Witness Name: Shelagh Margaret Garrigan
Statement No: WITN1229001
Exhibit: WITN1229002
Dated: April 2019
13th

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHELAGH MARGARET GARRIGAN

I, Shelagh Margaret Garrigan will say as follows:-

Section 1. Introduction

1. My name is Shelagh Margaret Garrigan. I was born on GRO-C 1950 and I live at GRO-C with my husband, Michael Garrigan. We have been married for seventeen years this September. I am retired.

2. I make this statement in relation to my late brother, David John Freeman (David) who was born on GRO-C 1961 and passed away on 30 July 1989, aged 27. I also have another brother, Steven Freeman (Steven) who was born on GRO-C GRO-C 1949 and who passed away on 16 April 1993, aged 44.

3. This witness statement has been prepared without the benefit of access to my David'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 infected

4. David was born with severe Haemophilia A. As Steven had been diagnosed with the condition at three years old, when David was born, he had symptoms and was tested. Our parents were informed that David's future was bleak and that they should accept that he could bleed to death at any time. His Haemophilia was so severe that they said even when in bed, the pressure of a pyjama button could turn into a small bruise which could then become a haemorrhage until the whole arm or leg swelled out of recognition. Consequently, David was not permitted to engage in physical sports or to go into the school playground.

5. I do not know if he received any blood products from birth but unless he had a massive accident nothing would be given to him. All that was available at the time were blood transfusions and Cryoprecipitate which would be administered for internal bleeds. Other than that he would be given pain killers but a lot of the time he would have to bear the pain.

6. We lived a hundred miles from the nearest haemophilia centre which meant long stays away from home. This was the situation and it carried on until David turned sixteen.

7. There is now produced and shown to me marked 'Exhibit WITN1229002' 'David's Story' that he wrote before he died. As can be seen he says that all of his prayers had been answered as when he turned sixteen, Factor VIII concentrate was introduced to him. He was overjoyed that he would no longer have to go to the hospital or spend his evenings alone. David finally felt free. We all thought it was an amazing product.

8. I cannot recall the names of the producers of Factor VIII that David was treated with, however I recall they were stored in the fridge and as he was able to

administer the treatment himself. He needed Factor VIII as preventative treatment from the age of 16 until he died.

9. No information or advice was provided to David or my parents regarding the risk of blood products carrying or exposing him to infections. The first that was heard about it was on the television where it was mentioned of a risk of AIDS to haemophiliacs.

10. David was treated by Dr Geoff Savidge at St Thomas' Hospital (St Thomas') in London for the majority of his life even though he lived in Brighton.

11. As a result of being treated with contaminated blood products, David contracted Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).

12. David regularly visited St Thomas' for check ups and to collect Factor VIII treatment. I suspect that he must have been tested for HIV during this time, although I cannot say exactly when that would have been. However, in 1985 during one of these regular check ups he was told he had HIV.

13. When he came home after being told he had HIV and rang me at home to tell me, he was devastated. I was living in Luton at the time. I rang Steven to tell him and Steven drove to Lincolnshire to tell our parents of David's diagnosis.

14. David was not given any information or advice on how to manage the infection or of the risk of transmission, nor was he told what HIV was. He knew what it meant in that it was not good news, but like all of us, we were not sure of the implications or if there was any treatment or cure as it was so early on.

15. About four to five months after his diagnosis, St Thomas' recruited a specialist nurse, Chris Harrington (RGN) who was assigned to help infected haemophiliacs as Dr Savidge could not handle the influx of patients on his own. Chris did her

very best to help and provided information about the infection and how it could be transmitted. However I believe that the information should have been provided earlier i.e. when David was diagnosed and to his family as well as for months we were kept in limbo not knowing what would happen.

16. After David's diagnosis, I attended the Haemophilia Centre, at St Thomas' and the manager told me that he was going to be blunt with me. He said that it was not good news and all the haemophiliacs would die. Even though I knew there was truth in what he said, it was still difficult to absorb. I do not know if there was a better way of conveying such terrible news, but perhaps some compassion would have made it easier for us.

17. By the time David was diagnosed with HCV, he already developed Acquired Immune Deficiency Syndrome (AIDS) and in comparison, HCV was not a major concern.

18. After a long battle against the infection, David sadly passed away on GRO-C 1989.

Section 3. Other Infections

19. I do not believe that David had any other infections as a result of being treated with contaminated blood.

Section 4. Consent

20. I cannot say for certain if he was tested without his knowledge or consent or without being given adequate or full information. St Thomas' were always taking blood samples from David so I expect he would have assumed it was a routine check up for his haemophilia as opposed to being tested for infections. It

certainly came as a massive shock to him when he was told he had HIV so it would appear that he did not know he had been tested.

Section 5. Impact

21. David was overjoyed when he started receiving Factor VIII treatment at the age of 16. It gave him freedom as his life was restricted by haemophilia. He thought he could finally prove his worth and put all of his efforts into starting up his own hairdressing business only to find he had HIV. Shortly afterwards in 1986, when he was about 25 years old and about to enter a hairdressing partnership David was diagnosed with AIDS and had developed Pneumonia.

22. He was shocked and devastated at the diagnosis. He felt as though his career and relationships were over. Having AIDS in 1986 left him feeling alone and vulnerable, especially as there was no cure or treatment. He described life like a game of snakes and ladders and felt that he had to restart his life as a young boy again.

23. Prior to the diagnosis he was 'happy go-lucky' but afterwards he was a different person. He came to terms with it as much as he could but eventually he started experiencing symptoms, mainly gastro and bowel problems. He was in hospital a lot at St Thomas' even though he lived in Brighton.

24. Toward the end of his life, he was too weak to attend St Thomas', although he ideally wanted to go there as he felt safer around familiar faces. He died in a hospital in Hove in a ward on the top floor which dealt with AIDS patients only. I believe he was there for a couple of weeks before he passed away.

25. David realised that he could die at any time, but he was a fighter. He never gave in to his illness and he certainly did not want to die. He showed tremendous

courage and fighting spirit to the bitter end and life has never been the same without him.

26. David was never offered any treatment. AZT was on the horizon at the time, it was probably at the trial stages but I do not believe it was offered to him. I expect that this was because he was too ill. David was hoping it would be made available and would assist.

27. No treatment was given to David for HCV probably because he was very ill with AIDS, but he looked very yellow, he always had infections and was prescribed antibiotics. But he was never offered anything else.

28. David faced difficulties in accessing dental care as no dentists were willing to treat a patient with HIV. The Haemophilia Society gave him a list of dentists in Brighton who were willing to take on HIV patients so one was found in the end. However he would have to have the last appointment of the day so that they could sanitise all the equipment. He was treated like a pariah. It was not nice, but at least the surgery treated him. This unsympathetic behaviour extended to his hospital care. Whenever he was at St Thomas' he was isolated in a room of his own and anyone who treated or cared for him was dressed in full gowns, they were concerned about contamination. Cleaners in the hospital would not enter his room either.

29. As David wrote in his story, (Exhibit WITN1229002), he was overjoyed to be able to start a business. My parents paid for his hairdressing course as they wanted to support him doing something that was not too physical. David told me that he wanted to be a jeweller, but that was not possible with his condition. Even though he had his own hairdressing business, David had to take a lot of time off work and when his infections became too much, he had to stop work completely. He knew he had to and he wanted to as he wanted to get better. In his mind it was a way of fighting on by dedicating his time to his health.

30. In terms of friendships, he had friends who came and went. Those closest to him stood by and supported him. David was honest about everything and was very open. He said it was not fair on the people around him to hide the fact that he had HIV, and after disclosing the information, many of his friends never saw him again thereby highlighting the stigma of the infection. He had a girlfriend who stayed with him until he died to whom we are very grateful.

31. Living in Brighton was a lot easier for David as it is very cosmopolitan and very accepting. There was a large homosexual community and several advice lines were available although he never used their services. David was very liberal, but he did not want to mix with just homosexuals because he would not fit in – he was by no means prejudiced towards the homosexual community.

32. Losing David was devastating for our mother. It completely finished her off. She lost both of her sons and had been particularly close to David. She was never the same person and she never got over the loss. It broke her heart and she passed away five years ago. My siblings felt that not only had we lost our brothers, but we also lost our mother. My father did not say much. He buried his head and kept strong for the family.

33. I was extremely close with David, I was the first person who he informed about his condition. Most of the time it was me who cared for him and I often accompanied him to his hospital trips. When we were both living in Brighton, it was convenient for me to help him out. Losing him was heart breaking for me. It took me a year after his death to pick myself up. It affected my marriage as I could not get over what happened to him. David was everything to me. Eventually I have moved on, but with the introduction of the Public Inquiry, all those memories have flooded back into my life.

Section 6. Treatment/care/support

34. If what happened to him happened today, he would have received far more care. David's GP was not very helpful at all and even when David was extremely weak, he would have to attend the surgery or hospital when it would have helped to have the doctor visit him at home. All he had was a direct line to Chris Harrington in London but it was not the hands on care he needed.

35. Neither David, nor I received any counselling or psychological support in consequence of what happened. I believe it would have benefited him.

Section 7. Financial Assistance

36. When David became too ill to work, he received Disability Living Allowance. After his death, as the Executor of his estate, I received an ex gratia payment of £10,000 from the MacFarlane Trust (MFT). I do not believe he received any money during his lifetime from any trusts or organisations, although the MFT may have assisted him now and then with large one-off purchases. If he was struggling financially our parents or I would help him.

37. I discovered the MFT through Chris Harrington who was a trustee. To obtain the payment from MFT, I completed the application form. It was a fairly straightforward application and the staff at St Thomas' assisted me. On agreement with my family, we decided to gift the £10,000 to David's girlfriend.

Anonymity, disclosure and redaction

38. 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.

39. I do 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

Shelagh Margaret Garrigan

Dated: April 2019

13th