Witness Name: Jim David Mortimer

Statement No.: WITN0808001

Exhibits: Dated:

#### INFECTED BLOOD INQUIRY

# WRITTEN STATEMENT OF JIM DAVID MORTIMER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 February 2019.

I, Jim David Mortimer, will say as follows: -

## Section 1. Introduction

- 1. My name is Jim David Mortimer. My date of birth is GRO-C 1945 and my address is known to the Inquiry. I intend to speak about how my late wife, Sheila Mortimer, was infected with Hepatitis C as a result of being treated with contaminated blood products. Sheila died from liver failure on 5 April 2012, aged 66 years.
  - I was born and raised in Bingley, Yorkshire. After I finished school, I took an apprenticeship in engineering and subsequently worked in this field until my retirement at age 61.

- 3. Sheila was born on GRO-C 1945. We met in 1967 while I was on holiday in Scotland. My aunt's sister lived next door to Sheila and she set us up on a date.
- 4. Sheila and I got married in 1969 and Sheila moved from Scotland to Yorkshire to live with me. She had trained as a schoolteacher by then and found a job in the local area. We had our daughter, GRO-B GRO-B in 1974.
- 5. Sheila's illness and death has had a devastating impact on GRO-B and I.

  I am providing this statement on behalf of us both.

## Section 2. How Affected

- 6. Sheila knew from a young age that she was prone to bad nosebleeds, as were a number of family members on her mother's side. However it was not until the 1970s that she was formally diagnosed with Hereditary Haemorrhagic Telangiectasia ("HHT"). This condition meant that Sheila's blood vessels were weak and she would get bloodspots, particularly in her oesophagus and nose. It caused her to have terrible nosebleeds. From time to time, she had to receive blood transfusions as a result of the amount of blood she would lose.
- 7. After GRO-B was born in GRO-C 1974, Sheila was diagnosed with Systemic Lupus Erythematous ("SLE"). We were advised by Sheila's gynaecologist that we should not have any more children due to Sheila's health complications, which seemed to be exacerbated by pregnancy.
- 8. Several years later, around mid 1983, Sheila began suffering with gallstones. She was told she would need to have her gallbladder removed and an operation was scheduled to take place at Bradford Royal Infirmary in Autumn 1983. At the time, not much was known about HHT and the doctors were concerned that Sheila would bleed

- uncontrollably during the operation. The doctors therefore decided to give Sheila Factor VIII as a precaution before the surgery.
- 9. Sheila was told to arrive at the Bradford Royal Infirmary a day early so that the doctors could give her the treatment in preparation for the operation. I sensed something was wrong when I went to visit Sheila as I saw the doctors and nurses rushing around and was initially stopped from going in to see her.
- 10. When I was allowed in, Sheila was sitting up in her hospital bed and was bright orange. It was shocking. Her face was the physical colour of an orange. Sheila also complained that she was hot and she felt hot to touch. The doctors told us that they had given Sheila Factor VIII and that she had reacted to it. It seemed they had got themselves into a panic trying to deal with it.
- 11. Neither Sheila nor myself were specifically told beforehand that she would be given Factor VIII. The doctors had mentioned that they wanted to give Sheila treatment to make the operation safer for her in terms of potential bleeding but it was not explained to us what this would entail, and Factor VIII was not mentioned. The risks of Factor VIII were also definitely not explained to us. We were never told that there was a risk of Sheila contracting Hepatitis or any other infection.
- 12. Sheila was not allowed to have the operation the first time around due to her reaction to the Factor VIII and so she was sent home. Her operation was delayed until Spring 1984, when she was again given Factor VIII as a precaution. Sheila did not appear to react to the Factor VIII on this second occasion and so they were able to go ahead with the operation.
- 13. Around six weeks after the operation, we were called back in to Bradford Royal Infirmary to see Sheila's haematologist, Professor Turner. He informed us that Sheila had contracted Non-A Non-B Hepatitis, now known as Hepatitis C, from contaminated Factor VIII. Professor Turner

said that it wasn't like the other Hepatitis infections and they believed that "it would not do her any harm." The doctors seemed to be sure that Sheila had contracted Hepatitis C from the first occasion she had been given Factor VIII in Autumn 1983, not the second treatment with Factor VIII or the previous blood transfusions for her HHT.

- 14. I do not feel that we were given adequate information for us to understand and manage Sheila's infection. We were just sent away and were not given any more information about Hepatitis C at all. Given what Dr Turner had told us, we certainly were not under the impression that it was anything serious.
- 15. At the time of Sheila's diagnosis, we were also not given any information about the risk of her passing the infection on to others. It was a long time before we were advised about what precautions to take. Given we had been told not to have any more children, Sheila had been sterilised after she had GRO-B. I therefore believed I had no need to wear protection. It was a shock when we found out, years later, that the infection could be passed on through sexual intercourse. From what I can recall, we did not find this out until 2002 when we were given an information sheet by Sheila's liver specialist, Dr Ellis.
- 16. No doctor ever suggested that GRO-B or I should be tested. There were even times when I got the impression that they didn't want us to be tested. After Sheila died, I took it upon myself to ask to be tested by my GP. He asked me whether I really wanted to know, which of course, I did. Fortunately, I was negative. GRO-B, however, has never been tested.

#### Section 3. Other Infections

17. As far as we are aware, Sheila did not contract any other infections.
When Sheila was diagnosed with Hepatitis C, she was tested for other infections, including HIV, which came back negative.

#### Section 4. Consent

- 18. After Sheila was diagnosed with Hepatitis C, I do not think she was ever treated without her consent. She always asked questions of the doctors and wanted to know about her treatment and why things were or were not being given to her.
- 19. However, when Sheila was first given Factor VIII, we were not given any specific details about this treatment until after she had the bad reaction. After this, we were also not informed that Sheila was going to be tested for any infections. We did not realise she had been tested until we were called in and told she had contracted Non-A Non-B Hepatitis. These tests were therefore done without Sheila's consent and meant that the result came as even more of a shock.

## Section 5. Impact

- 20. After Sheila's diagnosis, she initially did not receive any medical care, follow-ups, or support for her Hepatitis C. Then, around 1994, Sheila read an article in the Telegraph about how patients were developing liver disease after having been infected with Hepatitis C through contaminated Factor VIII. We contacted our GP, Dr Stephens, who immediately referred Sheila to a liver specialist at John Radcliffe Hospital in Oxford, as we had since moved to Brackley.
- 21. Sheila had many tests and invasive investigations at John Radcliffe Hospital, including ultrasounds and biopsies of her liver. When the results came back, we were told that Sheila already had cirrhosis of the liver. It was explained to us that this was very serious.
- 22. Sheila was put under the care of specialist haematologist, Professor Jim Wainscott, at John Radcliffe Hospital. For her liver, she was referred to

Dr Ellis who worked at both John Radcliffe Hospital and Horton General Hospital.

- 23. Unfortunately, because of Sheila's HHT and SLE, the treatment options for her Hepatitis C were very limited. Sheila's SLE meant that she was likely to react to various treatments. On top of this, her HHT meant that she was constantly suffering from internal bleeds to such an extent that her blood haemoglobin count was around five or six, which is very low. The doctors wanted to give her hormone replacement therapy ("HRT") to prevent further liver damage but, because this would have brought her blood count down even further, they decided it wasn't an option. Interferon was also mentioned by Dr Ellis; however, it was again decided by the specialists that this would not be suitable for Sheila.
- 24. Due to these complications, Sheila did not receive any treatment for her Hepatitis C or liver damage. She was monitored over time, which included three monthly visits to her consultant, Dr Ellis, and regular ultrasound scans. She also regularly visited the Brodey Centre, which is predominantly a cancer treatment unit at Horton General Hospital, as it was felt this unit was best equipped to provide Sheila's care. However, aside from this monitoring, we were told that there was nothing further that could be done to help Sheila.
- 25. As Sheila's illness progressed, she started to suffer from a number of physical symptoms. The cirrhosis caused her severe tiredness and there were times when she looked absolutely exhausted. She also had fluid on her legs, which meant she had to keep them up as much as possible. Her stomach was also very enlarged as her liver was so swollen; she looked like she was pregnant. Towards the end, she became very jaundiced and looked yellowish in colour. There were also occasions when she was very 'out of it' and didn't appear to know what was going on.

- 26. The Hepatitis C also took a toll on Sheila's mental health. I remember times when she would get very down and be in tears. She had what you could call bouts of depression. However, she would always pull herself together and bounce back, as she was generally very resilient and determined to carry on.
- 27. It is hard to separate the impact of Sheila's Hepatitis C from that of the SLE and HHT. However, her illnesses very much restricted what she could do. Sheila was a very determined woman and she wanted to maintain her independence for as long as she could. By this time, she was working as a teacher for children with special needs and she loved her job. Her doctor would frequently ask her when she was going to retire but she wanted to continue working for as long as possible.
- 28. As Sheila's health declined, she regularly had to take time off to attend hospital appointments. After she eventually retired in 2001, Sheila hated not having things to do and so she organised GRO-B wedding as a project and helped to look after her twin toddler granddaughters.
- 29. Sheila's Hepatitis C meant she was not able to go off and see the world after she retired. For example, Sheila really wanted to go to New Zealand but she wasn't able to because of her illness. We were able to travel overseas a couple of times, including to the USA and Canada; however, this was very difficult. Going abroad was very stressful because we were worried in case anything went wrong. Travel insurance was horrendously expensive so we stopped going abroad altogether and decided to restrict trips away to the United Kingdom. We were able to go to places like Cornwall and we did make it up to Scotland to visit Sheila's family, but even these types of trips became increasingly difficult.
- 30. As Sheila's health deteriorated, I got an allotment close to home so that I had something to focus on whilst also being able to get back to Sheila quickly. I occasionally played golf on a Saturday morning but I always had to be a phone call away in case Sheila needed me.

- 31. Before becoming very ill, Sheila spent a lot of time with friends and family outside the home. She was also involved in the Mothers' Union, attended church every Sunday, and helped me with the allotment, doing things like weeding. However, as her illness progressed, Sheila became a lot less active and went out less and less. Latterly, she sat at home a lot and didn't really go out at all. I got her a wheelchair to assist her to get her out and about. However, she got to the stage where she needed a lot of encouragement to leave the house, even for some fresh air.
  - 32. Sheila would have loved to have spent more of her retirement with her grandchildren. However, as her quality of life worsened, she became too unwell and fatigued to take care of them.
  - 33. The financial consequences of Sheila's illness on our family were never a major concern for us as Sheila's health was always the priority. However, it did make an impact given Sheila had to give up work sooner than expected. Sheila's illnesses also meant that it was impossible for her to get life insurance.
  - 34. The stigma around Hepatitis C was not a major issue for us; however, there weren't many people that Sheila told about the infection. She certainly did not broadcast it and only told people who she had to. For example, Sheila chose not to tell her younger brother as he is disabled and she didn't want to worry him. As time went on, he could see she was unwell but she didn't discuss it with him. Sheila's other brother is a nurse, so she did keep him more abreast of everything due to his medical background.
  - 35. There was one occasion when Sheila had to see a different GP and he asked her if she had got Hepatitis C through drinking. You could have cut the tension with a knife. It was a thoughtless comment and I remember it upset Sheila at the time.

- 36. Sheila didn't have any issues with dental treatment. She lost all of her teeth during her first pregnancy so she didn't have to visit to the dentist regularly.
- 37. Sheila was very careful in relation to her infection but other people were sometimes paranoid about the Hepatitis C. For example GRO-B husband would worry about Sheila cutting herself or having a nosebleed when she was looking after the granddaughters, as the risk was there.
- 38. We did appreciate that Sheila's illness was serious but initially the doctors didn't give us any indication as to how long she had left. In 2011, Dr Ellis said he would only tell Sheila if she asked him, which she did. We were told Sheila only had about a year left.
- 39. Sheila was very determined to carry on independently for as long as possible. Fortunately, she didn't have to spend long periods in hospital and was able to be at home. Sheila's brother who is a nurse helped out and we also had a carer during Sheila's final few weeks. However, the carer would only come for a couple of hours a day so I could pop out to the shops and run any errands. Overall, I received very little support in the months before Sheila died. GRO-B and I were essentially left to take care of her on our own. Sheila died on 5 April 2012.
- 40. Sheila's illness and death has had a devastating impact on our family.

  Although Sheila did have some other health issues, there is a strong argument that she would still be here today had it not been for the Hepatitis C. This has deprived our family of a much-loved wife, daughter and granny.
- 41. I have remarried since Sheila's death. My current wife lost her son and husband around the same time I lost Sheila. Fortunately, we have been able to support each other following these devastating losses. However, the reality is that if Sheila had not contracted Hepatitis C, she would likely still be alive today and here with me now.

- 42. In regards to the impact on GRO-B, things became increasingly difficult for her once she became an adult with her own children. It was devastating for her to watch her Mum's quality of life decline. What she finds most upsetting is that her Mum wasn't able to enjoy her retirement with her grandchildren as a healthy person. Sadly, my granddaughter's main memory of their granny is of her being ill.
- 43. For Sheila, the Hepatitis C was a bit of a silent killer. Her problems with bleeding and low blood counts were more at the fore, so it often felt like her Hepatitis C was on the back burner while her other conditions were being managed. Ultimately though, it was the Hepatitis C that killed her. It is "liver failure from Hepatitis C" that is on her death certificate.

## Section 6. Treatment/Care/Support

- 44. After her diagnosis, Sheila was not offered any specialist medical care or support. I know Sheila had medical problems that restricted any treatments for her Hepatitis C but I feel that there was no information about the infection, from her being infected to her reading about it in a national newspaper. If we had been told or informed earlier about the seriousness of her condition, there might have been some other treatment or precautions she could have taken that may have helped her.
- 45. Much later, once Sheila had taken it upon herself to visit our GP and was referred on to specialists, I feel she was well looked after. I can't say that there was any doctor that neglected her care once they knew she had Hepatitis C. They were all very good at looking after her, and I believe the consultants involved in her care kept each other abreast of the situation. For instance, Dr Ellis, who became Sheila's lead consultant, would have been communicating with other specialists like Professor Wainscott in respect of decisions on treatment and management of Sheila's health needs.

- 46. Sheila wasn't able to try the HRT or Interferon so we will never know how she would have reacted to this. We were not made aware of any other treatments if these were available. It is a great shame she wasn't able to try any of the Hepatitis C treatments as, knowing Sheila, she would have been very determined and persistent with any treatment.
- 47. There was never any offer of counselling or psychological support for Sheila, or for us after her death. We were not told of any support groups. We felt Sheila's situation was very unique as she did not fit into a defined group, such as those with Haemophilia who may have had their own support groups. Because of this, we felt like there was no one there for us as a family and we only had each other for support.

#### Section 7. Financial Assistance

- 48. Sheila received financial assistance from the Skipton Fund. I think we may have found out about the Skipton Fund when Dr Ellis informed us that Sheila might be eligible for some help.
- 49. We made the application to the Skipton Fund in the early 2000s. Sheila got one payment of £20,000 initially due to her having contracted Hepatitis C. The Skipton Fund later told us that Sheila may be eligible for a further payment if she had cirrhosis, which she did. She was given a further £25,000 on this basis.
- 50. I can't remember us experiencing any obstacles when applying for financial support and the application process wasn't difficult. We just had to get the consultant to confirm Sheila's diagnosis, which he did. From what I can recall, we received the payments relatively quickly once we had submitted the application.
- 51. Years later, Sheila started receiving monthly payments from the Skipton Fund. From what I can recall, we started receiving this quite late on,

several years after the lump sum payments. Sheila only received these monthly payments for 2-3 years at the very most before she died. We were never told whether the monthly payments could be backdated.

52. As far as GRO-B and I are concerned, the money Sheila received from the Skipton Fund was not enough to compensate our family for what we have been through. The infection meant we were impacted financially given Sheila had to give up work early. However, more importantly, Sheila's quality of life was not what it could have been in her final years and there's a strong possibility that she would still be here today had it not been for the Hepatitis C. Money is not our priority as there is no amount of money that can bring Sheila back; however, what Sheila was given was in no way adequate to recognise what we have been through.

## Section 8. Other Issues

- 53. Unfortunately, all the personal records Sheila kept were lost when I moved house and remarried in 2016 so I have had to rely on my own memory in writing this statement.
- 54. GRO-B and I are really hoping that someone will be held to account for what has happened as we feel that people at the Department of Health must have been aware of the risks before Sheila's gallbladder operation. From what I have read, it was known that someone in authority in England was buying contaminated blood products from America as early as the late 1970's, so why in 1984 were they still using these contaminated blood products?
- 55. What we have read suggests that Kenneth Clarke was aware of the risks. I also remember the former Prime Minister, John Major, suggesting that the lottery fund, not the government, should compensate victims. It was shocking to read this. We also do not understand why the United Kingdom did not start heat-treating blood products until long after many other countries.

- 56. If the Government knew of the risks associated with these blood products, they should have thrown them away or heat-treated them. In any other circumstance, this is what they would do. It makes us question whether they were only concerned with getting it from the cheapest source.
- 57. Deep down, we are angry. We are angry that Sheila's life was shortened because of the use of contaminated blood products, and that her quality of life was not what it could have been when she was alive. The Government knew that there would be consequences, yet they carried on playing with people's lives. If they had stopped when they knew the risks, would Sheila have been able to enjoy her retirement; would she have had a better quality of life and, most importantly, would she still be alive today?

#### Statement of Truth

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



Dated 29,04,2019