

Witness Name: S Fulker
Statement No: WITN2903001
Exhibits: WITN2903002-4
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SAMANTHA FULKER

I, Samantha Fulker, will say as follows:-

Section 1. Introduction

1. My name is Samantha Fulker of [GRO-C] Surrey, [GRO-C] [GRO-C] My date of birth is [GRO-C] 1988 and I live with my mother Amanda Fulker, who has also provided a statement to the Inquiry. I am currently unable to work due to ill health.
2. I prepare this statement as an affected daughter of my late father Robert Terence Fulker, who was born on [GRO-C] 1951 and sadly passed away on [GRO-C] 1990 as a result of having been infected with HIV and Hepatitis C after receiving contaminated blood products.
3. This statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How Affected

4. My late father had severe Haemophilia A which was continually treated with Factor VIII at St George's Hospital under Professor Flute and at St Thomas' Hospital under Dr Savidge.
5. He was treated with Factor VIII as soon as it replaced the previous cryoprecipitate treatment until his death in 1990.
6. My father was [GRO-C] Haemophiliac [GRO-C] Johnny, Paul [GRO-C] and my father. Johnny and Paul were mild Haemophiliacs, whereas [GRO-C] and my father were severe Haemophiliacs. [GRO-C] who is still alive.
7. My mother believes that my father was infected with HIV and Hepatitis C at St George's Hospital in the mid 1980s, as a result of receiving contaminated Factor VIII. My father's death certificate confirms that one of the causes of death was HIV.
8. My mother believes that my father was infected with Hepatitis C, despite the fact that this is not documented in his medical records, and she has fought with the NHS Business Services Authority in this regard. She recently appealed against their decision regarding Hepatitis C. **Exhibit WITN2903002** is a copy of my mother's appeal dated 3rd December 2018 and **Exhibit WITN2903003** is a letter dated 22nd March 1983 from Dr Flute to Dr Savidge which confirms that my father's "*alanine transaminase had been raised to 145iu/l*", which is an indicator for Hepatitis C. **Exhibit WITN2903004** is a letter dated 19th December 2018 confirming that my mother won the appeal.
9. My father tested negative for Hepatitis B in 1987 and my mother is unsure if he was tested thereafter. My mother believes that my father may have contracted Hepatitis B because he continued to receive Factor VIII up to 1990.
10. My mother has told me that my father was not given any advice in relation to the risks of receiving Factor VIII. However, he was very concerned about the

risks of Factor VIII and specifically raised this with his consultants. In fact, he was reassured that there were no risks involved in the use of Factor VIII.

11. In 1983, my mother and father attended an appointment at St Thomas' Hospital in which GRO-D a Haemophilia nurse, told them that my father was HIV positive. My mother recalls that this news was conveyed to them in a very matter of fact manner and as a result of this neither of my parents were particularly concerned about his HIV infection. They were provided with no information in relation to what HIV was or in relation to modes of transmission of the infection.
12. Originally my father was given the news that he was not HIV positive but afterwards, the nursing staff advised him that they had made a mistake and that he was in fact HIV positive. After this, astonishingly he was then told that he did not have HIV after all. However, this was only short lived and the positive diagnosis then came again and this time it stayed. The way in which the consultants dealt with my father, in relation to the diagnosis of HIV, was entirely unacceptable.
13. Once the consultants decided that my father definitely had HIV the advice they gave him in relation to the development of AIDS was contradictory, incorrect and extremely worrying. Initially my father was told that the risk of developing AIDS was low and that my mother was not at risk. About a year after this, my father was then told that the risks to my mother and him were much greater than the consultants had previously thought.
14. My mother and father got married in 1987 and desperately wanted a family but by this time the doctors were discouraging my parents from starting a family. However, as luck would have it, my mother was already pregnant with me. My mother told me that if she had not already been pregnant with me, my father would not have gone against the doctor's advice for fear of infecting my mother. My mother told me that she and I were tested for HIV throughout the pregnancy but luckily neither of us were infected.
15. My father passed away on GRO-C 1990 aged only 39.

Section 3. Other Infections

16. I believe that my father was also infected with Hepatitis C and probably Hepatitis B. He may also have been exposed to the risks of vCJD.

Section 4. Consent

17. As my mother recalls, every time they attended the hospital, the nurses took blood from my father without telling him for what purpose this blood was being taken. My father was definitely tested without his knowledge and consent.

18. On that basis, it is impossible to conclude that he was not used for the purposes of research.

19. I do not think that my father was treated without his knowledge or consent.

Section 5. Impact

20. I don't have very many memories of my father because I was only aged 2 years and 7 months when he passed away. However, one memory does stick in my mind which was when I was at my nan's house in GRO-C with my father. My nan was carving the roast dinner with a noisy electric knife which scared me so I jumped onto my father's lap seeking his protection. He gave me a big hug and comforted me.

21. Due to my father's infections and the negative effect they had on his health, he stayed at home with me whilst my mother went out to work. Therefore, when he passed away I struggled to adapt to any other type of childcare. My mother used to leave me at childminders as she had to work to keep a roof over our heads, but I was really unhappy and did not want to be left. I just wanted my father back so we could be at home again together.

22. My mother did her very best but things did not improve when I started at a playgroup in GRO-C I used to misbehave at the playgroup as soon as my mother had dropped me off. I think I worried that my mother was also going to leave me, like my father did. My grandfather used to help my mother look after me and he used to collect me at the end of the day once the playgroup had finished. He knew that I was unhappy so he started coming an hour earlier than the official collection time.

23. My memories of my father are a little confused in terms of whether they are something I actually remembered or whether they originated from something someone had told me about him. I appreciate that I was very young when he passed away but I do believe that some of my memories were from the actual time that I spent with him because we were very close and had a great bond. Everyone always tells me how much my father loved and doted on me and what a lovely man he was and how much he was missed.

24. Throughout my childhood I used to continually ask my mother about how and why my father died. I remember I always found the whole concept that my Daddy had died massively strange and so incredibly sad. I also remember making my Mum sad by asking as I got older. She was distraught and I understand now that that was because her memories of his final days were tarnished by the real horrific reason that he was so cruelly taken from our family.

25. For many years, I was led to believe that my father passed away due to a brain tumour. I then started developing tension headaches for which I sought medical advice. I recall being terrified that I would pass away in the same way that my father had done. My mother questioned why I sought medical advice and I told her that I was worried that I had a brain tumour and that it could be inoperable like my father's tumour was.

26. My mother kept telling me that although my father was not with us anymore he was watching over us and that someday we would all be together again.

Our family always tried to remember the good times we shared with my father and my grandparents regularly shared lovely stories about my father and they too said how much he doted on me. They always got upset talking about him, they never ever recovered from his passing.

27. When my father was still alive, we lived in GRO-C Our neighbours had children of my age and recently we made contact again on Facebook after over 20 years apart. Our neighbours invited me to a party and I jumped at the chance to meet up with them again. I loved seeing people who knew my father.

28. At the party our neighbour (who I have not named in case he does not want his name in this statement) and I were discussing my father and he said "*Oh Sammy, it is so heart breaking what happened with the AIDS*" and I responded with "*What AIDS?*" He then proceeded to tell me that my father had HIV. Our neighbour's daughter shot him a warning look but I could tell by our neighbour's face that he felt really uncomfortable and tried to back track about what he had told me. He had basically let the cat out of the bag.

29. I laughed and told our neighbour that he must be mistaken because my father died from a brain tumour. It was all glossed over and I returned home from the party in a very angry mood. I explained to my Mum that I had met up with our old neighbour's and told her how silly our neighbour's were to think that my father had died from AIDS. It was then that my mother said "*Well I had better tell you*" and she finally told me the truth. I remember asking my mother whether my father was bisexual because I was aware of how you could catch HIV by that time. I was so confused and angry. I spent the whole weekend in a bubble. I couldn't believe something so so horrific had happened, at such a large scale.

30. Approximately a week after she had told me the truth, my mother showed me photographs of my father which she had never shown me before because she was protecting me from how poorly he looked. He looked gaunt and looked like a different man to the man who I remembered as my father. My mother

showed me all of the newspaper cuttings and love letters which they wrote to each other. She also showed me lots of lovely wedding cards which was followed by very sad funeral cards only a few years later. It was a heart wrenching time for me, and heart breaking for my Mum to relive it once again.

31. My stepfather's mother's first memory of me was that I introduced myself as *"the girl whose daddy was in heaven"*. My stepfather is the father of my siblings, Katie and Daniel, and he has been totally supportive and lovely to me over the years.

32. I remember when the Panorama programme about Haemophiliacs and the blood scandal aired on television and my mother could not watch it because she was so upset. I watched all of it and was glued to the screen throughout. Once the programme had finished, I took it upon myself to find Jason Evans immediately. I searched the BBC website and I got all of his details. I could not believe that what had happened to my father had happened to thousands of other people. I then made friends with Jason Evans on Facebook and he added me to the following groups: The Fatherless Generation, Tainted Blood and Factor 8. I realised that I was not alone and that there were many other people like me which felt oddly comforting. It was reassuring that I did not have to keep pestering my mother with questions and that other people were willing to share their experiences with me.

33. I posted a photograph of my mother, father and me on one of the Facebook groups and Jason Evans then sent me a private message forwarding a YouTube link to my mother providing a series of interviews in 1991 about what had happened. I immediately viewed these and saw that my mother was talking about how much she loved me. She was struggling to speak about the scandal but pushed herself to do it because the story needed to be heard.

34. [GRO-D] bullied me continuously following my father's passing. When he passed away, [GRO-D] encouraged my grandparents to move away and they did so, to Suffolk. This meant that I was prevented from

seeing my grandparents on a regular basis and we had such a good relationship so this posed another challenge for me. We were each other's connection to my father and their son.

35. [GRO-D] was a horrific bully and she would say awful things to me while nobody else was in the room. I recall that when I was aged only 7, she told me that my father was haunting her and that she would prefer if he would haunt my mother and me instead.
36. When I was aged 14, [GRO-D] daughter was getting married in Wales and only I, and not my mother, was invited. [GRO-D] expected me to stay alone in a tent. I already struggled to sleep anywhere away from home and as I became older my mother used to have to pick me up from my friend's houses in the middle of the night because I could not settle.
37. [GRO-D] said to my mother: "*I promised [GRO-D] on his deathbed that I would watch over you and Sammy, and you have not allowed me to do so*" however, the crucial flaw in this promise was that she was not at his deathbed. On the Saturday before he died, the nurse stressed that people needed to come and say goodbye but [GRO-D] said that she was too busy to visit him. [GRO-D] and I think she felt bitter because she [GRO-D] because my father was so poorly. She made life difficult for my mother and me. She did come to the funeral, but did not come to the sprinkling of the ashes because it was during half term and she said that the funeral arrangements inconvenienced her.
38. [GRO-D] is on most of the Facebook groups because [GRO-C] [GRO-C] was infected with Hepatitis C through a blood transfusion following a [GRO-C] operation. She also posts messages as the doting affected [GRO-] in relation to my father but the truth is that they could not stand each other. Therefore, I tend to stick to The Fatherless Generation group to avoid contact with her and I do not engage with her at all now.

39. After my father passed away I struggled a lot and underwent counselling and Cognitive Behaviour Therapy (CBT) but nothing really helped. However, once I found out the truth I felt that I needed targeted counselling because I had not examined or dealt with any of the pertinent contaminated blood matters which caused my father's death.
40. Only last week I went to my GP to tell him how I felt about my father's death, now that I was aware of the truth. I tried to explain to my GP that I had suffered with depression in the past but that this time I was literally unable to get out of bed or to function in a remotely normal manner. However, my GP totally dismissed my concerns. He has asked me to email him an update on my mental health so that he can refer me to a psychiatrist as he does not know what to prescribe to assist me.
41. Over the past 10 years I have struggled with depression and have taken a number of medications for this, including citalopram, sertraline and fluoxetine, often at a very high daily dose of up to 150mg. However, some have had bad side effects and in particular fluoxetine made me nauseous. Since November 2018, I have been taking venlafaxine and I am also prescribed diazepam.
42. Due to my depression, I have not been able to hold down a regular job. Finding out about the truth about how my father passed away has totally floored me. I now feel much worse than I have ever done in my whole life.
43. Since my mother told me the truth, our family are now all very open with each other about what happened to my father. We all support each other and my sisters Aimee (20), Katie (25) and my brother Daniel (24) can all openly talk about things. I live with my mother, Aimee and her partner and their baby **GRO-C** and Daniel's girlfriend who is lovely and like another sister to us. Daniel is in the Army and currently based in Germany.
44. Katie has been in Australia for 3 ½ years now. She has never been able to settle or be happy in the UK but she is living the dream in Australia.

45. Despite the fact that we are more open about what happened within the family, there are still a lot of people in our lives that still do not know how and why my father passed away.
46. My mother has done a brilliant job keeping the family together especially considering what horrific experiences she endured. She has gone through so much and she is the strongest woman I know.
47. My mother rarely cries; I could probably count the amount of times I have seen her cry throughout my life. Therefore, I will never be able to forget how my mother completely broke down at the opening hearing on the first day that the Inquiry sat in London. We put a message in a bottle for my father and she sobbed and sobbed and I thought that she was going to faint. She was completely overcome. I have never heard a noise like it and I doubt I will again. The most horrific noise came out of her. It was heart breaking to see how she crumbled as a result of what happened to my wonderful father. The catering staff had to help her out of the room.

Section 6. Treatment/Care/Support

48. In 1989, my mother advised me that my father was due to undergo a left knee osteotomy and that he had his bags packed and was ready to go into hospital on the Sunday as scheduled, in readiness for his operation on the Monday. However, the doctors cancelled the operation and advised him that there was no room on the ward. However, my mother genuinely believes that they cancelled it due to his HIV status.
49. My father, mother or I have never been offered counselling as a result of what happened. We received absolutely no psychological or psychiatric support. My mother believes that such an intervention would have benefitted both her and my father. My mother has struggled to process everything and ultimately just dealt with it alone.

50. The NHS did not follow my mother or me up following my father's death and both my mother and I think that this is disgraceful. In fact my mother even had to source her own Hepatitis B test because there was no follow up for her.

Section 7. Financial Assistance

51. My mother told me that she made contact with the Haemophilia Society who put her in contact with the Macfarlane Trust (MFT). My mother thinks that she and I were added to their database but she felt that they were a faceless organisation. They used to bombard my mother with copious amounts of paperwork and it was really difficult for her to process all of this because she was already struggling at the time.

52. My mother received £60,000 in 1991 from the litigation which effectively set up the MFT. My mother was forced to sign a waiver because she was told that if she did not sign then no one would be paid. The High Court of Justice put £45,000 of this payment on trust for me which I received when I was aged 18.

53. My mother claimed grants from the MFT for my school uniform, school trips and a washing machine.

54. My mother told me that the process of applying was tough and it felt like she had to jump through a series of hoops. She told me that she had to write a letter to the MFT setting out why she needed the items being claimed and that it felt like begging. It was also hard for her to accept that she needed help to properly equip me for school. The cheques were posted to my mother and they had "Macfarlane Trust" written on them so everyone knew that our family was receiving help from the MFT.

55. I contacted the EIBSS in June 2018 to enquire about the possibility of receiving financial assistance and psychological support. They told me there was no available support in relation to either; their door was firmly shut in relation to me.

56. I have not received any further financial assistance from any of the Trusts.

Section 8. Other Issues

57. I want people to know what damage has been caused and how many people have been both infected and affected by this tragedy.


58. I grew up without a father and my mother lost the love of her life and was robbed of so many years with him.

Anonymity, disclosure and redaction

59. I do not want to be anonymous and I wish to provide oral evidence to the Inquiry.

Statement of Truth

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

Signe  GRO-C

Date 30-4-19