

Witness Name: Fiona Weeks

Statement No.: WITN0708001

Exhibits: **WITN0708002**

Dated: 18 February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF FIONA WEEKS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 November 2018.

I, FIONA WEEKS, will say as follows: -

Section 1. Introduction

1. My name is FIONA WEEKS. My date of birth is [GRO-C]1965 and my address is known to the Inquiry. I am the sister of an individual who was killed by infected blood. Sue was born on [GRO-C]1960 and died in 1996 aged only 36. I intend to speak about her illness, how the illness affected her, the treatment she received and the impact it had on us and our lives together.

Section 2. How Affected

2. Prior to being infected, Sue was a beautiful businesswoman. We grew up together with our sister Louise and brother Simon. [GRO-C]
[GRO-C]
[GRO-C] Sue left home just before 16. Sue and I were very close

The two of us were closer as our brother and sister were different to us.

3. Sue messed around in a few different jobs before settling down as a buyer for a company in Leicester where she lived in an awful basement flat. I would save my dinner money and sneak to see her as often as I could. It was whilst working in Leicester that Sue had the opportunity to go to the United Arab Emirates and work in Dubai as a ship chandler in her early 20s.
4. Sue did really well over there until she got pregnant with someone she shouldn't have. It wasn't possible for her to have an abortion in Dubai so she came back to the UK to have an abortion at a private clinic somewhere in London. I never asked for details about this. During the abortion she haemorrhaged and it was necessary for her to have a transfusion, though I don't know how much blood she was given. I do not know if she was advised of the risks of transfusion at that time. I believe this happened in 1985.
5. It was not until Sue had an annual health review in Dubai about 18 months later that she discovered she was infected. This was approximately 1986. She told me much later what had happened; a doctor told her that she was dirty and that she had to leave the country. The man had a handkerchief over his mouth and prodded her from a distance with a stick. Sue wasn't even told what she was infected with.
6. Sue returned to the UK and I believe she had a blood test and discovered she had HIV. I never asked for details and she never volunteered them. I know, however, that she was not told much about the illness other than that it had 3 stages: carrier, HIV positive and full blown AIDS. Back then, it was thought to be a death sentence and she was given 3 years to live.

7. Sue never had tattoos or anything, that just wasn't Sue and I believe she was infected through the transfusion as Sue's doctor, Professor Finch, who was involved with the Higgin's Trust said she and two others were infected at the same place.
8. Sue thought if she wasn't going to live a long life, she would live life to the full. She bought some land in Portugal to buy her dream house to escape and just curl up and die there away from everyone else so they would not have to deal with it and she wouldn't have to tell anyone.
9. She did not tell me until two years after she was infected approximately in 1987. She was visiting Dubai for work, though she could no longer live there and required sponsorship to visit. She couldn't tell me face to face so she decided to call from there. She hadn't told me before because she was afraid I would be different with her because of it and with my (then) three kids.
10. So she called to tell me, but they monitor calls over there so she said she was three letters and positive. At first I didn't understand what she meant and we had a laugh over my amusing misunderstanding. But then it sank in and neither of us could say the words so I just told her it was okay. I told her she better be sticking around with me and my three kids and everything.
11. When I put the phone down, my whole world crashed. It was in the news that this illness was an instant death sentence. I was losing my sister, my best friend, my world. I was glad, at least, that she had done it over the phone and that she didn't see me fall apart. I did tell her later and she felt guilty of all things!

12. She had moved back to the UK and I moved to be closer to her and to help her. She didn't know what to do. It was a case of doing things together as we always had. There wasn't a day that went by when we didn't see each other or at least talk on the phone. I joked I envied her lifestyle with the big house and Jacuzzi when actually she envied my life and the kids because hers was a lonely lifestyle. So my kids became her kids and we were one big family after I moved from Surrey.

13. Sue still hadn't been told anything about how to prevent infecting others or managing her illness. She would get ill every now and then and we knew we had to be careful; we understood that if I got a cold that she would get pneumonia and die! No one told us anything. We tried to read a book about it but it was horrifying and so it went in the bin!

14. I remember once she was with my kids and my third youngest at the time put a bottle in her mouth that Sue had drunk out of and Sue freaked out because we didn't understand the dangers! We decided to make an appointment with Professor Finch and we asked what the risks were for the kids and me. He said it would take us drinking a bucket full of her saliva for even a risk of getting infected, but that we shouldn't share toothbrushes and razors and such; anything with blood. So I think we should have been provided information sooner as she had already been infected for three years by the time we thought to ask the questions!

Section 3. Other Infections

15. As far as I know, Sue was only infected with HIV and not Hepatitis.

Section 4. Consent

- 16. As far as I know, Sue was always treated with her knowledge and consent. I didn't go to the appointments with her, though.

- 17. Sue was treated with experimental drugs, but with her full consent. She was asked if she wanted to undergo experimental treatment and she opted to as she had nothing to lose by trying them. I know there were various combination of drugs, a 6-drug combination and that she knew she was a guinea pig for HIV treatment, I don't know the names of the drugs. She was fully aware of the situation.

- 18. She was told there could be side effects. The very first set she was terribly ill. They swapped and changed them and she did get headaches and sickness and was monitored throughout, as it was research. She was always popping pills and I never knew if they were helping or making her worse. In the end, a few months following her death, it came to light that it was the combination she was on with one minor change, an additional pill, that they announced could keep HIV from becoming AIDS. It was too late for her and I was angry and upset, but she did play a role in helping so many people.

Section 5. Impact

- 19. Early on, Sue decided not to tell our family. GRO-D
GRO-D
GRO-D For the longest time, it was just Sue and me.

- 20. Professor Finch had encouraged her to take legal action as she and two others had got infected at the same time and place, but Sue didn't want to. The other two women went public and one had dog faeces put through her letterbox and the other had graffiti all over her house. These experiences made us want to keep it quiet. Sue even told me

that after she died I should tell everyone that she had leukaemia, as she didn't want the kids and me to suffer after she was gone.

21. We tried to make the most of the situation and decided to buy a pub so she could be upstairs with the kids and I could work downstairs and we thought it would be great! I did a course and realised I just couldn't do it and it wouldn't work out, due to the amount of care Sue needed.
22. A moment that sticks in my memory is one day Sue was walking the dogs (she had a mastiff and a spaniel). I heard her scream for me from out the back. On the walk another dog had gone for her dog and she had got caught in the middle. Her jacket was ripped and I remember seeing part of her arm just hanging and seeing the fat deposits and everything. She screamed at me to stay away, to get back and to get the kids in and to not come near. She screamed for towels and black bags. I got them and she stripped naked in the back garden in the rain. She wrapped her arm in the towels and then three bags over it and threw all her clothes in a black bag, too. She asked me to ring a friend to take her to the hospital. I just remember her fear and the total humiliation of her standing naked in the garden in the rain.
23. I remember another time when she picked a scab on her leg where she had cut herself shaving and it bled and, as you do, she licked her finger to clear the blood and then joked she had given herself AIDS and we laughed because you had to laugh.
24. Sue continued on just carrying the virus for a long time. She had good days and bad days. She became HIV positive 18 months before she died. That's when we knew things would change. She was in and out of the hospital with different things.

25. In July 1996 we got a phone call one morning from her to say she wasn't well at all and she could not breathe deeply. I didn't drive at the time, so my partner took us to the hospital. She was diagnosed with Pneumocystis pneumonia (PCP). We had never heard of it, but were told it was exclusive to AIDS and that she was drowning in her lungs. They said this was the end. They put her in a private room as always. She had been in the hospital about a week when I got a call saying I needed to come and say my goodbyes because she was going into intensive care and that she wouldn't come back out.
26. We had made a pact that she would not die alone. Every time she was in hospital I bought a beanie toy and the nurses were brilliant and would put the toy on her pillow so even when I wasn't there, I was still there in a way. I think she had 15 beanie toys when she died.
27. We had also made a pact that it would be just the two of us, we didn't want to involve the complication of having our mother and sister there, but when it came to it I freaked out and couldn't do it alone so I called mum who was working in Portugal and got a flight and met me at the hospital. It was horrendous. Sue was bright red, swollen and had the weirdest mask around her mouth and doctors everywhere. The doctors told me she hadn't wanted to be sedated. I had promised Sue I wouldn't cry, but I did. I was 'kiddo' to her, her younger sister, but when she was sick she became kiddo. I told her I had called mum and she nodded and squeezed my hand to say it was okay.
28. Whilst she was in hospital, we had to clean the clear mucous that would build up from her oxygen mask. As the mask forced oxygen into her lungs we had little time to do so. Sue and I were a team to get this done, as she didn't want to lose her dignity. She was very proud. Mum visited once when we were doing the clean and I asked her to pass me more tissues and she cringed and turned away. After I asked mum to go outside to get a drink, as you could on the family

ward.

GRO-D

GRO-D

29. Sue decided we should tell Louise, too, so she could say goodbye. Louise came to visit and I asked her to laugh with Sue and make her feel better. I wasn't sure about leaving Sue alone with Louise.

GRO-D

GRO-D

30. Sue got worse and as Power of Attorney, I wanted them to stop, I wanted her to fall asleep, I wanted her to stop suffering. I told the doctors so. Luckily, Sue didn't die that time. In typical big sister fashion she had forgotten to tell me some of the details about the money and such and had to hang on to tell me what to do. The doctors told her afterwards that I was like a lion protecting her cubs. I was embarrassed, but most of all I was sick of seeing her suffer.

31. She was never the same after that. She walked very flat-footed, whereas she had always been elegant before. We joked and called it her duck thing. She was drawn and drained. It seemed to drain everything from me just trying to keep her house tidy and look after everyone and by then I had given birth to my fourth daughter, Becky, too. My partner Steve knew something was wrong and we decided to tell him the truth. When Becky was born he put her in Sue's arms. He knew it was about Sue at that time and he was fantastic.

32. Sue decided to sell her big house in Welford and got a house much closer to us. She also had to get rid of her two dogs, as they were too much for her. Sue was scared at night, which wasn't like her. So we got her a little Westie named Hamish because she could handle him. I had a crash course in driving, as we knew I would need it. We would jokingly call Sue loopy because she wasn't quite alright in the head anymore and she would laugh.
33. In November she went into hospital for the last time. She had full-blown AIDS by then. The doctors explained the brain was being attacked and I took comfort in that, as she wasn't quite fully aware of the situation.
34. I decided to take the kids to visit. One asked why we spend all our time with Aunty Sue and I flew at her, I told her when she was older and a mum Aunty Sue wouldn't be around, but it was a terrible thing to say to her because she didn't understand at the time. Sue was always close with my third youngest Laura, but when we visited Sue told her to get out and was angry with her (and Sue was never usually angry). Sue said Laura had been stealing her sweets and trying to steal the bed. I told her she had been dreaming but I could see deep down she didn't believe me. Laura was scared and the kids were upset, as it wasn't the Sue they had known.
35. I visited on one day and Sue was crying that there was a man outside on a bike. She explained she had gone to the canteen last night to get us cookies and he had followed her wanting to cut off all her hair. She had not been out of bed in a few days at this stage. The physiotherapist would visit to try and keep her moving but after that she wouldn't let him come near her. I knew I was losing her.

36. It got to the stage where she looked awful and only one nurse, Karen, could get near her to change her. I banned everyone from seeing her as that was between Sue and me. We had made a pact that when she lost her dignity we would end it. She never wanted to lose her dignity or pride.
37. I saw Sue every day except Christmas when I rang. The nurses were brilliant. I went to visit and she was paralysed down her right side and her legs weren't working anyway by this stage. She was on morphine. Professor Finch said when I was ready we could just up the dosage and she would just fall asleep. I kept her awake as long as I could and she seemed to be back for a bit, she called me Fred as she always had. I told her she could sleep if she wanted to. She said everything was okay and that she was really tired. She tried really hard to say something more but all that was coming out were noises and there were tears rolling down her face. That was when I said to give her the morphine and she went to sleep. I sat with her every day.
38. One night I called a helpline, just for someone to talk to. I didn't hate her, but I know I resented her at that time. I said I didn't want her dead, but I wanted my life back. He offered me counselling but I didn't want it, just someone to talk to then as there was no one else.
39. It was New Year's Eve 1996 and we woke up to a lot of horrendous snow. Steve said to leave it and visit later, but I wanted to go. I left at 8am. The usual journey took just over an hour, but it took me two hours that day.

40. When I got to the hospital the nurse Karen was there and said she had tried to call me because it was the end and I needed to be there. She told me to make some tea and have a cigarette and when I was ready to come sit with her. I stopped in to see Sue and I had heard the expression death rattle before, but it was nothing like it. It was a click and then nothing, nothing, nothing and then another click and another horrendous pause. I went to make some coffee and as I passed her room again I went to check on her. I held her hand and stroked her head saying it was Fred and that I was there. Click and a pause. I found myself holding my breath with her, but she never breathed again. It was like she had waited for me to be there.
41. I called out for Karen and said something was wrong. Karen looked for a pulse and said Sue was gone. It was embarrassing, but I fell to my knees and asked them to bring her back.
42. They said I could stay with her as long as I wanted. Professor Finch came to see me and thanked me for staying with her as so many walk away at that point. He asked me what I wanted the death certificate to say. I didn't understand. He said he could put the illness that killed her on the certificate instead of AIDS but that if anyone asked he would have to tell them it was AIDS related. He said if AIDS was on the certificate insurance wouldn't pay out. At the time I couldn't give a damn, but he was brilliant. He put Encephalitis on the death certificate (the investigators have exhibited this as **WITN0708002**).
43. I called Steve, but there was no answer so I asked a neighbour to ask Steve to tell the kids for me because I couldn't. I stayed with her for a while and when I left I walked out with a white bag labelled hospital property. I sat in the car, realising I had to drive home still. It was horrible. I had lost my best friend. I remember walking across the green to my house with that bag. All the neighbour's kids were playing in the snow. No one said anything but I knew they were watching and it was obvious what had happened.

44. I called to tell mum, she didn't want to answer the phone so I told her boyfriend. I tried to call Louise, but she was on a retreat as she couldn't handle it all so I told her boyfriend, too.

GRO-D

GRO-D

GRO-D	I was angry that no one else had been interested in spending time with her.
-------	---
45. I had to register the death. After I went to the Coop funeral parlour and they told me I had to choose a coffin. It didn't matter as she was being cremated. The only thing I cared about was that a beanie toy went in with her so she wouldn't be alone. They said it would be closed casket because of what she had died of and that I would not be able to see her again. They told me lots of people had died over the Christmas period due to the frost and that they could not cremate her for another two weeks.
46. I thought there should only be 1 car behind the hearse, just me and mum and Louise. I didn't want my kids there as they were young and I didn't want to put anymore on them. This led to an argument with Louise who wanted her boyfriend and kids there, too. In the end it was just mum and me in the car.

47. The thing about Sue, though, was despite the businesswoman in her, she was always late. If she said she would be there at 10 then you didn't need to worry about getting dressed until half passed. The hearse was late and Steve said it was bloody typical and we laughed. Mum and Louise left as they said we were disrespectful. Sue's friends from Dubai who couldn't be there sent so many flowers. I asked for the cards to thank people and Louise said I was being morbid. I donated the flowers to the chapel. I fell apart because I knew this was the last thing I would ever do with my sister. I wasn't ready to let go. I can't explain how much she was my world. It was always Sue and me and I didn't want to let her go.

48. After the funeral Louise left straight away.

GRO-D

GRO-D

49. A few days later I got a call to collect the ashes. I only had a tacky green plastic tub. I remember putting her on the passenger seat and she tipped over and I said sorry as I picked her up, as ridiculous as it sounds. I kept her for two months and lied about it. I just wasn't ready. Eventually, just my girls and me went to a field we would walk the dogs in and scattered her ashes there. We still take flowers for her birthday.

50. The smallest things would remind me and set me off. Months later I wanted to call her but couldn't and when Princess Dianna died I was hysterical because I couldn't tell Sue and it was like she had died all over again. One time I was crying and my daughter Laura asked why. I said I missed Aunty Sue. Laura told me it was fine and that she was watching over me. I think that is what snapped me out of it.

51. After Sue died there was a big hole inside of me. And that hole just didn't go away.
52. The hardest thing was telling my grandfather. Sue had lived with them for a while and they were close. She hadn't wanted to tell him as he had already lost his wife and sister and we just couldn't tell him. When I told him about the HIV, he was angry and it was the only time he shouted at me. He told me I was selfish keeping it to myself and that he had a right to know. Things got better, but were never the same.
53. It is hard to understand which effects came from the HIV and which came from the treatment. We called her loopy and she laughed about it as her brain did start going, but it is hard to distinguish whether the drugs caused the effects. Physically she lost weight and looked very drawn. She would get tired and couldn't even Hoover without getting out of breath. She walked slowly and flat-footed. She became very forgetful.
54. The last 18 months, everything was hard and everything failed. She couldn't eat certain foods. She didn't like what she saw in the mirror. Mentally, I think the hardest thing was her worrying about the girls and me when she had gone. She should have been worried about herself, but that was just Sue. She dealt with the burden of knowing alone for two years and then she didn't have much support after; I was her support. She wouldn't get angry as in shouting but she hated the way it changed her. I think she found it incredibly frustrating because her illness was everything she wasn't and didn't want to be.
55. As far as I know, the HIV never affected my sister from getting the other treatments she needed.

56. The stigma attached to her illness was awful, it was disgusting and she deserved so much better. We never told my daughters because the stigma was so much and we didn't want it to affect them. For the longest time it was only Sue and me who knew. Near the end we told others. For the most part, people were afraid to ask so I never had to lie. However, after her death I was honest as I was proud of her; none of this was her fault so why should I be ashamed.
57. I told people and lost some good friends over it. I told one the day Sue died and she said she had to go and she never came to my house again. The children also suffered because it spread through the mothers at the school and people would avoid our home and say you never knew which cup was safe to use. The kids lost friends over it as they weren't allowed to visit anymore.
58. In terms of the impact on employment, for the longest time she just had HIV and she was able to continue working on a consultancy basis. She had to stop travelling to Dubai about 4 years before she died. She only stopped working completely the year before she died.
59. I gave up work about 5 to 6 years before she died. I had previously worked in the home for the elderly across the road as it fit around the kids, but with how much I was looking after Sue and looking after my four daughters as well it was too much. At the very end, my partner at the time had to take a lot of unpaid time off work, too, to look after the kids whilst I was in hospital with Sue. We had another good friend who didn't know the details, but would help out, too. It was very hard.
60. Financially, once I gave up work I couldn't afford the small things that were still important to me such as the Clarks shoes for the children. Sue would buy them and never made me feel the worse for doing so. The year before she died as neither my partner nor I were working we had a very basic Christmas; I remember only having a chicken because it was all we could afford.

Section 6. Treatment/Care/Support

61. I believe my sister was offered every treatment she should have been. I do not believe any treatments were withheld from her or that she ever had difficulties obtaining treatment. I am unsure about the initial period when I did not know she was infected.
62. Sue never had counselling, she wasn't the sort that would accept it. I don't know whether it was offered to her and she refused or if it was simply never offered to her.
63. Mostly, I was Sue's support. The team at Nottingham were excellent; we always had the same team and nurses and they were always amazing with us both. They did not have visiting times and Sue always got a private room and they respected her dignity. They would talk to us about things, not just one or other of us, which was great.

Section 7. Financial Assistance

64. My sister received no financial support. I am unsure if she was aware of it but never applied or if she just never knew of it. As her Power of Attorney, I know she never received any financial support.

Section 8. Other Issues

65. We all hear on the news the rumours about the circumstances of the infected blood and, if there is truth in it, then there must be an apology. If I went out into the street and shot someone, I would be prosecuted for murder. I cannot understand how it was allowed to happen and it can never be allowed to happen again. In the end, I only spoke to the Inquiry because I wanted to give Sue a voice; I am the only one who can give her a voice now. All those infected were treated badly and were made to feel awful and it wasn't their fault and they need a voice. After all these years, I am still so angry that we lived not only knowing how long she had left, but also with hiding her condition. I am angry to this day that my best friend was only 36 years old when she died.

Statement of Truth

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

Signed

GRO-C

Dated 10 February 2019