Witness Name: Sandra Audrey Butcher Statement No: WITN3677001 Exhibits: WITN3677002 – WITN3677007 Dated: October 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SANDRA AUDREY BUTCHER

I, SANDRA AUDREY BUTCHER will say as follows:-

Section 1. Introduction

- 1. My name is Sandra Audrey Butcher of GRO-C
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 My date of birth is GRO-C
 1958. I am married with one daughter and have been retired for seven years. My husband will retire next year.
- 2. As a result of receiving contaminated blood products (blood transfusions) I was infected with Hepatitis C. I have now cleared the virus.
- 3. This witness statement has been prepared without the benefit of access to my full medical records. In so far as I have been provided with limited medical records, I have referred to relevant entries in this statement.

Section 2. How infected

4. I was born with Congenital Heart Disease. I have had two major heart surgeries for this condition. The first surgery was on 21 May 1973 at The

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Bristol Royal Infirmary (BRI) at the age of 15 years old in which a mechanical valve (Bjork Shiley Valve) was fitted, and the second on 13 February 1979 at The London Brompton Hospital in order to close a VSD (hole in heart) and a resection of infundibular obstruction. These two surgeries necessitated blood transfusions.

- I was not provided any information about the risk of being exposed to infection from the blood transfusions. In 1973 my surgeon was Mr Keen and in 1979, Mr Lincoln.
- 6. As a result of being given contaminated blood products I was infected with Hepatitis C Genotype 1B. I found out about this infection in July 2015.
- 7. I was admitted into The Freemans Hospital (TFH) in Newcastle on 12 July 2015 in order to be assessed for a heart and kidney transplant, as my kidneys were failing. I was informed that I would need to have my blood tested. Having taken over 10 vials, it was revealed later on that I had Hepatitis C.
- 8. My husband and I were called to a small room. I recall feeling extremely anxious. I was told that my blood tests had shown that I had an infection Hepatitis C and that because of this infection they would not be able to proceed with the transplants. The hospital told me that the infection had likely come from the blood transfusions I received during heart surgery in 1973 or 1979. We were told that my husband and daughter would need to be tested for the infection and that I would be referred to Hepatology.
- 9. No further information was provided by the hospital at this point. My husband and I were very disturbed as we did not understand what Hepatitis C was and what impact it would have on my health. I had never heard of it prior to being told that I had it and I had to go online to find out more.

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11. I believe that information about my infection should have been provided to me earlier. The matter should have been investigated years ago when the news

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of contaminated blood first came to light. I have had heart problems all my life and have been attending hospital regularly. I should have been screened for infections years ago.

- 12.1 am very lucky to have been sent to TFH to have these blood tests as, had it not been for my kidneys failing, I would still be unaware of the Hepatitis C infection today and might have sustained further damage as a result.
- 13.1 was referred to Hepatology at BRI by TFH. My Hepatologist is Dr Fiona Gordon and I first saw her in November 2015, about 5 months after being told by TFH that I had Hepatitis C.
- 14.For my other conditions, I am under the care of TFH, BRI, Bristol Heart Institute and Southmead Hospital (SH).
- 15.1 have exhibited to this statement copies of the following documents:
 - a. a letter from SH dated 12 August 2015 which confirms that I was diagnosed with Hepatitis C following routine pre-transplant bloods and that it is very likely that I got this infection from blood transfusions (Exhibit WITN3677002).
 - b. a letter from TFH dated 2 October 2015 which confirms that my virology screen showed that I had Hepatitis C (Exhibit WITN3677003).
 - c. a letter of referral sent by my Cardiologist to the Hepatologist, both at BRI, dated 27 October 2015 which also confirms that my blood tests showed that I had Hepatitis C (Exhibit WITN3677004).
 - d. a letter from the Hepatologist at BRI dated 4 December 2015 which confirms that I had Hepatitis C Genotype 1b. The letter also states that it is likely that I acquired the infection via blood products and/or surgery at the time of my cardiac surgery in 1973 or 1979 (Exhibit WITN3677005).
 - e. A letter from the Hepatologist at BRI dated 14 December 2015 which confirms that I have moderate to severe fibrosis of my liver as a result of my Hepatitis C infection. The letter also states that my infection was

to be treated for 12 weeks with Ombatisvir, Paritaprevir, Ritonavir and Dasabuvir (Exhibit WITN3677006).

f. Fibroscan results from BRI dated 20 June 2017 and 10 July 2018 which show that I have liver fibrosis (Exhibit WITN3677007).

Section 3. Other Infections

16. To my knowledge, I have not received any other infections as a result of being given infected blood products.

Section 4. Consent

- 17.1 confirm that I consented to all treatment not knowing I was given contaminated blood products at the time.
- 18. Prior to my blood tests during the kidney and heart transplant assessment, I did not know that my blood was going to be tested for Hepatitis C, therefore I did not provide informed consent and was tested without being given adequate or full information.

Section 5. Impact of the Infection

- 19. When I was first informed that I had Hepatitis C, I was shocked. I had no idea of the impact of this infection and the damage it had caused until I was seen by the Hepatologist at the BRI.
- 20. After being told about my Hepatitis C infection at TFH in July 2015, I was kept waiting until November of that year to be seen by a Hepatologist at the BRI.
- 21.Prior to being told that I had Hepatitis C, I was suffering from achy legs in the morning and generally felt very unwell and lethargic. I didn't feel myself. I attributed this to my heart condition however whenever I was tested, I was always told that my results came out normal. I now believe that these problems were due to my Hepatitis C infection.

- 22.1 believe that the condition of my kidneys worsened due to being infected with Hepatitis C. When I was cleared of Hepatitis C, the condition of my kidneys improved.
- 23. In order to clear the Hepatitis C, in December 2015 I underwent treatment entailing a combination of Ombitasvir, Paritaprevir, Ritonavir and Dasabuvir for a period of twelve weeks. I completed the treatment in March 2016. The treatment was successful and I was told that I had cleared the infection. I was tested several times in the months following to confirm the results. My condition is still monitored.
- 24.As a result of my Hepatitis C infection, I now have fibrosis of the liver. I have to go to the BRI for scans every six months. To monitor my kidneys I also have to attend six monthly appointments at SH.
- 25. The only difficulty I faced in accessing treatment for my Hepatitis C infection was that it was not automatically available to me a meeting was arranged to consider me for treatment. The meeting went in my favour because I was also being assessed for a heart and kidney transplant. I refer to Exhibit WITN3677006 which confirms that I was approved for treatment because the hospital was of the view that without treatment my life expectancy would have been limited to 12 months.
- 26. Overall I was happy with the treatment I received as it was successful and I was well looked after by the Hepatology team at BRI. I was anxious about whether or not it would work as I was aware that if a second round of treatment was needed, the funding was not guaranteed and would be difficult to obtain. I also did not know what effects the treatment would have on my other medical problems and this caused me some anxiety.
- 27.Because of my Hepatitis C infection and treatment, I had to dedicate more of my time into attending Hepatology appointments. Making numerous trips to the hospital for tests and appointments and travelling on trains and buses was exhausting.

- 28.1 take Warfarin and the treatment interrupted my INR levels so these had to be monitored frequently while I was undergoing treatment for Hepatitis C. The trips to Newcastle and back were exhausting as these were over and above my routine appointments for my other health conditions. This caused a lot of mental and physical strain.
- 29. The main impact that the Hepatitis C had on my medical care was that, because Hepatitis C was identified in my blood, the hospital could no longer proceed with my heart and kidney transplant which I had been due to undergo in 2015. Once the Hepatitis C infection cleared, the hospital was willing to go ahead with the transplants, however, by this time my kidneys had improved and I declined the transplant.
- 30. It was difficult for my family to accept that I had received Hepatitis C from blood transfusions during surgery. My family were very upset to learn about my infection and did not understand the consequences of the infection.
- 31. When I informed my daughter about my infection she was concerned for me, and also concerned for herself as she understood that she could have been infected through me.
- 32.1 felt that my parents struggled to understand the infection and how I contracted it. My mother's first thoughts were that it was her fault. She believed she had given me the infection, so I had to explain otherwise.
- 33.Because of the stigma associated with Hepatitis C, I found it difficult to discuss my infection with my friends.
- 34. The financial effects of being infected were enormous as I travelled to and from hospital countless times to receive treatment connected with my Hepatitis C infection. My husband supported me financially and paid for the transportation costs.

Section 6. Treatment/care/support

- 35. No counselling or psychological support was made available to me in consequence of being infected.
- 36.1 have coped all my life with medical problems and I took the news of my infection as yet another problem which I just have to get on with. Having Hepatitis made my life even more difficult than it was previously.
- 37.1 really do not know if I would have benefitted from counselling or psychological support, but it may have helped me.

Section 7. Financial Assistance

- 38.I found out that financial assistance was available to me from the Hepatology Department at BRI in 2015.
- 39.1 received a Stage 1 payment of £20,000 on 10 October 2016 from The Skipton Fund (SF). Another payment of £2,250 was received on 19 December 2015. I am also in receipt of annual payments of £3,500 which included £500 for Winter Fuel payment. The monthly payments are made on the twentieth of each month. From July 2019 monthly payments amount to £1,538.17. This was backdated from April 2019 and on 1 July 2019 I received a payment on £3,590.47.
- 40.1 had to complete the application forms and send them off with evidence letters signed off by my doctor to confirm the dates on which I received blood transfusions.
- 41. Upon receiving my documentation the SF got in touch with me stating that they were unable to find any records of me. The confusion stemmed from the fact that I had applied with my married name and my records were all stated in my maiden name. As a result, the SF requested that I send confirmation of my marriage status and birth certificate. This caused considerable delay and in the end I had to redo my application in my maiden name.

42. The payments I have received do not in my view reflect how much damage and suffering I have experienced. The ex gratia payment also failed to address all those years I had been infected and the damage that having this infection has done to me and my family.

Section 8. Other Issues

43. Those who received blood transfusions during that time period should have been required to undergo testing. They would have had records of these people. There are still a lot of people out there who have been infected and may not know. For some, it may be too late.

Anonymity

- 44.1 do not want to be anonymous.
- 45. I am not willing to provide oral evidence to the Inquiry.

Statement of Truth

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

