Witness Name: Cass Steinbeck
Statement No.: WITN1982001
Exhibits: WITN1982002
Dated: 22 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CASS STEINBECK

Section 1. Introduction

1. My name is Cass Steinbeck. My date of birth and address are known to the Inquiry. I have 2 children and 2 grandchildren.

Section 2. How Infected

2. I have had a number of things happen to me in my life. My medical records reference blood transfusions and life events, but at times the year differs. I gave birth to my first child in 1970. I was in a really bad car accident, which I have seen referenced in my medical records as happening in 1971, 1972 and 1974, which is ridiculous. I can confirm that the accident happened in 1971.

3. My child died in that accident. I was injured badly; the gearstick went through my abdomen. I had to be rushed to Poole General Hospital. I underwent extensive surgery. My medical records to me *contracting Hep C in 1971 from blood transfusion*. There is also a record that states *hep C from blood transfusion 1971*

(following childbirth) and another record that states: *liver cirrhosis from hepatitis C; itself as a result of an RTA/blood transfusion in 1972* and another that states: *She has had the infection [hep C] since the time of her blood transfusion in 1972.* Once again this shows how badly the clinicians dealing with my care think about what they are recording to ensure all details are accurate. It is ridiculous. I do not understand how there can be such confusion in my records. [**WITN1982002**]

4. Clearly there is confusion amongst medical professionals as to when I contracted Hepatitis C and there is confusion about when I had blood transfusions. However, I know exactly when I contracted Hep C; it was in 1971 when I had the blood transfusion following the RTA. If I know this why can't it be properly recorded in my medical records? I do not think any of the blood transfusions were required as emergency lifesaving blood transfusions; if any of them had been then I would have expected that to be recorded in my medical records. I am aware that giving blood transfusions at that time was common place and I think sometimes given when not medically a necessity.

5. I can remember that I was in hospital for quite a long time after I had my car accident. I cannot recall anyone ever asking me to give them my consent before they gave me a blood transfusion. No one ever told me about any risks for blood and the fact that it might be contaminated. I have never heard of Hepatitis C until I was diagnosed with it.

6. I had an ectopic pregnancy, which took place at St Thomas's Hospital and I had another ectopic pregnancy in 1996 at Blackburn Royal. In addition, I had a miscarriage and a stomach hernia in Blackburn Royal.

7. I can remember that after the car crash, probably from them onwards, I always felt like I had flulike symptom – I always felt tired. I had no energy whatsoever and I just felt fatigued the whole time. I could not do my work properly. I just felt like I wanted to go to sleep. I was not eating properly and I felt awful. However,

it took 5 years before the doctor sent me to hospital for a test. I had no idea what was happening to me during that time. Whenever I went to the GP I was told to take paracetamol and go to bed, because I had a cold or the flu. No one was interested and nobody asked me about my history or thought about doing any tests.

8. There is a letter in my records from Blackburn HA dated 8 October 1982, which followed a gynaecological examination – it does not mention Hepatitis C. There is a note in my medical records dated July 89 *hepatitis ? cause*. I must have been diagnosed at that time, but I was not told and there were no further medical examinations into the hepatitis, its cause and any possible treatment.

9. Eventually, because of my ill health I was referred for tests in 2006 – this is some **20 years' later**. I came back as testing positive for Hepatitis C, Genotype 1 which apparently was the worst. I was given my diagnosis at hospital and my reaction was a stunned silence. I did not know what Hepatitis C was. I had no idea what it meant or what it might mean for me as an individual. I thought it was something like a flu virus. I did not know if it was serious and I did not know it would get more serious. I had been left without diagnosis for almost 20 years. I had been left without treatment for nearly 20 years.

10. I do remember people in the hospital not wanting to go near me or to touch me. This happened in Derriford and I can remember in those days if you had Hepatitis C the nursing staff used to think you were a drug user or a drinker. The staff just did not understand that individuals were being infected through NHS contaminated blood. I can recall on a few occasions there were a few choice words between me and a nurse about my diagnosis of Hepatitis C. I can confirm this was not with the hepatology nurses, but with the general nurses.

11. I had a little book all about the genotype of the Hepatitis C. I remember that I was given the little book when I was at the Hepatology Department at Derriford Hospital. I did not really understand what was written in the book as I didn't really understand about Hepatitis C.

12. I do not think that I was given enough information to be able to process anything. I accept it was a long time ago, but no one really seemed to know what was happening. I do not know whether the staff were not given sufficient information or if they just did not pass it on to the patients.

13. I was told about treatment options and the fact that there were not many. I was put on PEG Interferon and ribavirin. I think I had about three months' worth of treatment. It was absolutely horrendous and it did not work. After a while I was given another three months' worth of treatment but that did not work either. By that time I was very ill. In or around 2010 I was put on a trial called Aspire it was from America and it lasted 72 weeks. I have never been so ill in all of my life but it did get rid of the Hepatitis C. I confirm at that time I cleared the virus. However, I believe that by that time all the damage had been done. If I had been given Aspire years before then maybe I would not have suffered as much damage.

14. At one stage my kidneys were not working very well and I had kidney stones. I am not sure whether this was connected to the Hepatitis C, but I do know that Hepatitis C can lead to kidney issues. I also chronic Cirrhosis, which I know is caused due to the HCV virus. From a while after I received the blood transfusion my life was horrendous. I have set out above the fact that I have just felt ill, fatigued and poorly all the time. My life was absolutely horrendous. If it had not been for Professor Cramps, I do not know how I would have continued. It was Professor Cramps who said to me you have to get through this, you can do it. At that point I can remember I weighed as little as five stone. I was sick, tired and probably a bit loopy – I did not feel right in my head. It was an absolutely horrendous time.

Section 3. Other Infections

15. I do not think I contracted any other infections.

Section 4. Consent

16. I was given Hepatitis C without my consent. I was given a blood transfusion without my consent. At the time I was given a blood transfusion I was not told there was a risk that the blood was contaminated or that I might contract the virus that would kill me. If I had been given that information I would not have accepted the blood.

Section 5. Impact

17. I lost my home, my business and I have lost the ability to work. I have lost my income, my self-esteem and I do not have confidence any more. I am so angry.

18. I had a really good business which I was running for 25 years. I worked in trade upholstery, and I used to do interior design and soft furnishings. I loved my job and was very good at what I did. I restored old furniture and did interior design. I was not run of the mill; I was very high end. I used to employ a couple of ladies on a part time basis to do the sewing for me. I spent nearly two years looking for a person who could sew because everybody wanted me to do their curtains. However, I cannot do it anymore and so I ended up not being able to pay the rent.

19. When I first started having the treatment. I lost everything. I then I had to rent this horrible flat riddled with mould and damp – it was disgusting. It was just awful to go from a nice flat to an absolute dump and at the same time having to undergo the horrendous treatment. I was unable to obtain housing benefit because I was told I was self-employed, and therefore, I could not be given any benefits.

20. Mentally I no longer have any enthusiasm. I do not have any drive and I have no self- confidence. I would like to think that I am quite an open and friendly person, but I often do not want to see other people. I will often not answer the

telephone or open the door. I have lost part of me – it has gone somewhere and I cannot find it again. I don't think I can turn around and say I am depressed, even though I probably am.

21. I have liver cirrhosis with portal hypertension. I had to have a hysterectomy because I was told I had ovarian cancer. I have type 2 diabetes. I require ultra sounds every six months. I have had quite a few MRI scans. I have issues with my heart; I have a heart monitor – it is not a pace maker, but it does monitor my heart, but it is because at times I cannot breathe properly. The cirrhosis has progressed through my portal vein and I now have varices in my stomach. The medics will not put me onto the liver transplant list because I will not survive a transplant. Even during the time it has taken for me to provide this witness statement my health has deteriorated.

22. I no longer have a social life – I just don't go out. My daughter is neurotic about cleaning and she will not drink out of any of my mugs. She is paranoid. She is not able to talk to her friends about it and I do not talk to my friends about it either. The only people that knew that I went onto a trial were the other people on the trial with me.

23. Everywhere I went I felt there was a stigma attached. I could not get insurance because they would not touch me with a barge pole. People think I am better, but I am not better and I will never get better even if they put me down for a liver transplant. However, they said I am not well enough to undergo a liver transplant. I am not strong enough to be able to undergo major surgery.

24. I know my personality has changed completely. I used to be really happy and I loved life – I loved what I did – I was a very sociable hen. Now I am just a miserable sod. It was not just the stigma that made me not want to go out or to engage with people it was the treatment as well. The treatment is savage. I have had so many side effects and I felt so awful when I was taking the treatment, I just could not do anything.

Section 6. Treatment/Care/Support

25. There was not much treatment available when I was diagnosed with Hepatitis C. I was given the bog standard treatment on a couple of occasions but they did not work. Finally I was put on the Aspire trial. I believe if I had been put onto the Aspire trial earlier, then I would be in much better health because the HCV would not have damaged by body as much as it did. I can confirm that I was never offered any counselling.

Section 7. Financial Assistance

26. The Skipton fund did save me some money. I can recall that I had an initial payment and then I went onto stage 2 payments. Most of the financial support I was provided with on finding somewhere to live and paying off my debts. Most of it went on business and to cover fabric that I had ordered. All of that amounted to quite a lot of money, and therefore, I did not really benefit from any of the financial awards myself – the awards all went to pay the debts from my business.

27. I used to get about £1200 per month. Now it is EIBISS making the payments and it t has now gone up to £1500 each month. I do not have much left over but I do get disability benefit and state pension. I got just enough to live on and I think I am ok really. I think I probably get more than most people, but I do not have any money left over at the end of each month. If anything went wrong I would be pretty stuck.

28. I can remember that after I applied for the payments they did come quite quickly. I got a new washing machine and new boiler from Caxton.

29. I currently receive EIBSS monthly payments. I cannot really remember applying for the payments, I think I had to give proof to the Skipton Fund and I had to fill in a form online. I did find this hard because you have to prove

where you got the HCV, but it soon became clear that the only possible way I could have contracted HCV was through the blood transfusion.

Section 8. Other Issues

30. I want a proper apology. I want to know why so many of us, me included, have medical records that do not accurately reflect what has happened to us. I want to know why it took 20 years for me to be told I had HCV after it had been diagnosed.

31. I want to know why it has taken so long for us to have to fight for this Inquiry.

32. I want to know about all of the cover ups within the NHS and within the government. I know the cover ups went on for a long time – well into the 1980s. People were still receiving contaminated blood in the 19990s. Ideally, I would want to receive some compensation so that I can go and live my life. I only have enough money to get by each month. It is so tight that I have to be mindful when I put my heating on. I want a little bit of luxury; I have worked my socks off for years. I worked really hard and now I have nothing to show. If the Irish government can give their Hepatitis C people £750,000, why can't the English Government give this to us

33. I want this Inquiry to go into real detail and real depth. The Penrose Report was rubbish; it was a complete whitewash and so disappointing. I want people to be held accountable and I want the public to know what has been done to us.

34. In addition I want the Inquiry to make recommendations to the Government to make it easier to get financial assistance. At the moment you have to get three quotes and you have to send them into the Fund. People at the Fund will then choose which one and will pay the individual directly. Say for example if there are any problems such as a leak in the shower and I need to get it mended, then I have to go and get three quotes, send it into EIBSS and wait for them to

approve it and pay someone to do it. When my roof needed doing I decided that I would get a bank loan to get the ceiling done because trying to go through EIBSS would have taken far too long. You are made to feel you are begging and I just could not put myself through that again. I was made to feel guilty for applying in the first place – it's almost as if you are not entitled to the money. I do not know why we should be made to feel like that because the only reason we need the money is because we are infected through NHS contaminated blood.

35. This scandal has been covered up for far too many years. This is the last chance that individuals who have been infected with contaminated blood and those who are affected by the tragedy have to find answers. Please Inquiry make sure you do the best job you can do and get to the bottom of what happened for us. Please do not feel afraid to find people or departments accountable. We are all counting on you.

Statement of Truth

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

Signed. GRO-C ..

Dated..... 22 February 2019..........................