

Witness Name: Heather Hughes

Statement No: WITN2637001

Exhibits: [WITN2637002 -  
WITN2637008]

Dated: 23 June 2020

## **INFECTED BLOOD INQUIRY**

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### **FIRST WRITTEN STATEMENT OF HEATHER HUGHES**

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

1. I Heather Hughes will say as follows. My date of birth is GRO-C 1954, my address is known to the Inquiry.
2. I live with my husband David in Epping. I am now retired.

#### **Section 2. How Infected**

3. I do not know for sure how I was infected with Hepatitis C. When I was a child my father worked for Shell Oil and when I was very young we lived in Venezuela. At the age of 3 I started showing signs of having a blood disorder. They thought at the beginning that I had Leukaemia but eventually I was told that I had a very low platelet count. They monitored it but I did not ever have a blood transfusion. I may have been given plasma in 1957 whilst in Venezuela

but I am not sure about this. I have come across papers dated 1965 which state that I had asymptomatic thrombocytopenia.

4. We moved to the UK when I was 5 years old, however I regularly travelled to and from Venezuela until the age of 9 when I was placed in boarding school in the UK. I do not recall receiving or being told that I had received any blood products in the UK. I used to come up in bruises all over like I had been in a car crash. The symptoms cleared up at around the age of 12, when I started having periods. I was told that I would always have a lower white blood cell count than others but that it was normal for me. And that was it, I wasn't ill again for many years. When I have described this condition to my doctors in the UK, they have said that it sounds like I may have had idiopathic thrombocytopenic purpura.
5. I have three children; all were delivered by caesarean section at Whipps Cross Hospital. My children were born in March 1981, [GRO-C] 1982 and [GRO-C] 1991. I do not remember being told that I had had a blood transfusion during or after any of these operations. However, I was more concentrated on having the children and for the first I was given a general anaesthetic, so it is possible that I did have a blood transfusion without knowing.
6. I have not yet been able to obtain my records from Whipps Cross Hospital for these operations. My solicitors have requested confirmation of whether these records have been destroyed, however they have not yet received a response.
7. In 2002 I started to feel very tired. I went to see my GP because I thought I had the menopause, I thought that maybe it was time to start hormone replacement therapy. My GP took a blood test which showed abnormal liver function. At that time I had health insurance and so to speed things along I asked for a private referral. I saw Gastroenterologist Dr [GRO-D] in June 2002. Dr [GRO-D] did not seem very concerned, he took more blood tests and said that he would be in touch with the results [WITN2637002].

8. Soon after this appointment we went on a family holiday. I returned to find a letter from Dr [GRO-D] dated 27 August 2002 which states "*I am pleased that your liver tests are settling although my concern is that blood tests picked up the fact that you may be hepatitis C positive*". The letter invited me to contact him to discuss further [WITN2637003]. I feel that maybe I should have been told verbally, but I don't know what difference that would have made.
9. I went straight to see my husband at the restaurant that we owned in the city and told him about the results. We were in shock. I had heard about hepatitis A & B but did not know anything about hepatitis C. I went to the library and looked it up, everything I found said that it led to liver cirrhosis and liver cancer.
10. I don't remember clearly what happened next, but I must have got in touch with [GRO-D] soon after receiving his letter. My insurance wouldn't cover the treatment, so I was referred to Whipps Cross Hospital where eventually I was under the care of Jenny Broomhead. I did not have my first appointment with her until June 2003. I cannot remember what information if any was given to me about hepatitis C before this first appointment with Jenny. I was told that I would be referred for treatment and so I just think I hunkered down and waited.
11. The only things I knew about the infection and how it would affect me was from what I read which suggested that the stages would be cirrhosis, liver cancer and ultimately death. I was not told what to expect but I don't think anyone could have told me what to expect because the infection affects everyone differently.
12. I think I was given a list, or I found or downloaded a list of the risk of infection to others. I remember telling my daughters not to use anyone else's toothbrush or anyone else's razor in the shower.

13. During the early appointments I did not discuss with Jenny or Dr Greaves how I could have contracted Hepatitis C. During my first round of treatment a nurse told me that people in Canada were being given compensation because they had contracted hepatitis C through blood transfusions. I went to see my GP in 2004 to ask him about this. I asked him if I could look at my records to see if I had any transfusions. He said that I could but that it would be probably very difficult. He said that I would have to make arrangements with the hospital and a nurse would have to sit with me while I looked through all of my case notes. He said that I might not understand them anyway. I don't think that he was putting me off [WITN2637004].
14. As the time went by it seemed more difficult to pursue; I could not see how it would benefit me knowing where the Hepatitis C had come from. In my head I often wondered how I got it, but I was more focussed on getting rid of it.

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

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

### **Section 4. Consent**

16. I do not believe that I have been treated or tested without my knowledge, without my consent, without being given adequate or full information, or for the purposes of research.

### **Section 5**

17. In the months before I was diagnosed I suffered from extreme tiredness, I can't really pin point when it started. I was just very tired, more so than I should have been. The only thing I could put it down to was that I was approaching the menopause.

18. I started my first treatment in June 2003, almost a year after being diagnosed. During that time I tried to get my head around being told that I had hep C. It is like being diagnosed with cancer or anything like that, the initial feeling is shock and horror and then you go into the mode of right let's get this sorted, lets figure out a way to get rid of it and get better. Once you get over the shock, you get used to being ill.
19. I do not remember it being a year between diagnosis and starting treatment. However now that I have my medical records, I recall writing to Dr Greaves in February 2003 to raise concerns about the delay [WITN2637005]. I understand that following this letter Dr Greaves wrote to the Head of Pharmacy at Whipps Cross Hospital about treatment for hepatitis C. His letter states "*I have been told that there is no funding for any further treatment and this is clearly an untenable position for all concerned*" [WITN2637006]. I was not aware of any funding issues at the time and do not know how this was resolved.
20. On 3 June 2003 I started my first round of treatment, a weekly injection of PEG Interferon and daily Ribavirin capsules. To begin with I did not feel that the symptoms were too bad. I just wanted to get on with the treatment and get rid of the infection. I did not really know about the severity of the side effects and so I carried on working with my husband at our restaurant. But the treatment did have a big impact on me mentally, I remember being at work and everything became so much more intense. It was a busy and stressful environment, but we had always worked well as a team. My personality changed so much that I became aggressive at the slightest thing and was not being a good team member. The staff would handle me well but I was not pleasant, I was like Jekyll and Hyde. I knew that I wasn't behaving well but couldn't stop it and I often had to leave the shift early.

21. Over the course of the treatment, the dose of pegylated interferon was substantially reduced because of a drop in my immune system. The clinicians were concerned that I would get flu and die and so gave me a lower dose to enable me to cope with the effects of the treatment.
22. Despite the ongoing health concerns, I completed the course of pegylated interferon and Ribavirin. At the end of the treatment in May 2004, testing showed that my Hep C virus level was again raised. I was told that nothing more could be done for me. I felt abandoned.
23. I wasn't told anything about any follow up care. I tried for three or four months to contact Jenny, but I could not get hold of her and I could not get hold of Dr Greaves. They wouldn't or couldn't return my calls. This brought on great distress worry and feelings of hopelessness. I was left with the prospect that I was going to die, I felt that I was living with a death sentence.
24. Eventually I went to see my GP and asked him to help me. Shortly after this appointment I received a letter from Jenny dated 9 September 2004 **[WITN2637007]**. The letter stated that she had discussed my case with Dr Greaves and that he would be speaking to his colleague Dr Foster about the benefit of further treatment. She said that as soon as she heard anything from Dr Greaves, she would contact me immediately. But this is not what happened, I did not hear from Jenny or Dr Greaves again. I understand from my records that Dr Greaves wrote to Dr Foster on 23 September 2004 **[WITN2637008]**, I received an appointment with Dr Foster via my GP. I think it was my GP who really got on to Greaves and got me an appointment with Dr Foster. It was the care of my GP that gave rise to the opportunity to be placed under the care of Dr Foster and his team which eventually led to my being cured of hepatitis C.
25. I met with Dr Foster in December 2004. He said that I could start on a trial that was happening at the Royal London Hospital. This was a fantastic lifeline. Although it was a trial, the care and the information they gave me was second to none.

26. On 3 February 2005 I started the trial, the treatment was Pegylated Interferon alpha 2 A, Ribavirin and Amantadine. The side effects were terrible, I became very ill physically. I had managed the first treatment fairly well; because they kept lowering the dose it did not affect me too much. But with the second treatment I knew that the dose would not be lowered, that was the deal. If I was to get rid of the hep C, I would be on this medication without a break and without any variations. It was part of the trial that there would not be any stop starts, nor any adjustments. I was on the treatment for the best part of 18 months.
27. I had all sorts of symptoms, I had everything. I had nausea, sickness, uncontrollable itching for days and days and days which nearly drove me mad, I got the herpes virus, I think the skin or the immune system was going into overload. I could not eat, I could not bide anything that smelt even slightly greasy, I just could not eat. I was very ill and could barely move. I slept on the couch for at least a year.
28. At the end of the 18 months I was told that the virus could not be detected. However, I had to wait about 6 months before they gave me the all clear. In January 2007 the virus was still undetectable. Once I had this news, I felt that I could move forward with my life.
29. During the first treatment I was diagnosed with high blood pressure. I had to start taking blood pressure tablets which I am still on. I also had to start thyroid treatment; I think my whole immune system went into free fall so everything just started to change. Although I have cleared the virus I still suffer from extreme fatigue and have regular B12 injections. I now also have diverticulitis. Whether these things are part and parcel of the treatment I don't know. During the second treatment my hair fell out, which was horrendous. My hair used to be very thick and curly, what grew back was very thin and sparse hair, but it did grow back so I was lucky.

30. I am not aware of any other treatments which I think ought to have been made available to me.
31. I have not had to return to the hospital for follow up appointments in relation to my liver. But because of my diverticulitis I have had to go to see a gastroenterologist. He told me at the end of 2018 that my ALT levels were high. I was quite shocked. The first thing I thought was that if its back I will have to go through treatment again. He suggested that I have a liver check up and I said no. I don't want to have to go back, maybe it's putting my head in the sand, but I don't think I can do it again.
32. The infection and the treatment had a huge impact on my private and family life. For many years I was not able to be a mother to my children. It was very hard for David; I remember my children going to school but I do not really remember looking after them or being able to look after them at all. My son who was the youngest of the three would come and climb into bed with me when he was home from school. David would be out all day working at the restaurant and would then come home and cook dinner.
33. When I was diagnosed, I felt strongly that the children should know what was happening, they would have noticed me becoming ill anyway and I wanted them to be tested. I was terrified that I could have passed the infection to them before I knew I had it. We told our daughters, the two eldest, but our son was so young at that time that we waited a bit to explain to him what was happening.
34. We arranged for David and the children to be tested straight away. The results of all their tests were negative.
35. In preparation for providing this statement I spoke to our daughters about what they felt when I was diagnosed and going through the treatment. Our eldest



daughter Emily found it overwhelming to find out that I had hepatitis C and to be told that although research and treatment was continuous, there was no cure. It was hard for them to see the impact the virus was having on me physically, mentally and psychologically. Emily told me that when I was ill, she found that often it was easier to keep busy, to stay away from home rather than watch her mum deteriorate into someone she no longer recognised. Both of our daughters were devastated and frightened that they would lose me.

36. Several years later, after I had cleared the virus, our middle daughter, Luisa, tested positive for Hepatitis C. She had been feeling fatigued and went to see the doctor, she was 20 or 21. David told me that she had phoned to say that she had hep C, I was absolutely devastated, it blew me apart. In fact, I think that hearing that she had it was worse than receiving the diagnosis myself because I thought that I had given it to her. I do not know how she contracted hep C however she had the same genotype as me.
37. I managed to get hold of Dr Foster and he took her on which was wonderful. Her first treatment failed which totally devastated her and us. She had a second treatment with Dr Foster, and she has now cleared the virus.
38. I was not able to be open about my diagnosis with friends and my wider family, I didn't really tell anyone. I was worried that people would assume that it was HIV related because it was transmitted by blood. I felt that people would not understand and would think that they could get Hep C by being with me. It was about protecting the children as well, especially our son as he was so young. When you start telling friends, then they tell their children and I did not want to put Harry in a position where he had to go through anything unnecessarily.
39. Having worked in the restaurant trade we tend to listen to other people's problems rather than share our own. All you have to do when you meet someone new is ask what they do, and they love talking about themselves. So

often I walk away and not one person has asked about me, that's just the way I am. Its not in my nature to talk about what is going on in my life.

40. I stopped seeing friends, I wasn't well enough to see friends anyway. I just closed down really. No one really came around, nobody asked what was going on. I had been away so long that it was kind of out of sight out of mind. For the years before I was ill I had always been very busy bringing up children and working in a restaurant, and so seeing friends was an absolute luxury even then. I used to try to entertain at weekends, but that had to stop. You certainly realise who your friends are at the end of the day.
41. Since clearing the virus I have told a few people that I had Hep C, but I do not bring it up. I think it was more important for David to have release than me, he told a few of his friends. I still feel that there is a stigma attached to it. I just don't think that people realise what hep C is, it is easy to say you have cancer because everyone knows about cancer.
42. I gave up my job at the restaurant in January 2005 before I started the second treatment. I could not have carried on during the treatment. I did not work for some time afterwards. At the end of the treatment I was six stone and had very little energy and so I spent the next few months trying to build that up. When I was feeling a bit stronger, I started working from home doing reflexology and massage. I had worked as a beauty therapist and had done courses in anatomy and physiology before my son was born in 1991. I also went back to the city and worked at the restaurant when I was needed.
43. There was a significant financial impact on us as a result of my having Hep C. While I was ill, we had to employ someone else at the restaurant and had to employ someone to help with the cleaning and ironing at home. It was a difficult time to have a restaurant in the city then; it was just coming up to the 2008 financial crash, people were eating more at their desks in their offices,

they were not allowed to drink at lunch times anymore, things had changed in the city. We did not pay ourselves sometimes. We sold the restaurant in 2009.

## **Section 6**

44. I have not faced difficulties obtaining treatment, care and support in consequence of being infected with hep C. After I was diagnosed, I wrote to my dentist who said he was happy to continue treating me.
45. During my second treatment I saw Dr Foster's nurse once per week and she used to run through a tick form of how I was feeling emotionally. She did say that there were groups I could join if I wanted to talk to other people with hep C. But it is not who I am, I am not one to sit and talk about my problems. I did not ever have any other kind of counselling.

## **Section 7 – Financial Assistance**

46. The first I heard about the trusts and funds in the UK was when asked about it for the purposes of this witness statement. I heard about the compensation being paid in Canada but I was not aware that any financial assistance was available in the UK. My GP did not mention anything to me about the Skipton fund when I asked to look through my records.

## **Section 8. Other Issues**

47. I would like to know where the Hep C came from if possible. Once I had cleared the virus, I was quite happy to put it all to bed and to forget about it. I was glad to have my life back and wanted to get on and to move forward. However, hearing the evidence from the Public Inquiry and providing a statement has been quite an eye opener. I had put it all away but doing this has opened the door and now I would like to know how I got Hep C.

48. At first I thought it was from the treatment that I may have had South America in 1957 when I was 3 years old, this was my first port of call. But I hardly had any problems until around the time of my diagnosis in 2002, when I was 48, that's an awfully long time to have hep C without knowing. If I was to find out that I had been given a blood transfusion there would be some relief, some closure. At least I would know where it came from.

**Statement of Truth**

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

Signed GRO-C  
**HEATHER HUGHES**

Dated 23.6.2020