Witness Name: Alison Louise Lugg
Statement No.: WITN0966001
Exhibits: Nil
Dated: 5TH JUNE 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALISON LOUISE LUGG

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 08 May 2019.

I, Alison Louise Lugg, will say as follows: -

Section 1. Introduction

1. My name is Alison Louise Lugg. My date of birth is GRO-C 1965 and my address is GRO-C I am single and I am a self-employed gardener.

2. I intend to speak about my father, Arthur Sydney Lugg, and his infection with the Hepatitis C virus (HCV) which he contracted as a result of receiving an infected blood transfusion.

3. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My mother also assists me with names and dates, as I was very young when some of these events took place.

Section 2. How Affected

5. My father, Arthur Sydney Lugg, was born on GRO-C 1945. He was a service engineer. He contracted Hepatitis C after a blood transfusion in 1977 at the Ashford Willsborough Hospital, Kent.

6. In the 1970s my dad was poorly and I believe he was being treated for colitis. When I was young, around 12 years old, I found him on the lounge floor not fitting but shaking. He was curled up in the foetal position.

7. The doctor came and luckily for us it was the locum doctor not our family doctor, Dr Mickey. Dr Mickey had known us all our lives but the locum doctor did not know my dad and therefore he had fresh eyes. He looked at my dad, he said that he is very ill, that he did not have colitis and took him outside. The doctor said that he needed to take my dad into hospital. That evening he had a blood transfusion of about 4 or 5 pints.

8. I think the reason that he had the blood transfusion was that he was weak and had collapsed on the floor. I would that say he was not in hospital for that long, about 3 or 4 days more or less.

9. My mum went to visit him in hospital the morning after the blood transfusion. Dad was sitting up in bed and he looked like he had been on holiday. My mum said that he looked like he had been to south of France. We think he was jaundiced since he was so brown.

10. He said he felt awful and, in the night, during the blood transfusion, one particular pint of blood was physically putting him in agony. This is the only thing that dad told us, that it was thick blood, that it hurt and that it was

painful when it went in. I remember him saying that "he didn't know where to put himself" when they were giving it to him.

11. Considering my age and my brother's age, I think we were about 10 and 12 years old, so it was about 1977, when my father was diagnosed with Crohn's disease after coming back from the Ashford Willsborough Hospital following his blood transfusion. The Ashford Willsborough Hospital does not exist anymore, it is now the William Harvey Hospital.

12. When he came home he was still quite poorly. I think that after a week the doctor came for a home visit, to check on my dad and take samples of his blood. I can't remember if my dad had another relapse after the episode I assisted to. When I spoke with my brother about doing this statement he told me that he definitely remembers dad collapsing and having a shaking fit in their bedroom while I remember that he collapsed in the lounge. Maybe there was more than one episode. Perhaps, that was it and the episode was just one, the one I remember.

13. The doctor who came to visit my dad and who did the blood test was a locum doctor and not our GP Dr Mickey. I cannot remember the name of that locum doctor but he was from Ashford Willsborough Hospital.

14. The doctors at the hospital said that my dad didn't have colitis but they diagnosed him with Crohn's disease and started to treat him for that. Crohn's and colitis had very similar symptoms but Crohn's was quite rare at that time. Because of that, doctors would come home to take blood samples and look at him.

15. I remember one incident where a doctor came to take a blood sample from dad and while doing it, he spilled some blood on the floor. Mum went to clean it up and even if the doctor didn't scream he very affirmatively said to my mum "don't go near it" and "stay back I'll clear it up". The blood did not have yellow stickers on it. I thought it was very odd at the time. Nobody

ever told us that he had anything wrong. Looking back, I wonder if they already knew that he was infected.

16. After that, at some point in 1977, we were told that as a family, we had to keep all cutlery, towels etc that dad used, all separate from the rest of the family. I was young and I didn't question it and neither my mum did. Until one point, after a few weeks or maybe a month, I mixed up dad's cutlery with everyone else's. We realised that we hadn't all dropped dead, lived with it and did not continue separating cutlery and all the other things. My parents got a dishwasher and we assumed that everything that was going in there was then sterilised and we simply carried on with our lives.

17. My dad was a very mild, unassuming, quiet man. He would never complain, he would just carry on. He did it for quite a few years. My brother donated blood when he was old enough and so did I. Dad used to say "they'll never take my blood as it has bright yellow stickers and they put it in boxes". But we didn't know what he meant, what he had been told or he had seen.

18. As a family, I remember that we have never been told that he had Hepatitis C, it just somehow happened. It must have been in 1990s, where it all happened. In 1989, my mother, father and I moved to Northamptonshire from Kent. My brother had recently had a baby so he stayed behind in Kent. It was in Northamptonshire that dad was sent for liver biopsies. I think it all came out then, that he had Hepatitis C. It was just like that, we didn't know why he went for the biopsy or who referred him for the test; we just didn't question it and he didn't want people to worry about his ill health.

19. Between 1977 and 1990 life went on normally although dad was weak and tired. But he didn't complain, he was stoic. He had regular check-ups every 18 months to 2 years for his Crohn's disease.

20. Then after 1989, he talked about his blood being labelled with yellow stickers; we assume he must have been told why they were using yellow stickers, but he didn't tell us. That was his nature.

21. I am not sure when my father had his liver biopsy but I think that it was around the time my son, Joe, was born in 2004. My dad must have gone to the doctors and had a check-up and then they sent him for a liver biopsy. Although, this is all surmised. My dad had his liver biopsy in Northampton General Hospital. I do not know the name of the doctor who performed the biopsy.

22. My mother remembers a nurse saying that my father was "a very ill man". I've questioned my mum since all of this happened because at some point, someone must have said that dad has Hepatitis C, but she can't remember a conversation like that with anyone. After the liver biopsy in 2004 he did not come back to the topic and he did not say anything to me. We don't know what he knew about Hepatitis C but just that somehow, he had it. I quizzed mum about it but she doesn't remember the doctors saying anything.

23. Nowadays something like that would not have happened. I asked to my mum why she did not question it but she said that in those days you just carried on and you didn't question things.

24. My dad was always the same up until 2006/2007, when we really noticed that he started to look poorly, thin, drained and weaker. By then he had lost his job and made redundant. He then started working for Hillary's, a company that fit blinds in windows. He was an agent for them which was good but because he was weaker, I went to work with him. For about a year, I lifted his tool box and the blinds that were heavier. That's when we eventually told him that he needed to go to the doctor. He then had some very invasive tests on his bottom.

25. By this point there was quite a lot wrong going on with him. I am reminded of a time when mum and dad went for walk and he had such pains in his chest. The doctor, dad's new GP in Northamptonshire Dr Coombs, told him he had angina and that he needed to bring tablets with him.

26. So, my dad went to see a consultant at Northampton General hospital on 29 January 2008. He was then sent to a clinic in Daventry a week or two later. Whoever saw my dad there gave him a final inspection, with a finger up the bottom and with the use of a camera. Although my mum went with my dad to Daventry she did not go into the room with him. My mum and I have talked about it since and that's when we think that they said he had bowel cancer. It was a week or two later when they said this officially but it was too late for surgery.

27. Even at this time, as far I was concerned, Hepatitis C was not mentioned and it was all about his cancer. His kidneys were also playing up. He got stents in his kidneys. He was in and out of hospital for weeks from the end of January 2008 to just before he died. Our main aim was to get him home because we thought his health would be better and that he would eat better. In hospital, if you were asleep the nurse didn't wake you, so you'd miss a meal. He had a stoma bag and he had tubes coming from both kidneys into the bags. He was in a bed when we did get him home.

28. But he was too poorly and he had to go back to the hospital; he was in excruciating pain. He was admitted into the oncology ward and from there he was then taken through to radiotherapy. They connected him up to chemotherapy but as soon as he started the treatment he died there and then. It was 6 May 2008, 11 years ago. It was an awful death, horrible; according to his death certificate he died of bowel cancer and colitis.

29. We didn't do anything about it. We just lived with it. I remember being told he had contracted it, had it and lived with it.

30. Before his blood transfusion my dad was a healthy man but he had stomach problems. He was tired but mostly he had problems going to the toilet. It was horrible and had a very bad smell, like diarrhoea. He was embarrassed to stay with people because of the smell. He had never had a blood transfusion prior to 1977 and he did not have any bleeding disorder such as haemophilia.

31. Since this has all begun, I have asked mum regarding other HCV risk factors. My father was not a sexually promiscuous man and he never took drugs. He had no tattoos or piercings. Not my dad.

32. To the best of my knowledge no risks were explained at the time of my dad's blood transfusion. I was not told anything about where the blood came from.

33. I feel very guilty for not having done anything earlier, for years, when he was alive.

34. We do not currently have my dad's medical records but we have applied to two healthcare authorities to get them. His medical records would probably be a massive box load. We asked the hospital for his records when he died. I saw my dad's GP very soon after his death. I asked for my dad's medical records because I thought it would be interesting to read them and he said that the records had been sent off to central records. I have an awful feeling because I looked up online and it says that after 10 years deceased patient records will be destroyed and I am afraid that my dad's medical records may be destroyed.

35. I've been making my mum go through every document that she has. She has moved twice since dad died 11 years ago. Three years ago, she moved again. It's been a long time since my dad has gone. My brother dealt with his estate and he vividly remembers seeing a document that stated that dad has Hepatitis C but we now can't find it. Perhaps the document was related to life insurance as he would have had to disclose any medical conditions.

Section 3. Other Infections

36. I do not know if my father was tested for HIV or HBV.

37. My dad had terrible problems with his eyes. He went for a general eye inspection in the opticians. The optician said that he needs to go to the

hospital for a further scan. Then dad went to the hospital for the scan and from then on, he just kept going. He had an eye disease. I always say glaucoma but I do not know where I got that from. He never let my mum go with him in the room. We just picked him up and took him there. They were big injections with bits into his eye so they can see. You cannot see anything after those.

38. Looking back now I wonder whether all these things are all connected but I do not have an answer. The question we ask ourselves is, what would have happened if he didn't have all that when he got cancer. We wonder whether it made him weaker and whether he could have survived. Again, I don't think it's a symptom of cancer but we do not have any answer to these questions too.

39. My dad had psoriasis for years as well. He had really bad, itchy skin and he used steroid cream. Could be this be a side effect? I'm not sure.

Section 4. Consent

40. I don't think my mum was even at the hospital at the time that my dad was given his blood transfusion. We don't know if dad signed anything, or consented. We were probably not even aware what was going on. We stayed at home and they just took him because it was late at night. To the best of my knowledge nothing was explained to us.

41. We do not know if my father was told of the risk of having a blood transfusion. We assume that the night he was ill in 1977 he just let them do it.

Section 5. Impact

42. My father's infected status did not impact upon his treatment or dental care. He was a bit embarrassed by it all which is probably why he never spoke about it. I remember one incident in the 1990s when Nicola came over. It

came up in conversation that dad had Hepatitis C. Nicola's little girl was playing near dad and Nicola told to the little girl to come over to daddy and to get away from him. I recall my mum saying it was ok as "you can't catch it".

43. I would like to say that it was my dad's Hepatitis C that made him weak but I can't say it as I'm not a doctor. Considering his character and personality, he was such a lovely man and he just dealt with it. I would say he was stressed, but I wouldn't say that he was depressed. He was frustrated because he couldn't do what he wanted.

44. My father had a loss of appetite but we assumed that this was because of the Crohn's disease.

45. My dad was not generally forgetful. I don't remember him forgetting names and I don't think he suffered from any brain fog.

46. He was always a fatigued man, not weak. Because we knew he wasn't that well, we never made him do anything. I remember we once went to Menorca and he sat for most of the outdoor activities, but I think that this had to do with his cancer not HCV.

47. He never had any problems with the dentist. I don't know if my dad's doctors told him to tell his dentist about his HCV infection. My dad had rotten teeth and he always said that it was because they didn't have fluoride in toothpaste when he was younger. He did go to the dentist regularly.

48. My dad didn't really have friends. He didn't go drinking at the pub. He wasn't sporty. He would go to work, have his evening meal, watch some television and then he went to bed. He lived for his family. He was a family man. He did say he didn't want to come to events because he would have to stay with them. He hated staying with people because of his stomach problems. There was quite a lot of blood in his poo so he didn't like that.

49. I didn't notice any changes in his relationships or the way he was dealing with his family as a result of the Hepatitis C. My dad was always a quiet man to me. To the best of my knowledge there was no stigma associated with my father's diagnosis of HCV. I didn't even think about it.

50. To the best of my knowledge my father's sex life was not impacted by his hepatitis C and neither he nor my mother were told not to have unprotected sex.

51. I didn't think about it when I was a teenager as I had other things on my mind and now I am sorry about it. I always knew he was ill and weak with the other things. We always used to joke that he only had 10 years to live but he always outlived it. My brother on the other hand, he was always worried that our dad was going to die. My brother said that he was worried he would catch it but I never had this thought.

52. Both myself and my brother donated blood. I started in 2004 because I wanted to give something back after the birth of my son. My brother started giving blood in his 20s, I think he would have been 22. My brother was a prolific giver of blood. He got badges for giving the most amount of blood that you can possibly give. To the best of my knowledge we were not blood tested before we started giving blood. We just filled in a form. I assumed that they would test the vial and if it came back positive for something then it would be rejected.

53. When I worked with my dad at Hillary's blinds, he cut himself and he bled. He didn't freak out or anything, he just wrapped it in blue tape and dealt with it.

Section 6. Treatment/Care/Support

54. My father did not take anything for his Hepatitis C and he didn't take anything for his Crohn's disease too. He took aspirin for angina for his heart.

55. Again, dad was quite private. He kept most of it from us to stop us from worrying. The thing is that Crohn's was rare, so they did a lot of tests and took a lot of blood from him. They were always trying to probe him and carry out colonoscopies. It was so painful and every time he was physically drained. Until one day he said that it was enough "I won't be a guinea pig for you anymore". This was more in the 1980s than 1990s.

56. By time we moved to Northamptonshire my dad was not on drugs or treatment for his Crohn's disease. I remember him telling me, that it got better because they had stopped "messing about with him", as he put it and his Crohn's went into remission. Everything was fine apart from the unpleasant diarrhoea but simply he lived with it. He used to have to wait for a colonoscopy every 18 months to 2 years.

57. I don't know if any medical staff offered my dad any psychological support. He would have heard about it privately, when the doctors visited him but he didn't share that with us. I don't think my dad was ever offered counselling and I don't think he would have taken that up even if he was offered it.

Section 7. Financial Assistance

58. We did not receive any money from any of the Trusts and Funds set up to distribute payments. We knew nothing about them. I wish we had.

59. There was no financial impact on my family because Dad carried on working. He had a good career until he was made redundant. We were not rich but we weren't bad off.

Section 8. Other Issues

60. I have been asked whether I have any expectations from the Inquiry. I want to know how many people were infected. I just want dad to be counted in with everyone else: it was wrong, it was and it is still sad but I suppose I just want someone to say sorry.

61. There are no other issues in relation to which I consider that I have evidence which will be relevant to the Inquiry's investigation of the matters set out in its Terms of Reference.

62. I have not had any involvement in earlier litigation concerning the use of infected blood products or blood, or in other inquiries or investigations, or in campaigning in relation to such matters.

Statement of Truth

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

Signed GRO-C

Dated 5/6/19