Witness Name: Caroline Giles
Statement No.: WITN1882001
Exhibits: WITN1882002-
WITN1882005
Dated: 26 March 2019

INFECTED BLOOD INQUIRY
WITNESS STATEMENT OF CAROLINE GILES

Section 1. Introduction

1. I, Caroline Giles, will say as follows. My date of birth is GRO-C 1952 and my address is known to the Inquiry.

2. I was married to Christopher ("Chris") Giles in 1973 and have two sons Luke and Adam, aged 34 and 39.

Section 2. How Affected

3. I am writing this statement in memory of my late husband, Chris Giles, who was infected with Hepatitis C ("HCV") by a blood transfusion on 30 December 1987. He passed away on 7 June 2016 due to complications from HCV.

4. For some years before 1987, Chris had had acute abdominal pain that came and went. It was not diagnosed. He was told by his GP that his pain was due to depression and prescribed antidepressants, but refused to take them.

5. After a severe rectal bleed at home, Chris was admitted into Ipswich Hospital on 27 December 1987. At hospital it was discovered that Chris had a duodenal ulcer and on 30 December 1987 Chris had an emergency operation in which a vagotomy and pyloroplasty were performed **(WITN1882002).** He was given a blood transfusion during the operation, which I believe amounted to three units of blood. Chris was discharged from hospital on 7 January 1988.

6. Within 48 hours of the operation, while Chris was still in hospital, his skin turned yellow. I was concerned by this. We were told by the anaesthetist that they were not sure what this was caused by, but that it could have been due to the halothane anaesthetic. In retrospect, I am not sure that was the case.

7. I was with Chris as much as I could be before the operation and I do not remember him being given any advice about the risks of contracting infection from a blood transfusion. If he were given any advice, I do not think he would have been in a state to absorb that information.

8. We learnt several years later, in 1993, that Chris had been infected with HCV.

9. Chris had been to the GP regularly with complaints of exhaustion and pain in his liver area since the time of his operation, and had had blood tests about two to four times a year. However, we were never told of the infection after any of these tests.

10. After one visit to the GP in 1993 Chris was referred to the haematology department at Addenbrooke's Hospital and it was confirmed that he had "Non-A Non B Hepatitis", which is how HCV used to be known.

11. There was no advice or information given to Chris at the time of his diagnosis about the options for treatment, his prognosis or the cause of the infection. It seemed like the doctors didn't know much about HCV and were not sure what information they should be providing us. All they could offer us, they said, was to monitor the virus.

12. I think it was about five years after Chris was told of his HCV infection that he was informed by his treating doctors at Addenbrooke's Hospital that he had likely become infected due to receiving contaminated blood during his transfusion in 1987. The doctors did not have proof of this but said that it was the only way he could have become infected with HCV.

13. Finding out that Chris had contracted HCV due to receiving contaminated blood was a shock. I didn't push for more information than this at the time because I didn't understand that there had been a scandal involving contaminated blood on a large scale. I was told the very minimum that we needed to know, and all I was concerned about was how to help Chris cope with his symptoms.

14. I don't remember being told about the risks of infecting others or any measures to take to prevent this. We were never given any information about how the virus could be transmitted. The only reason we knew to take precautions at all around Chris's blood was because I saw the words "high risk" written on his blood test paperwork and noticed that the professionals treating him were wearing protective clothing and protective gloves.

15. As a result of this, I started being careful around Chris's blood. At home if Chris bled or pricked himself everything was destroyed or disinfected. I also organised an HCV test for myself, which was negative.

Section 3. Other Infections

16. Chris was infected with HCV only.

Section 4. Consent

17. I do not remember Chris being told about the risks of a blood transfusion before being operated on. However, the transfusions were performed during an emergency surgery and Chris may not have been able to give informed consent at the time.

Section 5. Impact

18. The physical symptoms of HCV affected Chris very severely for the last 20 years of his life. Chris had consistent liver pain and back pain, for which he regularly attended hospital. However, the most debilitating symptom was extreme exhaustion. He was so tired that he was unable to work, and leaving the house at all had to be planned for two days so that he could shave one day, shower the next, and then leave the house on the third day. Sometimes even after planning the outing in advance, he was unable to go out as he was in too much pain or could not face the outside. If we wanted to go on holiday we had to go somewhere where he could stay home and sleep for most of the time.

19. Chris became very weak and eventually needed help standing. At one point he had a bad fall and broke his leg. He was then admitted to hospital, where he was told that the HCV had weakened his bones and that his white blood cell count had gone down to 1. I remember his doctor saying that he had never known anyone with such a low white blood cell count.

20. The exhaustion and other physical symptoms took a substantial toll on Chris's mental health. Chris dropped into deep depression that came and went in waves of time. He had to go on an antidepressant, which was gradually increased over the years. He had to be encouraged to eat. I had to be with him all the time to encourage him to do things. Television became his world. He also had a sense of guilt about having HCV, and truly believed that somehow he had become infected because he didn't love his mother enough, and this was the price he had to pay.

21. Chris regularly attended Addenbrooke's hospital complaining of liver pain from the time of diagnosis. He had two liver biopsies in 1996 and 1999, the latter of which confirmed he had stage 4 fibrosis **(WITN1882003)**.

22. At this point Chris was told that he was not eligible for a liver transplant because he had HCV.

23. Chris was offered two courses of interferon and ribavirin treatment for his HCV, the second of which was in 2003. However, he had a violent reaction to the second course of treatment shortly after starting it, suddenly becoming very agitated and thrashing about on the bed. The treatment had to be stopped immediately, and the doctors told us he could not be given that drug again.

24. After this point Chris was not offered any other options for treatment for his HCV. It was confirmed that he had cirrhosis of the liver but that there were no further treatment options for him **(WITN1882002).**

25. On 12 May 2006, Chris was admitted to Ipswich Hospital as he had stopped eating, drinking and had spinal pain and was unable to walk. After about five days he was reassessed and scans showed cancerous tumours on his spine which had been caused by the HCV. He was in intensive care for the first two weeks and then remained in hospital for about 7 months in total to have radiotherapy. He did come home for a short period in the middle of this.

26. During his stay in hospital Chris suffered from many complications and infections. He contracted MRSA in his mouth from his oxygen tube, which required him to be isolated on a different ward. He contracted C difficile infections twice, and urine infections from his catheters. On one occasion he fell from his bed and broke his ribs. This is just a small amount of the trauma Chris had to go through. He was not expected to recover from this illness, and did come close to death on many occasions.

27. Chris was discharged from hospital around November 2006. On his release home he had to wear a metal body brace for two years if he needed to be able to go in the car or anywhere away from home. I have a letter from the Spinal Clinic at Ipswich Hospital on 31 October 2006 detailing his condition at the time and the need for continued use of his brace. **(WITN1882004).**

28. From this point, Chris's health got progressively worse. We continued to care for him at home until his body eventually shut down. He died on 7 June 2016 after four weeks of hospice care at home.

29. Chris did not encounter any obstacles accessing treatment for HCV, aside from the fact that he could not progress with interferon treatment due to his bad reaction to the drug.

30. I cannot put into words the impact this illness had on Chris's family and social life. He was a quiet, shy, very determined man, who pushed himself constantly. He was stoic in the face of exhaustion, and worked through a lot that other people wouldn't have been able to. As a result of the HCV, his confidence was destroyed and his home life was taken away because of the amount he needed to sleep during the day. While he was still working, it felt like he was either at work or asleep. Once he stopped working, the only activity he could bear to do was watch television or occasionally walk across the road to the pub and play crib with his friends.

31. I admired Chris so much, and was so grateful for the wonderful life he had given me. I was in no position to complain and felt I had to do everything that I could to help him. However, the stress of caring for him did take a toll on my health. In 2005, I had a heart attack which was believed to be due to stress.

32. Chris didn't always need nursing but needed me around all the time to help him with physical tasks and encourage him to do everything. Every day had to be worked round what Chris could do that day. It restricted everything that I did. Everything I did was measured in the amount of time I would be away from him, which could not be more than three hours at a time. Once a year I had friends care for him for a week while I went paper crafting but the guilt of leaving him was unbelievable. In the first 18 months after he died, I just got in the car and drove and stayed in a hotel miles away from anywhere just because there was no time restriction.

33. I do feel that there is a stigma against people with HCV. Once when Chris was at the pub playing crib with his friends, one friend shouted across a busy bar “Stay away from Chris, he has a disease”. For a shy man like Chris, that was soul destroying. It shook his confidence so much. That one interaction put an end to Chris spending any time socially away from me. He felt ashamed and worried all his life about what people would think. He felt everyone knew about his infection, even though most people didn’t know.

34. I am just now starting to talk about the impact of what happened to other people. I do not know why I felt I had to keep it quiet before. We did not talk about it and I don’t know why. The only thing we could tell friends was that it was a serious blood disorder that came from the blood transfusion but we didn’t know anything about it. Our friends knew about the debilitating effect it was having on Chris because we could never go out to see friends, they had to come to us.

35. While Chris was alive, my children unfortunately came second to Chris’ care. I felt it was my duty to do the best I could for Chris, and this meant not being able to give my sons a normal family life. There was a lot we could not do, such as holidays and day trips out as a family.

36. My sons accepted Chris’ illness because he himself accepted it. If he had had a different personality, it may have been more difficult. My sons were in their teens and early twenties during his illness and did not talk to their friends at school about it or discuss it with anyone. However, in retrospect I realise I did protect them from the medical aspect of what was going on. They were there to help if I needed them but I didn’t involve them in doctors and hospital appointments.

37. My sons did witness Chris’ distress near the end of his life. We, as a family, watched Chris suffer for four weeks while his poor body shut down. The drugs for his syringe driver took one hour per day to prepare. We had to go out of the house while hospice staff moved him to get him comfortable. We could not bear to hear his screams.

38. Chris worked as a semi-skilled engineer at a company called Cranes. He was committed to his work and would not retire until his work-mates had to carry him up the stairs for break time. He had to stop working in January 1995 due to ill health, but was kept on the books and did not fully retire until August 1997.

39. Having to care for Chris full time meant that I was not able to pursue my career as I would have hoped. I am trained in catering, and I had intended to make a career out of it so that could support my family alongside Chris' work. However, when he got sick I was only able to leave him for very short periods of time and could only take part-time jobs that were flexible and did not have any opportunities for progression. I worked at a supermarket for a period of time, worked as a cook at a pub and a school, and then for 13 years at a local co-op.

40. If I had been able to work full time and progress in my career, our lives would have been totally different. Because both Chris and I had stopped working, there was never any money. We were always working to the next benefit. Fortunately I was able to buy our house with some money I inherited from my parents, so that at least we didn't have any mortgage bills each month. However, we still struggled to make ends meet. I remember at the time we received our first payment of compensation from the Skipton Fund, we had £36 in our bank account.

Section 6. Treatment/Care/Support

41. Our GP was very supportive medically and so were the staff at Ipswich Hospital and Addenbrooke's Hospital. We did not face any difficulties in accessing good care from them.

42. We did not know of any support at all as far as counselling or education or advice was concerned. We felt we needed to "get on with it" as nothing else could be done.

43. If counselling had been offered to us, I don't think Chris would have taken it but I would have.

Section 7. Financial Assistance

44. Chris received compensation from the Skipton Fund.

45. He received the following payments from the Skipton Fund from 2004 to 2014 **(WITN1882005):**

    a. £20,000 in November 2004
    b. £25,000 in January 2005
    c. £25,000, £2,845 and £1,100 in April 2011
    d. £1,100 each month from May 2011 to March 2012
    e. £1,157 each month from April 2012 to February 2013
    f. £1,159 in March 2013
    g. £1,182.50 each month from April 2013 to February 2014
    h. £1,183.50 in March 2014

46. I do not have documentation of his monthly payments from March 2014 to his death in 2016 but I believe they were similar to those listed above.

47. I believe it was Addenbrooke's Hospital that informed us about the possibility of applying for compensation.

48. I was not very involved in the application process but did allow the Skipton Fund to have access to Chris' medical notes, and Chris' treating consultants at Addenbrooke's Hospital provided a letter evidencing his transfusion and current condition in May 2004 in support of his application for compensation **(WITN1882003).** We never had any trouble showing that Chris qualified for the payments.

49. After Chris died I received £10,000 from the Skipton Fund.

50. When Skipton was replaced with the England Infected Blood Support Scheme (EIBSS), my details were transferred to EIBSS and I started receiving monthly payments of £166 initially. My income was then assessed and I started receiving £1,000 a month in mid-2018. My payments will change to about £850 a month in April 2019.

51. I am grateful for the money and assistance of a monthly amount that helps pay the bills to keep me in my home and gave us enough for Chris not to worry about finances. I cannot criticise it. It's all I have coming in now other than my state pension and a payment of £19 per month from a private pension of Chris'.

Section 8. Other Issues

52. I have never been involved in any campaigning or other action regarding the contaminated blood scandal. I don't know anyone else who is infected or anywhere to go to find out more about it.

53. We did not speak to any government officials, charities or other organisations regarding Chris' infection. We were not aware of the larger significance of his infection, we were simply concerned with managing his care.

54. Throughout Chris' illness, I was his spokesperson in terms of pushing for medical care and treatment, because he was painfully shy. I did all the pushing and the talking. However, it never crossed my mind to go and find other people who had it for support, or to look into the scandal in any way. I must have just accepted that I can't change it, so I've got to live with it.

55. I have some excerpts of Chris' medical records which I have attached to this statement as exhibits. My solicitors are requesting the rest of the records.

56. I do remember Ipswich Hospital telling us at one point that the paperwork for one pack of blood from the transfusion had gone missing. I am not sure what the

significance of this is but feel it may be relevant as the paperwork could have told us more about where the blood came from.

57. I have no complaints about the care Chris received at Ipswich Hospital or Addenbrooke's Hospital. He was treated very respectfully by hospital staff, especially specialist HCV nurses Tracy and Sally and Consultant Dr Alexander at Addenbrooke's Hospital.

58. My main hope for the Inquiry is that it makes sure something like this never happens again. Psychologically, the preparation of this document has taken me to the very edge, and everything has been brought to the top of grief all over again. No family should have to go through what we did.

59. I would also like to see compassion for the families that have had to go through this. It was a terrible thing to happen and it took Chris's life away from 1988 until his death in 2016 for something that was not his fault. I would like an acknowledgment of what happened.

Statement of Truth

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

Signed GRO-C

Dated ......26 March 2019......