Witness Name: Jill Brown Statement No: WITN0863001 Exhibits: WITN0863002 Dated: October 2019

# INFECTED BLOOD INQUIRY

# FIRST WRITTEN STATEMENT OF JILL BROWN

I, Jill Brown will say as follows:-

## Section 1. Introduction

- 1. My name is Jill Brown. I was born on GRO-C 59 and I live at GRO-C , GRO-C
- I am married and have a daughter who is 29 years old. I retired nearly 10 years ago. I used to work as a primary school teacher and prior to that I worked as a technician for the National Blood Transfusion Service (NBTS).
- 3. My husband, Simon Brown has also made a statement (WITN3179001).
- 4. I was infected with Hepatitis C as a result of receiving contaminated blood products in the course of my employment at the NBTS. I was injected on several occasions with Human Gamma Globulin (HGG) as a precautionary treatment against Hepatitis B.
- 5. My husband was infected with Hepatitis C through me.

6. 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 in this statement.

## Section 2. How infected

- I worked for the NBTSbetween 1976 and 1989. The NBTS was originally located at Roby Street in central Manchester. They moved from Central Manchester to Longsight, also in Manchester, around 1981 or 1982.
- 8. At the NBTS, when someone gave blood, the bulk of the donated blood went into a large plastic bag and we would also take a small test tube sample of blood for testing.
- 9. I worked as a technician in Blood Grouping and our job involved testing the blood. We would test the blood samples for Hepatitis B and the results for that test would come in the afternoon. If any sample was found to contain Hepatitis B, the bag of blood taken from that donor would be withdrawn.
- 10. The test tubes containing the blood were made of glass and my team would process 1500 test tubes during the course of the day. There were often breakages and sometimes members of staff would cut themselves on the glass. If during the course of the day a staff member had cut themselves and a sample had come back as infected with Hepatitis B, that staff member would be given a shot of HGG as a precaution so that they do not contract Hepatitis B. This was the practice throughout the time that I worked for the NBTS.
- 11. During the 13 years that I worked for NBTS, I believe I was given these shots on no more than five occasions. I remember two of these vividly.
- 12. The first time was in the late 1970s. At that time the NBTS was based in Central Manchester. I cut my finger and was told that one of the patients whose blood was taken that day was Hepatitis B positive. I was given a HGG

shot by a female trainee doctor who was on staff at the NBTS. I cannot remember her name.

- 13. The second time that I was given a HGG shot would have been around 1983 at the Donor Suite of the NTBS which had by this time moved to Longsight. The Donor Suite was a specialistcentre within the NTBS that dealt with harvesting plasma and platelets. I remember that I cut myself but there was no HGG available in the building that day and so I was asked to come in to work on the next day, which was a Saturday, in order to receive a HGG shot. My husband took me to work on the Saturday and I was seen by a male doctor, Dr Carter. I wasn't prepared to have the injection in my bottom by a male doctor and so I had it in my arm.
- 14. I received HGG shots on perhaps three other occasions but do not recall the particular details.
- 15.1 was infected with Hepatitis C as a result of being given HGG shots at the NBTS.
- 16. I first tested positive for Hepatitis C on 14 December 2018 and was told about my infection in January 2019. I am currently under care of the Peterborough District Hospital (PDH). My consultant is Dr Knikovitch.
- 17. In early 2016, my husband was not well and he went to his GP for some tests. These tests showed that his liver enzymes were high. He was then sent to hospital, and the liver enzyme count came back lower. He was told by our GP that everything was fine and to go and have a happy life'.
- 18. In November 2018, my husband became very poorly and developed hyperthyroidism. Within an hour of being admitted to Peterborough hospital, the doctors said to him 'you do know you have Hepatitis C'. This came as a shock to us and we were confused.
- 19. We later found out that my husband was actually diagnosed with Hepatitis C in 2016 by the hospital who had requested our GP to do further tests, but our GP had failed to do that.

- 20.1 was tested for Hepatitis C in December 2018 and the results came back positive.
- 21. Our daughter was tested in around late January or early Feb 2019 and thankfully her test results came back negative.
- 22.1 was asked to give a further sample of my blood for the doctors to check my genotype and viral load. My GP handed me an appointment slip saying I had an appointment the next month, January 2019 with a Hepatologist. The slip had my viral load on it and I asked her what it meant to which she said she didn't know how to interpret it. I then asked one of the partners at the GP and he said the same. They said they weren't qualified to interpret it!
- 23. Our GP messed up really badly by not telling my husband that he was diagnosed with Hepatitis C back in 2016 and I believe that's the reason why they wouldn't tell me anything. They should have picked this up 3 years ago.
- 24. After I left the GP Surgery I sat in my car and looked up the result of my test on Google in order to try to understand what "viral load" meant.
- 25.A fortnight later, a Hepatologist called from the hospital and told me that I had Hepatitis C and would need to attend a hospital appointment to discuss this.
- 26.1 have exhibited to this statement marked WITN0863002 copies of the test results dated 14 December 2018 and 18 December 2018 which confirm my Hepatitis C status and viral load at the time.
- 27.1 did not make the link at the time between the HGG injections I received during my employment at the NBTS and the fact that my husband and I were infected with Hepatitis C. My husband and I wracked our brains as to how we may have acquired this infection. We had been together for 35/36 years at this point, we were both respectable people my husband worked for the NHS and we had not used drugs.

- 28. My husband and I went to PDH for a joint outpatient appointment in January2019. The hepatologist asked me whether I have any tattoos or piercings and whether I had previously received any blood products. During the course of our conversation, he observed that I was quite knowledgeable about blood products and that is when I mentioned to him that I used to work in the NBTS and received HGG shots. To this he said 'you do know that those are a human blood product'. I was quite shocked because I had thoughtthe HGG shots were synthetically made. I had no clue that they were produced from human blood. That's when the connection was made between the HGG and both my husband and I being infected with Hepatitis C. I had been infected first and my husband was subsequently infected by me. The doctor said there was no other means by which I could've been infected with Hepatitis C. I have genotype 3 Hepatitis C and so does my husband.
- 29. We were then told about treatment options. At the time my husband was not well enough to have the treatment. We were told we would hear from the Hepatitis C nurse who would do fibroscans and blood tests on us before putting us on treatment. It was explained to us that this was not a quick process.
- 30.1 was not provided information prior to being given the HGG shots. I was never informed of any risks associated with being given HGG. I did not know it was made from human blood. If I had known this I may have looked into it and decided whether I wanted it or not. At the time, I do not think though that anyone knew about Hepatitis C, that came later.
- 31. With hindsight I do think that at least from the early 1990s the NHS and NBTS must have known there was a potential that the HGG shots we were given carried a risk of infection with Hepatitis C. The NBTS is an NHS service and I could have been contacted by my former employer or by the NHS a long time ago in which case my infection could have been picked up earlier.
- 32. At my GP, I was not provided with any information about Hepatitis C other than being told to attend the appointment with the Hepatologist which was booked for the end of January 2019.

- 33.1 do not believe I was given adequate information to help me understand and manage the infection. I went very quickly from finding out I had Hepatitis C to knowing I was going to be treated for it. I got most of my information from the Hepatitis C Trust who I called twice, and from my own research.
- 34.1 believe that information should have been provided to me and my husband earlier. If my husband had been told 3 years ago when he was first tested by our GP, we would have potentially received treatment back then. We expressed our concern to the GP about this and we received a letter of apology from the GP explaining where they went wrong. That letter is exhibited to my husband's statement.
- 35.1 am shocked at the way that my GP communicated the test results to me. It was appalling the way she sent me away saying she couldn't interpret my results.
- 36. At the hospital I was given a little bit of information about the potential risks of others being infected through me and was told to avoid sharing certain things such as razors. However, I don't remember being actually told much about Hepatitis C in that appointment, other than what the treatment process was going to be. It was very clinical.

### Section 3. Other Infections

- 37.1 donot believe that I received any other infections but I did have the horror of thinking that I might have contracted HIV which really freaked me out.
- 38.As part of the initial testing, in addition to Hepatitis C, I was tested for Hepatitis A, Hepatitis B and HIV and those came back negative.

### Section 4. Consent

- 39.1 do not believe that I have been treated or tested without my knowledge and consent.
- 40.1 was treated with HGG without being given adequate or full information I was not made aware of a risk of infection. Perhaps they did not have this information at the time.

41.1 donot know whether I was treated or tested for the purposes of research.

42. After I gave my first sample of blood for testing, the doctor phoned me and said that the blood sample had been lost and they took another one from me.I don't know whether that sample was genuinely lost or whether there was another reason for them requesting another one.

### Section 5. Impact of the Infection

- 43.1 have suffered mentally as a result of the infection. When I first found out about the diagnosis, I was absolutely devastated. I was a mess and I completely fell apart.
- 44. When I worked at the NBTS, I was also a blood donor, giving over 20 units of blood over 13 years. The fact that I could potentially have given Hepatitis C to around 20 people played on my mind. I worried about this and also about the fact that my husband was infected through me.
- 45.1 becamepsychotic and I kept seeing coffins and dead people. I started to self harm. After my diagnosis, I tried to take my life twice by overdosing. I never had mental health issues prior to being diagnosed with Hepatitis C.
- 46.1 am currently being treated for chronic depression and am taking antidepressants, beta blockers and sleeping tablets. I am not able to take antipsychotic tablets as that could affect my liver which would make my Hepatitis C condition worse. I'm under the care of a local crisis team called the GRO-C

**GRO-C** which is part of PDH.I go to both group and individual therapy. I used to have weekly sessions with Prism and now have them with Mind.

- 47. I think the treatment I'm receiving for my depression is helping a little bit but I have a long way to go. I'm getting all the help that I can at the moment.
- 48. I started antiviral treatment called Epclusa (Sofosbuvir and Velpatasvir) on 23 May 2019.My tablets were delivered to my door on a monthly basis and during the treatment, I went to the hospital for blood tests fortnightly to check that the viral load was going down, which it was. The treatment was a 12 week course and I have now completed this.
- 49.1 had a test at the end of my treatment which confirmed that Hepatitis C was not detected in my blood. I am due to have another test in November to confirm.
- 50.1 did not suffer physically side effects from the treatment but I suffered mentally.
- 51. My husband also received the same treatment for his Hepatitis C infection as I did but he started his treatment later than me. Unfortunately he has developed cirrhosis of the liver.
- 52. The trouble that I have in accessing treatment is that it's not like going to the doctors and being given a pill. The funds are released by the government monthly and so the medication is not just given to anyone. Also, I am not happy with the way our GP handled our situation. If my husband had been told 3 years ago that he had Hepatitis C, then both my husband and I could have been put on treatment sooner.
- 53. My infected status has impacted upon my treatment and medical care. When I go to the hospital to have a blood test, the words "High Risk" are written on the form in big letters. This is never removed from your notes and will be a rerminder forever. This makes me feel dirty and stigmatised.

- 54. My blood is lethal, and I am scared of infecting other people. The first time I saw blood while cleaning my teeth I nearly lost it. I have put up an exclusion zone around me. I don't touch people, or let them touch me. For about a month after my diagnosis, I showered 3 or 4 times a day and washed my clothes every couple of hours because I felt so unclean.
- 55. There has been a huge impact on my private; family and social life as a result of being infected with Hepatitis C.I have told a limited number of people about my health as I don't want them to judge me. I find myself drifting away from friendships. The fact that I'm always feeling low and depressed makes me become distant to my friends. People tell me it is not my fault but it does not make me feel better. Blood is given to people who are already poorly. The thought that I could have made 20 people more poorly than they were already or even killed them is with me everyday.
- 56. Prior to my diagnosis, I used to be out and about quite a lot but now I'm just at home. Hospital appointments have taken over our lives.
- 57. My husband is a sick man now and so we don't have a physical relationship anymore. When he was first diagnosed, he assumed it was through him that we got Hepatitis C and then we realised it was from me. Neither of us blamed each other. Our relationship hasn't been brilliant due to both of our mental health problems since being diagnosed with Hepatitis C.
- 58.1 have suffered from the stigma associated with Hepatitis C. I always associated Hepatitis C with drug users and unsafe sex as that's how it has been portrayed by the media. Knowing I had Hepatitis C was difficult for me particularly when I did not know how I contracted it. Knowing how I came to be infected made me feel a little better but not significantly so. I used to tell people that I could feel, smell and taste the Hepatitis C in me and people asked me whether there was a light flashing in my head telling me I was unclean. As a matter of fact, there was.
- 59.1 have suffered from financial effects due to my infection. I pay for prescriptions and anti-depressants. Due to my overdose, I'm not trusted with

multiple prescriptions and so have to get them on a weekly basis. I have to pay £9 per prescription and I take 4 drugs which totals to £36 per week for me.

- 60. We own a house in France but have not been able to go back since our diagnoses. As a result, we have to pay for people to look after the house and garden.
- 61. GRO-C as a result of my husband and I being infected and the fact that I tried to take my life. Our whole family has been impacted.

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

- 62.1 have not faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with Hepatitis C, other than the stigma of having 'high risk' written on my medical forms.
- 63.1 was not offered counseling or psychological support as a result of being infected with Hepatitis C. The only form of counseling I had was when I called up the Hepatitis C Trust. It was only when I took an overdose that I came under the care of the hospital and started to receive counseling.

## Section 7. Financial Assistance

- 64.1 have not received any financial assistance from any of the Trusts or Funds set up and I haven't applied for any.
- 65. A nurse at the hospital gave us a reference to a website where we can apply for financial assistance but we haven't done this yet. One of the reasons for this was that my husband and I were still having treatment and we wanted to wait to know what the outcome of treatment would be.

## Section 8. Other Issues

- 66.1 would like to know why I was never contacted in all the years after I stopped working for the NBTS. The doctors knew the HGG concentrates were infected and could have contacted me to let me know.
- 67.1 would like the Inquiry to find out the truth. My understanding is that the government covered up what they knew and I want this to come out for people to know what really happened. I believe everyone should be told the truth, not just Haemophiliacs and those who were infected or affected.
- 68. These HGG injections were meant to be given to me to keep me safe, not to do the opposite.

## <u>Anonymity</u>

69.1 do not wish to remain anonymous.

70.1 wish to provide oral evidence at the Inquiry.

### Statement of Truth

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

Signed. GRO-C

Dated 5.10.19