Witness Name: Anthony Owen Hughes
Statement No: WITN00262
Exhibits: NIL
Dated: 24 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ANTHONY OWEN HUGHES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 November 2018.

I, ANTHONY OWEN HUGHES, will say as follows: -

Section 1. Introduction

1. My name is Anthony Owen Hughes but I am mostly known as 'Tony'. My date of birth is GRO-C 1944 and my address is known to the Inquiry. I am a retired university academic and I have been married to my wife Jill for 55 years. We have two children together, a daughter and a son.

2. I intend to speak about how being infected with hepatitis C and the accompanying treatment has had an impact on my life.

Section 2. How Affected

3. On the 7th November 1988 at approximately 4AM I was rushed to Southmead Hospital in Bristol with severe rectal bleeding. The doctors in

the Accident and Emergency department could not initially ascertain what the cause of the bleeding was. I was admitted to a ward for observation.

4. By the end of the same week they were still unsure what was causing such excessive bleeding and as the blood was rushing out faster than the doctors could control it, I was taken into surgery so they could examine the actual cause of the bleeding.

5. I was 44 years old at the time. This operation occurred 30 years ago and I am fairly sure my medical records would no longer be attainable.

6. I was in surgery for approximately 6 hours and the procedure involved the removal of all internal organs below my diaphragm so they could be individually examined to identify the source of the bleeding.

7. The chief surgeon believed the bleed originated from my colon but was unable to identify the precise spot(s). The colon is quite large so they had to remove a large portion of it for examination, leaving only a little smaller part of my colon to join back together.

8. During pathology tests on my colon they discovered two increasingly large spots of blood where the bleeding had come from. I was told that the bleeding was as a result of an E.coli infection which had damaged my colon.

9. I remember 2 days prior to the hospitalisation, this being the 5th November 1988, I had eaten hotdogs at a school barbeque which in all probability caused the infection and rectal bleeding.

10. I remained in Southmead Hospital for a week after the operation and I gradually regained my strength. During this time I was receiving blood via a drip to restore all the units I had lost upon my arrival in the hospital and during the surgery.

11. I received a blood transfusion prior to the operation and it may have been two transfusions. Subsequently, I was also given a further thirteen units of blood during and immediately after the operation. This in itself shows the severity of blood loss suffered as a result of the E.coli infection.

12. After the operation I returned home and continued with normal life. I believed the operation was a success as the doctors had discovered the cause of the bleeding. I had three month's leave from work to recover fully and I resumed work as a senior academic at Bristol University in February 1989.

13. Thereafter all appeared to be well with my health. I was getting older and becoming more tired than usual but I associated this with age and believed it to be a normal part of growing older.

14. I continued playing all the sports that I had been doing prior to the operation until the early 1990's which is when the lethargy and fatigue got noticeable.

15. In the summer of 1995 I returned from holiday to find a letter from the Regional Blood Transfusion Service (RBTS) which said they were doing a 'look-back programme' for the period of 1986-1990 and they wanted me to get in touch with them. They didn't explain why but my professional knowledge gave me a strong clue as to what it was about.

16. I received my transfusion in 1988 which was in the middle of the Regional Blood Transfusion Service's concerned period. I had previously heard about the infected blood issue and I knew they were unearthing all these different cases at the time.

17. In 1988 the general assumption was that blood was screened and checked prior to usage and that there was a genuine clean supply of blood in British hospitals. They then realised in the early 1990's that the blood wasn't clean.

18. I was aware of this at the time and had read a few articles but I didn't give it any serious thought until I received the letter from Regional Blood Transfusion Service prompting me to get my blood tested.

19. I believe the Regional Blood Transfusion Service started the lookback programme because most blood donors are very regular and when they looked at the units of blood subsequently found to be infected, they were able to identify that a specific unit came from someone who had hepatitis C. However in 1995 they claimed to not have known about this before.

20. Consequently, I visited the hospital and met with a consultant who arranged for my blood to be tested. It took around three weeks for the doctors to establish that I did indeed have hepatitis C.

21. Despite the 3-week long delay in obtaining the result, I waited patiently and refused to fall to pieces despite knowing that if a patient was given blood that had been contaminated with hepatitis C there was a 99.9% chance of contraction in that patient.

22. In the third week of waiting, the head consultant of the Blood Transfusion Service contacted me whilst I was at work and said he wanted to come to my office to inform me of the results.

23. I instantly knew that the only reason he would want to deliver the news in person, and indeed doctor to doctor, was that it was bad news.

24. The consultant came to my office along with an entourage which I imagine was for moral support. In these situations there is always uncertainty as to how a person will react to such devastating news and he was probably worried as to how I would respond.

25. He then told me it was bad news as the test results came back positive for hepatitis C but that there was nothing that they could do to treat or manage it. I know he wasn't enjoying the meeting which is probably why he brought his entourage along with him.

26. What was most appalling was that the Blood Transfusion Service were doing this look-back programme and informing people of their hepatitis C and indeed HIV prognosis but telling them that there was nothing to be done.

27. When I asked the consultant who came to deliver the bad news what the survival rate for hepatitis C was he told me that I 'wouldn't live to see the next century'. At that time it was generally believed that there was a 5 year life expectancy rate for hepatitis C patients.

28. The whole process wasn't done in a patient-centred manner at all and there wasn't any treatment discussed or given to me by the consultant so I was simply told and left alone to deal with the aftermath.

Section 3. Other Infections

29. As far as I am aware I wasn't infected with any other viruses separate to that of hepatitis C.

Section 4. Consent

30. I consented to having the blood transfusion prior to my operation in 1988, however I was not made aware of the risks associated with the transfusion such as being infected with HIV, hepatitis C and other viral diseases.

Section 5. Impact

31. I wasn't offered any counselling upon being told I had contracted hepatitis C as a result of my blood transfusion in 1988. My GP was not able offer any help.

32. Even though having hepatitis C did not affect me physically, it has had a predominant effect on my marriage as I have always had to live with the fear of passing the infection to my wife Jill.

Impact on Employment

33. In the wake of my hepatitis C diagnosis I remained under the care of Bristol Royal Infirmary clinicians, Dr Barry and Dr Gordon, over various time spans. I decided to soldier on valiantly without any chemo-based drugs and I did so until 2014. However I had to retire earlier than expected.

34. I was referred to the University occupational health department where I already knew the consultant and we both agreed, in light of the 5 year expectancy rate, that I would cease working so I retired from full time employment in the summer of 1996.

35. I moved to the medical research side of things in a part-time working capacity. A lot of people relied on me but I couldn't go back to full time work.

36. Later I taught classes for teachers instead and it was good because even though it was different to my previous work it gave me a new interest at least. I wouldn't work more than 10 hours per week but in 2010 I had to give up working completely.

Impact on Wife

37. There has always been an impact on my wife, Jill. When I received my diagnosis for hepatitis C Jill was also tested but fortunately her test results were fine.

38. We always knew thereafter that there was a risk of Jill contracting hepatitis C from me, particularly through sexual intercourse which was a normal part of our marriage.

39. Jill wasn't offered any counselling and I think that should have been in the remit of a general practitioner. It should have been included in my general

care. It was hard on her during those times and she should have been given some form of support too.

40. When I reduced my working hours after diagnosis, Jill had to continue working as a headmistress even beyond her planned retirement age. As a result there was a lot of financial insecurity.

41. Jill had to shoulder the stress of being the sole worker in our household and the devastating reality that (at the time) it was believed that I only had approximately 5 years to live.

Section 6. Treatment/Care/Support

42. After I was informed of my hepatitis C infection by the head consultant at the Blood Transfusion Service, I went home to tell my wife, Jill and later on our 2 children who were in their early 20's at the time.

43. It was hard at first as the only advice I can recall receiving was to ensure that I carried a pair of rubber gloves around with me so if did bleed anywhere I could give them to whoever came to attend to me.

44. My wife and I were also warned about hepatitis C contraction via shared toothbrushes and sexual contact but we were told this as part of basic public health by our GP's rather than the Regional Blood Transfusion Service.

45. Shortly after I was diagnosed with hepatitis C, I was contacted by Dr Barry in the haematology department within Bristol Royal Infirmary whom I knew quite well. He said he had received a phone call about my case and wanted me to visit him.

46. Dr Barry was very kind to me and he wanted to me to know that he was there for me and as he had expertise in hepatitis C I could talk to him whenever I needed to. Shortly after our meeting I became his patient.

47. When I started visiting Dr Barry's clinic I found that it was difficult separating what I knew as a patient and what I knew as an epidemiologist myself so they were somewhat entangled.

48. Dr Barry and I were both University academics so I didn't feel as though I was left to struggle on my own as we were part of the same world. I conducted my own research and looked through the literature on hepatitis C to find out more about it.

49. I came across vast amounts of international data which stated that most of the drug abusers that acquired hepatitis C died within approximately 5 years so naturally it was just assumed that those that had been infected would die 5 years after contraction too.

50. In 1995 the Blood Transfusion Service found all those that had been infected with contaminated blood and then left us in a pile with absolutely no treatment to offer.

51. However at one point in the 1990's treatment became available in the form of chemo-based drugs, namely Interferon and Ribavirin. Both drugs had terrible side effects and I was adamant that I would not use them for that reason.

52. In 2000 Dr Barry retired from Bristol Royal Infirmary and was replaced by Dr Fiona Gordon (a consultant hepatologist from Kings University Hospital). She took over my clinical care from her arrival in Bristol.

53. I informed her of my decision not to have any form of treatment that would interfere with my quality of life. I had seen the effects of Interferon in cancer patients and I knew how debilitating it could be.

54. In the same year I had a liver biopsy and despite the fact that I had informed Dr Gordon of my choice not to have chemo-based treatment the medical team tried to prescribe Interferon in an effort to persuade me to take it, however I refused.

55. I had fibro scans every 3 years to determine the disintegration rate of my liver. I also had private medical insurance which allowed me to have a biopsy procedures at a private hospital and they discovered that my liver had holes in it which indicated the early stages of cirrhosis.

56. The doctors continued to monitor my liver. But apart from showing the natural signs of being cirrhotic, nothing drastic had to be done at that stage.

57. In 2014 I had an annual check-up with Dr Gordon in Bristol Hospital and either she or her husband were on the research panel for a drug called Harvoni which was to be used to treat hepatitis C.

58. At the time, Harvoni was said to be the 'magic treatment' from the United States which would provide the 'cure' for hepatitis C. I was aware of it as it had been discussed in the medical literature I had been reading and I saw it as a possible form of treatment for me.

59. In the UK the NHS combined Harvoni with Ribavirin as a form of treatment for hepatitis C. This was mostly due to the cost of Harvoni as they couldn't afford to have it as a sole form of treatment. Dr Gordon believed I would decline the joint course because it was to be taken with Ribavirin which I had spent years avoiding.

60. However, I challenged the method of treatment from an academic perspective and told Dr Gordon that I wanted to have the Harvoni treatment and they could cut the course of treatment in half so I would avoid the Ribavirin. She agreed as it was a cost effective option.

61. I wasn't allowed to begin the Harvoni treatment until my fibro scan results showed early signs of cirrhosis. It was shocking that I had to wait until my liver started getting worse before they could provide me with the Harvoni treatment to cure the hepatitis C that they originally caused!

62. Nevertheless, I began the Harvoni treatment as part of the NHS research programme. It was also given to other patients who were also monitored severely.

63. I had taken a look at the evidence for Harvoni and I told Dr Gordon that I was happy to use myself as an experiment to test its efficacy in clearing the hepatitis C infection.

64. Although Dr Gordon agreed to my chosen course of treatment I couldn't initially have the treatment at the Bristol Royal Infirmary as I didn't live within the immediate vicinity of the hospital. I had to be transferred to Southmead Hospital which was within walking distance from my home.

65. Unfortunately, Southmead Hospital lacked the facilities to accommodate my hepatitis C treatment as it would have cost approximately £40,000, a figure they couldn't commit to.

66. Dr Gordon's equivalent in Southmead had informed me upon my transfer that he could deliver effective treatment but in the end he was unable to deliver at all. It almost felt like a postcode lottery to receive good treatment.

67. I was transferred back to Bristol Royal Infirmary and began the Harvoni treatment under Dr Gordon. I took one tablet a day and I don't think I had many side effects from it at all.

68. Even though I had a hard time separating what symptoms were attributable to age and treatment, I don't believe I suffered any physical ailments or issues during the course of the Harvoni treatment. Thus, in isolation, I don't feel it had an immense impact on my physical abilities.

69. I had regular blood tests at Bristol Royal Infirmary as well as Viral Load tests to determine the presence and measure of hepatitis C in my blood. Dr Gordon wanted to ensure that the treatment was working to effectively eradicate the hepatitis C virus.

70. In the first week of my 2 month Harvoni treatment my Viral Load was 6,000. It was monitored every week thereafter and dropped to 100 in the second week, it fell again to 40 the following week and in the final week the test showed that the hepatitis C virus was undetectable.

71. I was very pleased with the result of the treatment as I didn't anticipate the rapid rate at which the treatment worked. As it currently stands there is no evidence that the hepatitis C virus is present in my blood.

72. I believe as a former academic I had the advantage of being able to advocate for myself so I could have the Harvoni treatment as it wasn't well known at the time. What is most saddening is that others were unable to have Harvoni due to it being an incredibly expensive form of treatment on the NHS.

73. Since I was informed that the hepatitis C virus is undetectable I wouldn't say I have felt remarkably better, despite feeling generally well.

74. As I am now approaching 75 years of age I believe my fatigue, lethargy and on some occasions, short temper is linked to age as opposed to the lasting effects of the treatment.

Stigma

75. I honestly believe there was a lack of information for patients in UK about the hepatitis virus.

76. I met a wide variety of people in the hepatitis C clinics most of which were drug users and over the years I realised I was cast with the same view despite having never used drugs.

77. I felt the most stigma in the early stages when the hepatitis C treatment centre was within the sexual health clinics so everyone would look at us differently.

78. People would say to me in the waiting rooms that I didn't look like a drug user but they still believed we were all part of the same group so there was definitely a stigma attached.

Section 7. Financial Assistance

79. The Skipton Fund came to my knowledge after the first Court case. They wrote to me and requested for my bank account details so they could arrange for payments to be sent to me.

80. The first payment I received from the Skipton Fund was £20,000 as a lump sum during the mid-2000's. The payment was somewhat unanticipated but went towards a 6 week trip to Australia which was nice for Jill and I.

81. We both had a lovely time in Australia as it was an experience we could both share and enjoy. Also approximately 3 years ago the Skipton Fund began paying me £1,000 each quarter.

82. Although I believe it is good that the government were and indeed are providing financial support, I think it's still rather pathetic considering the wide ramifications triggered by this far-reaching infected blood issue.

83. If the government believed they needed to provide financial recourse then, in my opinion, it should have most definitely been more than what was given. Yet I imagine this was because they didn't feel they were obliged to as we were not in a litigation situation.

84. Although the payments have helped, I am not sure how long I will continue to receive payments from the Skipton fund.

Section 8. Other Issues

85. My view is that if I didn't receive the blood transfusions in 1988 I would have died so I can only be grateful, despite the circumstances that arose thereafter.

86. I believe someone tried to do a good deed and they were working on the best of their knowledge at the time so I cannot bear any malice to the National Health Service.

87. Some of the activities that I did 30 years ago I still do today. I wasn't tremendously scared at the time of my hepatitis C diagnosis or subsequently during my course of treatment because as a former medical academic I was somewhat aware of what we were dealing with.

88. My wife would say my health is not wonderful but I believe I have always been very resilient and have taken the rough with the smooth over the years.

89. Although I am not severely upset by all that has happened I can understand why people are upset as it has affected everybody in a myriad of ways.

90. What we all have in common is that we were all infected with something we shouldn't have been but the way we have all approached it has been different.

91. There was someone, somewhere in the system that knew about the risks of contracting hepatitis C from blood transfusions and blood products and that person or indeed set of people should have been made to stand up and admit their errors as was the case in other countries.

92. I don't believe I would derive any comfort from finding out the person or group of people that caused all this. I was adopted at birth and I haven't

ever had the urge to find out who my birth parents were because I believe there is no point.

93. There is a risk that it could be more damaging than healing for there to be a person to blame. I suspect it was a Minister of Health but I doubt they would ever have learnt from their mistakes.

94. As a former academic, I wasn't able to do anything about the infected blood issue as I didn't know about it as it was occurring. But someone definitely knows what went on and that is what I hope this Inquiry brings to light.

95. Despite being rather ambivalent about the how much information the Inquiry can retrieve and uncover, I do hope that this Inquiry can be successful in unearthing all the hidden factors that led to this issue.

96. Lastly, the Department of Health should be held to task on its slowness to act and respond to the issue in the first instance. I imagine they will always blame it on the lack of funds as a contributory factor.

Statement of Truth

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

Signed GRO-C

Dated 24th April 2019