Witness Name: Alan Kilcoyne
Statement No: WITN3841001
Exhibits: **WITN3841002-10**
Dated: 8/3/ 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALAN KILCOYNE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 21 November 2019.

I, Alan Kilcoyne will say as follows: -

Section 1. Introduction

1. My name is Alan Kilcoyne. I was born at GRO-C GRO-C and my date of birth is GRO-C **1971**. I reside in GRO-C and my full address is known to the Inquiry. I married my wife in 2009 and I have no children. I am currently working as a primary school teacher.

2. I intend to speak about my infection with Hepatitis C ("HCV") after receiving blood products as a child. In particular, the nature of how I learnt about my infection, how the illness has affected me, the treatment I have received and the impact it has had on my life.

3. I confirm that I have chosen not to have legal representation and that the Inquiry Investigator has explained the anonymity process to me. I am not seeking anonymity as I wish for my story to be known in full.

4. The Inquiry Investigator has explained to me the 'Right to Reply' procedure, and I understand that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

5. I wish to acknowledge that naturally as time passes, memories can fade. I have been able to provide approximate timeframes for matters based on life events. However, these timeframes should be accepted as 'near to' rather than precise dates.

6. Some particulars referred to throughout this statement have been passed down through conversations I have had with my mother, who has recently passed away. It may not necessarily be personal recollections of mine as my memory cannot accurately revert back to the point in question. This is as a result of treatment I have received for my HCV having caused partial memory loss.

7. I have constructed this statement through memory, with the addition of limited medical records I have been able to obtain from the Royal Free Hospital, Hampstead, London. I also applied and received medical records from St Mary's Hospital, Paddington, London, but they only provided online access to a limited amount of records.

Section 2. How Infected

8. Between my birth in 1971 to 1978, as far as I knew, Haemophilia B ("Christmas Disease") was never a consideration in my mind. Christmas Disease is a rare genetic disorder caused by a deficiency in the blood-clotting factor IX.

9. The only indication that I had haemophilia B was when I underwent eye operations and would bleed profusely, which was much more than a normal patient. Also, the nearest relative to me who had the condition was my distant cousin, so there was no significant trigger for me to

realise I had this condition. I do not remember receiving treatment for my Haemophilia B between this period.

10. However, in 1978 aged 7 years old, I had a tooth extraction at my local dental practice in Willesden, North West London. After my operation, I returned home and bedtime was normal. In the middle of the night, I remember waking up covered in a vast sheet of blood which derived from my mouth, so I ran in panic into my mother and father's bedroom. My father who is blind, reached out to settle my screaming and was completely horrified by the sheer amount of blood.

11. My parents rushed me to St Mary's Hospital, Praed Street, Paddington. Here, I later discovered that I had haemorrhaged after my surgery, and received treatment of Factor IX coagulant in an attempt to stop or reduce the heavy bleeding I was experiencing. Due to me only being 7 years old at this point in time, it would have been my mother who gave informed consent to being treated with Factor IX for my haemorrhage in 1978.

12. I believe it was at this point in 1978 that I was given contaminated blood product, where as a result, I was infected with HCV.

13. From my limited medical notes, I have identified the following letter which outlines my medical problems for the reader to assimilate. A letter dated 10 November 1999 from Dr Jason Coppell MA MRCP at the Royal Free Hospital to Dr T Wilson Consultant Neurologist at the Royal Free Hospital (Exhibited at **WITN3841002**, extract below) states:

Para.1	*'I would be grateful if you see this 28 year old man as soon as possible. He has mild haemophilia B and contracted Hepatitis C genotype-1, as a result of exposure to blood products before screening was available.'*

14. I do not have tattoos, I have never taken intravenous drugs and have never had any dental work outside of the United Kingdom. I do not believe there was any discussion prior to the treatment about the risks that were associated or known about with Factor IX.

15. Shortly after my dental extraction I was diagnosed with mild Haemophilia B ("Christmas Disease") by Dr Dodsworth at St Mary's Hospital, Praed Street, Paddington in 1978. My mother's family has a history of this coagulation deficiency.

16. From the point of diagnosis, I was treated differently to all the other children, which was largely positive. The teachers and children were fully aware that I had medical issues and always took care to keep an eye out for me. I went to secondary school in Kenton, North West London in a private taxi each school day rather than public transport, which was in an attempt to minimise the risk of injury to myself and prevent any bleeding.

17. Also, my school had a medical plan with the local hospital (Northwick Park Hospital) in Harrow, to ensure there was a sufficient amount of blood products available just in case a problem had occurred with my bleeds. For example, if I was involved in an accident whilst out playing. My bleeds were usually internal, on my wrists, elbows, ankles and knees, except for an episode of passing blood in my urine when I was around 14 or 15 years old.

18. I guess the one thing that sticks in my mind is when I was not allowed to go on a skiing trip organised by my school. I remember being a bit hurt by this, but in hindsight I can now definitely see there were risks to the whole party if anything went wrong.

19. I truly started to realise I was treated on an individual basis at the age of 11, where for this reason, my parents told me I had haemophilia B. I did not know what haemophilia was when I was in primary school as I

did not know any other children who had the disorder It was not until I was told by my parents, that I knew I had the disorder personally. It all fell into place in my head and it would explain my bleeding episodes.

20. I remember receiving Factor IX as treatment for my bleeds throughout primary and secondary school. When I was an out-patient and had injured myself in some way, my mother and I would visit Doctor Dodsworth the haematologist on duty at St Mary's for treatment until around 1990.

21. I would normally visit the Haematology Unit where they would ordinarily have sufficient supplies. However, on one occasion, when I was in casualty and out of office hours, they had limited supplies in stock so I had to wait for the Factor IX to arrive by courier. I would sit in a room and watch her in the laboratory next door through the glass wall, mixing up a solution in jars filled with cotton wool, plasma and saline. It would then be extracted into a syringe and injected into my arms and hands.

22. I would also receive Factor IX for the purposes of coverage during operations. For example, in 1980, I had a haemorrhage in my right eye, multiple eye surgeries, and a tooth extraction in 1986 aged 14 years old.

23. In January 1991 aged 19 years old I was working at a cinema in Marble Arch London, when I suddenly felt lethargic and light headed. I thought this was odd as I never felt this way. It was so out of the blue. That being the case, I went to see my local General Practitioner Doctor Shah in Sheldon Road, Cricklewood, NW2. I cannot recall the exact name of the practice but it is now called The Sheldon Practice. Here, my GP referred me to Willesden Hospital, who took a blood sample for the purpose of analysis.

24. As a result of the blood sample taken, my mother rang me later on the telephone, to tell me that the GP had told her my blood count outlined in my haemoglobin level results was extremely low at around the count

of 6. I felt alarmed at hearing this, and was referred immediately to St Mary's Hospital. They admitted me and placed me in a single room.

25. The doctors could not ascertain what was wrong with me, so in an attempt to cure me I was given a series of blood transfusions over the course of the weekend. I cannot remember the exact number of transfusions I received. It was anything in the range of 3 to 10, but I am unable to specific the exact number of units used.

26. To clarify and make my position clear, alongside having initially been given contaminated blood product in 1978 (see paragraph 12), a letter contained in my medical notes confirms that I may have also been given contaminated blood during the blood transfusions I received at St Mary's Hospital in 1991. The letter dated 12 November 1999 from Christine Lee Professor of Haemophilia to Miss R Green Housing Officer, (Exhibited at **WITN3841003**, extract below) outlines:

Para. 2	*'This man has Hepatitis C infection as a result of previous transfusions with unsterilised clotting factor concentrate.'*

27. I was diagnosed with Red Cell Aplasia in January 1991, which is a form of Anaemia and underwent my first bone marrow biopsy as a treatment. I have a vivid memory of being in hospital for a number of weeks, and being in excruciating pain, whilst my mother was upset at the doctors for acting unpleasantly during my time as an inpatient and during treatment. The Doctor's attitude was always quite curt so mum made a complaint.

28. In March 1991 I was still not well, so in another attempt to ascertain the diagnosis of my low blood count I endured a second bone marrow biopsy at St Georges Hospital, Tooting, London.

29. I have a vivid memory of going in for the day and being placed in a four-bed ward with one other man in the opposite bed who was about to undergo the same operation as myself. The doctor drew the curtains around the other man and started to go ahead with the procedure. I could hear the patient moaning and yelping clearly in pain, so I did not want to go through the same as him minutes later. However unsettled I was, I did manage to go through with the biopsy.

30. Between 1991 and 1994 I did not receive any further treatment for my Red Cell Aplasia, or Factor IX for my Haemophilia. I did however receive treatment for glandular fever.

31. I discovered that I was infected with HCV somewhere between the end of 1994 and if not early 1995 at St Mary's Hospital. Doctor GRO-D the haematologist specialist at St Mary's Hospital sat me down in a consultation room with my mother, and explained I was HCV positive in a calm manner. I do not remember much information around that time, but I do recall her making out like testing positive for this virus was not a big deal, particularly as I had not displayed any symptoms until that date.

32. Doctor GRO-D did not go into detail about the effects it would have on my body or what it meant for me in the future. She simply referred me to Professor Thomas at St Mary's Liver Clinic, Paddington not long after, who also did not make a big deal about the information he was relaying to me. It was such a quick process.

33. Professor Thomas would say things like "*Hepatitis C is a friendly little virus. If you could get any virus it would be this one, as there is nothing to worry about.*" I remember feeling dismayed and shocked. In hindsight if I had been told this news in the modern day, it would be called fake news. It is a virus. There is nothing friendly about it. I am a trusting and laidback individual I unreservedly believed in the medical profession. I was not concerned.

34. At this point in time I was not fully aware about my condition, as I was not given adequate insight into the true ramifications of how serious HCV could be for me. Doctors knew what it could lead to. Information was not given in a way which is comparable with that of the facts produced in advertisements made available to the public about HIV.

35. I was not given much advice on how to manage my HCV. I was never provided with leaflets on how to deal with it or how it could be passed to others. Merely that the infection could be transmitted through sex. On reflection, I do not remember being told explicitly, do not do this, just almost err on the side of caution. I was not happy about the perfunctory way I was told about the potential severity of this virus. I did not carry out any action to resolve my feeling of unhappiness surrounding the way I was told about my infection, as this information was given by a Professor.

Treatment One

36. The Inquiry has discussed with me a Department of Medicine Chronic Hepatitis Investigations Request Form dated 28 January 1998, from Professor Christine Lee, obtained from my medical records from the Royal Free Hospital. This states that I have been HCV positive from 1975, and is suggestive that whilst I believe I was infected in 1978, potentially I may have well been infected in 1975. The extract from this investigation's request form (Exhibited in **WITN3841004**, extract below) states:

> Handwritten entry 2. *'HCV from 1975.'*

37. My first treatment for HCV started in late 1995 at St Mary's Hospital where I was given Interferon Monotherapy. Interferon was administered through subcutaneous injections 3 times a week by myself. The

Interferon was prescribed every two weeks. The only time I used a sharps box was when I self-medicated the Interferon.

38. I was told by the doctor that percentage wise I had a very low chance of clearing the virus, estimated at around 25% of people. I was instructed that treatment would last around 6 months, but in reality, it was much longer.

39. I remember I would visit the hospital every two weeks, where I would have blood tests taken and talk about the side effects I would experience. I cannot remember being told the results of these tests in the end.

40. During the treatment, I was told I would experience flu-like symptoms that would "Knock you sideways," but, they might get better after a while. Mood swings, hair loss, and loss of appetite. Itchy skin, severe stomach pain and a torturous fever. This was an understatement as in reality, the symptoms I experienced were a lot worse.

41. I felt like I was an 80-year-old man. I was constantly weak, short of breath and lethargic. I would sleep all hours and when I was not, I would walk up and down the road and have to stop every 200 metres to rest due to exhaustion. I was in agony due to suffering from soreness in the infection sites on the fleshy bits of my body, my arms and stomach area. I also had a rash that had spread all over my back that I would treat with an over the counter cream. I felt like I had no purpose, just pretty useless.

42. Around September 1996, I finished my first round of HCV treatment with Interferon Monotherapy. I cannot remember the exact date, but around that time I recollect going for a celebratory drink in anticipation of clearing the virus.

43. However, much to my dismay, it was not long after that I learnt that the virus had not cleared as Professor Thomas at the Liver Clinic at St Mary's Hospital had told me that the treatment had not worked. A letter dated 02 March 2011 from Dr James Uprichard Clinical Fellow at Royal Free Hospital to Dr Shah Local General Practitioner (Exhibited in **WITN3841005**, extract below) provides confirmation of the failure of treatment one. It states:

> Point. 5 *'Failed Hepatitis C virus, clearance with Interferon Monotherapy 1995.'*
>
> Point 6. *'Cleared Hepatitis C virus with Interferon and Ribavirin in 1999/2000.'*

44. I felt that I had always expected the worse, because after all the percentages of success were not great to begin with. I had to go through the pain and suffering I had experienced formerly all over again.

Treatment Two

45. In 1997 I changed from St Mary's Hospital to the Royal Free Hospital, Hampstead. This was because there was a haematology unit within this institute which would have benefitted my health the most. After all, Professor Thomas's quote and subsequent contrasting ending, did not fill me with much self-confidence.

46. Initially I met with Professor Christine Lee. I was not allocated a specific nurse for my treatment as there was a specialist nurse always on call. We went through my medical history and she informed me there was an alternative combined treatment of Interferon and Ribavirin which would have provided a higher percentage of successfully clearing the virus.

47. As Interferon and Ribavirin treatment was not readily available at the Royal Free Hospital, I remember writing a letter to St Mary's Hospital to request a document which outlined why it was so important for me to be

given the authorisation to receive funding for this treatment from St Mary's Hospital, where it was freely accessible. Therefore, my mother and I carried out a long chain of correspondence with St Mary's Hospital to obtain a document which gave authority for treatment. With much persuasion this was granted to me.

48. Although valuable, it is likely that the letters referring to the authority will have been destroyed. My mother passed away earlier this year and she was the sole person who dealt with all the retrospective paper work we have accumulated over the years. My wife, sister and myself searched her house for its existence but it could not be found. Therefore, I am unable pass these documents onto the Inquiry for their reference, they should be presumed lost.

49. A letter dated 02 September 1999 from Steven Fouch HIV Development Worker Haemophilia Society to Mr Chris Ward Royal Free NHS Trust (Exhibited in **WITN3841006)**, regarding funding of Interferon and Ribavirin combination therapy for Hepatitis C with respect to Mr Alan Kilcoyne.

50. A letter dated 23 June 1999 from Baroness Hayman Department of Health to Roger Godsiff (Exhibited **WITN3841007)**, explains the Government's view on Hepatitis C and the look back process.

51. I started my second treatment for HCV at the Royal Free Hospital on 19 August 1999. Professor Lee had outlined what the treatment would entail, the side-effects that came with it and the expected length of treatment. It was said, I should expect to encounter similar adverse side-effects to the first course of Interferon such as exhaustion, flu like symptoms and hair loss.

52. I would visit the hospital weekly, where Professor Lee would test my blood and weigh me to ensure I was reacting to the drugs as normal. Interferon would be injected at home by myself 3 times a week every

Monday, Wednesday and Friday, and then I would take 1 or 2 tablets of Ribavirin daily after food. I was taught how to self-administer Interferon once through a demonstration on an orange.

53. The side effects I suffered were exactly the same as what I had experienced previously. This was the worst period of my life. To this day I struggle to remember anything around that time because those drugs bewildered my memory.

54. A letter dated 12 November 1990 from Christine Lee Professor of Haemophilia to Miss R Green Housing Officer, (Exhibited at **WITN3841003**, extract below) states:

Para. 2	*'He is now undergoing a year of intensive treatment with Interferon and Ribavirin. This is an extremely debilitating treatment, but he does stand a one in three chance of cure, and it is very important that he completes this course.'*

55. Around October or November in 1999 I finished my second course of treatment for Hepatitis C. However, I was told you could never be sure whether the disease had completely cleared or was in a state of remission. Therefore, Professor Lee kept me under a monthly regime of monitoring for approximately a 6 to 12 month period, to ensure the condition did not return.

56. In March or April 2000 after 6 months of observation, there was no evidence of HCV coming out of the remission stage. I was finally cleared. I was absolutely delighted about the outcome and words could not describe my happiness. This was the start to the rest of my life. It meant I could go back to work part-time.

57. A letter dated 02 August 2019 from Thynn Thynn YEE, Katherine Dormandy Haemophilia and Thrombosis Centre to Dr L Grant Water

Meadow Surgery (Exhibited at **WITN3841008**, extract below) explains my position with regards to my clearance of HCV.

> Para.1 *'Regarding his hepatitis C, he had treatment with Interferon monotherapy in 1996 and had Interferon and Ribavirin in 1999. His HCV PCR has been cleared since the early 2000. The patient has yearly follow-up and this time, it would be via a nurse phone clinic.'*

58. Post 2000, existence was much more like 'Real life' in the fact that I spent more time out of the Hospital than in it. I would go back to the Hospital every 3 months to test my blood and from then, I would get a check-up every year. One year being discussed over the phone and bi-annually I attended the hospital in person.

59. I would only really receive Factor IX BeneFIX in vials when I would go on holiday, as it was a specific requirement of my travel insurance for me to carry them overseas. I changed to BeneFIX in the early 1990's. I was not given BeneFIX by the Hospital for me to personally administer as treatment. Instead, if I was holiday and had a bleed, I would have to attend a hospital in a foreign land, where medical staff would administer BeneFIX themselves.

60. The first time I was given vials of Factor IX by St Mary's to take with me for coverage abroad was in 1996 when I visited San Francisco. I then broke my ankle in Sicily in 2006 and instead of Factor IX, the medical staff wanted to give me anti-coagulant which was the opposite to what I needed. Also, between 1986 and 2012 I was given Factor IX for several eye operations.

Section 3. Other Infections

61. In 2004, there was talk by Professor Lee at the Royal Free Hospital, that there was a small percentage of risk of having been infected with vCJD as I was given UK plasma product between the "relevant timeframe" of 1980 and 2001. I received a letter dated 26 November 2004 from Professor Lee to my Local General Practitioner Dr U Shah (Exhibited at **WITN3841009,** extract below) outlining:

Para. 1	*'I saw Mr Kilcoyne this morning to discuss vCJD. As you know, for public health purposes he is regarded as a risk.'*

62. I subsequently met with Professor Lee to discuss this risk.

63. However, I believed it was a nationwide risk of infection with vCJD, which lead to all haemophiliacs who had been treated with Factor VIII and IX being endangered. Of course, I was worried, but I knew the chances of me contracting vCJD was slim.

64. I believe I was assessed for the presence of vCJD, but did not receive any results to that effect. This is outlined in a Confidential Patient vCJD Exposure Assessment Form dated 24 September 2004 from Doctor Carolyn Miller, with my personal details on it in **WITN3841010.** This exhibits the numerous batch numbers of blood products I had received between 1987 and 1997. I cannot remember the process of this assessment, I just recall being in a consultation office.

65. I understand there was, and may still be, physical damage to my liver from Hepatitis C. This is why I feel that the development of Red Cell Aplasia in 1991 was a direct consequence of my HCV.

66. Apart from HCV, vCJD and Red Cell Aplasia, I do not believe that I have received any other infections as a result of being given blood products

in 1978. I assume that I would have been tested for the presence of other viruses as part of routine screening when I had bloods taken for other purposes. I do not know this for certain, if or when this occurred.

Section 4. Consent

67. I believe my blood has been tested without my knowledge and/or consent since I was infected with HCV. This stems down to the period of 1991 when doctors at St Mary's were unsure what was wrong with me. Also, their attitudes towards my prognosis were not respectful so I believe they could have done anything without me knowing. Either way, I was always careful about what questions I asked and when to ask them, to ensure I was aware of all the information I needed to know.

68. I believe my blood may have been tested without being given adequate or full information, and for the purpose of research. Knowledge surrounding Hepatitis C has evolved a vast amount over the years, and I believe this is down to medical professionals carrying out as much research as possible where they can.

Section 5. Impact

Physical and Mental Impact of HCV Infection

69. At the point of my infection taking centre stage, I felt worthless and mentally I could not see what future lay ahead. The treatment itself and the knowledge of my infection was so hard to comprehend. There was an ever-present fear of passing the infection to someone else without knowing. Especially having a partner, I would worry about passing it on through contact fluids, whether it be sexual relations, a shared toothbrush or even flannels. It was something, I was conscious of all the time.

70. I believed this meant I could not have possibly thought about having children, which was my life-long dream, but the infection kicked in at wrong time. Is that not what everyone hopes for? To have children of their own?

71. My infection had a big impact on my life, so it did not fill me with much confidence. I had lots of plans for what I wanted to do in the future, but at the time my life was in limbo as I did not know whether I would ever clear the infection. I felt frustrated as I did not want to keep my life on hold. Working in a shop did not exactly provide me with the financial foundations to buy a property, get married, or do things my friends from school, and where I grew up were doing. Especially living in London. Life was just meandering along without any purpose. It was just existing.

72. Physically, I was no longer confident in myself in the way I once was. This had a massive impact on my family and love life. This stemmed from the impact the treatment had on me and what happened in 1991 with the development of my suspected Anaemia.

73. Whilst I did not show any obvious tell-tale signs of HCV day to day, since discovering that I had this virus, it now offers an explanation for my constant tiredness and flu like symptoms. It had occurred after I had received the blood products in 1978, and it was a long-term common symptom described by doctors at St Mary's.

74. However, since 2000 I have managed. Having my friends and family around me has helped me get by and I can never thank them enough for that.

Access to Health and Dental Care

75. From the point of being made aware of my HCV, I had received mixed signals regarding dental care. When I was treated at St Mary's for

Haemophilia B, I was advised to go to my local dental practice as normal as there was no obvious risk of infecting others. There was no mention of needing blood products for my bleeds as protection. Since I was told limited information by the doctors regarding management of Hepatitis C and prevention of transmission of infection, I did not think twice.

76. In contrast, when I changed to the Royal Free Hospital, doctors told me I could no longer receive dental care at my local dentist as I would need Factor IX to control my bleeds should I need treatment. I remember the doctors being surprised that I had previously only used a normal dentist whilst I was at St Mary's Hospital. The doctor also told me I was at risk of infecting other patients who attended the dentist if I had not informed the medical professionals of my HCV previously.

77. The Royal Free used to have a dentist within the building itself so I would receive Factor IX before any tooth extraction. Now they have shut down, I only go to a dentist who would take patients with Haemophilia.

78. I was never treated badly by a dental practitioner with regards to my HCV after my diagnosis. This is because I did not attend the dentist until my infection was completely cleared.

Stigma

79. I have not experienced any particular stigma resulting from my HCV infection. There has been nothing to date which my family or I was denied of carrying out or experiencing. I did not let it cast a cloud around my life where it would have otherwise been dark.

Life Impact

80. The impact of being tainted on my private family and social life was always difficult. The thought of walking around with this virus and of members of society finding out about my HCV which could easily be

passed on was hard to comprehend. I felt devalued in the eyes of others. It was as though I was not a useful member of society anymore. I had no qualifications, I was in a dead-end job, living at home with my parents and I had no clear future whilst living with HCV.

81. I was lucky to have the group of friends and family I had at the time as it could have been in a much more closeted area. I was fortunate with who I had.

82. Before I was weighed down by this virus, I had the greatest social life. As I had worked in the music industry at the time, I was forever out partying. However, I then chose to moderate my behaviour during a time in which I would have otherwise been out enjoying life, as any person is entitled to do in their early age. Late nights became less frequent due to tiredness, especially post Interferon treatment. I took it upon myself to stop drinking alcohol for health reasons. I was not advised to do this.

83. Although you could not have called my situation positive, I still believe I have been lucky compared to other people in a similar position to me. I consider myself fortunate that I was diagnosed and subsequently cleared before infecting someone else. I did not deserve that life.

84. From the period of developing Red Cell Aplasia in 1991; where I underwent two separate bone marrow biopsies and developed glandular fever, to my initial HCV treatment with Interferon in 1995, and second HCV treatment with Interferon and Ribavirin in 1999, I had around 20 months off work. This had a massive impact financially. I was living with my mother and father, as I had no alternative solution. I was on statutory sick pay and could not afford to pay my mum.

85. As previously stated, I believe I was infected on one occasion in 1978. However, according to a letter contained within my medical records, I may have also been infected on a second occasion in 1991. This was at the point I would have been in full time education. By my own

admission, as I was growing up I was not a role model student and there were other things going on in my life which affected my education such as Haemophilia B. This meant I did not do as well as I could have done.

86. However, clearance of this virus gave me a second chance in life. It gave me a kick up the bum and inspired me to complete an undergraduate degree in Literature between 2002 and 2006 at the Open University. I graduated in October 2006. This allowed me to gain the qualifications in order to apply to train to become a primary school teacher which I would not have otherwise done.

87. I do not believe my infection impacted of my family adversely. If it did, they did not show it.

Section 6. Treatment/Care/Support

88. Access to the second course of medical care with Interferon and Ribavirin in 1999 was difficult as it was not readily available at the Royal Free Hospital due to insufficient funding. As a result, my mother and I started a long process of correspondence of letters with St Mary's Hospital, asking for a written document which eventually provided the relevant authority to grant funding at the Royal Free for my treatment.

89. I was determined to gain the second course of treatment as it gave me a more successful chance of clearing the virus. Although Professor Lee said it would be hard to jump over the hurdles to access medical care, I did not think I would have to fight to get access.

90. After much persuasion, I was granted permission to start the second course of treatment.

91. I was not offered any counselling or psychological support at the time of receiving treatment of Factor IX, nor at the time of being diagnosed with HCV and/or throughout the treatment of the virus.

92. The Inquiry Investigator has discussed with me the existence of the Hepatitis C Trust as a useful confidential source of information and support to navigate my way through this experience.

93. The Inquiry Investigator has also discussed with me the presence of the counselling and psychological support service provided by the British Red Cross, which is running in collaboration with the Inquiry. I have been provided their contact information and will consider using it where necessary. I believe this is a very useful resource during the emotional aspects of revisiting areas of old memories and bringing them to the surface, both during my witness statement and from this point forth.

Section 7. Financial Assistance

94. Around 2000, I was informed about the existence of financial assistance provided by the Skipton Fund through my mother as she was a member of the Haemophilia Society. I completed the application and subsequent forms I was sent by Skipton, which is now referred to as the England Infected Blood Support Scheme (EIBSS). I did not face any difficulties in applying for and/or obtaining payments throughout the whole process.

95. I received a one-off lump-sum payment of £20,000 from the Skipton Fund in 2000. I cannot recall the exact date. I did not receive monthly payments subsequently.

96. I understand that payments are categorised according to the severity of an individual's illness, and see that this is a logical approach given to the needs of each individual.

97. I believe my case is relatively straightforward. They asked for a lot of evidence such as personal and private information for the purposes of

obtaining payment, but I cannot recollect exactly what was asked of me or what was provided.

98. There was a pre-condition attached to accepting payment from Skipton. By this I mean I was not entitled to any further funding in the future if it was offered to me. I believe the phrase "*ex gratia payment*" was used with regards to the lump sum I received, which describes the fact that Skipton would not take on any liability for the money beyond that point. At the time, I was in a low paid job and struggling financially, so of course I accepted the payment. I could not have bitten their hand off any faster to get the money.

99. However, on reflection, if I was offered this sum to date I would not have taken it. £20,000 is not nearly a substantial enough sum for the price of adversely effecting a person's life. You do not expect to go to hospital to get better and come out in a worse condition. I am still lucky to have received the funding I was given.

100. I am frustrated that my postcode has dictated how much financial assistance I have received. My cousin who is located in Ireland and was infected with HCV from contaminated blood in similar circumstances received a substantial pay out of £250,000, when I received not even a tenth of that amount. It should not be one rule for one and not for the other. They are my family too, the same blood.

101. HCV has also affected my finances with regards to life insurance. I have not contemplated obtaining life insurance, as I feel the premiums would be too much for my finances to match.

102. Also, I am restricted in the travel insurance companies I am able to use when I holiday abroad especially due to my Haemophilia B. The amount that is needed for adequate insurance cover was very expensive. It was approximately £200 for one trip. Although, the market is slowly becoming more sympathetic to my medical condition. It is now about

£38 for one trip. This is a big thing for me and my Australian wife, as we frequently travel to her country.

Section 8. Other Issues

103. In the process leading up to this statement, I have felt emotions I did not realise I had. I feel let down by various Prime Ministers who have stood in 10 Downing Street. They have said time and time again that they would do something about the Infected Blood Scandal, but they have done nothing. It is so frustrating about how long it has taken for the Inquiry to come to fruition in the first place.

104. You are meant to trust doctors and you do not expect that they would lie to you. From the period of first being infected with HCV in 1978 to being told in late 1994 early 1995, they may have known the blood I received was infected. I guess you could call this subjective and not strictly a lie. Now, it is impossible for me to know who knew about it, and the fact that haemophiliacs were being knowingly transfused is a scandal. Whether doctors were part of the people who knew, it is impossible for me to say.

105. However, when I went to the Liver Clinic at the Royal Free Hospital, a doctor with whose identity I am unaware of had mentioned that a Minister in France had been put in prison with regards to their involvement in the Infected Blood Scandal. However, in the United Kingdom no one has been held accountable. Almost protected from the same fate as the Minister in France.

106. It is unbelievable that no justice has been achieved. The ball of responsibility seems to be passed between Prime Minister to Prime Minister and they can no longer get away with this. It seems inherent in political life that you think you can get away with anything you feel feasible.

107. I believe there needs to be a campaign that comes from the Government and the NHS, as there are without a doubt, people with similar circumstances and situations to me who should be tested. I am disappointed that HCV is not being given the attention it requires. Something like this can never happen again, and I think people need to be made aware.

108. My anger is directed at Government on behalf of all those people who have lost their loved ones to contaminated blood. Husbands, wives, children. There are still people dying and it is almost as if the Government are trying to brush it under the carpet until there is no one left. It is as if the Government are trying to keep it all going so they don't have to be held as culpable.

109. In reality, it all comes down to money. The Conservative Party have not put anything surrounding the Inquiry in their manifesto, so I am unsure if at the end of all this whether findings will all be adhered to? I do not trust that the right thing will be done in the end.

110. I have exhibited the following documents:

Exhibit No:	Description:	Dated:
WITN3841002	Letter from Dr Jason Coppell to Dr T Wilson, which regards Mr Kilcoyne having contracted Hepatitis C as a result of exposure to blood products before screening was available.	10 November 1999
WITN3841003	Letter from Christine Lee (Professor of Haemophilia) to Miss R Green (Housing Resource Centre), which regards Mr Kilcoyne having contracted Hepatitis C as a result of previous blood transfusions with unsterilised clotting factor concentrate.	12 November 1999
WITN3841004	Letter addressed from the Department of Medicine to Ruth Jacobs and Professor Lee (Royal Free Hospital), which shows Mr Kilcoyne having being HCV positive from 1975.	28 January 1998
WITN3841005	Letter from Dr James Uprichard (Clinical Fellow at the Royal Free Hospital Hampstead) to Dr Shah, regarding Mr Kilcoyne having failed to clear his hepatitis C in 1996 with Interferon Monotherapy, and then subsequent clearance of Hepatitis C with Interferon and Ribavirin in 1999/2000.	02 March 2011
WITN3841006	Letter from Steven Fouch (HIV Development Worker, The Haemophilia Society) to Mr Chris Ward (Royal Free NHS Trust). This regards Mr Kilcoyne having acquired Hepatitis C through treatment with blood products for his haemophilia. Also regards funding for Interferon and Ribavirin treatment.	02 September 1999
WITN3841007	Letter from Baroness Hayman (Department of Health) to Roger Godsiff. This regards a look back exercise on patients who had contracted Hepatitis C through blood transfusion before 1991 when screening of blood donors was introduced, which focused on people who received blood from donors screened and identified as HCV positive.	23 July 1999
WITN3841008	Letter from Thynn Thynn YEE (Associate Specialist at Katherine Dormandy Haemophilia and Thrombosis Centre, Royal Free Hospital) to Dr L Grant (Water Meadow Surgery), which outlines Mr Kilcoyne having cleared HCV in early 2000.	02 August 2019

WITN3841009	Letter from Christine A Lee (Professor of Haemophilia) to Dr U Shah, regarding a discussion with Mr Kilcoyne that he poses as a risk for public health purposes of vCJD.	26 December 2004
WITN3841010	Confidential Patient vCJD Exposure Assessment Form, outlining batch numbers of blood products received between 1987 and 1997.	24 September 2004

Statement of Truth

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

Signed **GRO-C**

Dated 8/3/2020