

Witness Name: Simon Francis Brown

Statement No: WITN3179001

Exhibits: WITN3179002

Dated: October 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SIMON FRANCIS BROWN

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I, Simon Francis Brown, will say as follows:-

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

1. My name is Simon Francis Brown. I was born on GRO-C 1956 and I live at GRO-C  

GRO-C
2. I am married and have a daughter who is 29 years old. I used to work as a business manager for the NHS but retired 8 years ago.
3. My wife, Jill Brown has also made a statement (WITN0863001).
4. I was infected with Hepatitis C through my wife. My wife was infected as a result of receiving contaminated blood products in the course of her employment at the National Blood Transfusion Service (NBTS). She was injected on several occasions with Human Gamma Globulin (HGG) as a precautionary treatment against Hepatitis B.
5. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are referred to this statement.

## **Section 2. How infected**

6. My wife Jill was infected with Hepatitis C through contaminated blood products and I was infected through my wife.
7. Jill worked for the NBTS between 1976 and 1989. She received HGG in order to protect her against contracting Hepatitis B. Jill told me that all the technicians at NBTS received HGG as a precaution if they cut themselves on a broken glass vial and Hepatitis B was detected in a batch of blood on the same day. Jill believes that she would have had 4 or 5 doses during the period that she worked for the NBTS.
8. I personally remember one of the occasions that she received HGG. It was around 1983, on a Saturday. Jill had dealt with a tube of blood from someone who had Hepatitis B the day before, and she had to have the injection within 24 hours. I drove her to the NBTS in Longsight, Manchester so that she could receive the injection. The treatment was described to me at the time as quite viscous and so it had to be warmed before being injected. I remember Jill telling me that the injections were quite uncomfortable. I also remember that she had a bit of a lump afterwards at the site of the injection.
9. At that time, I worked at a company called Telephone Rentals in Wythenshawe, Manchester, that company was subsequently acquired by Cable & Wireless PLC for whom I worked for until 2006. Later in 2006 I started work as a business manager for the NHS and remained with the NHS until my retirement.
10. In 2016, I had blood in my semen which I understood to be one of the signs of prostate gland cancer. I went to the doctor and they did blood tests on me. They said I had 'raised liver functions' after which I had an ultrasound scan and additional blood tests. The doctor said to me that the test result was just an anomaly and nothing to worry about and gave me a clean bill of health. The doctor didn't provide any further information or follow up appointment.

11. In around October or November 2018, I became ill and attended A & E at Peterborough District Hospital (PDH). I was suffering from hyperparathyroidism as one of the glands around my thyroid gland had become swollen. The surgeon at the hospital said to me 'Do you know you have Hepatitis C?'. I was shocked and confused by this. I did not know that I had Hepatitis C before this conversation. I recall saying to him that I had had a liver thing a couple of years prior but was told by my GP that it was nothing to worry about.
12. I went back to my GP and demanded that both Jill and I had blood tests. The results came back in December 2018 confirming I had Hepatitis C. Jill's test results also confirmed that she had been infected with Hepatitis C. Both tests came back positive with the same genotype. The doctor referred us to a Hepatologist at PDH.
13. Since then I have found out that there were indicators for Hepatitis C in the blood test results I had back in 2016. At that time my GP passed this off as an anomaly and never followed up or told me about the infection. If my GP had followed this up in 2016, my wife and I could have known about our diagnoses 3 years ago and started treatment back then.
14. Both Jill and I attended an appointment with the Hepatologist and she mentioned to him that she used to work at the NBTS. He told us that the HGG shot was made from human blood. That's when we realised that Jill had infected me. Before this we had no idea where the infection had come from.
15. I had a Fibroscan and the results came back as borderline cirrhosis, with a reading of 14.3.
16. I feel aggrieved that I got Hepatitis C in the first place. I feel even more aggrieved that my GP did not recognise it in 2016 when all the details were there. My liver function tests in 2016 clearly indicated a problem which should have resulted in treatment then and not having to wait almost 3 years until

2018. If I had been treated earlier I do not believe my cirrhosis would have been as bad or possibly not developed at all.

17. Jill and I put in a complaint about my treatment to our doctor. I have attached to this statement marked WITN3179002 a copy of the response received from my doctor acknowledging that they should have arranged a repeat blood test or referred me to a liver specialist back in 2016.

18. I was not provided adequate information by my GP. After I was told that I had Hepatitis C, I went back to my GP as I wanted an explanation as to why I hadn't been told earlier about my Hepatitis C infection when they clearly knew about it. Getting information from my GP was like wading through treacle. It was only after I demanded blood tests for me and my wife that I got any response. Even then no one sat me down and explained what the infection was or we were going to do until we saw the Hepatologist. I received some information from the Hepatologist but most of the time, I went online and I did my own research on Hepatitis C genotypes and viral loads.

19. I believe that information should have been provided to me in 2016. I'm really annoyed that I missed 3 years of treatment. The medical staff treating me now have been quite good with me, especially my Hepatologist.

20. The fact that people, like my wife, who had been exposed to a risk of infection were not tested or treated back in the 1980s and 1990s is terrible. Jill would already have been infected at the time our daughter was born. Our daughter could have contracted Hepatitis C through us. Thankfully she has not been infected with Hepatitis C.

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

21. I have not received any other infections. I was tested for HIV but the results came back negative.

### **Section 4. Consent**

22. I do not think I was treated or tested without my knowledge, consent or without being given adequate or full information.

23. I do not believe I was treated or tested on for the purposes of research.

#### **Section 5. Impact of the Infection**

24. I suffer from physical effects which I believe are related to the Hepatitis C. I have a lack of appetite and have suffered greatly since October 2018 with my eating. I'm tired and fatigued all the time. I can't walk very far and I find it difficult to climb the stairs. In the past, I was never an ill person. I was always active and I used to go on long walks with our dogs regularly. Over the last year I have become very ill. Now I just spend my time sitting in a chair not being able to do anything and just waiting to feel better. It is very frustrating not to be able to do the things I could do previously.

25. After finding out that I had Hepatitis C, I was diagnosed with transverse myelitis, a condition where the immune system attacks the nerves on the spine. I have become aware that transverse myelitis can be caused by Hepatitis C. As a result while I was receiving treatment for the transverse myelitis my Hepatitis C treatment was delayed as there could be a potential conflict between the 2 treatments and I had to wait to get the okay from my Neurologist before commencing treatment for Hepatitis C.

26. I also suffer from the mental effects related to Hepatitis C such as anxiety and depression. I was diagnosed with depression in November 2018 which was around the same time that I found out about my Hepatitis C infection. I am on anti-depressants.

27. I started receiving treatment for Hepatitis C in June 2019. The treatment I received was Epclusa and Ribavirin and the tablets were delivered to my home address. The information that I received regarding the treatment was good and the treatment seems to have worked quite well on me so far. I took my final tablet on 19 September 2019. I have a follow up test in October to check the results of my treatment.

28. I have been told that my last blood test showed no evidence of the Hepatitis C virus so I am hopeful that my final blood test will confirm that I have cleared the virus. Because I have sustained borderline cirrhosis as a result of the Hepatitis C infection, I will have to continue to see the doctor on a regular basis to monitor my condition.
29. I faced some difficulties in accessing treatment as the hospitals said they could only put a certain number of people on treatment per month and that the next month was full. I had to wait another month before I could get treatment. I also had to wait for the doctor to give the go-ahead
30. The treatment made some of the symptoms that I already had even worse. I had pins and needles in my leg which made it even harder for me to walk. If I walked 10 yards I would be out of breath. With physiotherapy, my mobility has been slowly improving. I still cannot walk more than 100 yards without needing to have a rest.
31. I felt utterly drained all the time and my blood pressure was high. I found it difficult waking up in the morning and I had shakes in my hands which made it difficult for me to write.
32. Prior to starting the Hepatitis treatment, I had lost my appetite and suffered from a dramatic weight loss, going down from being 80kg to 63kg. I was then put on a course of tablets which improved my appetite, and I started put the weight back on. However after starting treatment for Hepatitis C my appetite decreased once again and I started to lose weight, going down by 7 kg. Additional side effects was a chesty cough and excess phlegm in my throat which combined to cause regular vomiting. I also suffered from nausea for which I had to take anti-nausea tablets.
33. The treatment and its side effects for Hepatitis C also made my depression worse.
34. I told my Hepatologist about the side effects I was experiencing but she was keen for me to finish the treatment.

35. My neurosurgeon was of the view that the Hepatitis C treatment was making my transverse myelitis worse. I have recently stopped treatment and hope that my symptoms improve.
36. Thankfully, my infected status has not really impacted on the treatment, care and support that I have received. When medical staff take blood samples from me, I feel the need to tell them that I'm a high risk patient and that they should wear gloves. I feel like I have to watch out for them. Apart from that, no one's labelled me or anything.
37. I cannot stand long enough to go shopping and so Jill has to do the shopping on her own. She also now can only shop for about two days at a time because of my eating issues as she tries to get food that I will eat.
38. Our life before this was very active. We use to spend 3 to 6 weeks at a time in France where we have a home, come back to the UK for a similar period and then go back to France. We did this on repeat throughout the year. I have not been well enough to drive to France since October 2018.
39. We have had to hire someone to cut the grass once a month at our home in France, as we have not been able to get there due to my condition.
40. I was halfway through installing a bathroom in our cottage in France when I was taken ill. I have had to stop this project and have not been able to do anything about it since.
41. We usually buy 10 one way Eurotunnel trips for our visits to France per year which have to be used within a year of purchase. We were unable to use the ones we had left over at the time of our diagnosis and have therefore now lost these. The lost Eurotunnel trips cost about £300.00
42. We don't have a big social life in the UK but we did in France. Unfortunately all that has had to stop as we are not physically fit to go to France anymore. I don't have a great deal of friends in the UK and most of my friends are in

France. My social life has gone because of my illness. If I'm not at the hospital or GP, I just sit in front of the TV.

43. My mother in law and father in law have been helping us out with walking our two young dogs. Our neighbours help us by mowing our lawn.

44. My relationship with Jill has been affected. We get upset and emotional with each other. She doesn't understand how I can't eat and my lack of appetite upsets her. Jill tried to commit suicide after finding out that she had Hepatitis C. I try to tell Jill that it is not her fault but she blames herself for the fact that we are infected with Hepatitis C.

45. Our daughter has GRO-C  
GRO-C When we first found out about the infection, we all worried that she could have been infected too. Jill would have already been infected with Hepatitis C when our daughter was born.

46. It feels like our Hepatitis C infections have cast a shadow on all our relationships.

#### **Section 6. Treatment/care/support**

47. The GP has not been great with providing treatment, care and support but the Hepatologist at the hospital has been very supportive.

48. I was not offered counselling or psychological support directly as a result of the Hepatitis C but have received treatment due to my depression.

49. I have contacted a charity that I found online which helps with eating disorders but they are not a part of the NHS.

#### **Section 7. Financial Assistance**

50. I have not received any financial assistance



## **Section 8. Other Issues**

51. I hope the outcome of the Inquiry stops anything like this happening again.

52. I believe that the authorities should have had the skill to recognize and identify that these blood products were infected before the problem got so big. It has impacted large amounts of people from decades ago. There was a previous Inquiry regarding this but no one told those who were at risk to be tested. I believe they should have said something like 'whoever received blood products between so and so date, are recommended to be tested'.

53. How many people in the NBTS like my wife could've been infected and not known about it as they didn't know they were being given human blood products?

54. The focus seems to be on the here and now, however I believe the authorities should also look back and inform people who may have been given contaminated blood products in the past so that they can be tested for infections.

## **Anonymity**

55. I do not wish to remain anonymous.

56. I do not mind giving oral evidence to the Inquiry.

## **Statement of Truth**

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

Signed..... GRO-C .....

Dated..... 5/10/2019 .....