

Witness Name: Sarah Taylor

Statement No: WITN3033001

Exhibits: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SARAH TAYLOR

I, Sarah Taylor will say as follows:-

Section 1. Introduction

1. My name is Sarah Taylor. I was born on GRO-C 1982 and I live at GRO-C
GRO-C
2. I'm 37 years old and I live with my husband and 2 children. My eldest child is
GRO-C
GRO-C
3. I make this statement on behalf of my late father, Ralph Hitchcock, born on the GRO-C 1944 and died on the 29 August 2014 aged 71 as a result of Hepatitis C (Hep C). I also make this statement on behalf of my late uncle, Andre Edward Gilbert Hitchcock (my father's younger brother) who was born on the GRO-C 1952 and died on the 9 October 1995, aged 43 as a result of HIV.
4. This witness statement has been prepared without the benefit of access to my late father's and late uncle'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

5. My father suffered with severe Haemophilia A and I believe he was diagnosed when he was very young.
6. My uncle also suffered severe Haemophilia A and I believe he was also diagnosed when he was very young.
7. Both my father and uncle were initially treated with cryoprecipitate and then I believe they were treated with Factor VIII concentrate (FVIII). I do not know when they started using FVIII. However, I know my father never learnt how to administer it himself. Both my father and uncle would attend the hospital to have treatment. I started to administer FVIII to my father when I had my son.
8. Both my father and uncle were treated at the Queen Elizabeth Hospital, in Birmingham (QEH).
9. I believe that my father and uncle were not told beforehand about the risk of being exposed to infection from the FVIII products. The way my father was told about the risks was played down a lot more than what it actually was. I do not recall what information was provided to them.
10. As a result of the contaminated FVIII concentrate, my father was infected with Hep C. My uncle was infected with HIV and I also believe that he was infected with Hep C, because when my uncle died his face was a yellowish colour, which suggested that he had Hep C, even though this was not mentioned in his death certificate. I do not know when they were told about the infections as I was not told about their condition or the infections until my teens.
11. I do not know what information was provided to both my father and uncle when they found out. However, I believe that adequate information to understand and manage the infection was not provided. They were both in a self-destructive mode and were provided with no support.
12. I believe that information should have been provided to both of them earlier. My uncle had a partner at the time and when they spoke about children and

marriage, he left her as he did not want to have children who would become fatherless. He had a few relationships and I believe he had left them all when a conversation about children and marriage came up.

13. I believe that when both my father and uncle were told about the infections it was poorly done. It wasn't handled properly at all.

14. I believe when my father found out, he told his first wife who promptly left him and divorced him. Then he met my mother in 1977 and in or about the mid 1980s he told her that he had Hepatitis. He didn't know if it was Hepatitis A, B or Non A Non B). I believe my father was told that the Hep C cleared itself, but I am not sure when he was told this.

15. My mother found out that my uncle had HIV in or about the late 1980s. My mother told me that she had asked my uncle to be my godfather but he refused as he had HIV and didn't think he would live long enough.

16. I do not believe that my father or my uncle received any information about the risks of others being infected as a result of their infections. I believe at a later stage they found out that there was a risk, but it was through their own research.

Section 3. Other Infections

17. In or about the mid 1990s, my father received a letter from the QEH about vCJD. I believe the letter stated that he may have received a batch that was possibly infected with vCJD. My mother asked my father whether he wanted to know if he was also infected with vCJD. My father's reaction was that he ripped up the letter and threw it away. My father did not receive any follow-up information or appointments and we were never told if he was infected with vCJD.

18. In relation to my uncle, as previously stated, I believe he was also infected with Hep C but he was never told about it.

Section 4. Consent

19. I do not know if my father or uncle were treated without their knowledge, but I believe they were tested without their knowledge as they did not know that they were being tested for the infections until they were told that they were infected.
20. I believe that both my father and uncle were treated and tested without their consent. As stated above they had no knowledge that they were being tested for the infections. When they used to have blood tests they always thought it was in relation to their Haemophilia and that it was a routine blood test.
21. I believe that both of them were treated and tested without being adequate and full information.
22. I am not sure if either my father or uncle were treated or tested for the purposes of research.

Section 5. Impact of the Infection

23. As soon as my father found out that he was infected, he did not trust the medical professionals. He was very private about his Haemophilia and nobody knew that he had it let alone Hep C. His employers were not aware of his medical condition, until after his death. He was very guarded, very fiercely protective of nobody knowing at all to the point that I did not know he had Haemophilia until my teens. My father stopped going to the hospital for treatment and my mother would just beg him to get treatment, but he would refuse until he was seriously ill. My mother had to call the doctors to come to the house so that my father would get treatment. He didn't want treatment as he lost all trust.
24. When I found out that I was pregnant and I had a baby boy my father cried for a very long time and thought it was his fault that my son had Haemophilia. He blamed himself. He got a bit aggressive with my mother and me. My father was genuinely terrified about my son receiving contaminated blood products. He would keep telling me to check the products and question the doctors to make sure that the products that were being used on my son were safe and

not infected. I can't express how fearful he was every time my son required treatment.

25. I noticed that my father was always exhausted and slept a lot of the time. He would fall asleep whilst watching TV or during a mid conversation. I used to tease him for being sleepy all the time, but now I understand that the fatigue and the exhaustion were a result of the Hep C.
26. The HIV infection affected my uncle. He was always angry. He was very self-destructive and would destroy anything in his path. He hated everything that had happened to him. Towards me however, he was a different person. He was loving and treated me like his own daughter. He became very poorly in the end. He had drastically lost weight and he had zero appetite. I recall that we went to the cinema together and he left me in the midst of strangers as he was very sick and had diarrhoea. He kept leaving his seat to go to the toilet. I was so protected by my family and I wasn't told about their Haemophilia or their infections until I was much older. My uncle died in 1995 as a result of his infection.
27. I tried to move my parents to where I was living as they lived in Birmingham at the time. I was my father's main carer and I was administering him FVIII. However, before both my parents were able to move closer to me my father died.
28. My father's last few years were very tough. He had pockets in his intestines (diverticula). He had colon bleeds. He didn't want to have treatment because he did not trust the doctors. On holiday he had a colon bleed and he stopped breathing he was treated at a hospital and we headed back to UK. Various tests were carried out and he was also tested for cancer. Then in July 2011 he was told that he had bowel cancer and liver cancer and the doctors told us that it was probably caused by the Hep C. He was told that the doctors were going to remove the infected bowel/intestine and then he could start chemotherapy but unfortunately he had a bleed and died. It was the worst 2 weeks of my life to watch him go through that.

29. My uncle was a stock controller. As a result of his infection, he got pneumonia because of his low immune system. I was told that my uncle dated a girl who worked in a pharmacy and stole medication and, as a result, he was imprisoned for it. The last year of his life was awful and he passed away tragically. I remember going to see him in the flat where he lived. He was a yellow skeleton and people were bringing him tablets and water. His demise happened very quickly. He was a very fun, loving and active person before he was infected. The last 6 months were absolutely tragic. He always had emphysema and urine tract infections and as a result he was constantly on antibiotics. No one told me he had AIDS until the funeral when I was handed a red ribbon and was told it was a family secret and that I should not to tell anyone.
30. I do not know what treatment my father or my uncle had for the infections. As previously stated their conditions and infections were kept a secret in my family and the information that I did receive in my teens was very limited.
31. I do not know if my father and my uncle faced any difficulties or obstacles in accessing any treatments and I do not know if there were any treatments which I consider ought to have been made available to them.
32. I do not know if their infected status had an impact on their treatment, medical or dental care. My father did not have any dental treatment because (a) he did not trust anyone and (b) I believe he was worried that they would not treat him because of his Hep C. I remember doing some campaigning for AIDS after my uncle died and someone said he must have been gay. I went off the rails when they said that to me.
33. My father was petrified of people finding out about the infection. At his funeral, when I did my speech, all his work colleagues attended and when I said my father had Haemophilia they were all shocked. He was such a good person and kept his condition and infection very private so when everyone found out, they were mortified that he kept that secret for so long. He was not going to let his condition stop him from doing what he wanted to do. He was a

determined person and worked very hard. He didn't have a social life at all as he was always exhausted.

34. I do not believe my mother GRO-C

Being his wife wasn't easy. He wasn't emotionally available to her. He wouldn't show her physical love. Towards the end he would hold her hand in public but after he was diagnosed he would not show any affection in public. He led a very private life even in the household. My father didn't want to get involved in any campaigns and whenever I said that we needed to get to the bottom of it, my father would say no and tell me to leave it. I promised him that their voice would be heard and I would fight for justice.

35. My uncle was a very loving person and after he was told about his infections he became a different person. He knew deep down that he was never going to have a wife, and I believe that was the reason why he did not marry. This destroyed him mentally. He was very angry and bitter. He aimed it at me once in the car, but I know he didn't mean to as he absolutely adored me. He had never been like that with me before. I didn't blame him for the way he acted. What my uncle went through was soul destroying. He carried a big burden his whole life.

36. I was affected more emotionally than anything else. When I was about 13 years old, I remember going to my grandfather's house. I was given a red ribbon and I knew what it meant. I remember asking if my uncle had HIV and I was told that he did. I didn't ask anymore questions after that. After the funeral, I had a bit more knowledge as to what happened to my uncle. I remember asking what it meant for my father, and I was told he had Haemophilia and as a result of receiving FVIII treatment he was infected with Hep C and that was when I became aware that my father was in a similar situation. My husband found out about my father's infected status when my son was born with Haemophilia.

37. I recall being in a psychology lesson and I was given a red ribbon and one of the girls in the school made a rude comment about it. I went bonkers at her in front of the whole class. The head teacher took me out of class and told me

that he knew what my family were going through and told me that I should go in and educate them. I went back in and explained to them that the red ribbon was for people who had HIV/AIDS and my uncle got it through no fault of his own. I then did a charity event the following year. That was the first time I felt like I had a voice. It was very much a campaign for my uncle as my father was still alive at the time.

38. It was very hard for my mother. She feels responsible because she always told my father to get treatment and surgery and feels guilty about it. It tore a hole in her when my father died.

39. My grandfather was affected very badly when he found out about the infections, it tore him apart. He got cancer and died shortly after when my uncle died.

40. I was heartbroken when my uncle and my father died. I was very close to my uncle. My uncle would give me hugs and kisses and take me out. I idolised him. When he died, I had a breakdown; I lost the equivalent of a father. It killed me losing him, and then when I lost my father, I felt broken and a part of me is now gone.

41. There was a period where I was really down and unable to concentrate at school. However, I realised that I needed to sort myself out and push to get myself an education. My uncle left me some money and I was able to use some of it towards university and a deposit on a house.

42. As previously stated, my father did not tell anyone at work about his Hep C. He was frightened about their reaction and that he would be sacked because he had the infection. Both my father and uncle did not tell anyone that they had Haemophilia because they were scared that people would automatically think they were infected.

Section 6. Treatment/care/support

43. I do not believe that my father and uncle received the care and support that they deserved.

44. I do not believe that my father and uncle received any counselling or psychological support. I believe that it would have helped them had they been offered it. I was not offered any sort of support and I believe it would have helped had I been offered it.

Section 7. Financial Assistance

45. When my father died, there was no life/ health insurance policy in place for my mother. We had to sell their car and sell their house in order for them to move closer to me. We received no help with financial assistance in relation to my father's funeral. My mother never applied to a trust or a fund or anything as she was told that she would not be entitled to financial assistance because my father cleared the Hep C naturally. My father wasn't even given a blue badge or disability living allowance until much later in his life. My mother never got a penny. It was not easy for her.

46. I believe that my uncle received some financial assistance from the Macfarlane Trust. I do not know when or how much he received, but he left me about £11,000 in his Will.

47. In or about 2011, I received £20,000 from the Skipton Fund in relation to my uncle. I believe it was my uncle's ex-partner that told me about it. I had no problems applying for the payment.

48. In relation to my father, it feels like the doors were slammed in our faces when we were told that we were not entitled to anything. The money could have really helped my father if he was offered it.

Section 8. Other Issues

49. My mother got no help. She works a very low paid job, doing ridiculous hours. She's not eligible to retire for another 6 years. She is GRO-C GRO-C and she has no husband.

50. It was probably my father's refusal not to have more treatment (FVIII) that saved his life. I feel that I am lucky that my father was a stubborn git sometimes, but I am heartbroken that through no fault of their own, they were given horrible infections. It's debilitating, unfair and I want justice.

51. It's not about money, but there are two children in my house who do not have a grandfather and a great-uncle. My eldest GRO-C
GRO-C

52. I will never be able to forgive the NHS for what they did back then.

Anonymity, disclosure and redaction

53. I do not wish to remain anonymous and I understand that this statement will be published on the Inquiry's website.

54. I want 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

20/6/2019