Witness Name: Edward Priestley
Statement No.: WITN1960001
Exhibits: WITN1960002 -WITN1960020
Dated: 12 August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF EDWARD WILLIAM PRIESTLEY

Section 1. Introduction

1. My name is Edward William Priestley and my date of birth is GRO-C 1940. My address is known to the Inquiry.

2. I am now retired. I used to work in the water industry in various roles, most recently as a plant operator. I retired due to disability in May 1987. I live with my wife, Patricia Ann Priestley, whom I have been married to for 57 years. She is a state registered nurse.

Section 2. How Infected

3. I was diagnosed with aplastic anaemia in early 1986. Aplastic anaemia occurs when your body stops producing new blood cells, which puts you at a high risk of other infections and causes bleeding. This condition was caused by the

work I did for Yorkshire Water, which exposed me to harmful chemicals and radiation.

4. After being diagnosed with aplastic anaemia I spent time as an inpatient at hospitals in Halifax and at Leeds General Infirmary before I was transferred to Hammersmith Hospital in May 1986 and remained there as an inpatient until September 1986.

5. Because the anaemia caused me to have difficulty producing new blood cells, I was required to have regular blood transfusions as treatment. From April 1986 to September 1986 I had over 100 blood transfusions, mostly of platelets but also whole blood. There are examples of the records kept of these transfusions in my hospital records **(WITN1960002).**

6. As a result of these blood transfusions I was infected with Hepatitis C (HCV).

7. I was tested for hepatitis and other infections several times during my stay in hospital. I tested negative for Hepatitis B on 13 June 1986 and 17 July 1986, but was never informed of these results or the fact I was being tested. **(WITN1960003).**

8. In early September 1986, my consultant at Hammersmith Hospital, Dr Jill M Hows (now Professor Hows at Bristol University), informed me that I had been infected with Non-A Non-B hepatitis from a blood transfusion. She was quite upset when telling me this as I had had a long battle for survival over the previous months due to other complications of aplastic anaemia. She informed me that having hepatitis can exacerbate the symptoms and complications of aplastic anaemia, and that having both aplastic anaemia and hepatitis can be a fatal combination.

9. Handwritten notes in my hospital records from 9 September 1986, state: Imp [important]: probably viral hepatitis. ?type" and on 19 September, "Hep B negative. CMV and Hep A awaited but probably is non-A non-B...counts

appear to be recovering somewhat following hepatitis which probably caused a temporary suppression." On 24 September 1986, my notes read: "Discharged August 86. While at home – non A/B hepatitis. Readmitted. Discharged 10 days ago. Felt unwell at discharge, general deterioration since then, worse today, fever, shivers, feeling leady and achy." **(WITN1960004).** I understand from these notes that I was suspected of having hepatitis at this time but had tested negative for Hepatitis B, and doctors were therefore considering that I could have non-A non-B hepatitis.

10. A note from sometime in October 1986 reads: "Imp [important] – aplastic anaemia. Multiple transfusions. Episode of previous jaundice." **(WITN1960005).** On 23 October 1986, I tested negative for Hepatitis B, CMV, HIV and herpes. The note on my test result says "Jaundice – multiple transfusion". **(WITN1960006).** At this stage it seems the doctors were starting to make the link between the transfusions and the hepatitis.

11. Until I reviewed my hospital records for the purposes of the Inquiry, the first date I had written evidence I was infected with hepatitis is in a letter from Dr Michael Lafan of the Royal Post Graduate Medical School at Hammersmith Hospital in London, to my consultant at my local hospital, Dr Humberstone, in Halifax, dated 23 October 1986. **(WITN1960007).** This letter is a summary of my medical condition at that time listing aplastic anaemia and hepatitis. However, it does not mention that the hepatitis is from a contaminated blood transfusion.

12. Although HCV was officially called Non-A Non-B hepatitis at the time I was infected, the staff at Hammersmith Hospital called it Hepatitis C when discussing it with us, so I understand the virus had been identified at that time. I believe that the staff there knew it was becoming a public health issue but did not investigate this further.

13. Dr Hows sent further letters to Dr Humberstone in Halifax on 28 October 1986 and to my dentist on 2 December 1986, confirming that I had contracted Non-A

Non-B hepatitis from a blood transfusion and that the virus had caused a serious deterioration in the aplastic anaemia, so I had been admitted to hospital for treatment. In both letters she seemed to view my hepatitis as a temporary infection that I had recovered from, like a cold or flu. In the letter to Dr Humberstone she wrote "His current obstructive jaundice is probably associated with his recent bout [of] transfusion related non A non B hepatitis." **(WITN1960008).** And In the letter to my dentist, she noted: "His progress was complicated in September by an attack of non-A non-B hepatitis, resultant on his blood transfusion therapy **(WITN1960009).**

14. This view that my hepatitis was a brief 'attack' that I had recovered from persisted throughout the next year. In a letter from Hammersmith Hospital to Halifax in February 1987, my diagnosis was referred to as "Severe Aplastic Anaemia and Previous Non-A Non-B Hepatitis" **(WITN1960010)**, and a similar letter from 13 May 1988 noted: "As you know, last year he had a clear cut episode of hepatitis which we attributed to non A non B". **(WITN1960011)**. The end of this letter suggested, however: "I think his symptoms are most likely to due to ongoing non A non B hepatitis."

15. Meanwhile I continued to be tested for other infections. In August 1987, I tested negative for both Hepatitis A and HIV, with the note "HIV – multiple blood products". **(WITN1960012).**

16. The first reference to Hepatitis C (rather than non-A non-B) in my records was on 9 October 1989, when Dr Hows wrote to my consultant at Halifax to note that she had sent off a sample for hepatitis C antibody testing. **(WITN1960013)**. However, 9 months later, in May 1990, it seems that my diagnosis had still not been confirmed. Another doctor from Hammersmith wrote a letter to Halifax stating "I note that he has had an episode of jaundice in the past, either Non A Non B or hepatitis C and we are still awaiting the serology results." **(WITN196014).**

17. I was not warned before receiving my transfusions that blood transfusions carried a risk of HCV. When looking through my hospital records, I did find an information sheet that appeared next to each of my transfusion notes, containing directions for administering a transfusion. **(WITN1960015).** However there is no information on this document about the risk of any infection.

18. After several patients were infected when I was a patient at Hammersmith, the problem was considered so serious that the hospital sent a Dr David Swirsky, Registrar, to work at the blood transfusion service for a week or so to see if there was anything that could be done to prevent the infection from entering the blood, as it was having very serious adverse effects on their haematology patients.

19. Dr Swirsky did not tell us what he found at the blood transfusion service, and I believe he has now sadly died so cannot be asked to testify as a witness in the Inquiry. Other doctors at Hammersmith Hospital at the time might have information useful to the Inquiry and I can list some of these.

20. Staff at Hammersmith Hospital at the time seemed very reluctant to discuss the problems of contaminated blood transfusions. I received no help or information to help me cope with the virus.

21. In my hospital records, there is a form entitled "National HCV Lookback Form LBF1", which was filled in on 15 June 1995. It appears that the form was filled in partially from information found in the blood bank records, and partially from my medical records. The form relates to the details of a platelet transfusion I received on 22 June 1986. I do not know if this is the only lookback form that was completed in relation to me, or if that particular transfusion was the one that infected me with HCV, but it can be inferred from the form that that transfusion was identified as having potentially come from an infected donor. **(WITN1960016).**

22. I do not have any issues with the way my diagnosis was communicated to me. It was done as soon as the doctors found out, and Dr Hows was very

concerned herself when she delivered the news; the first thing she said was "I'm so sorry". I did not feel it was being taken lightly.

23. I was not told of the risks of infecting others at this time. My wife Patricia is a nurse, so she knew from her training the precautions to take and I followed her advice. Patricia was regularly giving blood at the time, but she stopped doing so after my diagnosis just in case she had contracted it as well and could pass it on. She was subsequently tested and was all clear.

24. I always let doctors and dentists know of my HCV status before they treat me so they can take appropriate precautions.

25. I also did my own research on HCV and wrote my own survival guide, and have avoided the many agents which are toxic to the liver as much as I can. For example, I have avoided alcohol and prescription drugs. I have only taken antibiotics twice in the past 30 years, because I know that all drugs are metabolised by the liver and I do not want to put any more pressure on my liver. I only take medication when I have a very serious life threatening infection such as pneumonia. I also avoid drinking out of the same glasses as other people to avoid infecting them.

Section 3. Other Infections

26. I do not know if I received any other infections from blood transfusions, but I think if I had, they would have shown some effects by now - except perhaps in the case of CJD, which was also a risk in blood transfusions at that time.

27. There is a record in my hospital notes that says I tested negative for Hepatitis B and HIV.

Section 4. Consent

28. I believe I could have been tested and the effects observed without my knowledge or consent to monitor the progress of the HCV virus. It was known at the time I was infected that HCV would become the world wide problem it now is, affecting many millions, and there was research on it being carried out at the time.

Section 5. Impact

29. My experience of becoming infected with HCV though a contaminated blood transfusion is somewhat distorted by the severe aplastic anaemia I was suffering with at the time, which was a bigger immediate threat to my life. I spent many weeks in isolation in intensive care at the Royal Post Graduate Medical School at Hammersmith Hospital to treat other serious and more immediate life threatening infections I contracted whilst in hospitals, including aspergillus pneumonia, and septicaemia.

30. It is difficult to tell which of my symptoms are from the aplastic anaemia and which are from the HCV. I am often fatigued, which I know is a symptom of HCV. My HCV is still active, and over the years my HCV symptoms have flared up on several occasions.

31. In 2016, during my last flare up, my liver function was shown to be declining in laboratory tests and I was sent for scans for liver cancer and cirrhosis which are high risk with the virus. The scans, which I was told should have been done within two weeks because of the high risks, took nine and ten months to schedule. I repeatedly chased the hospital and asked for the scans to be scheduled but to no avail. The staff who performed the scans eventually said that there should have been no delay and they could have done them days after they were first requested.

32. Because of the care I take to avoid any agents - alcohol, drugs etc - which affect the liver, my liver function tests show little damage so far. However, in 2016 the scans confirmed that I was a candidate for HCV treatment as the damage is progressing.

33. I was offered a drug, Harvoni, to treat the HCV after the above mentioned scans, but I asked the doctors what the side effects were as I was concerned they could exacerbate my aplastic anaemia. The doctors confirmed that the treatment could cause blood disorders related to aplastic anaemia, so I refused it at the time. Instead, I signed an agreement that I would have regular liver function tests every three months and that if these show the virus affecting my liver more, I can take up the offer of the drug in the future. However, when I asked for liver function tests recently I was told my condition was stable so I did not need them.

34. I have therefore never received any treatment for my HCV but will consider it if my liver deteriorates further and the medication does not pose a significant risk to my aplastic anaemia.

35. As a result of complications from the aplastic anaemia (which, as my doctor says, were contributed to by the active HCV virus), I have been assessed as 80% mobility disabled (I use a walking aid called a rollator to get around and am in near constant pain. I am able to be transferred from my house into a car and out of the car into another house with assistance, but it is painful. I am unable to do it myself and I cannot cope with public transport, which limits my independence.

36. Having the HCV virus has affected my interactions with medical professionals. After my diagnosis, when I was still being treated at Hammersmith Hospital I was taken into a side ward away from all the other patients, and there were stickers all over my medical records to warn staff that I had HCV. I felt like a leper.

37. I always warn my dentists to be extra careful because of my HCV. I have never had any professionals express reluctance to treat me, however. One dentist even offered to treat me for free when I mentioned my aplastic anaemia and HCV.

38. The HCV virus also does have some effects on my lifestyle and relationships to others. I do not broadcast I have the virus but if it comes up I don't try to hide it, and I notice that some people tend to keep me at arm's length.

39. I was forced to retire on the grounds of ill health in May 1987 at the age of 46 after 30 years' service in the water industry. I have a 30 years' service award letter from them thanking me for service over and above that expected of employees. I had expected to work there for about 40 years, so lost about a quarter of my projected pension. My wife and I have lost out hugely financially over the years with a reduced work pension and loss of earnings.

40. In 1991 my wife and I moved to live in rural France, and remained there until 2012. In 2012, the local government was planning to dump nuclear waste near to where I was living, and I was very involved in campaigning against this due to my experience being exposed to toxic chemicals. As a result of this campaigning I was targeted in the community by supporters of the plan, who threatened me and smashed my car. We decided to move back to England as a result of this and also to be closer to my daughter and grandchild.

41. When I first moved to France I was assessed by the government there for disability benefits, and was told I had 100% mobility even though I struggled to walk and used crutches. However, a review was conducted in about 2001 and I was assessed as 80% mobility impaired. **(WITN1960017).** The assessment listed my condition as 'complications of aplastic anaemia, which include Hepatitis C'.

42. I am now registered as disabled in the EU. I require help with every day activities like getting dressed and moving around. My wife has been an

enormous help with this ever since my mobility deteriorated. I feel I would have been lost or in care without my wife. I would struggle to survive. I don't like to think about it. She's not well herself and spends much of her time assisting me.

43. I have two daughters; one nearby, with two grandchildren, and one who moved to Perth in 2009. I see the daughter nearby regularly and she is aware of my condition but has not had much involvement in it over the years as I was in France.

Section 6. Treatment/Care/Support

44. As I mentioned above, I have had trouble obtaining regular liver function tests to monitor the effect of the HCV on my liver.

45. I have been offered no counselling or psychological support to help cope with the HCV.

Section 7. Financial Assistance

46. In 2004 I found out that I could register and perhaps claim some financial help through media reports. I then obtained the necessary registration from the Skipton Fund and was registered and paid £20,000.

47. For many years after this I heard nothing from anyone in connection with the HCV, until about 2016 when I was informed by the Skipton Fund that with my low level of liver damage I would be paid £3,500 in compensation. This was then raised to £4,500 a year later, plus about £500 fuel allowance.

48. This was around the time that I was having a flare up of HCV symptoms and went to get a referral from my GP to see the liver specialist. After a lengthy battle with my doctors to get an appointment for a liver scan, it was confirmed

that I qualified for further payments from the Skipton Fund due to my level of liver damage. I was paid £6,060 for HCV caused disability and in 2018 I was paid a means tested £245 per month. My regular payments were re-assessed again in July 2019 and I now receive about £7,000 per quarter.

49. I can never be compensated financially for being made disabled by HCV for over 30 years. I feel that despite the government's awareness of the contaminated blood scandal (David Cameron made a public apology for it in 2016), I am being made to jump through hoops for the small amounts I am now being paid.

50. However, after many years just scraping by financially, the compensation being paid does help a little. If I had any further compensation I would use this to pay privately for a hip replacement, which I need but do not want to have on the NHS due to my experiences in NHS care.

Section 8. Other Issues

51. I have several documents which may be helpful to the Terms of Reference of the Inquiry.

52. A medical paper I have from the Lancet dated 10 November 1984 which I obtained in 1986 showed that Non-A Non-B Hepatitis (Hepatitis C) could have been screened from donated blood by that date, two years before I was contaminated **(WITN1960018).**

53. I have a page from the French Cancer Research Association I obtained when I was living there at that time which warns sufferers of HCV that all drugs should in the same way as alcohol be avoided if possible. **(WITN1960019).** I had already worked that out for myself in 1986. This warning to sufferers to give them a better chance of survival is not to my knowledge given today in the UK.

54. I also have a medical paper on Gilbert's Disease, a chronic liver condition which shows that fluoride causes the condition to worsen **(WITN1960020).** Fluoride with other chemicals toxic to the liver I have been avoiding also as much as I can to prevent the virus progressing to fatal liver disease.

55. I have not done a large amount of campaigning on this issue but have written the odd letter to politicians, and help others campaigning when I can. I have mainly been focused on campaigning to do with toxic waste and the environment.

56. I don't know what I would like to be achieved by the Inquiry. I know that in the Irish infected blood inquiry, compensation was paid right away, and in the French inquiry, people were jailed for criminal negligence. I am not sure about the compensation awarded because it was all confidential. I am not sure if I would prefer compensation at this point or justice. I used to be a racing cyclist. Suddenly overnight, I'm disabled and in constant pain. I can't take medication to cure my HCV as it could cause my aplastic anaemia to kill me. No compensation can account for how much my quality of life has suffered over the years, my permanent mobility impairment, and 10 years of lost income and pension.

Statement of Truth

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

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

Dated .... 12th August, 2019