Witness Name: Sue Stephens Statement No: WITN6011001 Exhibits: **Nil** Dated: 24 May 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUE STEPHENS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3 September 2021.

I, Sue Stephens, will say as follows: -

Section 1. Introduction

- My name is Sue Stephens. My date of birth is GRO-C 1956 and my address is GRO-C . I married in 1978 and divorced twenty years later in 1998. I have two daughters, both of whom are married. The oldest is 43 and the youngest will be 40 in GRO-C I have two grandchildren, a boy and a girl. I am retired through ill health. Prior to this I was a house wife and also worked in retail.
- I intend to speak about my infection with Hepatitis C (HCV) contracted from a blood transfusion following an emergency C-section in 1978. It was a shock to learn of my diagnosis many years later. I have since suffered with various physical and mental health difficulties.

Nevertheless, I cannot be certain as to the extent to which these issues were caused by my Hepatitis C, my treatment and/or other causes.

- I can confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me.
 I am not seeking anonymity.
- 4. I can also confirm that the Inquiry Investigator has explained to me the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.
- I wish to acknowledge that naturally as time passes, memories can fade.
 I have been able to provide approximate timeframes to matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

- 6. I was born and raised in <u>GRO-C</u> I married in 1978 at 22 years old. The same year, I fell pregnant with my first daughter. On <u>GRO-C</u> 1978, I was rushed into Derriford Hospital by ambulance because there was a problem with my pregnancy. The baby had suddenly turned and had caused a rupture.
- 7. When I arrived at the Hospital, the doctors told my husband that there was no chance that the baby would survive but that they would try to save my life. The baby was delivered five weeks early by Caesarean section. After the operation they had trouble bringing me around as they thought I was slipping into a coma. Fortunately, my daughter survived.
- I experienced a fairly significant blood loss during the procedure. As a result, between GRO-C 1978, I was given six units of

blood. I was not aware of this at the time, but it was an emergency and the Hospital were trying to save my life. Confirmation of the six units of blood that I received is detailed in a letter from Dr M Pachal to my GP, Dr Houston on GRO-C 1979. It reads:

'This 22 year old gravida 1 was delivered of 2,330gm. Female infant on GRO-C 1978, by emergency Caesarean section for severe ante-partum haemorrhage (which was due to abruptic placentae). She was transfused six units of blood.

The puerperium was complicated by a lingering temperature, which settled on Ampicillin and Flagyl.

Mother and child were discharged on 9.1.79. for follow-up in the Post Natal Clinic. The mother's post-natal haemoglobin was 13.2gms.%. She is Rubella immune.'

In 2013, this document was sent to the Skipton Fund by a very kind nurse at Derriford Hospital as proof of my blood transfusion.

- In <u>GRO-C</u> 1979, I was discharged. I recovered and went on to have another daughter three years later. I don't remember feeling any symptoms of ill health. I maintained a healthy diet and have never been a heavy drinker.
- 10. Many years later, in 2012, I consulted with my GP, Dr Holland, as I was experiencing severe fatigue. I would often fall asleep for no particular reason. Other than this, I didn't experience any noticeable symptoms of ill health. I was diagnosed with severe anaemia. I also explained that I had recently split up with my then fiancé because I found out he had been unfaithful. My GP recommended that I also undergo STI tests. I agreed.

- 11. Shortly afterwards, my GP called me back into the surgery. She told me that I didn't have any STIs but that I had tested positive for Hepatitis C. This was confirmed by a test on 31 October 2012. She explained that it was not an STI as such, albeit that it was transmitted by blood-to-blood contact which could include sexual intercourse.
- 12. She asked if I had ever been an alcoholic. I explained that I had never been a heavy drinker nor intravenous drug user. My piercings were done at a reputable establishment. My tattoos were performed after my diagnosis. She then asked if I had ever had a blood transfusion. I explained that I had received blood in 1978 following the birth of my daughter.
- 13. I was asked if I had ever shared earrings with anybody. I explained that I had shared earrings with my children. GRO-C GRO-C GRO-C
- 14. My GP advised that the family all get checked for Hepatitis C. I also had my second daughter after I had been transfused with the contaminated blood. I was very worried that I had unwittingly passed the virus onto my family. GRO-C
- 15. Dr Holland explained that she would refer me to Derriford Hospital. I don't remember how long after my diagnosis that I was referred, but I believe it was relatively quick. During my appointment, I was weighed and given various blood tests. One of the nurses asked if I would be interested in a drugs trial. I was keen to do whatever I could to clear the virus. I will go on to discuss the course of treatment in Section 5 on 'Impact'.

Section 3. Other Infections

16. When I was given an STI test, I was also tested for HIV. The result was negative.

Section 4. Consent

17. As mentioned previously, I was not aware that I was receiving blood at the time of the emergency C-section. However, it was an emergency and I understand that I needed this to save my life.

Section 5. Impact

- 18. I was shocked to learn of my diagnosis with Hepatitis C in 2012. Until this point, I did not notice any symptoms of ill health except from severe fatigue. My memory was fine as far as I can remember. It is no longer what it used to be, but I mostly attribute this to old age.
- 19. As previously mentioned, I experienced a great deal of worry and concern when I thought that I could have unwittingly transmitted the virus to my close relatives. GRO-C GRO-C
- 20. Two weeks after my referral to Derriford Hospital, I was initiated onto a drug trial. Half the group were given a placebo and the other half the drug; a tablet to be taken daily. During this time, I underwent various tests including blood tests and ECGs. I don't remember the name of the medication.
- 21. The course of treatment lasted 13 weeks, after which I was discharged. At the end of this period, I was told that it had been successful. Liver scans confirmed that my liver was fine and that I did not have any cirrhosis. I was happy with the way that I was treated. As we couldn't

eat before treatment, afterwards we were given a cup of tea and a couple of slices of toast. The staff were lovely.

- 22. Treatment didn't affect me at all. I did not experience any noticeable side effects. Around this time, I was diagnosed with anxiety and depression. However, I cannot be sure whether this was brought on by Hepatitis C, the treatment or other causes.
- 23. I don't believe that my infection with Hepatitis C has affected me on any significant level. Other than my family, I have not told anybody about my infection. If I met a new partner, I would tell him. Nevertheless, I've been through a lot in my life and I've got through it. I'm a survivor. As with other life events, I dealt with my diagnosis and moved on.
- 24. I also experience frequent chest infections. During covid, I shielded for two years. My daughter was very protective of me and wouldn't let me go anywhere. She still does all my shopping. Due to my COPD and the problems with my back, I cannot walk very far.
- 25. In 2005, I was experiencing problems with my right lung. I was initially diagnosed with pleurisy and then pneumonia, for which I was given various cocktails of antibiotics. I was subsequently told that I had cancer. The surgeon explained that I could either have a biopsy and wait six weeks for the result or immediately get the bottom lobe of my right lung removed.
- 26. I can remember sitting opposite him and feeling pressured to go ahead and accept the procedure. I asked him what he would do. He advised me to undergo the operation. I now regret this as after the operation, he told me that I did not in fact have cancer. I felt that I'd lost the bottom half of my right lung for nothing. He tried to assure me that the infection was so severe that it would have been necessary to remove the right lung lobe regardless.

- 27. When my children were young, I began to experience a terrible back ache. I have quite a high pain threshold but I was in agony. I was given various painkillers. When these did not work, I was eventually sent to Mount Gold Hospital in Devon to see a specialist. I was advised to perform various exercises. I tried to tell him that I could hardly walk. My youngest was just a baby and I couldn't reach down to play with her. The other women in the classes would come out feeling great, whereas I would continue to feel excruciating pain.
- 28. I was then referred for three epidurals and prescribed numerous drug cocktails. The doctor told me I had Ankylosing Spondylitis. The specialist then referred me to Bridgewater Hospital in Devon for an MRI. It was discovered that one of the discs in my back had completely worn away. A nerve had then slipped into where the disc should have been. The pain was worse than childbirth.
- 29. In 1986 or 1987, I was given a spinal fusion under general anaesthetic. The procedure was successful. I'm still left with nerve damage in my hip. I was working at the time. The consultant explained that I would need between three and six months off work. The head office kept the position open during this time. I'm not sure if they tested me for any blood borne infections before the operation.
- 30. After the six months, my specialist told me that I would never work again. This was a shock as whilst I was in pain, it was nowhere near as acute as it had been. I got paid all the holiday money that was owed to me. I was lucky in some ways as two months later the company went into receivership and the other staff got nothing.
- 31. I wasn't angry at anyone when I was diagnosed with Hepatitis C, but I was annoyed that the problem with my back was misdiagnosed for some thirty years. As a result, I received successive courses of unnecessary treatments, the problem only got progressively worse.

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Section 6. Treatment/Care/Support

- 32. Derriford Hospital have been brilliant. As far as I can remember, I wasn't offered any counselling or psychological support following my diagnosis or during the course of treatment, but the nurses were lovely. I couldn't fault the treatment that I received here for my HCV.
- 33. To the best of my knowledge, I have never been refused any medical treatments as a result of my Hepatitis C.

Section 7. Financial Assistance

- 34. In around 2013, one of the nurses at Derriford Hospital informed me of the Skipton Fund. She explained to me that I would be entitled to compensation. When she told me that I could expect £20,000, I nearly fell through the floor. They completed the application on my behalf.
- 35. Shortly afterwards, I received a one-off payment of £20,000. I do not receive any additional payments. The Inquiry Investigator has explained that Skipton has since been replaced by the English Infected Blood Support Scheme (EIBSS). I spoke with them this morning and they are emailing me some documents.
- 36. Had the nurse at Derriford Hospital not informed me of Skipton, I would have just sailed through life getting nothing. I would never have expected financial assistance. I never thought it was anybody's fault so I didn't feel any anger nor was I looking for this.
- 37. I applied to PIP in August 2021, which was backdated to the previous January. I receive the lowest living allowance. I had applied prior to this but my application was refused. I get my pension in December, when I am 66. I currently receive Employment and support allowance.

Section 8. Other Issues

38. I am glad that the Infected Blood Inquiry is investigating what happened with regards to contaminated blood. I would hope that nobody has to experience this in future.

Statement of Truth

I believe that the facts stated in this witness statement are true. Signed ________GRO-C Dated 244. 2 and 2022