Witness Name: Shirley Hunkins
Statement No.: WITN1906001
Exhibits: WITN1906002 – WITN1906004
Dated: 18 December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHIRLEY HUNKINS

Section 1. Introduction

1. My name is Shirley Hunkins and my date of birth is GRO-C 1955. My address is known to the Inquiry.

2. I have one son and one daughter. I currently live in Hackney with my three grandchildren whom I have adopted.

Section 2. How Infected

3. I was infected with hepatitis B (HBV) from a blood transfusion in the 1980s.

4. I had a hysterectomy in the early 1980s at Leeds General Infirmary. I was told after the operation that I had lost quite a lot of blood and would need a blood transfusion. I then received the transfusion. I was not given any information about the risks of receiving a transfusion.

5. I do not remember exactly when I had my hysterectomy, but it was after I had my last child which was in 1982. I believe it may have been around 1985.

6. Shortly after my operation I began to feel sick as if I had the flu. I felt very lethargic and had no energy. I was also jaundiced, and I had a pain in the back and side of my abdomen that was so bad that it was hard for me to function.

7. I was worried that I might have a sexually transmitted infection, so I went to a sexual health clinic to be tested. I was then told that I had tested positive for HBV.

8. I had never heard of hepatitis before, and was not given much information about it by the clinic. They just told me that whoever I had had sexual contact with should be tested, and that I should also have my children tested. They also told me that I would have to live with hepatitis for the rest of my life, that there was no cure or treatment available for it, and that I could develop cirrhosis of the liver. They told me that going forward I should use condoms during sex.

9. I do not think that I was given adequate information about hepatitis by the clinic. I went back to the clinic a few times to ask for more information, because I had just been given a potentially life limiting diagnosis and didn't know what I should be doing about it. However they didn't have any more information to give me and it seemed like they were not really familiar with the disease themselves.

10. At some point I was referred back to Leeds General Infirmary for more testing. They did lots of tests but did not tell me any more information about the infection or the impact it would have on my life.

11. I was not told by anyone at the sexual health clinic or at Leeds General Infirmary that the reason I was infected was because of my blood transfusion.

12. In 1989 I moved to London and my care was transferred to the Royal Free Hospital. At that point I was provided much more information about HBV, and many more tests were conducted on my liver as I still had the debilitating pain in my side. I was then told more about my prognosis and steps I could take to live a healthier

life, like not drinking alcohol. I was still not told about the cause of my HBV infection right away but after I continued to enquire about this over several years it was admitted that I was infected as a result of the transfusion. This is documented in my medical records for the avoidance of doubt. **(WITN1906002).**

13. I think that more information should have been provided to me at the time of my diagnosis in Leeds. I would have liked to have known how I got the hepatitis and why they didn't screen the blood before they gave it to me. Instead, they swept it under the carpet and tried to downplay the seriousness of the illness, as if they didn't want to admit that they had done something wrong. They just kept telling me that it wasn't a big deal.

14. I feel that the way the diagnosis was communicated to me was handled very badly. I was a young single mother with two young children, and was given this diagnosis of something I had never heard of before and told that there was no cure for it and that it would eventually kill me. It left me feeling scared that I would die and leave my children on their own with no one to take care of them. I felt that the hospital didn't explain anything to me at all about how to manage life with the infection, they just left me on my own to deal with it.

15. I was also advised to have all of my past partners tested, which was very embarrassing and humiliating as the hospital was trying to put the blame on me by saying I was sleeping around and that I got it from that, which was a lie as the infection proven to be the hospital's fault.

16. Once I moved to London, I felt the hospital staff were much more knowledgeable about HBV and able to provide me with the information I needed, such as the treatments that were available to me and ways to avoid infecting my children and others. For example, they told me to keep away from the children if I bled or cut myself.

Section 3. Other Infections

17. I was infected with HBV only.

Section 4. Consent

18. I do not feel I was treated without my consent.

Section 5. Impact

19. After I was diagnosed with HBV I continued to feel like I had the flu a lot of the time. I often felt nauseous as well and would throw up. But the most debilitating part was that I continued to have the pain in my abdomen. Some days the pain was so bad I had to constantly use hot water bottles, couldn't get our of bed or function.

20. I was also very depressed as I struggled to cope with the diagnosis. I felt like I was constantly going from doctor to doctor to try to find a cure or treatment, which took a toll on me. I spent a lot of time and money doing research into hepatitis, possible treatments and alternative medicine therapies that might help. Especially after moving to London I was determined to get rid of the HBV because I was so scared that if I died and left my children behind, there would be no one to care for them as I had no family in London.

21. Once I was put under the care of the Royal Free Hospital, they conducted some investigations into my liver and it became clear that this was the source of my abdominal pain. I felt they did a good job and were trying to help, although no one could figure out what to do to cure the HBV or alleviate the symptoms.

22. In the early 1990s I was put on multiple courses of interferon treatment to try to clear the virus. I had to take the treatments for up to 12 months at a time. I think I took this treatment at least twice, but I cannot remember how many courses there were. In the end they told me to stop because it was making no difference.

23. I believe I had treatment with another medication as well but I am not sure what it was. This was not successful in clearing the virus either.

24. The side effect of the interferon was that my symptoms of HBV got worse. I vomited, had headaches and felt dizzy. I was told I might have these side effects before the treatment so expected this.

25. I did not have any trouble accessing treatment; I was given interferon treatment shortly after I started attending the Royal Free. I do not know if the treatment was available earlier in Leeds; if so I believe I should have been offered it then, but it does not make too much of a difference as it didn't clear the virus.

26. After the treatments failed, I continued to attend the Royal Free regularly for monitoring. As the years went on my test results got worse and my doctors told me my liver was becoming scarred and my liver function was deteriorating.

27. About 4 or 5 years I was so determined to cure the virus that I sought help from a private doctor on Harley Street who specialises in alternative medicine. He used a technology involving electric shocks to attempt to cure the HBV. I received this treatment regularly for about 6 months to a year, at which point the doctor told me to return to the Royal Free and ask for an HBV test because based on improvement in my symptoms he thought I might have cleared it.

28. I attended my regular checks at the Royal Free in July 2016 and when the HBV test was conducted they told me that there was no evidence of it in my system. In my hospital notes from that time it states that in fact my viral load was undetectable in March 2015 **(WITN1906003).**

29. The doctors asked me what I had done, because it looked like I had spontaneously cleared the virus. I wasn't comfortable telling them about the private doctor so I didn't say anything about that. They then decided there was no longer any need for monitoring of my liver now that I had cleared the virus, but that I should tell doctors in future that I used to have HBV if I need any treatment. **(WITN1906004).**

30. My private doctor told me that I was only the second person he had ever managed to clear of hepatitis using the electroshock therapy.

31. I have been refused treatment by dentists and GPs as a result of having HBV. They don't tell me that this is why they are refusing to treat me but sometimes they just remove me from their list and then when I go in I am told I am not a patient there.

32. When I go to hospital for any treatment they are very careful when treating me so as not to get infected. They treat me in a room on my own, and arrive all gowned up. If a friend of mine is attending the appointment with me they make my friend put on protective gear as well.

33. I have suffered a great deal from the stigma surrounding hepatitis. The only reason I moved away from Leeds in 1989, where all of my family was, was because of how horribly I was treated there as a result of my HBV. When my family found out about my infection they simply refused to talk to me or have anything to do with me or my children. They told me I couldn't go to their houses or interact with their children. They didn't know much about hepatitis and knew it was contagious, so they were afraid of being infected. Even when I told them it wasn't my fault, they wouldn't listen. They were all just very afraid and not educated enough to know it was safe for their children to play with my children.

34. In the wider community, news of my infection spread and I began having horrible things done to me. I was treated as though I had AIDS. People put faeces in my letterbox, and broke my windows. The abuse was so bad, it was a shock to me. I didn't think people could be so nasty and horrible about something that was no fault of my own. The doctors did not prepare me at all for the huge stigma around this illness where we were living. I decided I had to move to London so that my children would not be subject to the same abuse I was.

35. There needs to be more education about hepatitis, because although the stigma may have lessened I think it's still pretty hidden. People are still very ashamed of

having hepatitis. It doesn't matter how they got it. People just see you as having this sickness. As soon as you mention it to anyone, they will take a step back. So I did stop mentioning it to people. I was driven away from my family and friends in Leeds as they were not educated enough to know I was not a risk to them.

36. The impact of the illness on me socially is that I was isolated from my family and living in London with just my two children. I did make friends through connections that I had there, but I didn't have the family support that I had before I was diagnosed. In terms of dating, I found it very difficult to have boyfriends as they would leave as soon as I told them about the infection. As a result I just kept to myself really, and still do. I feel that if I had not been infected I would be more confident in myself. I would be able to go out instead of hiding away in my home.

37. I think I still fear the stigma of people knowing I have had it. Even though I no longer live in Leeds, and the stigma has lessened over time, and I have cleared the virus, I still live as though I have got it and am afraid of people's reactions because I had it for so long. I feel that the hepatitis has ruined my entire life and has robbed me of a normal and healthy life with my children. I was forced to withdraw myself and my children from society in order to protect us from being hurt if anyone was to find out. It's only recently that I have chosen to tell my children, and it's only just the one child I have told as the eldest has autism and will not understand.

38. Back in Leeds I had been working as a school cleaner and sometimes a dinner lady. However I stopped working after a while because I was feeling so unwell as a result of the HBV, I kept losing jobs due to poor attendance. Caring for my young family on my own and working was not possible due to how tired and unwell I was. Since I have moved to London I have not worked. I would very much liked to have worked much longer, and I think I would have if I had not been so ill for so long.

39. Financially, not working has meant that I have always struggled to make ends meet. Every tiny bit of money I saved, I spent on trying to cure the HBV. For example, the private treatment I paid for cost about £6000 in total. I have had about six treatments at around £1000 per treatment. But it was worth it, I would have paid anything to clear the virus.

40. I do fear that me being so ill has had an impact on my children. I tried to keep it from them and to be as normal as possible, but most of the time I was sick and in bed and they knew something was wrong. I tried not to let it affect how I brought them up, and tried my best with them. The older one is 8 years older than the younger one, so for much of their childhood she was helping me take care of him when I felt too ill.

41. I still see my children regularly. They are grown up and have children of their own, whom I have adopted. My grandchildren don't know of my infection. I am now raising three of them, and they are all teenagers. They do cause me a lot of stress as I am still not well.

42. I would say that before the blood transfusion I had a normal life, and from that point everything went downhill. If I hadn't become infected then I would have worked, had a normal relationship, and spent time with my family, but instead I have been unable to work, unable to have boyfriends and estranged from my family.

43. I also find it difficult to go on holidays as the insurance companies always charge such a very high price because of the hepatitis and it does not matter to them that I no longer have it. I have to pay on average £5,000 to £7,000 just for the insurance alone. My life is completely ruined and I am now in my 60s and just existing and waiting to die.

Section 6. Treatment/Care/Support

44. I was never offered counselling in relation to my HBV. I feel the doctors tried to sweep it under the carpet and make me feel it wasn't a big deal so I shouldn't worry about it. I was never given the opportunity to speak to anyone about it. I did a lot of research myself, and ended up finding out about the private doctor I used from a friend in London.

Section 7. Financial Assistance

40. I have not been able to apply for any financial assistance as a result of my HBV. I understand that there are Trusts available for people infected with HCV but not HBV.

Section 8. Other Issues

41. In terms of what I think the Inquiry should look into, I would like to know why there was not more information publicly available about this scandal earlier, and why they tried to cover it up for so long. I would also like to know why the blood wasn't screened if it was known that you could catch hepatitis from blood.

42. I would like the Inquiry to ensure that the people responsible for this acknowledge that what they did was wrong. I would also like for there to be more help for people who have just been diagnosed with hepatitis. I think people should receive more education on how to deal with it, because I wasn't told anything for several years until I moved to London, and counselling to support them. If more support was available, people wouldn't have to suffer what I went through. I would also like people to be compensated for the trauma of what they have been through.

43. I feel that I was deliberately misled by doctors in the years after my diagnosis when I tried to discuss the origin of my infection with them. I repeatedly asked them what the cause was and told them that I thought it might be my blood transfusion because I felt well before that and unwell immediately after it. However they kept telling me that I couldn't have gotten it from the transfusion and wouldn't explain what other risk factors were or how else I could have gotten it. Eventually they did admit that I had gotten it from the transfusion. I believe they didn't want to admit responsibility for the infection because they knew they would be in trouble.

44. My solicitors have obtained my GP records and records from Royal Free and Homerton hospitals. However they were not able to obtain my records from Leeds General Infirmary because they have apparently been destroyed. I feel it is a shame

that these records were destroyed as they contain the key evidence of my transfusion and diagnosis.

45. I myself tried to apply for my GP records and they never responded to my request.

Statement of Truth

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

Signed GRO-C

Dated …18 December 2019………