

Witness Name: Ruby Gilkes
Statement No.: WITN0805001
Exhibits: **WITN0805002-06**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF RUBY GILKES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 6th February 2019.

I, Ruby Gilkes, will say as follows:

1. Introduction

1. My name is Ruby Gilkes. My date of birth is GRO-C 1940 and my address is known to the Inquiry. I am a retired nurse, mother, grandmother and great-grandmother. I was born in Barbados but reside in London. I currently undertake missionary work in Barbados from time to time. I intend to speak about my younger sister Anne Jordan-Clarke, born GRO-C GRO-C 1963, and her infection with Hepatitis C (HCV). In particular, the nature of her illness, how the illness affected her, the treatment received and the impact it had on myself and my family. My family and I were unaware of Anne's infection until after her death.

2. How Affected

2. Anne was involved in a major road traffic accident in 1982 in which she suffered serious injuries including a split liver. As a result, Anne was transported to the hospital where she had an operation to have her spleen and part of her stomach removed. During these operations, Anne received multiple blood transfusions and was infected with HCV. I think the operations occurred at Paddington Hospital but I cannot be sure.
3. In addition to the injuries suffered in the accident, Anne suffered from renal failure which led to a kidney transplant in 1989 at St Thomas' Hospital in London during which Anne received further blood transfusions.
4. Anne discovered she was HCV positive in 1999. If Anne was given infected blood in the 1982 operations then she potentially spent over 16 years living with undiagnosed HCV.
5. I do not know if Anne was given any information about the risks of the operations or the risks of exposure to infections as I only became aware of her HCV infection after her death. I do not know much about her diagnosis, the circumstances around it or whether she felt that she had been given adequate guidance or information. All the information I have is from reading her medical records.
6. Myself and my family have been affected by the loss of Anne and the knowledge we now have that she was infected with HCV and felt that she could not let anyone else know.

3. Other Infections

7. I do not believe that my sister was infected with any disease other than HCV.

4. Consent

8. I am not aware of my sister being treated or tested without her knowledge, consent or for the purposes of research with regards to her HCV infection.

5. Impact

9. I did not know that Anne had HCV until after her death. She never told me, she just suffered in silence. I discovered Anne had HCV when I went through her medical records.
10. After the road traffic accident in 1982, Anne lived a normal life and seemed to make a full recovery. Even after the kidney transplant she was up and about as her usual self, though she soon discovered she had diabetes. Whenever I was in London we would spend time together, such as shopping on Liverpool Street. Occasionally, we would go on holidays to Barbados.
11. Anne got married in 1992. Unfortunately, her husband died in 1999 in tragic circumstances which was very difficult for Anne. Around this time, Anne struggled to communicate with people and became closed off. I have since learned that around this time, Anne was diagnosed as having HCV and her health began to deteriorate as she had a number of medical conditions. Anne was not very open about her health issues so I wasn't aware just how sick she was. I know that she was struggling with her diabetes and that she developed rectal cancer in 2003.
12. Anne was dependent on Insulin to manage her diabetes and underwent radiotherapy for her cancer. Sadly, in 2005 Anne's

transplanted kidney began to fail. In February 2007 I received a phone call from Anne's neighbour who advised me that Anne was found unconscious and bleeding in her house. She was taken by ambulance to the Norfolk and Norwich Hospital ("the Norfolk Hospital") where she was treated for septicemia, requiring blood transfusions. While an in-patient at the hospital, Anne suffered a stroke and required surgery for bleeding on her colon. I was in Barbados at the time and called the hospital on a daily basis prior to returning to the United Kingdom on 5 March 2007.

13. Anne spent the next month at the Norfolk Hospital as she was very unwell. I understand that while at the Norfolk Hospital, Anne received a number of blood transfusions and required dialysis and new kidneys to replace the failing ones. I understand the doctors were unable to start Anne on dialysis due to complications with her HCV. I visited her Anne or spoke to her on the phone every day after I returned to the United Kingdom. When I saw her in person, I was shocked how unwell she was. She had no appetite and had lost so much weight that she looked like a skeleton.
14. On 12th March 2007 Anne passed away during surgery to remove part of her intestine. Anne and I had previously discussed the operation and Anne had told me she did not want to have the procedure as she did not wish to live with a colostomy bag. She said "I could never live with that". I understand from Anne's medical records that the surgery was later discussed with Anne and her son who provided consent for the surgery. Unfortunately, the hospital did not inform me prior to Anne's surgery.
15. I do not completely understand the details surrounding her death but I believe the doctors were unable to stop her bleeding during the

operation.

16. I would have liked to have been told by the hospital that Anne was going into theatre so that I could see her beforehand. I was on my way to see Anne when the hospital called me and informed me she had died.
17. I worked for forty years as a nurse, thirty-three of which were as a theatre nurse and I always made sure the relatives of patients were fully informed. I did not receive such treatment. When at the hospital visiting Anne, the hospital staff did not explain anything to me and I was not included in discussions about her final procedure. I do not think that Anne, or myself, received adequate information from the medical professionals in the lead up to her death.
18. I don't know if Anne was on any medication for the HCV. I remember reading a medical note where it was discussed whether Anne would benefit from receiving anti-retrovirals or not. I think that this was because of her other conditions. At one state, Anne was on Prednisolone as a daily immunosuppressant.
19. I am not aware if Anne's HCV infection had an impact on her medical conditions such as her kidney failure, which may be linked to the HCV. I think that Anne's complicated medical history and her HCV was a reason the doctors did not put Anne on dialysis when she was in hospital in February. At the end of her life, she was insulin dependant, had suffered from cancer, her failing kidneys and suffered from HCV all at the same time. Perhaps her illnesses were linked to each other or made worse by each other.

20. Other than the second round of dialysis I am not aware of any other obstacles Anne faced accessing treatment.
21. I believe Anne felt the stigma of her infection and I believe it explains why she never told any of us. She probably thought of it as a deadly disease. 'Contagious' is what people think of when they hear of HCV and HIV. The reaction of others would be to turn off the television when HIV/AIDS came on the screen, and this same stigma is felt with HCV.
22. Anne was a model. She made clothes, handbags and hats and her house was full of sewing machines and mannequins. She had beautiful drawings and a bubbly personality. Overtime Anne lost the spark in her personality and began to slow down. She would say she couldn't be bothered with much anymore. She stopped modelling and making her own outfits. I wonder now if these were side-effects of the HCV infection.
23. In her final years, Anne became less talkative. I would have to push her to talk to me and even then it would still only be about simple things like walking her dog Freddie. She no longer spoke to me about more personal things. I would have to push her to tell me what she had eaten that day..
24. In her final years, Anne became very withdrawn and would often want to be alone as she said she felt tired and weary. Anne used to love to travel. She had friends all over the world in Australia and Barbados for example. She would even travel to Singapore to buy her favourite Rolex watch. Towards the end of her life, this all stopped. I wonder if her tiredness was a result of her HCV.

25. In 2006, when I visited Anne and stayed with her for a few days, I noticed how easily tired she had become. On one occasion, Anne was too tired to come up the stairs of her house. She looked so frail, like a 90-year-old. When I mentioned this to Anne she shouted at me saying that she did not want my sympathy.
26. In her later years, Anne became very ill tempered. In person, she was very on edge. You couldn't sit and look at her because she would just ask what you were looking at. When we would speak on the phone often and she would talk about the pain she was in. Anne would say things such as "I can't take it. I would rather die than take this pain". I would do what I could, but there is only so much you can say over the phone. She had never been this way before as she was previously a positive person. She was strong minded but always tried to stay positive.
27. For years I did not know why any of this was happening to Anne. I thought to myself that it was her diabetes or perhaps her kidneys. However, now that I know that she had HCV her tiredness and general state makes sense to me. I know she did not want to discuss her diagnosis with me and that her illness was making her act this way.
28. I think Anne felt ashamed of her illness and that is why she never told me. Even when the kidney was failing for a second time I had no idea how bad it was. She mentioned the possibility of asking family members to see if they were a match for her kidney but I had no clue that she was desperate at this stage.
29. Finding out about Anne's HCV infection has had a psychological impact on me and my family. My family have really struggled with losing Anne and her death and the lack of answers surrounding it has

put a strain on us all. It has impacted us to know that she suffered on her own. We wish we could have helped her.

30. I am aware that HCV can be transmitted by bodily fluids and after finding out about Anne's HCV I thought about when I would wash her underwear and whether the HCV could have been passed to me. Our neighbours cleaned up Anne's blood when they found her unconscious in her house that February before her death. I had to let them know about Anne's HCV and I am sure this affects them mentally.
31. As the doctors were unable to stem Anne's bleeding during an operation the doctors did not allow my family to view Anne's body after her death. The chaplain and the doctors all agreed that we should not see her. I was a nurse and understood the decision however my sisters have struggled to accept this. To this day they feel that they should have been allowed to see Anne's body.
32. I like to remember Anne as the beautiful younger sister she was. I do not like to remember how she was just before she passed away when she was as thin as a stick and looked so ill. I did not take photos of Anne during that final month as I prefer to remember her when she was well. It makes me happy to remember Anne when she was well and think of Anne doing her catwalks like she used to.

6. Treatment/Care/Support

33. I do not know if Anne received any psychological support for her HCV. I know she was still seeing her GP.
34. I was never offered any support after Anne's death, not even at the hospital. When I was a nurse, the practice was to ensure the relatives

were fully informed and referred to appropriate support services.

- 35. My christian faith has been my only source of support. My family are fortunate that we are able to go to church and ask for people to pray for us and for Anne.
- 36. I am aware of the support service being offered by the British Red Cross and the Inquiry.

7. Financial Assistance

- 37. I do not know for certain when Anne was made aware of available financial assistance. Some of her medical documents suggest that the Norwich Hospital informed her of the Skipton Fund in August 2005.
- 38. In September 2006, Anne's consultant, David Hamilton at the Norfolk Hospital, wrote to the Skipton Fund to confirm that Anne had been diagnosed with HCV most likely as a result of blood transfusions received during surgery in 1982. I exhibit a copy of this letter (WITN0805002). The Skipton Fund did not approve Anne's application for financial assistance prior to her death. I do not have an explanation why Anne's application was not approved.
- 39. Mentally, for Anne, it must have been stressful to not only be infected with HCV but to have to fight with the Skipton Fund for compensation. Money cannot buy health but at least she could have used the money to improve her quality of life.
- 40. In the days prior to her death, Anne made numerous attempts to contact her solicitor Mr Allen. Anne was rather distressed that she was not able to speak to him. I asked Anne why she needed to speak to Mr Allen and she said it was about insurances and documents in

safe keeping. I now think it was about her application to the Skipton Fund.

41. In 2011 I contacted Nicholas Fish at the Skipton Fund regarding Anne's application. On 28 July 2011, Nicholas Fish wrote to me to advise that Anne's application was never approved but I could make a fresh application on her behalf. I exhibit a copy of this letter **(WITN0805003)**. From here I made a posthumous application to the Skipton Fund on behalf of Anne. This process was a really stressful, difficult and time consuming process for me as the Skipton Fund wanted copies of Anne's medical records from the time of 1982 road traffic accident which were not in my possession. On 13 August 2013, The Skipton Fund advised me they had declined the application as they did not accept as evidence a hospital diagnosis summary which mentioned the 1982 road traffic accident and multiple blood transfusions as they stated this information would have come from a consultation with Anne rather than being from the time of the road accident. I exhibit a copy of this letter **(WITN0805004)**.
42. After my application was initially rejected, I provided further medical evidence to the Skipton Fund including the letter from David Hamilton dated 11 September 2006 and a letter from Anne's hepatologist, Dr Mike Allison at the Norfolk Hospital, dated 22 August 2006 which stated that Anne likely received HCV as a result of a multiple blood transfusions received after a road traffic accident. I exhibit a copy of the letter dated 22 August 2006 **(WITN0805005)**.
43. I appealed the Skipton Fund's decision to reject the application. I felt very frustrated that the Skipton Fund did not accept as evidence letters from Anne's medical professionals stating she was likely to receive the HCV from a road traffic accident. I felt like I had to battle with Nick Fish from Skipton to get acceptance. I feel he didn't

communicate well with me and that decisions were not properly explained to me.

44. That on 10 February 2014 I received a letter from Nicholas Fish at the Skipton Fund who advised me that Anne's application had been accepted. All in all, the whole process took nearly three years.
45. I feel the Skipton Fund acted as though I was only upset because I could not access money on behalf of Anne but it was never about the money. Noone ever explained why Anne's application had been refused and it was this attitude that made me feel bullied.
46. Even after the Skipton Fund accepted Anne's application I had to send them documents to show that I was the executor of Anne's estate and her beneficiary.
47. In 2014 I made a further application to the Skipton Fund for a second stage payment which was refused as the Skipton Fund found there was no evidence that Anne had been diagnosed with primary liver cancer, liver cirrhosis, B cell non-Hodgkin's lymphoma or had been on a waiting list for a liver transplant. This decision was based on information the Norfolk and Norwich University Hospitals NHS Foundation Trust provided to the Skipton Fund ("the Trust"). The Trust found Anne's HCV did not contribute to her death.
48. I felt that Anne's HCV may have contributed to Anne's death but the Norfolk Hospital did not share this view. I feel I was never given a proper explanation of Anne's death such as why the Hospital could not stop Anne's bleeding when she died. No autopsy was ever performed on Anne.

49. I was not happy with Anne's care at Norfolk Hospital or the information the Trust provided to the Skipton Fund about her death and I made an official complaint to the Parliamentary and Health Service Ombudsman ("the Ombudsman"). My complaint was that the Trust did not advise the Skipton Fund that Anne's death was linked to her HCV or liver issues. However, the Ombudsman did not substantiate my complaint. I also found this process distressing as the Ombudsman's Report incorrectly stated that Anne died on 6 March 2007 when she died in theatre on 12 March 2007. I exhibit a copy of the Ombudsman's Report (**WITN0805006**)
50. Overall, I faced a lot of obstacles when trying to obtain financial assistance from the Skipton Fund. I first contacted Skipton in 2008 and I was only paid an ex-gratia payment of £20,000 on 10th February 2014. I have not received any other payments.

8. Other Issues

51. None of this has been a pleasant experience. I would advise people to talk and get to know their loved ones more. I feel terrible that I could have done something more for Anne; if I had only pushed through the barriers when she didn't want to talk.
52. I feel that dealing with this Inquiry and attending the engagement meetings in London have been the first positive things to come from Anne's death. I have found the Inquiry's help a blessing. Had I known of their help beforehand it would have been easier and less stressful for me knowing there are people who are understanding. I can now pass on the Inquiry's information to help others.

Statement of Truth

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

Signed

GRO-C

Dated

25/03/2019