Witness Name: Sheila Thubron
Statement No: WITN2043001
Exhibits: [WITN2043002 –
WITN2043007]
Dated: 26 October 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHEILA THUBRON

Section 1. Introduction

1. I Sheila Thubron will say as follows. My date of birth is GRO-C 1952. My address is known to the Inquiry.

Section 2. How Infected

2. In March 1989 I was GRO-C pregnant with my fourth child. I had not had any problems with my previous pregnancies, however with this one I was extremely exhausted and had to have a lot of bed rest. I contacted my midwife who recognised that I was anaemic, I was admitted to the Queen Elizabeth Hospital in Gateshead and had 2 units of blood transfused **[WITN2043002]**. I think I was in hospital for three days, so that they could keep an eye on me. I did not require any further treatment for anaemia for the rest of my pregnancy or after my son was born.

3. I was not informed of there being any risk of infection as a result of the blood transfusion. I would have refused if I had been told of any risks.

4. In July 2006 I received a letter from the blood transfusion services stating that I had been called for an appointment **[WITN2043003]**. It was quite brief, the letter said just come. I was puzzled, I did not know what on earth it could be about.

5. I went to the transfusion centre in Newcastle a few days later. The appointment was with a consultant, I don't remember her name. She told me that I had been given Hepatitis C through a blood transfusion. As she described some of the symptoms associated with Hep C I realised that it explained a lot about how I had been feeling since my son was born. She told me that depression and anxiety were linked to Hep C and described what I had been feeling for years but had not been able to explain. Then we went on to speak about the rest of my symptoms which were all because of Hep C.

6. She told me that I had been transfused with blood from a donor who used to donate regularly before 1971. Apparently, the donor did not give blood for a number of years and then when they returned more recently they were screened and found to have Hep C. It seemed totally believable at the time, who was I to think any different. I no longer think this is true, but at that point I totally accepted it, I trusted her as a professional. I think she told me this at the time to make me feel better and to provide some kind of explanation.

7. I was tested at that appointment and later told that the result was positive for Hepatitis C **[WITN2043004]**.

8. My memory is that the consultant did not tell me much about Hep C at that appointment, but I may not remember everything she said. She sat and held my hand throughout our interview which scared me to bits.

9. I don't think there was much more information that she could have given me at that stage. I was told what Hep C was but I was not in a place to receive and remember the information. I had no prior knowledge of Hep C to base any information on.

10. I think she spoke to me about risks at that appointment. She did say that my son Jack should be tested in case it passed on to him while I was pregnant. This caused even more anxiety at the time, GRO-C GRO-C I was very careful after that to tell every medical professional that I came into contact with about my diagnosis.

11. I believe that I should have been told absolutely as soon as they knew. The consultant did not give any explanation of why the look back was only happening then and hadn't happened earlier. I believe that my clinicians knew prior to 2006 that I had Hep C but that they only told me at that point because they knew it was all going to come out in the news.

12. I understand that my medical records show that my GP was contacted by the Blood Transfusion Service in March 2006 but that he did not think I was ready to be told about the infection as I was recovering from severe depression and suicidal ideas. He wrote for a psychiatric opinion from Dr Williams and a decision was made to delay the discussion temporarily **[WITN2043005].**

13. It was years later I finally found a site online called Tainted Blood. It amazed me that there were people just like me who had been through the same thing. Since then I have joined other sites and groups on social media. I have received most of my information from support groups online.

14. Soon after the appointment with the National Blood Service I was referred to a Hepatologist at the Freeman Hospital. I was told that there was damage to my liver. I was later told I have HCV genotype 1a **[WITN2043006]**

Section 3. Other Infections

15. I really don't know whether I have received any infection or infections other than Hepatitis C. I understand that my records indicate that at the time I was diagnosed with Hep C I did not have antibodies for Hep B but I don't know about other infections.

Section 4. Consent

16. With hindsight I do believe that I was tested without my knowledge and my consent. I could have been tested for whatever they wanted to look into. I believe they were aware of the infection from the beginning and were tracking me for research; I think they knew my name and have watched my symptoms develop. I do wonder why my GP did not tell me, I believe that he must have known before receiving the letters from the blood service in 2006. I had several procedures and hospital admissions between having the transfusion and being formally diagnosed, including for a total hysterectomy 2001. I do wonder why my diagnosis was not mentioned to me.

17. I never questioned the medical profession until I found out via a website that it had happened to other people and recognised so many of the things they were saying in myself. After reading the experiences of others I was in shock for such a long time. Before that I had trusted everybody implicitly.

18. When I started looking through my medical notes I couldn't find a batch number for the blood I was given. There is a note stating that I had a blood transfusion but there is no batch number. Leaving the batch number out of the records makes it more difficult to prove. I believe that if it was as simple a case as they said it was, they would have recorded the batch number.

19. I feel as if the blood service consultant fobbed me off with the story about the donor. I believed it at the time because I had no reason not to. Now that I know more, I believe that I was infected with blood from America.

20. A few years ago, I was finally given time and space to speak to a nurse in the liver clinic. She was brilliant and explained such a lot it was obvious that she knew where my blood had come from. I can't really remember the conversation, I just had a general feeling that she was looking out for me and being honest.

Section 5. Impact

21. A couple of years after Jack was born I just did not seem able to cope as I had done previously. Jack was a very active toddler and I had three other children to look after. I was exhausted and depressed, it was so hard to live every day. At first I thought it was baby blues. I was so fatigued, way beyond normal busy family life. I felt guilty about not being the mum and wife I wanted to be and was before

22. The doctor I had at the time knew me well. The best he could do for me was to help me get jack into a nursery. When that happened it helped a little and meant that I could plan my days. I knew Jack would be safe, the other children were at school.

23. I was later introduced to Fluoxetine; over the years the dose was increased to the highest dose I could have. But to be on the highest dose and still feel so depressed was awful. It was destroying. I felt there was nowhere else to go apart from not being here at all.

24. For years I experienced deep clinical depression and anxiety and suffered regular panic attacks. I had several depressive episodes. I lost the ability to process everyday life, I just would not leave the house or answer the phone. I tried to take my own life twice, on one occasion I had my stomach pumped.

25. I was furious when I found out that I had been infected with Hep C, I was so angry. I am still furious to be honest, not just about what has been done to me but also about what has been done to my family.

26. In terms of physical symptoms I suffer with joint pain and have osteoarthritis which I believe may have been caused by Hep C. I had to have my gallbladder removed in 2012, I understand this is common in people that have Hep C.

27. When I read about brain fog online, I recognised that it had been happening to me for years: forgetting things, getting muddled in conversations, entire minutes of nothingness. I was not me at all.

28. I was told by the specialist at the Freeman Hospital that there was a treatment, Interferon. I spoke to my doctor about this who said I would have to come off all of my anti depressants for six months before I could even attempt the interferon. On top of that he told me that the side effects of Interferon are depression and anxiety. I felt that this was not an option for me. I was offered nothing else instead, I just got on with it for many years. I would go to the clinic regularly and they would take my bloods and sometimes I had a scan of my liver but that was about it.

29. Eventually I was told that there was a new treatment called Harvoni. I started this in September 2006. It was brilliant; after an eight week course the Hep C was not detected. They say you are never cured because apparently it can come back. This frightens me to bits. I did not suffer any side effects from the treatment; I just took tablets at home. It was not difficult for me to access the treatment; I think I was one of the first to have it.

30. When I first found out it that the Hep C was gone, I felt as if I was seeing life anew, the whole world was different. That feeling lasted for about a week and I came back down to earth again. But my exhaustion is slightly better, I am still on Fluoxetine, I now take two tablets per day.

31. I do not believe the damage to my liver has progressed. It has been a while since I had a scan now, so I am not sure. I do not have cirrhosis.

32. I had to declare that I had Hep C at every appointment and endure all of the stigma that came with it. I was told to make sure that I informed everybody, whether a dentist or whoever so that they would be aware of my diagnosis. At the Freeman Hospital liver clinic there were drug users and alcoholics and people who had been sent from the sexual health clinic. The people who were sitting in the waiting room for other clinics could see who was waiting for the liver clinic.

33. I did feel that once I was seen by the staff at the liver clinic, I was looked after very well and perhaps given special treatment because my infection was from a blood transfusion.

34. Every area of my life has been impacted. In the years after my son was born I became reclusive. Before the diagnosis I was reluctant to leave the house because of my depression but after the diagnosis it got worse and worse until I spent my time just in the house and garden and that was it. Social life, family outings, school trips, church: everything went.

35. I used to work at Marie Curie Hospice Healthcare. I loved working there, the hospice is such a special place, you walk in and there is a calmness, everything about it is so lovely. I enjoyed seeing patients come to day care when they had first been diagnosed, I helped to look after them on their first visits. Later they would be introduced to the inpatients area, so they would become familiar with the nurses and the ward environment for when they came to the end. I had job satisfaction that everything that could have been done for them was being done. Because the hospice was run by a charity there were lots of staff and volunteers so we could spend as much time with the patients as they needed. That was what was enjoyable about it. It was the job of my dreams, I loved it and I made many friends there.

36. Over time I started to drop a day, and then two. Because of brain fog, tiredness and depression I felt that I was not able to do my job. I realised that I was just going to have to give this job up, not because I was not capable but because I

was exhausted. I was there for about 10 years, but by the time I gave up the job I felt that I could not leave the house. This meant a loss of earnings and pension rights, I felt as if I became a burden on my husband. Our family resources were greatly affected.

37. The family were impacted in so many ways. Due to my low energy levels GRO-C. My relationship with each child changed over time, they had to witness my illness, the mental impact on me, and me being taken to hospital. Their everyday changed too because physically I could not join them in activities or go on outings. They went where they could without me; I tried to keep things as normal as I could but there were many complaints because mum wasn't there, or mum would not come. How do you explain that to children? They would have been 13, 11, 5 and 2 at this time.

38. It was so difficult to try to explain how I was feeling to my husband and my children. My world became very small which was the opposite of how I had lived before. I felt that I wasn't being the mother or the wife that I should have been.

39. When I was diagnosed with Hep C I was finally able to give them some kind of explanation for it all. It was a huge relief in a way to be able to say that it was because of the Hep C that I had been so exhausted and depressed. Their reaction was at first disbelief and shock but gradually when I showed them the information I had found on the websites they started to understand. But many unhappy memories came back for them. We do now talk about it as a family.

40. My wider family was affected too. I was so close to all of them. I come from a family of 10 children, I am one of the eldest and have always been the one the others turned to. I was a really outgoing personality and happy. But over time I stopped visiting them and did not want people to visit me either. I would say I did not want to leave the house and eventually people gave up. They did try. Sometimes they would tell me to pull myself together, I found this really difficult

and became upset and angry. There was a lack of understanding about how I was, but I did not really understand either. It caused disruption and arguments within the family and there are relatives I have now lost touch with.

41. All of my relationships have been impacted: family, friends, colleagues. I feel that I lost so much: my social life and shared experiences; the relationship with my husband and all that he lost; my self esteem, my self confidence and self image all shattered. I had thoroughly enjoyed being a mum and wife, but I lost all of that. I lost myself to the point of trying to take my own life.

42. I told friends and colleagues about the Hep C but most people were not aware of the implications of the illness. I did suffer stigma both in relation to my depression when I was told to pull myself together, and then having to declare my Hep C to friends, family, and strangers at appointments.

43. I still suffer from depression and all that it entails. I am not exactly housebound but won't leave the house unless I have to and won't go out unaccompanied. I have tremors which I cannot get rid of. I still have dark thoughts and am having problems fitting my life back in to how it used to be, I am nowhere near the person I was.

Section 6. Treatment/Care/Support

44. I feel as if every time I go to see the GP I have a new symptom or issue to discuss but I often don't raise it because I need to discuss treatment or other parts of my life in the short time available. I now have such a long list and many of the issues on it I have never brought up in appointments. I think it would be great if I could have an hour with a professional GP just to talk through all of these things.

45. Over the years I did try to speak to my GP who eventually referred me for counselling in around 2005. I was told I would have to wait 12 months for an appointment so I ended up paying privately. I had 10 sessions at £100 each but

could not afford any more. By that time, I was not earning, and money was tight. I did not feel as if I had been supported.

46. After I left work I applied for DLA. That process was horrendous because of the assessments and how I was treated. Some of the notes that had been sent to my GP afterwards were lies. My church minister had attended the appointment with me, she had taken notes which were different from what had been sent to my GP **[WITN2043007]**

Section 7. Financial Assistance

47. Somebody at work told me about Skipton, I am not sure when this was. I looked online and applied. My application was successful. I received the stage 1 payment. I first found out about the Caxton Foundation when I was looking at information about Skipton, but I did not seem to be able to apply for anything from them.

48. I receive £1,500 per month from EIBSS. I have not applied for other things.

49. I found the application process very difficult given I was not in my right mind. It took me a long time to fil in all the forms. I applied for my medical records and was pleasantly surprised when I received my full medical records within about 6 weeks. I know that there are so many people whose notes have gone missing.

50. When I applied for the Skipton payments I had to sign something which more or less said that I wouldn't be able to claim any other money. But I was so relieved to be getting this sum of money, by then we were extremely poor and in debt.

51. Although I was greatly relieved to receive the money from EIBSS, I still do not think that it is anywhere near enough. The money has helped us to catch up after years of poverty, to pay bills off. But once those are paid there isn't much left.

Section 8. Other Issues

52. The issues for the Inquiry to address are so varied. Justice for me means someone saying we did this, I am sorry. Someone coming forward and talking about what happened and admitting to the lies and deceit which are ongoing. I have friends whose husbands were infected and having cared for them for years, once they died have nothing. I don't want to have to worry about this for the rest of my life. :financially, mentally, everything. I want an end.

53. I have attended some of the Inquiry hearings and have been pleased with what I saw.

Statement of Truth

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

Signed GRO-C ....

Dated ……26 October 2021………