Witness Name: Joan Irene Thompson
Statement No: WITN0171001
Exhibits: WITN0171002-WITN0171015
Dated: 11. 10. 2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOAN IRENE THOMPSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 March 2019.

I, Joan Irene Thompson, will say as follows: -

Section 1. Introduction

1. My name is Joan Irene Thompson. My date of birth is GRO-C 1940. I was born in GRO-C. My address is GRO-C GRO-C. I was married to Martin on the GRO-C GRO-C 1965. Sadly my husband Martin has now passed away and I have been a widow for 16 years. We have three sons aged 52, 48 and 46.

2. I intend to describe my infection with the virus Hepatitis C (hereinafter referred to as 'HCV') from contaminated blood given to me during a blood transfusion after the birth of my youngest son, Lee. I will go on to describe how this affected my family and myself. I will also describe the treatment that I received and the impact it had on our lives.

Section 2: How Infected

3. I gave birth to my youngest son, Lee, at Kingston Hospital Maternity Ward, Kingston On Thames in Surrey on GRO-C 1972. The next day I collapsed and haemorrhaged when getting up to go to the toilet. I lost a lot of blood so a decision was made for me to have a blood transfusion on GRO-C 1972. I recall the blood transfusion lasted for 12 hours. I cannot recall how much blood I was given but I remember it started at 8am and finished about 8pm. Martin was allowed to stay with me during the transfusion. I remember that when the transfusion finished I started shaking and I was shaking so much that they wrapped me up in tin foil. I was kept in hospital for about 10 days after the birth after which I was allowed to go home.

4. I used to bleed a lot in the years following Lee's birth and my GP recommended that I have a hysterectomy. I attended Guildford Hospital, London Road in Surrey for the operation two years later in June 1974. In my mind I simply thought I was a person who bled a lot so I did not really think anything else of it.

5. When Martin retired from the Fire Brigade in 1999 we sold up and went to live in Spain. Whilst out there I started to have lots of nose bleeds but this did not really worry me. I decided that I would like to come back to the UK so we returned in August 2002. We stayed with my brother in GRO-C until October 2002 when we bought a park home near GRO-C, Sussex.

6. It was during this time that my nose bleeds got really bad. In October 2002 just before we moved I went to see my GP, Dr M Desor in GRO-C and she referred me to Leatherhead Hospital where they did tests on my nose and I also had blood tests. After we had moved to Sussex a letter from the hospital plus blood test forms were sent to my brother's address, as this was the address I had given. They sent the

letter on to me but at the time I was very busy and not registered with a GP in GRO-C. My sister in law told me that they had received a letter for me at their home as my mail was being sent there when we returned from Spain. I received the letter whilst we were in GRO-C saying I needed more blood tests but as I was so busy I didn't take it any further.

7. In early November Martin was taken ill and after several visits to Eastbourne General Hospital he was diagnosed with lung cancer. He had chemotherapy in December 2002 and January 2003 and during this time I was too busy looking after him to go for a blood test myself.

8. Martin passed away on the GRO-C 2003. It wasn't until early May 2003 that I saw my GP Dr Hope-Gill and had blood tests and he referred me to Eastbourne General Hospital.

9. I was then sent a letter with an appointment to see a lovely doctor called Dr C D Gillen. After a general chat Dr Gillen held my hand and said, "I am very sorry to tell you but you have hepatitis C". Dr Gillen asked me if I had ever had tattoos or had ever used drugs that could have caused the infection. I said I had not. He then asked me if I had ever had a blood transfusion and I said yes I had one when my son was born in Kingston Hospital in GRO-C 1972. Dr Gillen said that this must have been what caused me to contract HCV.

10. Dr Gillen explained that I had HCV Genotype 2B. He explained it would affect my liver and I would be monitored and probably need treatment. I confirm I was infected with HCV by being given a blood transfusion with infected blood on GRO-C 1972.

11. I feel that I was given adequate information about the HCV infection when I received the diagnosis. I also believe I was given adequate information to help me to understand and manage the infection but I did not receive anything in writing about how to manage the infection. I was

not offered any particular psychological or counselling support but they did arrange for me to speak to someone in person or over the telephone if I had any questions or needed support. I recall I did telephone somebody when I felt really ill. I think I probably only ever rang once. I also recall that when I went down for my six monthly check-ups at Eastbourne Hospital I used to see a lady.

12. I believe the results of my blood test were communicated to me very quickly after the results were known. The doctors at Eastbourne Hospital kept me informed thereafter and I was told I needed to tell my dentist in case anyone else came into contact with my blood and also anybody that was likely to come into contact with my blood.

13. Before I received the diagnosis of HCV I had never heard of the infection. I didn't know it existed. I felt upset to think that the UK could have imported blood that would give me an infection. You don't think things like this could happen. I would never have thought that I would ever need to have imported blood.

Section 3. Other Infections

14. I do not believe that I have received any other infection other than HCV as a result of the blood transfusion following Lee's birth.

Section 4. Consent

15. I don't believe that I have been treated or tested without my knowledge, or consent, without being given adequate or full information, or for the purposes of research. As regards consent for the blood transfusion I received in 1972 I do not remember signing any forms to consent to the blood transfusion. I think the doctor at the Hospital just decided that I needed one. I understand Kingston Hospital destroyed my medical records after 8 years. **(WITN0171002)** When I was tested for HCV

there was no mention that they wanted to test me for any other infection.

Section 5. Impact

16. In July 1993 I started to exhibit symptoms of vasculitis. I have provided to the Inquiry, a copy of four photographs of my skin condition, which were taken in the period 1993-1996. **(WITN0171003)** When I first experienced symptoms to my legs I went to my GP and initially he had no idea what the condition was. My current treating hospital doctors now confirm the vasculitis was a side effect of the HCV infection. I have provided to the Inquiry a copy of a letter from Dr Giosue Gill, Consultant Neurologist and Stroke Physician dated 30 November 2018. **(WITN0171004)** It is not likely to get better and the hospital doctor advised me to use a walking stick and not to go out alone in the dark. The condition is persistently itchy and I have to apply itch relief cream twice daily, which I have to pay for myself and it is very expensive.

17. These symptoms continued until 1996 and the lasting effects were that it damaged the nerves in my legs. My legs are numb from my ankles up towards my knees and I have no sensation in my ankles which means I can trip easily.

18. I still continue to suffer from the condition. I can only wear flat shoes with straps. I cannot walk well or easily and I tend to stagger. I am unable to keep my shoes on unless they are fastened to my feet via a strap. If there is no strap they simply slip off and I can walk out of them without realising I am no longer wearing shoes. I tripped over in Cobham High Street on 1 November 2016, which I feel, is related to the loss of sensation in my ankles. Some people helped to pick me up and sit me on a bench. I felt very embarrassed. I was taken by ambulance to Guildford Royal Surrey Hospital where they found I had broken my left hip. I had a complete hip replacement. I was kept in

hospital for a week. I found some of the exercises hard to do due to the numbness in my feet. I feel that I have to wear trousers or long skirts to my ankles to cover the awful marks on my legs. I have provided to the Inquiry a recent photo taken in July 2019, which show the lasting effects of the condition. **(WITN0171005).**

19. During the time from 1972 when I received the infected blood until 2003 when the HCV infection was diagnosed (31 years) I suffered from a lot of health problems which I can put down to the infection ie fatigue, sleeping problems, night sweats, digestive problems, headaches, itching, bloating, floaters and blurred vision and oesophageal varices. I worked in offices part time from 1974 to 1982 when my three sons were young and I then worked full time from 1982 to 1999. I tried not to let my health problems interfere with work which I did find hard at times, especially not knowing why I felt like I did.

20. I attended for two courses of HCV treatment. Prior to the first course of treatment I was being monitored with regular blood tests at Eastbourne District General Hospital. I had an ultrasound of my liver and kidneys on 9 June 2003 and my first liver biopsy in 2004 at Eastbourne Hospital. After the biopsy I had to stay with my neighbour for 24 hours. I attended with Dr D A Neal at Eastbourne Hospital on 26 March 2004 and he advised me that the results of my liver biopsy showed that there was cirrhosis of my liver. Dr Neal also confirmed I was HCV positive and advised me not to drink any alcohol.

21. In January 2005 Dr Gillen said that he wanted to put me forward for HCV treatment. I had arranged with my friend to go on holiday for three weeks to Canada and Alaska to celebrate our 65th birthdays. Dr Gillen advised me to take the holiday and make an appointment to see him when I returned to the UK. I made an appointment to see Dr Gillen after I had returned from holiday. He confirmed then that he was going to put my name forward for a course of HCV treatment.

22. I was accepted and started HCV treatment on 8 August 2005. The treatment ended on 22 January 2006. I was under the care of Dr Segwagwe at Eastbourne Hospital. The treatment plan was a combination therapy that was to last for 24 weeks. I was required to take both injections and tablets. I was shown how I had to do the injections. I self-administered 180mcg of Pegasys (Interferon) once a week by way of injection and took 800mg of Copegus (Ribavirin) a day, consisting of 2 tablets in the morning and 2 tablets in the evening. I finished treatment in January 2006. I felt as if I spent my life going to and fro to hospital. I have provided a copy of my Day Planner for this course of treatment to the Inquiry. (**WITN0171006**)

23. I had to self-administer the injection into my stomach every Monday. It was hard because I was living on my own. When I was on the treatment I couldn't eat and it also affected my social life. I had started going to the Inn on the Park for Sunday lunch with my neighbour but stopped going because I couldn't eat very much. The landlord was kind enough to say that I could go and just eat what I could so we started going again. He charged me accordingly.

24. I always felt really ill between Monday and Thursday. I would feel a bit better by Friday and would feel well enough to go out on Saturday and Sunday. My doctor and I worked out my timetable so that it worked as well as possible. I also received the treatment by courier, which was very helpful, as I did not have to travel all the way to Eastbourne Hospital to collect it.

25. I lost a lot of weight during the treatment and my weight fell to below 8 stone. I also started to suffer from anxiety whenever I went out. I was often taking the bus so I would always carry something to eat and drink in an emergency if I needed it. Sometimes I had panic attacks and had to often get off the bus to get some air. Also this happened sometimes when I was in a shop and I would have to leave my friend in the shop while I went out to get some air. I was too scared to go anywhere on

my own. I felt very tired, panicked and suffered from headaches. I just felt ill. My hair also went thin. I didn't know that this treatment was a form of chemotherapy until on one occasion my GP mentioned this to me. I lost my eyelashes, which have never grown back. Since then I have always suffered from eye infections and runny eyes.

26. Unfortunately the first course of HCV treatment did not cure the infection. When I initially saw Dr Neal after having the treatment my blood test results showed I was clear of HCV. However, I had a blood test six months later and I was told the results of the blood test showed that the HCV had returned. I was very upset and very disappointed. I had hoped that the treatment would work and I felt that I now had another hurdle to deal with.

27. After this I felt that I just had to wait until the doctors were ready to treat me again. In the meantime I felt that I just had to accept it and get on with things. In 2006 I moved back to GRO-C to buy a bungalow with my eldest son. I registered with Dr Desor in GRO-C Centre and she referred me to Epsom Hospital. I attended with Dr Guam Lim at Leatherhead hospital and he phoned Eastbourne Hospital and got all the details from them. I started to attend Epsom Hospital every six months for ultrasounds during 2007 to 2018 and for blood tests. It felt like I had had so many ultrasounds and blood tests.

28. I also used to speak to a nurse called Ting at Epsom Hospital. Ting seemed to know a lot about HCV as she has attended meetings. In December 2013 Nurse Ting said I was to be referred for a trial drug. Dr S Matthew at the Research Department at Frimley Park Hospital wrote to me on 30 December 2013 to advise me that there was a treatment trial that was taking place at Frimley Park. I have provided a copy of this letter to the Inquiry. (**WITN0171007**)

29. The drug was called Sofosbuvir (Sovaldi). I attended Frimley Park Hospital on 20 January 2014 for tests. They informed me about two

weeks later that this particular trial did not suit me due to my kidney function and as such I could not be included in the trial. I had known that there was a possibility that I wouldn't be given the drug even if I satisfied the tests so I didn't see any point in worrying about it. Also it was one of those trials where some patients would be given a placebo.

30. I started having fibro scans from 1 July 2015. Dr Lim had a nurse called Ting Tang who was trained to do the scan. Ting seems to know a lot about HCV as mentioned before. Before my actual scan I had been asked if I would be interested in allowing Ting to train using the fibro scan on me, which I was happy to do. I have been under the care of Dr Guam Lim, Ting and various other nurses from 2006 until now.

31. I waited ten years after the first course of treatment, as I had been told that there was no other treatment available. The treating consultants did not suggest I repeat the first course of treatment, as the first course had not been successful. Dr Lim put my name forward for a second course of HCV treatment in 2015 and I was accepted. I was told that my case had to go before a panel of three doctors from Epsom, Kingston and Guildford Hospitals before I could be accepted for treatment.

32. I started the second course of HCV treatment on 9 November 2015 and this lasted until January 2016. I was required to take one 400mg tablet of Sovaldi in the morning and two 200mg Copegus tablets also in the morning and a further three 200mg Copegus tablets in the evening. Six months after completing the treatment I had a blood test. Due to breaking my hip my next blood test got deferred. It was a long time before my next blood test and I really don't know why I did not get the forms. My last ultrasound was on 1 November 2018 and a letter I have received from Dr Lim stated that the HCV was showing clear.

33. I do not feel that I faced any particular difficulties or obstacles in accessing treatment. Each time my name was put forward I was

accepted. There was a period of ten years between the two treatments, however, I understand the reason for this was that there was no alternative treatment plans available during this period which would have suited me.

34. My hair went thin with both treatments and still is. I lost my eyelashes during my first treatment and they are now very tiny and I tend to get a lot of eye infections and runny eyes. I still suffer from indigestion and acid reflux, mostly at night but sometimes during the day. I have bought a wedge to go under my pillow, this raises me at an angle from my waist up and does seem to be helping with the problem.

35. I am left with lasting symptoms, which I feel are due to my infection of HCV and the treatment. I always feel tired. I suffered with pneumonia in January 2019 for ten weeks and was still feeling poorly in April. Now I rarely go anywhere. I used to go to Sussex a lot by bus and stay there with friends, but now I do not feel I could physically manage this. I do not have the confidence to travel far, whereas I would have done this on my own two years ago. I now only go into Sussex when my eldest son is able to take me and bring me back. Whenever I go out now I always carry Kit Kat bars and a bottle of water, which I think is a type of safety behaviour. I always stop and have a coffee too. If I forget to bring something to eat I buy something to eat with my coffee. I still can't manage to eat big meals and tend to pick.

36. I moved back to GRO-C temporarily in 2010 for about six months, where I rented a flat. After I had been diagnosed with HCV I had to go to the dentist because I had broken my two front teeth when I was in Spain and the replacement had become loose. I informed the dentist whose name I cannot recall nor the name of the practice, of my diagnosis of HCV. I told him that I bled a lot. I feel that his attitude changed when I said that I had HCV. I was upset in the way in which he carried out the examination and he didn't treat my teeth that day and told me I had to come back for another appointment. He was not

pleasant at all. He did it in such a way that my teeth hurt. I had to ask him for a mouthwash and I noticed that he plonked it down. I didn't like his attitude and I left straight away. I remember I came out of the dental practice crying.

37. I found this dentist to be extremely rude and I reported him to the Head of the Dental Practice and I never went back. I wrote a letter to the Practice Manager to express how I had been treated. The Practice Manager telephoned me and apologised and said he would have taken me on as a patient but he only saw private patients. Since this experience most dentists have been ok with me when I have informed them of my diagnosis.

38. Martin and I had moved to GRO-C, Sussex in October 2002 and he was taken ill in November 2002. I was looking after him until he died in GRO-C 2003. It was an awful shock to be told in May 2003 that I had HCV. My husband had died just two months before I was diagnosed with HCV. I was on my own in Sussex and all my family lived about 60 miles away in GRO-C. I hadn't had any time to make new friends so I did feel very lonely. My three sons visited when they could. I was already upset at the loss of my husband and then I had to contend with the upsetting news of my HCV diagnosis.

39. After the diagnosis I felt completely alone as I had nobody in Sussex and this wasn't something I really wanted to talk to anybody about. I did talk about it to my neighbour and she would often accompany me to the hospital. I subsequently found it very hard to cope without family support when I had my HCV treatment in 2005/2006. I tried not to let the diagnosis of HCV affect my social life too much. I did find it hard to explain to friends why I couldn't drink alcohol as the hepatitis affected the liver. I never talked about it and only a few people such as my neighbour and some friends knew I had HCV.

40. I have at times felt that people didn't understand what I was going through. I tried not to discuss it too much. There definitely was a stigma at the time associated with the infection. When I was diagnosed my boys were in their thirties. We were of the same mind-set, namely that I was unlucky to have received an infected blood transfusion and that I should have treatment to help me to overcome this. Otherwise I kept the diagnosis private and it is only since I learned of the Infected Blood Inquiry that I now feel I can talk about it. At the time my youngest son Lee felt it was his fault as I had to have the blood transfusion when he was born. Even when I spoke to him recently he said that if I hadn't had him I wouldn't have been infected.

41. The timing of the diagnosis had no impact on my work. I had already retired from work in 1999, four years before I knew I had HCV. When I reflect back I can now associate a lot of things that affected me during my working life that I can now attribute to the hepatitis. As I had already retired from work at the time I was diagnosed, I didn't lose out financially. However, I did have to travel to Eastbourne Hospital for a lot of appointments for blood tests so I had to pay bus fares and when I had a liver biopsy I had to get a taxi home. At the time I didn't think about the cost.

42. I fell in a restaurant once and cut my face. The staff had rushed out with tea towels, throwing them down to mop up the blood. I quickly told them to stop and not to touch the blood. I felt obliged to inform the manager I had HCV. The Ambulance crew dealt with it all and took the tea towels away with them. I was then taken to Eastbourne hospital.

43. I now suffer from acid reflux for which I am being treated and as mentioned above. I don't know if this condition has been triggered by the HCV. I went to see my GP in January 2019 and she said that she had received a letter from the hospital following an endoscopy for my acid reflux. I am waiting for them to let me know what happens next.

44. My GP has told me that there is a problem with my kidneys and that one is bigger than the other. I do not know yet what the problem is but it is being monitored. I have ultrasounds every six months and my last one was in September and I am having another one on 7 October. I recently went for a blood test at Epsom General Hospital and I am awaiting the results. I have been told that I will have to continue having blood tests and ultra sounds indefinitely.

Section 6. Treatment/Care/Support

45. I would not say that I experienced any obstacles in obtaining treatment for the HCV. I expressed my interest for the first course of HCV treatment in 2005 and Dr Gillen referred me. I was accepted very quickly. When Dr Lim referred me ten years later for a second course of treatment, I was again accepted very quickly.

46. I have never been offered any psychological support or counselling following my diagnosis of HCV or prior to, during or after any course of HCV treatment.

Section 7. Financial Assistance

47. My sister in law's daughter in law told me that people were receiving compensation for being infected with HCV. I saw an article in a newspaper where John Reid had mentioned that people who had been infected with HCV should receive compensation. I have provided a copy of a photograph of this article to the Inquiry. (**WITN0171008**) One of my friends looked it up on the computer on 7 July 2005 and found details of the Skipton Fund and I wrote to them.

48. I made my first Application for financial assistance on 13 July 2005. I needed help in filling in some of the forms and I asked some of the medical professionals to help me to complete them. My first application

was denied. I received a letter from the Skipton Fund dated 17 October 2006 informing me that an Appeal Panel had been established so I appealed their decision. **(WITN0171009; WITN01710010)**. I have also provided to the Inquiry a copy of two letters from the Skipton Fund declining my application and acknowledgement of my intention to lodge an Appeal. **(WITN0171011; WITN0171012).**

49. I was successful on appeal on 1 December 2006 and I received a financial payment on 18 December 2006. I have provided a copy of the letter confirming the appeal outcome to the Inquiry. (**WITN0171013**) I applied for a second stage payment on 8 April 2008 but this was declined on 17 April 2008 because I wasn't at 'trigger point'. I have provided a copy of a letter from the Skipton Fund dated 17 April 2008 to the Inquiry wherein they notified me of their decision, (**WITN0171014**)

50. I waited 8 years before I tried again for a payment. I didn't understand the reference to 'trigger points' and the medical professionals never explained it either. I was never prompted to re-apply by any medical professionals or the Skipton Fund. I don't know if I would have been entitled to any compensation during that 8 year period.

51. I put in another claim on 12 December 2013. This was accepted on 4 March 2014 and I received a lump sum payment on 18 March 2014. I also started to receive monthly compensation payments from 25 April 2014. This sum has been increased twice since and the payment did increase depending upon the cost of living.

52. The Skipton Fund issued monthly payments until the Department of Health took over in November 2017 and as from July 2017 I received a payment from them each month until March 2018. This amount increased in April 2018. I have provided a copy of a letter from NHS Business Services Authority dated 28 March 2018 to the Inquiry that

confirms the payments. (**WITN0171015**) I also received a winter fuel payment paid by EIBSS on 1 December 2017 and December 2018.

53. I learned that I could receive a top up payment each month upon supply of documentation. This was backdated to July 2018 when they gave me two separate payments for August and September. As from July 2019 but backdated to April 2019, I continue to receive a monthly payment.

Section 8. Other Issues

54. I am pleased that there is an Inquiry making investigations into why this scandal happened. It happened so long ago that I had just accepted it. I am happy that I have been able to give my story.

55. I feel lucky that I have been receiving some financial assistance. My understanding of the scheme is that financial assistance will be paid but if my health deteriorates my payments could increase but if my health improves I may not receive the same or any payment. I will challenge this if it comes down to it because I will be left with a lasting medical difficulty and I am worried how I will survive. My landlord increased my rent and I was only able to meet the increase because I had received an increase in payments from the Skipton Fund. I am in rented accommodation and I worry that the rent will increase again. I will not be able to live in GRO-C if the payments stop and if there is a further rent increase. I recently received a letter from Dr Lim stating that my blood tests show that I am now clear of the HCV virus. However, I need to be monitored every six months because of the condition of my liver. This will involve blood tests and ultra sounds. My last blood test was on 27 September 2019 and I am waiting for my next ultra sound appointment.

56. After quite a lot of house moves I am living back in the village where I was born. I have been here for 5 years now. I hope that in time I will be able to start ' living a life ' again.

Statement of Truth

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

Signed GRO-C: Joan Irene Thompson

Dated 11. 10. 2019