Witness Name: Daphne Whitehorn
Statement No.: WITN0191001
Exhibits: **WITN0191002**
Dated: 20.03.2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DAPHNE WHITEHORN

I Daphne Whitehorn provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 February 2019.

I, Daphne Whitehorn, with input from my husband Reg Whitehorn will say as follows: -

Section 1. Introduction

1. My name is Daphne Whitehorn. My date of birth is GRO-C 1951 and my address is known to the Inquiry. I am a retired Library assistant and currently live with my husband, with whom I have two children.

2. I intend to speak about my infection with Hepatitis C Virus ("HCV"), which I contracted as a result of an infected blood transfusion.

3. In particular, I intend to discuss the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life, the life of my family and our lives together.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. I have always suffered with kidney disease; in fact, I have suffered since birth. This meant my kidneys deteriorated until at the age of eight I had to have one of my kidneys removed.

6. My other kidney continued to suffer and I started two and a half years of dialysis in 1971 and had to have a second removal in 1972. During this period, I had a few blood transfusions. Being on dialysis requires a blood transfusion as you lose some blood.

7. On 4 December 1973, I received a kidney transplant, the kidney was kindly donated from GRO-C and the transplant took place at St. Paul's Hospital, London, which shut in 1992. I suspect that this transplant was where I was given an infected blood transfusion, which consequentially led to me being infected with HCV. The problem in determining this is however, is that I had multiple transfusions during dialysis and could have contracted the virus from any of these. I had never received a transfusion before my dialysis, so I must have been infected from a transfusion either during my dialysis or in the course of the kidney transplant.

8. Whilst attending a routine check-up in 2001 at St Mary's in London a member of staff, whom I remember only as Sister GRO-D verbally told me that I had contracted HCV. This was twenty-eight years after my blood transfusions and subsequent kidney transplant. Sister GRO-D informed me that it had not affected my liver yet. I was not told when I contracted the virus or when I had been tested for the virus. They had just used an old blood sample. Back then I had to have my blood taken every month for testing in relation to my transplant.

9. I felt embarrassed by the way that I was told; it was done publicly in front of everyone else in the hospital room. I would have preferred to be told in a private and personal setting.

10. There was no information given to me, I was working in a library at the time so I went to the reference section and looked up what the virus was myself. When I read what the virus was I was mind-blown. I thought I was going to die. I read about what the possible side effects were, it frightened me to death.

11. I feel as though I should have been informed earlier as I was potentially infected for 28 years before I was told. The hospital did not tell me anything about when I was infected and I never received an official letter detailing or confirming my infection. As I have had two children since the transplant it was suggested that I tell them to get tested. They were at university at the time.

12. GRO-C My daughter GRO-C did not mention HCV during her blood tests so she was only tested for HIV. Nobody had given my daughter advice to get tested for HCV then and subsequently nearly eighteen years later she was diagnosed as having contracted HCV.

13. The hospitals gave us no advice on how to manage the infection or the precautions to take in order to safeguard other people from potentially catching the virus. I feel that we should have had much more of an explanation about the condition and more information on how to manage and deal with the virus. This is something they definitely should have told us.

14. After being diagnosed I was required to go to the University College London Hospital and my appointments became more regular as my liver was now infected alongside my kidney problems.

15. It was not until 2016 that I was told I could go onto a course of medication in an attempt to clear the virus. I was continually told that my liver was not damaged enough to start the course and that there were people with much worse liver damage that needed the treatment before me. That meant I had to wait fifteen years to start treatment from the date of my diagnosis. I found this to be very unfair. From my point of view, I wanted to clear the virus whilst my liver was still healthy. I was also told I could not go on certain drugs because of my kidney's.

16. To finally get started on the medication in 2016 was not made easy. I had always struggled before this to get any medical treatment~~.~~ I felt I was being fobbed off so I contacted my local MP in Bedfordshire: Andrew Selous. He obviously connected with the relevant authorities as soon after I was allowed me to start the drug trials.

17. I started the trials on 27 May 2016 and finished on 19 August 2016. I was required to take a combination of Sosbuvir and Ribavirin, two tablets in the morning and two in the evening. This was almost immediately cut down due to the side effects being so severe. My haemoglobin dropped and I had trouble breathing, plus I suffered with a complete lack of energy. When they cut down the medication I was worried it that it would not work as I was on such a low dosage. However, the end of the medication saw me clear of the HCV.

18. My liver now has a percentage of scarring. I have been cleared of HCV but it still lays dormant. I am currently taking no medication for my liver.

Section 3. Other Infections

19. I do not believe that as a result of me being given an infected transfusion that I have contracted any other infection other than HCV. However, I do believe that as a result of the infection I have suffered from a series of other related illnesses, which has impacted the rest of my life.

Section 4. Consent

20. I have been asked if I have ever been treated or tested without my knowledge or consent and the answer is yes. I had consented to the blood tests in relation to my kidneys but I was never made aware that I was being tested for HCV or any other infection during this time. It would have been the right thing to tell me about the possibility of an infected blood transfusion, instead I was not told for twenty-eight years.

Section 5. Impact

Daphne Whitehorn

21. The mental and physical effects that I have suffered as a result of being infected with HCV have been profound. Physically, I have suffered with arthritis for quite some time and at times could not sleep because of the pain. I am sure that this was because of my HCV. Unfortunately, I cannot prove that it is the HCV, because of the damage previously done to my kidneys. However, I will say that I don't think it is my kidneys causing the above side effects. My arthritic pain was far greater when I started the HCV treatment and eased as the treatment progressed. Although my joints still hurt, the pain is not nearly as bad as it was in the period prior to the HCV treatment and for that reason I believe the HCV adversely affected my condition.

22. The treatment I received as a result of being infected with HCV also caused many adverse side effects. Whilst on the course of medication I could not stand in the shower, suffered from skin problems and suffered from breathlessness, which still affects me greatly. I remember one time I had suffered a broken ankle and because of this, I was told by the hospital that I was "deconditioned" [See Exhibit W0191002]. I had been told that because I had a broken ankle I was not used to doing physical exercise and that was the cause of my breathlessness. This made me extremely

angry, I wrote to my General Practitioner to challenge this because I had suffered from breathlessness since the start of my HCV medication, which was long before the broken ankle.

23. The infection and treatment also impacted my leisure time. My joint pains and breathlessness mean that I struggle to go on long walks with my husband, something we have regularly enjoyed doing since we were married. I can walk around three miles now but get very out of breath. I even get out of breath walking to the shops. I have had tests completed in which the doctors said they could not find anything wrong. However, from my perspective the treatment seems to have left me with these side effects. I cannot prove this but I recall I was told it could cause long-term breathlessness.

24. The treatment further affected my behaviour. I became very aggressive. It changed my personality. I was never an aggressive person and it took some months after the treatment for me to revert back to my normal self. I also started being more assertive saying things that I would not normally say. Often this was private details I gave out in public causing great embarrassment. It changed me somehow and I can't really explain it.

25. My infection with HCV has massively impacted my family. As previously mentioned, my daughter had also contracted HCV from birth and did not find out about it for thirty-seven years. This has had a major effect on her life. At first because we all thought she was clear, we were not sure why she was experiencing certain effects that we eventually discovered were the effects of HCV. She was constantly being told to lose weight; she was constantly tired and had achy limbs. This had a massive impact on her mental and physical wellbeing. When eventually diagnosed there was still a failure to accept any responsibility. She was even told that the HCV was probably contracted from a tattoo that she has on her back. During the years leading up to her being diagnosed, I did tell the doctors that I was infected with HCV, still at this time. Her doctors conducted no further blood tests on my daughter to see if she had contracted the virus. The doctor, her GP, did apologise later that he did not test her for the virus.

26. My daughter had eventually found out about her infection whilst she was attempting to have children. While she was attending a fertility clinic she had a blood test and subsequently was told via a phone call that she had HCV. They take blood tests at the clinic to see if you are suitable to receive fertility treatment. She went through two lots of drugs and was given a course of the cheaper drugs, which had a less chance of working.

27. It was very stressful that my daughter was placed on the cheaper drugs as I was personally told that they were not very effective. We had finished the treatment near enough the same time but she still had not cleared the virus. It took her over two years. The delays in the treatment led to her to not being able to receive further fertility treatment due to her age. She is now trying to adopt but is struggling because of her current mental state. She continually suffers 'meltdowns'. This is all due to what has happened to her in the past, her delayed diagnosis and extended treatment period as a result of being given initially, inadequate drugs.

28. The effect on her mental state has been enormous. When she is upset it gets me upset. She is currently receiving counselling, which she is paying for as there is a waiting list on the NHS. My daughter is now also clear of the virus but the effect of the drugs on her mental state have been really traumatic. She became very aggressive. She was diagnosed only three years ago, it makes me feel guilty. She says she doesn't blame me but she is cross. She feels under further scrutiny at the adoption centre as they ask her so many questions. She is still currently being deemed not ready to adopt a child due to her mental state. I think if my daughter had not contracted HCV I would have felt much better. I feel guilty that I had put the virus onto somebody else.

29. Had my daughter known about and received treatment for HCV a few years earlier she then would have been clear of HCV before she started

Fertility treatment on the NHS eliminating any possibility of passing HCV on to her children. She has now passed the cut off age of 37 for the fertility treatment and so is now no longer not eligible for that treatment.

30. My illnesses have also over the years massively impacted my husband. He has had to have a lot of time off work and use annual leave. He was also a regular blood donor until I found out I was infected with HCV and then he was told he was no longer able to donate. My husband was luckily never infected.

31. When it comes to my social life a year or two after my transplant I did not have the energy to do an awful lot. I was a keen gardener but I encountered problems, as I could not stand up for long. I had to do a lot of gardening sitting down. I am never sure if it was my kidney causing the problems. However, I can say that now I have a working kidney and still struggle with my joints, so it appears that it is likely connected to being infected with HCV. Three years ago, I went to a demonstration outside parliament about Infected Blood. I did not know how many people were infected and affected. It was at this demonstration that I noticed that nearly everyone there was using walking sticks, this made me realise that HCV and the treatment must affect the joints of people who are infected.

32. The stigma associated with having HCV has hugely impacted my life. It was very upsetting, I felt obligated to tell the people that I worked with that I was infected with HCV. I thought it was the right thing to do. I asked about telling my children when I was infected and was given no advice. I had to learn about it and do it myself. I was put under pressure and this caused me stress, as I believed they would think that they might catch it from me and would want to keep their distance. I also had to tell my dentist and this caused me further anxiety, I often thought that people might think that I had taken drugs or something. When I was working we used to go for meals at Christmas. Some people didn't want to sit next to me. People would often try each other's food but this was not the case when it came to me. Even my daughter in law was cautious around me. It was emotionally draining.

33. Dealing with the infection had adverse work-related effects; I used to work for a local library for Hertfordshire council. I worked there for roughly fifteen years. I was part time when my kids were infants, as they got older I still could not have gone full time due to my kidney and hospital appointments. I always continued working as I found work helps me. However, working started to become increasingly difficult, due to the joint pain. I used to work on the library van and it became more and more difficult to climb up the stairs, as I was suffering with these joint pains. I now believe these pains where caused by the HCV.

34. Financially my husband and I always managed as we lived within our means. We have always been careful with money so we were lucky to have savings that helped us. Our main expenses were travelling too and from hospital in London. If it were not for my husband Reg I would have lost a lot of my hospital appointments, he would always drop me off at hospitals before parking. It was always hard to find parking.

Reg Whitehorn:

35. My husband, Reg Whitehorn present during the interview was asked to provide a few comments on how mine and my daughter's infection has impacted his life, he says as follows:

36. Dealing with my wife's infection became a regular thing for me. It just became normal; it was our normal life, going to hospital. I was fortunate that my work would let me take some time off; I used to just make up my hours. It often meant longer hours for me and further separation from my family at a time when it would have been better to be there to lend support. I do remember a time when I was made redundant and was offered a job in Derby but could not move as Daphne's hospital appointments were in London, so I had to find another job around the area. This could however, have been more to do with her kidneys problems but it is hard to say one way or the other. It was extremely also hard to see both my wife and my daughter upset all the time. My daughter was a very outgoing person before she was diagnosed. However, the treatment along with the side effects and the consequences have left her a different person.

Section 6. Treatment/Care/Support

37. I have been asked if I faced any difficulties in obtaining treatment and the answer is yes, I was always told I did not require the drugs to clear the HCV, as my liver was not sufficiently damaged. I did not know if I actually required the treatment, my doctors always guided me. I have only been told what I needed at the stages I have been given treatment. I would have liked the have started the treatment earlier so I could clear the virus whilst my liver was still healthy.

38. As previously stated, I was not allowed to start the course of medication to clear the infection until I took action and wrote to my local MP. This made me feel particularly guilty, I felt as though I was cutting in front of people that were in desperate need of the treatment but I needed to clear the virus whilst I was still healthy. It was unfair that I was only put on the course of medication after I took drastic action.

39. I would like to add that I was offered Respiratory exercise assistance by the Royal Free to help with my breathing but shortly after, I was given a letter saying that I had been withdrawn. I was told there was an extremely long waiting list. My GP has now arranged for me to attend some Pulmonary Rehabilitation classes.

40. I can confirm that in the past we have never been offered psychological support or made aware of such support in relation to ourselves or our family.

41. I can also confirm that during my interview with the inquiry, we have been informed about the access to the support mechanism that the British Red Cross provide.

Section 7. Financial Assistance

42. I was never told by medical professionals that there was financial assistance available. Someone who I had worked with had read an article in the paper that someone was claiming £20,000 in Scotland. After this I looked into getting payments.

43. I then found out about the Skipton fund and how to claim the ex-gratia payments they were offering. I received Stage 1 from the Skipton Fund for £20,000. As of April 2017. I received roughly £250 per month from the England Infected Blood Support Scheme, ("EIBSS"). This has now gone up since March 2018 to £1500 and I was back paid for the money I had missed out on. To receive this, I had to get a statement signed by my HCV consultant, Penny Smith.

44. The process was reasonably ok but it was a lot of form filing. It was always down to my husband and I to make sure the paperwork was correctly filled out. It took a long time to get the papers signed and often I had to ask multiple doctors to get my forms officially signed off. I would like to have known earlier about the available payments. I often think that if I did not work with the person that told me, then I might never have found out and not received anything.

Section 8. Other Issues

45. I would like the inquiry to know that I think the whole of the Infected Blood Scandal is extremely bad. I feel as though institutions have tried as hard as possible to not admit to any wrongdoing.

46. I feel as though people may have known about the possibility of infected blood early on but did not say anything as it could have caused riots and could have had a massive financial impact.

47. My husband had once seen a television interview from the early days of the problem that said that there was a potential for blood to be dodgy, but the individuals were saying that they could not get enough blood from the donor system. The documentary stated that the blood was not being tested and that people were not being told blood was being imported from America again.

Statement of Truth

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

Signed GRO-C

Dated 20.3.19