Witness Name: Michelle Baker
Statement No.: WITN1825001
Exhibits: WITN1825002 -
WITN1825005
Dated: 11 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS MICHELLE DELIA BAKER

Section 1. Introduction

1. My name is Michelle Delia Baker. My address and date of birth are known to the Inquiry. I live with my three daughters, aged 18, 16 and 14, and my brother Darren.

2. I spend part of my time caring for Darren, **GRO-C** and work part time at Tesco as a shop assistant.

Section 2. How Affected

3. I am writing this statement in memory of my late husband, Vincent Baker, who was infected with Hepatitis C (HCV) by a blood transfusion on 11 March 1983. He passed away in March 2010 as a result of liver and heart failure.

4. My husband had a motorbike accident on 11 March 1983 and was taken to Worthing Hospital, where he was given a blood transfusion. He was given

4 units of blood. As a result of the accident he fractured his right femur. A pin was placed in his leg (skeletal traction) to help his bone realign, and spent about 4 to 6 months in hospital recovering before returning home.

5. As far as I am aware, my husband was not given any information about the need for a transfusion at this time or of the risks of being exposed to infection. He was treated on an emergency basis due to the amount of blood he lost in the accident. I do not know exactly what information was given as I was not there at the time.

6. I met Vincent in 1999. As far as I know, from what he has told me and from my own experience, he did not have any other operations or spend any time in hospital from the time of the transfusion in 1983 until around 2008.

7. Around 2008, he started to become ill. We noticed that his skin had become very thin and started to break very easily. The slightest knock would cause him to start bleeding. He also kept getting infections that would be cured with antibiotics but then return several weeks later. While he had these infections he would be 'out of it', and wouldn't act like himself. He was in and out of Worthing Hospital for over a year having various tests to determine what was wrong with him. I believe he had four endoscopies. Eventually, in 2009 his gastroenterologist, Dr Andy Li, diagnosed him with cirrhosis of the liver. Dr Li told him that the cirrhosis was probably caused by alcohol, which I found strange as my husband drank socially but had never been a heavy drinker. Dr Li did not mention anything about HCV.

8. My husband worked as a long distance lorry driver delivering operating tables to hospitals. In August 2009, he was working in Manchester when he got into a major accident. He had gone to work even though he had one of his infections and did not seem mentally himself that day. I got a phone call from Manchester Hospital saying that he had blacked out at the wheel, crashed the van and that they were not sure if he would survive.

9. He survived the accident, but remained at Manchester Hospital for 4 days. During this time, the doctor told us that he had HCV, that he had contracted it from the blood transfusion in 1983, and that it was likely responsible for the cirrhosis of the liver. He said that there was a note in my husband's medical records that he had HCV. He did not say when the note was from, which hospital had made the note or when his doctors had first become aware of the infection.

10. After 4 days Vincent was transferred to Worthing Hospital, as he was eager to return closer to home. He was then being treated by Dr Li again – the same doctor who had diagnosed him with cirrhosis of the liver earlier that year. Dr Li did not provide us with specific information about HCV. By the time we were told about the HCV, we were also told it was too late for Vincent to undergo specific treatment for the HCV as he was too ill already. The focus at that point was determining Vincent's treatment options for the liver cirrhosis and trying to obtain a liver transplant, at which point we were given a leaflet from Kings College Hospital about the transplant process. Dr Li did inform us about obtaining financial assistance through the Skipton Fund and helped us with that process.

11. I believe that Dr Li knew Vincent had HCV, as he had been treating him for over a year and would have either seen, or made, the note in his medical records about it. However, I never confronted him about the fact that he didn't provide us with this information until after it was discovered by Manchester, and instead attributed his liver cirrhosis to alcohol. I was too afraid to confront a doctor about a medical issue, and all of my energy was taken up trying to support Vincent and get him the treatment he needed while this was still possible.

12. I think that Worthing Hospital should have told us about the HCV as soon as they knew Vincent had it. If he had found out about it even a few months earlier, his liver failure would not have been as advanced and he would have been able to receive a liver transplant. It is likely that he would still be alive today.

13. I also think that once it was discovered that some people had received contaminated blood during the 1980s, hospitals should have contacted anyone in their records who received blood from the batches that were at risk of contamination and arrange for them to be tested for HCV. This would have saved a lot of lives. Instead, my husband was not told of his infection until 26 years after he contracted it and was too ill for treatment. I understand it was not the hospital's fault that the blood was contaminated but do not understand why they didn't contact people once the contamination was discovered.

14. My husband and I were never told of the risks of others being infected as a result of the infection. In the last two years of his life Vincent was bleeding very regularly, as his skin broke with every slight knock. I was treating these wounds and could easily have been infected. We also have three daughters who 4, 6 and 8 at the time Vincent was very ill, and could have been put at risk. I have since tested negative for HCV, and I asked my GP if my daughters could be infected as well but was told that they wouldn't be as I do not have it. However, I do think I should have them tested just in case.

<u>Section 3. Other Infections</u>

15. I do not think Vincent received any other infections, apart from the complications from his HCV.

<u>Section 4. Consent</u>

16. Vincent was treated on an emergency basis after his motorbike accident in 1983, and after his car accident in 2009. On both occasions he was given necessary treatment to save his life that he could not consent to as he was not lucid at the time.

17. As his illness progressed in 2009 and 2010, we were provided with adequate information about the treatment options. Vincent was often too ill to understand the information but I felt informed about what was happening.

Section 5. Impact

18. Vincent did not have any physical symptoms of HCV until he began to get ill in 2008 and was diagnosed with cirrhosis of the liver. From that point he began to suffer from very thin skin, causing him to bleed often. He also lost a significant amount of weight, and suffered from various recurring infections, such as urine infections, due to his weakened immune system, which caused him to become feverish and confused.

19. From his accident in August 2009 until his death in March 2010 Vincent spent most of his time as an inpatient at Worthing Hospital. He came home briefly for Christmas. He was placed on a liver transplant list in October 2009, but didn't reach the top until 15 February 2010, at which point he was transferred to Kings College Hospital in London to receive it. However, at that stage he had heart failure and liver failure. After the pre-operation examination it was determined that he would likely not survive the transplant, so he was sent back to Worthing Hospital for palliative care on 3 March 2010. **(WITN1825002).**

20. He did come home briefly in February 2010, but it was extremely difficult for me to care for him and also manage to care for my daughters and brother. I called the paramedics to pick him up, but he refused to return to hospital. I eventually convinced him to return, and he remained there but refused all further medication. He then caught an infection in hospital and was placed in isolation during the last week of his life due to being highly contagious. He passed away on 20 March 2010.

21. Throughout his illness, his recurring infections altered his mental state, causing him to behave differently and make decisions that weren't like him.

He became confused, angry and impulsive. On one occasion he ordered something from the internet and missed the parcel delivery, so decided to go pick it up. I told him he was not well enough to drive, but he refused to listen and drove off. He then became confused, drove to the wrong location and crashed the car in a field.

22. He also got easily angry, trying to escape from the hospital, and refusing to return to hospital when he was briefly home. On one occasion he succeeded in escaping from the hospital, after which he required a police guard to prevent him from escaping.

23. In the later stages of his illness, he became depressed as he realised there was nothing that could be done to help him. He sometimes expressed this in strange ways, such as phoning me and telling me he was having affairs, in an effort to try to make me angry at him so that I would be less distressed when he passed away.

24. Vincent did not receive any treatment for the HCV, as by the time he was informed of the infection it was too advanced for treatment to be effective. He was told that he would not have responded to HCV medication as he was suffering from multiple organ failure. Instead of treating the HCV Vincent was placed on a liver transplant list but was too ill to receive the transplant. I am not sure what medication he was on in the meantime. He then received palliative medication to manage his symptoms until he refused it. By then we knew it was a waiting game, and the objective of any medication was to keep him comfortable.

25. After the accident in Manchester, Vincent did not have any trouble accessing treatment for his liver cirrhosis. However, he had been ill since 2008 and had been in the care of Worthing Hospital for over a year at that point. If any of the medical professionals treating him knew he had HCV at that time, I believe he should have received HCV treatment at that time as he would have been more receptive to it at an earlier stage.

26. Dr Li at Worthing Hospital was the main obstacle to Vincent accessing treatment for HCV as he did not tell Vincent about the HCV and instead told him that his liver damage was due to drinking alcohol. I do think that if Vincent had received a liver transplant before February 2010 he would likely have survived. However, he was not placed on the transplant list until October 2009 and did not reach the top until February.

27. I think the mental confusion that Vincent suffered from as a result of his illness sometimes affected his treatment because he was a very difficult patient to care for. However, the doctors were generally patient with him.

28. The impact of having HCV on my husband's family life was that it shortened his life by many years. Our daughters were 9, 7 and 5 when he passed away, so he will never get to know them as they grow up. If he had not contracted the infection he would still be alive today and would have many years left to enjoy his family.

29. My husband's illness and resulting death has of course had a profound effect on me. However, throughout his illness and his death I have had to stay strong for my children. I have kept myself busy with caring for my children, working part time and caring for my brother. I am the type who prefers to get on with things as a way of coping.

30. I did not feel there was a particular stigma against HCV. However, when I spoke to family members about my husband having HCV, they googled it and then kept expressing their concern to me that I could catch it from his toothbrush or his cutlery. I knew they were trying to be helpful, but this was upsetting for me so I stopped talking to them about it.

31. The impact of Vincent's illness on our family is that his daughters have spent a large portion of their childhood without a father. During his illness they did not understand what was wrong with him and it was quite scary for them. I tried to shield them from the illness by keeping him in his bedroom during the short times when he was home. All they remember of him is him being in and out of the hospital during this time. We also had both of my

twin brothers Sean and Darren living with us at the time, who were 19. Sean understood what was happening and kept out of the way, but Darren GRO-C did not really comprehend what was going on.

32. After his accident in Manchester, Vincent gave notice at work and did not return. He was not mentally capable of continuing to drive after this time, as the crash had proven. Once Vincent left work, we went on benefits, as his job had been our main source of financial support.

33. Before Vincent's accident I had not worked, as I was caring for my children. In November 2009 I started a new part time job as a dinner lady to help us cope with the loss of income. After Vincent's death I was given a widow's allowance, which, combined with my part-time income, meant that we were no longer eligible for housing benefit. I therefore tried to pick up as many hours as possible at work even though I was technically part time. In February 2018 I changed jobs and I now work as a shop assistant at Tesco.

Section 6. Treatment/Care/Support

34. Once Vincent was diagnosed with HCV, he did not have any difficulties accessing treatment. However, before he was diagnosed he did have trouble accessing the proper treatment because his doctor thought his liver problems were due to alcohol.

35. I do believe we received a leaflet about counselling when Vincent was diagnosed and potentially also after he passed away. I am not one to go for counselling; I prefer to talk to my family and my best friend.

Section 7. Financial Assistance

36. My husband received financial assistance from the Skipton Fund. After his accident in Manchester, Dr Li at Worthing Hospital told us about the Skipton Fund and explained the application process to us. Vincent

received two payments from the Skipton Fund: a Stage 1 payment of £20,000 and a Stage 2 payment of £25,000.

37. Dr Li helped us apply for a Stage 1 payment in August 2009 by filling in the required paperwork, and confirming that Vincent had received contaminated blood and was diagnosed with HCV. The payment came through on 13 January 2010. To apply for the Stage 2 payment Dr Li had to confirm that Vincent had liver failure. He did this as soon as we had received the Stage 1 payment and we received the Stage 2 payment on 2 March 2010. **(WITN1825003)**

38. In 2011, after my husband's death, I received a letter from the Skipton Fund saying that the government had decided that the earlier compensation was not sufficient and that we were entitled to apply for a further £25,000. To do this, I had to fill in a form confirming that I was still at the same address and provide a copy of Vincent's death certificate.

39. We did not have any difficulties obtaining financial assistance from the Skipton Fund. However, I do not believe that the amount of compensation was enough given everything that happened to Vincent and to our family. Although £70,000 seems like a lot of money, it has to be considered that his life was taken from him and he left behind three young children. I am aware that people who were infected with HIV instead of HCV were awarded up to £500,000, which does not seem fair to me because HCV is also life-threatening.

Section 8. Other Issues

40. After Vincent's diagnosis, in early 2010, I went to see a solicitor in London to see if I could take any legal action on his behalf. They investigated the case for about 6 months and then told me they were not prepared to take it on as they had never seen a case like this before. I sought advice from two more solicitors in Brighton after he passed away. One firm had the papers for about 18 months before turning me down.

They both told me that although they thought I had a case, they had never acted in a case like this before and turned the case down.

41. I do not have copies of my husband's medical records. I have copies of his death certificate **(WITN1825004),** the letter from Kings College Hospital confirming he could not be given a liver transplant **(WITN1825002)**. and discharging him back to Worthing, and two appointment letters from Worthing Hospital **(WITN1825005).** I also have a copy of our Skipton Fund application **(WITN1825003).**

Additional questions for witnesses

42. I think the most important issue for the Inquiry to address is, once the hospitals knew that the blood was contaminated, why didn't they contact the people who had been given this blood? Why did this issue get brushed under the carpet, at the expense of everyone who was infected? If they had contacted the infected people, more people could have gotten treatment earlier, lived longer and suffered less.

43. I hope that as a result of the Inquiry, the people responsible for brushing this scandal under the carpet will put their hands up and admit that they should have contacted patients who were at risk of infection.

44. I also would like the Inquiry to determine who else is at risk of infection who has still not been told about it, and agree to tell everyone who could possibly be infected so they can get tested.

45. I am concerned that the medical professionals at Worthing Hospital knew from my husband's records that he had HCV but did not tell him until his accident in Manchester, even after he had been diagnosed with cirrhosis of the liver. I was present for many meetings with these professionals in 2008-2009 before the accident and they never mentioned the HCV, but always indicated that his liver problems were due to alcohol use.

46. I have not seen my husband's medical records. However, I do have his discharge letter from Kings College Hospital, which states one of his problems as "alcohol misuse and alcoholic liver disease" **(WITN1825002)**, and his death certificate which states that the secondary cause of death as "Diff diarrhoea, Alcoholic liver damage" **(WITN1825004)**. I do not believe this is accurate. He was not a heavy drinker, and HCV when untreated is known to cause cirrhosis of the liver.

47. I have not tried to access any of his medical records but understand that the Inquiry will have access to them.

48. I am angry with Dr Li and Vincent's other doctors at Worthing Hospital for not telling my husband that he had HCV. However, after the diagnosis was confirmed, Dr Li was helpful in letting us know about the Skipton Fund and keeping us updated regarding my husband's treatment. I had no issues with any of the hospital staff; they were always helpful despite the fact that my husband was sometimes challenging to care for.

Statement of Truth

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

Signed **GRO-C**

Dated 11-2-2019