitis C Virus (HCV) and Hepatitis B Virus (HBV) as a result of being treated with contaminated blood products.
4. Paul's younger brother Kevin Mark Slater was born on GRO-C 1963. Kevin passed away from AIDS on 23 June 1985 aged 22. He was infected with

HIV and Hepatitis as a result of being treated with contaminated blood products.

5. My daughter Rachel has provided her own Witness Statement to the Inquiry (Witness Number WITN3408001).
6. This witness statement has been prepared without the benefit of access to Paul and Kevin's full medical records.
7. My daughter Rachel has been able to obtain limited medical records for Paul and Kevin. I refer to Rachel's statement in relation to those medical records and the information they contain.

Section 2. How infected

8. Paul and Kevin were both diagnosed with Haemophilia A in 1963. I understood from Paul that there was a complication during Kevin's birth in 1963 which led to both boys being tested and diagnosed with Haemophilia.
9. Paul suffered from severe Haemophilia A. Kevin's Haemophilia A was less severe than Paul's, although I understand that it was also categorized as severe.
10. Paul and Kevin both received treatment at the University Hospital of Wales (UHW) under Professor Bloom. Prior to moving to Cardiff they lived in London. I understand that they received treatment at the Oxford Haemophilia Centre, Churchill hospital in Oxford (OHC) when they lived in London.
11. Paul and Kevin attended St Lloyds College in Exeter in their late teens. I was at college at the same time and this was where I met them. While they were at college they were treated at the Royal Devon and Exeter Hospital (RDEH) under the care of Dr Edgecumbe. Later, Paul was under the care of Dr Richard Lee.

12. When I met Paul in 1978 or 1979 he had been on Factor VIII concentrate (FVIII) for a few years and he was administering it himself. Paul was administering it most days because he suffered badly in his knees. Kevin was also self administering FVIII, but he needed it less frequently than Paul. I believe he was administering it to himself about once a week.
13. Paul was infected with HIV, HCV and HBV through contaminated blood products.
14. Kevin was infected with HIV and Hepatitis through contaminated blood products.
15. I refer to Rachel's statement for more information about Paul and Kevin's infections and illnesses.
16. Kevin found out first that he had HIV. This was in 1983 or 1984. He was ill so the hospital ran a lot of tests and the results showed he was HIV positive.
17. Following this Paul was asked to be tested as well. Paul had moved back to his parents' home in Wales at this time while I still lived in Exeter. Paul phoned me and told me that Kevin had been diagnosed with HIV and that the hospital had asked him to be tested. He was very upset about Kevin's illness. He was also upset at the fact that he too might have contracted the same illness. Paul's test result showed he was HIV positive as well.
18. We only found out Paul had been infected with HCV after he had died. Paul's Dad was investigating what had happened and I believe he found out by looking through Paul's medical records.
19. Paul's medical records show that he also had HBV. Kevin's medical records show that he also had "Non B Hepatitis". It is not clear what type of hepatitis Kevin had.

20. I do not believe Paul or Kevin received adequate information or advice to help them understand and manage their infections. There wasn't a lot of information available about HIV or AIDS at that time.

21. Paul and I were still in a relationship at the time he found out about his infection. We were told that we had to use condoms to protect me from being infected as well.

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23. Over time Paul and I did our own research about the condition. We were also able to get more information from the hospital (RDEH).

Section 3. Other Infections

24. I do not know if Paul or Kevin received any other infections.

Section 4. Consent

25. I believe Kevin was tested without his consent because he did not know at the time that he was being tested for HIV.

26. Paul consented to being tested for HIV. I believe he may have been tested for HCV without his knowledge or consent.

27. I do not know whether Paul or Kevin were tested or treated for the purposes of research. However if they thought they were helping somebody else I believe they probably would have agreed to it.

Section 5. Impact of the Infection

28. Kevin was strong willed and seemed to take everything in his stride. He never seemed to let things get to him, never seemed to get stressed. It was

hard to read him or know how he was feeling. He must however have found things very difficult.

29. Kevin was already ill with AIDS at the time of his diagnosis. I remember him having sores in his mouth and on his body. From then on his health deteriorated very rapidly. He spent a lot of his time at home surrounded by his few friends and family. His Mum tried to care for him at home for as long as she could. Kevin was a big tall lad and eventually she could no longer cope physically with his care. Kevin ended up in isolation in hospital for the last few weeks of his life. In the final weeks of his life Kevin was suffering from AIDS and pneumonia. Kevin passed away on 23 June 1985 aged just 22.

30. I believe Kevin received some treatment but I do not know what treatment it was. I do not know if Kevin faced any difficulties or obstacles in accessing treatment.

31. Kevin's social life was greatly affected by his illness. I remember that he tried to go out on a few occasions but because he was already in an advanced stage he could not manage it physically. He was very weak and he had a severe cough. He was in and out of hospital a lot.

32. The stigma associated with HIV really affected Kevin. Some of Kevin's friends stuck around when they found out he had HIV and others decided they could not deal with it.

33. I remember that the hospital staff would not bring food into Kevin's room near the end of his life, no one wanted to enter his room. It was really sad; he was not treated like a human being. When he passed away no one wanted to go into the room. The funeral director did not want to enter his room to collect his body. Trying to arrange a funeral was difficult, no one wanted to know. It was a difficult and horrible time. I was not there at the

time, but I was told by Paul and his parents, who were not only distressed but very angry.

34. Kevin had been working for about 6 months before the HIV diagnosis by which time he was already too ill to carry on. Not being able to work would have had financial implications on him.

35. Paul and I were still together when he found out about his infection. Rachel was born in 1980 and was still very young. Paul and I split up after about 5 years together. After our relationship ended, Paul would come to Exeter to pick Rachel up for weekends. We remained close friends after our relationship ended.

36. The news of his infection hit Paul very hard. From the day Paul was diagnosed he gave in to it. He was frightened from the word 'go'.

37. Paul was working with electronics, in the field of Circuit Boards when he was diagnosed with HIV but as far as I can remember within a month or so of being diagnosed he gave up his job. He didn't want to go on.

38. He did not want to talk to me and he cut me off because he did not want me to go through the pain with him. I wanted to be there for him but he would not allow me. It was very hard going. Even when he came to visit and collect our daughter Rachel he would hardly say anything to me. He shut himself off completely from me. He told me that I had a life and I needed to get on with it.

39. When Paul saw what his brother was going through he became even more devastated. Paul was ill himself at the time that he was told that Kevin had died. The news hit him hard and if he could have run out the room he would have done so, but he was ill himself and he couldn't even walk. Paul really struggled after Kevin died.

40. Paul's health went downhill quite rapidly. He had always been very slim, weighing around 9.5 stones. He lost a lot of weight, becoming extremely thin. He was losing weight he could not afford to lose. At the time of his death he was 4.5 stones. He would wrap bandages around his legs to make himself look bigger and he would put two or three jumpers on. He had constant sores in his mouth so he could not eat or drink much.
41. He had seen his brother go through the same illness and he had seen how things had ended. I think Paul lost the will and ability to battle against his illness and gave in to it.
42. I do not know if Paul had any treatment to help him. When I tried to talk about his illness he would shut me down. He said it was better that I did not know.
43. On the last few occasions when it was time for him to collect his daughter he said he could not travel so his parents would come down and collect Rachel.
44. Paul's health and dental care was affected because of his infected status.
45. There was one occasion when Paul needed dental treatment and was put in isolation. The hospital staff appeared disgusted by the fact that I would not wear gloves or an apron and that I gave him a kiss. They didn't say anything to me but I could tell by the way they were looking at me.
46. Like Kevin, Paul also suffered from the stigma of having HIV. Many of Paul's so called friends wanted nothing to do with him even though they knew he was infected through no fault of his own.
47. Paul and Kevin lived in a small village so word quickly got around about their illness. People would walk on the other side of the street because they saw Paul or Kevin. The postman would leave letters at the end of the drive

instead of putting them through the letter box. People wanted to protect themselves.

48. Paul and Kevin's Mum used to work in a school but she gave up her job to care for Kevin. Their Mum and Dad were also a big part of the community. Their Mum used to love dancing and their Dad used to play golf. All that just stopped when Kevin became ill. I don't know if it was their choice or if it was because of the stigma they faced.

49. It was really hard for Paul and Kevin's Mum. She had to come to terms with the fact that she was going to lose both of her children. During Kevin's illness they found out that Paul was also ill so she had two children to look after. She did not know it herself at the time but she was also suffering from breast cancer.

50. I believe it hit Kevin and Paul's Dad hard. He was always there for the boys' appointments but other than this he just threw himself into his work.

51. Knowing that such a young lives could be taken because of somebody else's mistake was very hard for everyone.

52. The hardest thing for Paul was letting go of his daughter. Rachel was only a baby when Paul was diagnosed with HIV. I was scared and frightened she was going to lose her Dad. I was worried and did not know what the future held. Rachel has had to grow up without a Dad.

Section 6. Treatment/care/support

53. I do not know if physiological support was offered to Kevin or Paul or to their parents.

54. I asked for help when Paul was diagnosed because I was struggling and I had Rachel to look after as well as myself. I found it difficult that Paul

wanted to shut me off so I asked for some counselling. It was not offered to me though - I had to ask for help myself.

55. The counselling I had was not to do with the HIV diagnosis specifically but to help me move on from the relationship.

Section 7. Financial Assistance

56. I do not know if Kevin or Paul were offered any financial assistance.

57. I believe my daughter received around £75,000 from the Skipton Fund and Macfarlane Trust combined.

58. I also believe Kevin and Paul's Dad received some money but I do not know how much.

Section 8. Other Issues

59. Paul, Kevin and their parents trusted the medical staff to give them safe medication. Sadly that did not happen.

60. Paul and Kevin passed away so young and their parents lost both their children. They never got over it. Rachel had to grow up without a father and uncle.

61. I hope that the Inquiry will give everyone some answers.

Anonymity, disclosure and redaction

62. I am not seeking anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

63. I would be willing to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated 05-09-19.