

Witness Name: Paula Liddon  
Statement No.: WITN1923001  
Exhibits: WITN1923002 –  
WITN1923005  
Dated: 14 February 2019

## **INFECTED BLOOD INQUIRY**

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### **FIRST WRITTEN STATEMENT OF PAULA LIDDON**

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#### **Section 1. Introduction**

I, Paula Liddon, will say as follows: -

1. My date of birth and address are known to the Inquiry.
2. I am recently divorced and live in south west France. I was given a blood transfusion which contained hepatitis C (HCV) in May 1991.

3. I want to say, before I write this statement, how very difficult I, and I am sure others, am feeling right now. Writing this down is a rollercoaster of reliving certain memories in this continuous saga that I would just like to forget, but I am not allowed to... EVER, because it is always there, year after year, tormenting me, either physically or mentally.

## **Section 2. How Infected**

4. In 1990 I became pregnant and gave birth to my daughter Emily and, two years later, in 1993, I gave birth to my son George. In between these two pregnancies I suffered a miscarriage with twins on 18 May 1991. I was admitted to Lancaster Royal Infirmary Hospital where I was given a blood transfusion. I was given three units of blood and later discovered that one of those units contained HCV. I had no choice with regards to the transfusion, if I had not had it I would most certainly have died that day, so the transfusion saved my life. However, because of it, I now have a slow death sentence.
5. I was not given any information or advice before the blood transfusion about the risk of being exposed to infection. At the time I had passed out, so I didn't even sign anything. Afterwards, I was told I had had an operation and a blood transfusion, but no one said anything to me about any risk of infected blood. When you are admitted to hospital you don't expect this to happen, you expect to be cared for and not poisoned with contaminated blood.
6. As a result of being given the blood transfusion I was infected with HCV. I found out that I had been infected with HCV through the Look Back

programme. I received a letter on 22 January 1996 from South Thames Blood Transfusion Service (WITN1923002) which said,

*'I am writing to you in relation to the blood transfusion you had in the Lancaster Royal Infirmary Hospital in 1991.*

*We have now discovered that the blood may have been carrying an infection known as hepatitis C virus which could have been passed on to you. We would therefore like to see you to explain further and to take a blood sample for testing. You and your doctor will be informed of the result and you will be offered specialist medical care if the result is positive.*

*[...]*

***I should emphasise that hepatitis C is NOT related to HIV (the virus which causes AIDS).'***

7. I knew nothing about HCV at the time but was shocked and confused at the mention of HIV and AIDS. A copy of the letter was sent to my doctor and I had to go up to London to have a blood test. I went to my doctor for the results and they told me I had HCV, but didn't know what it was, and neither did the GP. Nobody seemed to know what it was. The closest comparable disease seemed to be AIDS, but my doctor didn't know, so I was sent to a specialist at King's College Hospital.
8. The GP did not give me adequate information to help me understand and manage the infection. I was told to make sure that I didn't share toothbrushes or razors with any of the family, which we never did anyway, and if any blood spills to keep the other family members away. The GP did not have much

understanding of the disease. At King's, I was not given any more information about the disease. I had bloods taken every few months and had a liver biopsy. I was treated like I had AIDS. I was looked down on, particularly by the nurses in local clinics, and treated as if I had been promiscuous or injecting drugs.

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10. I believe that information should have been provided to me earlier. My GP should have been better informed about the disease and able to tell me more.

11. Most of my test results were communicated by letter. One such letter, sent in 2001 (WITN1923003), discussed my HCV diagnosis and liver biopsies. In the middle of the letter it mentions that I was involved in a class action against the National Blood Service. I cannot see how this information is relevant to my care and treatment and do not think it should have been mentioned.

### **Section 3. Other Infections**

12. I do not believe I have received any infection other than HCV as a result of being given infected blood.

### **Section 4. Consent**

13. I believe I was not given full information regarding my treatment for HCV and feel that it was for the purposes of research.

## Section 5. Impact

14. I used to be very healthy and I was into lot of sports.
15. The mental and physical effects of HCV for me included poor concentration, fatigue and stigma. I was very upset when I found out I had been infected with HCV and this led to mild depression over the years.
16. At the age of 33, due to my HCV, I had a sterilisation because my consultant confirmed there was a possibility that I could pass the virus on to a baby. I opted for sterilisation and couldn't have any more children. This was a devastating decision to take.
17. As a result of my infection with HCV my consultant, Dr Tibbs, described my prognosis as follows in a report to the court dated 15 February 2002 (WITN1923004), *'Given that she is a female and infected before the age of 40 and does not drink excessive amounts of alcohol her prognosis is good, though her lifetime risk of developing significant liver disease must be in the order of 20. Thus, there must be a statistical reduction in her life expectancy, notwithstanding the likely effects that treatment may have.'*
18. As a result of HCV I have developed rheumatoid arthritis and have a lot of problems with my hands and hips as a result. This affects my ability to enjoy one of my greatest passions which is driving horses. I now find this very difficult, as I cannot always hold onto the reins. This might not seem important but to me my horses are my world and escape. To help with the pain I take ibuprofen and now need to see the rheumatoid arthritis specialist. I also have

problems with my lungs and get out of breath very quickly. I am currently going for tests here in France but have been putting this off. I have problems with my teeth, suffer with bleeding gums and lost teeth after the treatment.

19. I was diagnosed with HCV in 1996 and received treatment with Interferon and Ribavirin for six months in 2003. After some weeks I was told that I had cleared the virus.

20. I do not know whether there were any difficulties or obstacles in accessing treatment. I was not told of any, but looking back, I was diagnosed in 1996 but did not start treatment until 2003, so there was a period of seven years when they knew I had the virus in my body but did not treat me: I just had blood tests and liver biopsies during that time. The report for the court from Dr Tibbs (WITN1923004) says, *'this claimant has chronic hepatitis C infection acquired at blood transfusion in 1991. She has relatively mild liver disease at present and is asymptomatic. She is likely to be a candidate for treatment in the near future, particularly if her next liver biopsy, scheduled for later this year, shows evidence of deterioration.'* I knew they didn't want me to have treatment, and I understood this was because my specialist was putting me off because I wasn't particularly ready for it due to my liver function tests. But it may have been down to the cost, I don't know. I recall the specialist saying that I needed to get to a certain level before I could have treatment.

21. I do not know whether there were any treatments which I ought to have been offered but was not, I just followed the advice of the specialist.

22. The mental and physical effects of the treatment I received were as follows. I have a Patient Information Sheet (WITN1923005) which describes the

treatment and says it is a combination therapy for treatment of HCV of Interferon and Amantadine, but I did not receive Amantadine, I received Ribavirin instead. The side effects are described as follows,

*'Interferon treatment usually makes people feel unwell for the first two weeks of treatment. Most people feel as if they go[t] flu – they have a temperature and feel very tired. These symptoms usually settle down after the first few weeks.'*

I feel I was a guinea pig for the Interferon and Ribavirin treatment. Dr Tibbs told me it is was the best time to have treatment because the results were looking good, and he thought I would have a good chance of clearing the virus. On that he was correct. However, what I went through on treatment was nothing like flu like symptoms. The effects of the treatment were so severe that I feel lucky to be alive. It was the worst time of my life. The side effects did not clear up within a few weeks but lasted the duration of the treatment. I was told afterwards that some people suffer worse side effects, some have even died.

23. During treatment I lost my job because I could not work. My husband had to take time off work to look after me. I didn't see my young children properly for six months.

24. The treatment made me so ill, I could hardly lift my head off the pillow. After I had injected myself and taken the Ribavirin tablets I know I would be in bed for days. I could hardly move to get to the bathroom to shower. I just wanted to lie in bed. My children would come in to see me but I had no energy for them at all. They were seven and five at the time. I had not wanted to start treatment because I didn't want to lose that time with them. I lost two stone, my hair fell out and I was completely physically wrecked. I felt very low. My diary

at the time says that if I had pills I would have taken an overdose. I went to my doctor and was prescribed anti-depressants but I was too scared to take them. I think the long term effects of the treatment and the length of time I have had the virus in my body have taken their toll. I have lost my health and it has never fully recovered. Since I finished treatment I went into early menopause at the age of 39. I wondered if the same thing had happened to others. I believe there is a connection with the treatment and early menopause.

25. I feel my infected status has impacted on my treatment. I have to tell anyone treating me, and feel stigmatised as a result. I have been made to feel like I have been promiscuous, or a drug user. I feel I have to explain my infection and how I came to have it, but nobody really seems to understand.

26. The impact of being infected with HCV on my private, family and social life has been as follows.

27. My husband found it difficult to cope with my depression and mood swings. I try not to let things get me down but the treatment took its toll. We married in 2002, so were only recently married when I started treatment. He knew about my illness but he didn't have any children himself and I could not have any children, so that was a big issue and a great sadness. He looked after me very well during my treatment, and took care of my children when I couldn't. I think he was very upset and was worried he was going to lose me: he thought I was going to die when I had the treatment.

28. In terms of our family life, during treatment I couldn't work, I couldn't do the house work, I couldn't take the children to school. My husband had to do all of that, and he had a business to run. My children had to attend after school



clubs and I saw a lot less of them, both during treatment and for a long time afterwards whilst I tried to recover. They said it would take six months to get out of the system and I felt unwell for a long while after treatment ended. I have never felt completely cured, especially when I have had blood tests and they show positive, but I understand the virus is dormant.

29. When I received the all clear I assumed that was it. No one told me I had to go back every six months for follow-up. In 2004 we decided to make a whole new life for ourselves and move to France. When we first arrived in France I was not well. I went to the doctor who took a blood test as I thought the virus had come back. It hadn't, it was just lying dormant. We only subsequently found out that they wanted to see me every six months for check-ups. I don't know what follow-up I am meant to have every six months.

30. I have suffered with the stigma associated with HCV. I want to keep it quiet, and only tell those closest to me who will understand. The worst thing is when people talk about you behind your back. It has become a little easier over the years as people are more open to understanding and I care less about whether people like me. I am not a carrier because I have cleared the virus, but it is always there, it is just dormant.

31. When I left my job at social services one of my colleagues came up to me as I was leaving and hugged me, then jumped back and said, 'oh my god, I can't catch it from you can I?' This was someone who worked in a caring environment and should have known better. That sort of behaviour made me feel bad and was deeply hurtful.

32. The work-related effect of being infected with HCV for me was having to give up a job I loved. I had previously worked for Surrey County Council as a play link visitor working with children and families. This was a job I loved. I had to take six months off work for my treatment, but was only paid sick payments for three months. I had no option but to hand in my notice. My line manager was aware of my situation from the start of my employment but I did feel that because of my illness Surrey County Council were very glad when I left.

33. The financial effects include losing my job, and all the associated benefits. If I had not been infected I would probably never have left the UK. When I was undergoing treatment I was too ill to fight to keep my job, I was not in a fit state to fight for anything. As I am recently divorced, I have no income or pension. Living abroad, I am not entitled to the same benefits as people in the UK and this does not seem fair, particularly as I want to return, and have contributed financially in the past.

34. At this stage of my life, being 54 years of age, I would like to return to the UK to be with my family, but unfortunately I do not have the funds to move back.

#### **Section 6. Treatment/Care/Support**

35. I have not faced any difficulties or obstacles in obtaining treatment, care and support in consequence of the infection, other than as set out above about the possible delay in receiving treatment. Here in France, I have to pay for my healthcare, it's not free like in the UK. When I have an appointment with my GP it costs me €25 each time. If I go to hospital it is considerably more. No treatments or drugs are free and top up insurance is very expensive.

36. I have never been offered counselling or psychological support in consequence of being infected, either when I was diagnosed, or when I received treatment.

### **Section 7. Financial Assistance**

37. The Skipton Fund must have written to me as I did not have a computer or an email address so would not have found out about them online. I applied for funding in 2004. I received the Skipton Fund Stage 1 payment of £20,000 quite a few years later in around 2010/11. At the same time I started to receive monthly payments of a few hundred pounds a month from the Caxton Fund, together with the winter fuel payment. I did not experience any difficulties applying for financial assistance and no preconditions were imposed that I can remember. From March 2018 I started to receive the EIBSS Stage 2 payment of £18,000 per year and the SCM top up of around £498 per month.

38. In terms of the level of financial support, the Stage 2 payment is certainly very helpful but the worse you are the more you get, and you don't want to get to Stage 2. I think everyone should be entitled to the same amount. We have all been infected and affected. I think the regime is quite discriminatory and the level of financial assistance is not enough.

### **Section 8. Other Issues**

39. I was part of a group action claim against the National Blood Authority. I was awarded £9,000 in court, and paid £5,000 of that to my solicitors towards their fees of £40,000, although I also had Legal Aid.

40. This situation I have found myself in, through no fault of my own, has been unfair and cruel and I truly hope that through this Inquiry we will be able to find the truth, and some kind of justice for ALL who have been affected, because we certainly deserve it. I hope that the Inquiry can get to the truth of what happened, why it happened, who was responsible, and what financial gains were made from the scandal. We need this for our peace of mind.

41. I feel that through greed of the government at the time people have suffered and those who were involved in importing blood products that were known to be contaminated should be held accountable. Their blatant actions have caused early deaths, pain and sheer misery to hundreds and hundreds of families, and we did not deserve this.

42. I hope the Inquiry achieves justice and financial recompense for all those infected and affected, although it is impossible to put a price on all the lost years.

### **Statement of Truth**

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

Signed

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Dated 14 February 2019