Witness Name: Jacqueline Kennedy
Statement No.: WITN1059001
Exhibits: **WITN1059002- 007**
Dated:13 March 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JACQUELINE KENNEDY

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

I, Jacqueline Kennedy, will say as follows: -

Introduction

1. My name is Jacqueline Kennedy. My date of birth and address are known to the Inquiry. I suffer from haemophilia A and was infected with Hepatitis C ("HCV") through contaminated factor concentrates. I intend to speak about my haemophilia and infection with HCV. In particular, the nature of if my illness, how the illness affected me, the treatment received and the impact it had on me.

2. I was born in Glasgow in 1957 and I am a member of a Haemophiliac family with a long standing history, which was originally researched and reported in The Lancet in 1958, by Professor Andrew Douglas. My sister is Colette Wintle who has also given evidence to the Inquiry.

3. I was diagnosed in 1962 at the age of five, at the Glasgow Royal Infirmary, Castle Street, Glasgow. Scotland, and, along with my GRO-C sister, was placed under the care of Professor Andrew Douglas until he left for Aberdeen Royal Infirmary a few years later.

4. Throughout my childhood, which was a physically active one, I recall experiencing somewhat excessive bruising disproportionate to the level of minor injuries suffered. From an early age we were aware that many of the women on our maternal grandfathers side of the family (there was a 200 year history) suffered from symptomatic Haemophilia A, even though it was generally understood that only men could suffer the manifestations of having such a bleeding disorder.

5. I had a generally healthy childhood. Menstruation began at 14years old and whilst I had a regular cycle , it became progressively very heavy and longer in duration than would be considered normal, A year later my sister began to menstruate following the same pathway. Unfortunately for both of us, this experience impacted badly at times, on our school attendance and we often missed days from school due to our difficult menstruation. We were never offered any treatment for our haemophilia condition, despite my mother raising concerns with our GP and the Royal Infirmary Haemophilia Unit both of whom were dismissive; my memory was that no advice or intervention was ever offered.

6. In fact, the doctors used condescending terminology by referring to us directly, (GRO-C my sister and myself) as ' the little grey matters' presumably because we did not conform to what was understood in the medical journals regarding the inheritance of Haemophilia A. It was clear that none of the doctors looking after us, after Professor Douglas left, wished to continue his investigations and research into the expression in Haemophilia A in female carriers who demonstrated unusual bleeding traits.

7. GRO-C

How Infected

8. I was infected with NHS supplied contaminated blood product Factor 8 in 1982, at Pembury Hospital, Kent, during the birth of my child and then three weeks later following an emergency admission for post-partum haemorrhage.

9. This was the first and only time I was ever treated with Factor 8 clotting blood products, for my haemophilia condition, which I later was to discover was commercial factor 8 imported by the NHS from America and known to the Dept of Health as being extremely high risk for the contraction of Hepatitis viruses.

10. I left Scotland in late spring 1978 to move to London and I registered at the Haemophiliac Unit at The Royal Free Hospital, Hampstead, London under the care of Dr Eleanor Goldman. I then moved to Tunbridge Wells in September 1979, registered with a local GP, Dr Stephen Hall, and was referred by him to Dr Colin Taylor who was the local Consultant Haematologist at Pembury Hospital in Kent.

11. At this point I was considering the commencement of my SRN nurse training due to start in September 1980 at Pembury Hospital. My GP considered it prudent to introduce me to the local Consultant Haematologist should I require any medical assistance in an emergency situation. On 20th November 1979 Dr GRO-D wrote to my GP Dr Hall with a summary of our meeting during which there was a brief discussion on the possibility of my having a family, and the genetic inheritance risks in male/female children, as well as the most up to date diagnostic techniques **[WITN001059002]**. Throughout this period, I was in good health and never required any haemophilic treatment.

12. In September 1980 I married and began nurse training within a few weeks. I unexpectedly fell pregnant in May 1981, which was totally unplanned, and

at this point, my GP referred me to Mr J G Hill, Consultant Obstetrician at Pembury Hospital.

13. I was told that Dr Hill was the best Consultant to deal with my particular issues so therefore was horrified that during our first appointment he expressed an extremely disturbing viewpoint on my pregnancy. With my family history of haemophilia, he said that in his opinion, I had been highly irresponsible for falling pregnant and should immediately terminate the pregnancy. He also suggested that I should not have any children at all. I was shocked and upset by his attitude and remonstrated with him. I asked him to contact Dr GRO-D to discuss my medical needs when my baby reached full term and delivery, and to advise me as to the outcome of what would be planned between them.

14. I was not contacted by either of these Consultants regarding any of their plans, and despite asking my GP for assistance was told that I must deal with any bleeding concerns and potential care plan, only with the consultants.

15. My health was good through the pregnancy and my only concerns were that I had highlighted that GRO-C developed unexpected post-partum haemorrhage after both of her pregnancies and I wanted to make sure that they were aware of this important fact and be prepared for a potential similar eventuality.

16. Subsequent to this I never saw Dr GRO-D, in his capacity as my consultant, throughout the pregnancy. Mr Hill advised me that the matter was in hand but refused to discuss anything about it with me at any stage, indeed he responded to my very measured questions, by suggesting to me, and my GP, by correspondence [**WITN1059003**] that I was 'more than a little anxious and extremely frightened'.

17. I tried to make appointments myself, twice via Dr GRO-Ds secretary without success and, out of frustration, approached him on two separate occasions

when he made an appearance on the Male Medical Margaret Ward, (where I was working) reviewing patients under his care.

18. I was rebuffed by him on the first occasion and told to call his secretary again, which again produced no appointment and on the second occasion he spoke to the ward sister who admonished me for approaching him on the ward as it was seen as being unprofessional behaviour.

19. I went into labour in the evening of GRO-C 1982. I was admitted to Pembury Hospital at 11.30pm and as the labour progressed at ten minutes past midnight, an unnamed person appeared by my bed and swiftly administered according to my records, Factor 8 by IV infusion [**WITN1059004**].

20. The entry in my notes for the administration of Factor 8 is unsigned which I know from my time as a nurse, breaks the protocol for administering blood products. Also noted is the absence of any batch numbers related to this specific treatment, which the Haematologist was obliged to keep.

21. Haemophilia is a life-long condition which obligates the treating clinician to hold a record of any treatment used due to the risks of a patient either having an adverse clinical reaction or developing an inhibitor. Therefore, this information should be kept for the life-time of a haemophiliac and can provide a look back history should any issues have occurred. Dr GRO-D would have known this.

22. I recall that I questioned the individual who had approached me with a large syringe during my labour and asked who they were, and what was happening. I was told it was just my 'funny drug'. The member of staff did not identify themselves to me and on checking my records I note that this Factor 8 blood product was administered but, as I say above, was not signed for or recorded as it should have been. I think it is important to point out that this was done without any previous consultation with Dr GRO-D nor indeed had I given my verbal or signed consent to receive Factor 8.

23. My understanding for the management of the post-birth was that I was to have a planned stay of seven days, but I was unexpectedly discharged after three days with no follow up care plan, or an appointment for a haemophiliac follow up visit with Dr GRO-D whilst I was still on the ward. I returned home to the care of my husband and my mother who had travelled from Scotland to help me during the first week of my daughter's life.

24. By the end of that of that first week, I was feeling a degree of malaise which nothing seemed to alleviate. My mother returned to Scotland and I began to feel extremely unwell and unable to cope. I struggled, however three weeks after the birth I suffered a sudden and substantial post-partum haemorrhage. I had an emergency admission to Pembury Hospital where the Obstetric Registrar Mr Sheckelton performed an ERCP procedure. I was again administered with further Factor 8 treatment.

25. Upon checking my hospital records **[WITN1059005]**, I note that post operatively, I received 1000 Units of Factor 8 via slow infusion, yet can find no detail of who specifically, was the member of staff responsible for administering the clotting factor, nor any details of the drug, such as batch numbers or any other records. I was then discharged the following day but not before Mr Hill, my Obstetrician, in front of several witnesses, including Mr Sheckleton, told my husband and I that "people like you should not be allowed to breed".

26. My mother was forced to return to England due to my deteriorating condition, to care for me. I continued to suffer further malaise and increasing nausea with loss of appetite and falling energy levels. This distressed me greatly as I was unable to care for my new baby and had to stop breastfeeding and fully hand her care over to others.

27. The attending community midwife was of little assistance and, despite a request to her, to inform the GP of my condition, by my now, very concerned mother and husband, both health professionals failed to react and, in my opinion, failed in their duty of care to me and my new born child.

28. An extremely difficult decision had to be taken due to my husband's professional commitments with his employer and his inability to be able to care for me at this time. With no offer of any form of assistance, I was therefore forced to leave my home and fly to Scotland with my mother and child, to be cared for in my family home.

29. Within three days of my arrival in Scotland, my condition dramatically deteriorated. I became extremely jaundiced, had severe upper abdominal pain, with pruritis (severe skin itching), and immense overwhelming nausea with subsequent complete loss of appetite and began to feel very depressed.

30. The local GP, Dr GRO-D was summoned to the house where he diagnosed a potential hepatitis and took blood samples for definitive diagnosis. Unfortunately, after a ten day wait for results and diagnosis, we discovered that my blood sample had been lost. The test was repeated and the same happened again!

31. Within that initial ten-day period, I lost one and a half stones in weight and was suffering from constant and debilitating muscle and joint pains (later diagnosed by another practitioner as fibromyalgia), leaving me even more weak and diminished in energy. At this stage, due to my acquired nursing knowledge from my training, I realised that I was suffering from a severe hepatitis attack and could only surmise that the culprit for my infection must have been related to the Factor 8 blood products, that I was given for my haemophilia care.

32. I suspected that the twice loss of my missing blood samples was more than coincidental, coupled with the failure of Dr GRO-D to follow me up post treatment.

33. Retrospectively, I have discovered through my sister's campaigning over 25 years on the contaminated blood disaster, which cost the lives of thousands of haemophiliacs, that the doctors treating haemophiliacs during the 70s and 80s knew that all of the imported commercial blood products

for the treatment of Haemophilia carried a 100% risk of transmission of hepatitis viruses.

34. I have now seen some evidence of this in a book called HIV The Myth, published in 1989, and a quote by Dr Charles Rizza, Director of the Oxford Haemophilia Unit (and ironically as my sister discovered, who was a close colleague of Dr GRO-D of the extent of their knowledge as haemophilia specialists. They knew of the terrible and disastrous consequences of exposing haemophiliacs and, in particular mild haemophiliacs like myself, to commercial blood products.

35. After the disappearance of my blood tests in Scotland, we did not ask the family GP Dr GRO-D to return, as I feared that he may, by that stage, have had me admitted to a major hospital ten miles away in Glasgow where I would be further separated from my baby and family. By this stage, I was worried and highly suspicious at the unfolding events and did not wish to be in the care and control of any other medical professionals, such was my distrust.

36. Frankly, at this point I felt profoundly let down and very angry by the appalling failures of those charged with my care, both in Scotland and in England. Due to my condition I was forced to remain in Scotland for a further two months without seeing my husband, who could not take leave at that time, and eventually a plan was made for my return to my marital home. My sister, who had applied and been accepted to take up nurse training at Pembury Hospital, came to live with us, to help me try to regain some hold on my life and support us as a family unit.

37. On my return home to Tumbridge Wells, I saw my GP, Dr Stephen Hall, to inform him of the events which had taken place in Scotland. Despite writing to Dr GRO-D, he too could obtain no further information of those events or any explanation as to the whereabouts of my two blood samples. I told Dr Hall of my suspicions regarding the blood products I had been administered at Pembury Hospital and asked him to request an analysis of any retained

portion of each batch of clotting products given, which as a student nurse, I was aware was a legal requirement in blood products protocol.

38. When I inquired of him the outcome, I was told any record of the treatment batches had either been lost or destroyed by accident, further bolstering my feelings of distrust of the whole situation and the health professionals involved.

39. I note in a letter from my medical files dated 25 January 1983 [**WITN1059006**] that in correspondence to the Haemophilia Centre at the Royal Free Hospital in January 1983, a further explanation is given by Dr Hall, that my jaundice had been fully investigated and 'the origins and destination of the remainder of the Factor 8 batch which she received all had negative results'.

40. This is clearly a ridiculous statement as it was not possible to conclude 'the Factor 8 batches all received negative results' because there were no samples by Pembury Hospital's own admission, to run any tests on, due to the fact they were lost or destroyed by accident.

41. In response, Dr Kernoff of The Royal Free Haemophilia Unit wrote to my GP on 3rd February 1983 [**WITN1059007**] effectively handing over the monitoring and ongoing care of my Non-A Non-B condition. Although I recall attending the Royal Free to have a Barium swallow and ultrasound, I have no record or recollection of being followed up on a regular basis by a Hepatologist at that time, although I was referred by my GP to a Dr Thomas at the Royal Free Hospital in 1985 as I was still suffering symptoms of exhaustion and nausea.

42. In the same letter to Dr Hall on 3rd February 1983, there is a discussion between my GP and Dr Kernoff about my Non-A Non-B diagnosis. My recollection is that I was only then told by my GP, of the type of hepatitis from which I was suffering.

43. In the July of 1983, I holidayed in Spain with my husband, my 16-month-old daughter and a group of family friends. Unfortunately, I had a further

attack of hepatitis symptoms including mild jaundice, severe nausea and heavy vomiting along with bile stained urine. I was so obviously very unwell that a flight was obtained for me to return urgently to England, and yet again having to leave my husband and child behind.

44. A locum doctor who was covering for my GP called to my home and made record of the situation. On his return Dr Hall advised me that I should have a liver biopsy, however I was not prepared to take the attendant risks involved in this particular test, namely the risk of bleeding from the biopsy site into the abdomen and the need for further Factor 8 concentrates, with the risk of a further infection of Hepatitis virus. At this stage I frankly had lost any trust and faith in the level of care I was receiving via the NHS and decided upon a more naturopathic course of action to try to recover.

45. Fortunately, over a period of time, this course of action proved to be positive in that subsequent liver function tests showed a marked improvement which was noted in communications between Dr Christine Lee at the Royal Free and my GP.

Other Infections

46. I am not aware of having been infected with anything other than HCV.

Consent

47. At no point prior to the first and only occasion I was treated with commercial Factor 8 was I ever informed by Dr GRO-D at Pembury Hospital of the high risks of contracting Hepatitis viruses or HIV.

48. I can also confirm that I was equally never informed by any of the Haemophilia consultants at The Royal Free of these risks either.

49. Clearly had I known I would never have allowed Dr GRO-D to advise and direct the use of this treatment during and after my pregnancy. As my notes identify there is no evidence of any discussion or request for consent for

the use of these products. Any blood samples which I gave both at Pembury Hospital and at the Royal Free, I assumed were purely for the testing of blood clotting levels or research into the future of eliminating haemophilia.

Impact

50. Being invited to revisit and collate the events of 1981/82 has been a very disturbing and upsetting experience and has angered me afresh, that as a mild haemophiliac, I need never have contracted Hepatitis C. In fact, it has only been in fairly recent years, that I have been told that I am a mild sufferer, at much less risk of bleeding and should consider myself in the 'low normal Factor 8' category.

51. It takes little imagination to realise that the impact of these events on my life was enormous and extremely harmful.

52. In preparing this statement, I have been again shocked and angered at reading over the correspondence between doctors, which can only be described as arrogant and dismissive of my very reasonable and measured inquiries as to my situation, condition, and planned care.

53. It beggars belief that a Consultant Haematologist would ignore the reasonable requests of their patient, who was also a fellow member of staff, to have a consultation with him, leaving me anxious and ignorant, regarding my approaching labour and about what might happen to myself and my baby whilst I was in a vulnerable, potentially painful position and unable to make clear decisions. It would be fair to say that I found myself bewildered, which then turned to worry and a strong degree of anxiety, not a state of mind one wishes to be in whilst pregnant for the first time.

54. It is inexplicable too that in his professional capacity, Mr GRO-D as a Haematology Consultant, was unaware that a mild haemophiliac like me would not have needed treatment. I subsequently found out that in a patient like myself, Factor 8 levels would have normalised during pregnancy, due to the hormonal shifts of the pregnancy. If he was unaware of this, and how

to support me in pregnancy, it is also inexplicable that he took no advice from a major treatment centre such as the Royal Free, as to my ante-natal care in this matter, at which point he would have been correctly advised.

55. Had he done so, or even bothered to take a blood sample to ascertain my Factor 8 levels at that time, I would never have received any of the contaminated product. To take such a cavalier attitude with a young pregnant woman seems reprehensible to put it mildly. It seems too, astonishing that he did not see me post-haemorrhage either. I was attended at my bedside, after the D and C procedure, three weeks after childbirth, by Mr Hill, the obstetrician, and Mr Shackleton, his Registrar.

56. I was then utterly appalled when in answer to my query about why I had suffered a haemorrhage post-partum, Mr Hill said in a loud and disparaging tone, with reference to my Haemophilia status and in front of other ward staff and patients, 'People like you should not be allowed to breed'. At this point they both turned and left me feeling rage and humiliation. I was then discharged with no follow-up appointment for myself or my child

57. My husband had spent a significant part of the pregnancy, undertaking work related compulsory training courses, at some distance from home, returning at weekends. He was worried about the lack of communication from the Consultants but felt in the end that perhaps they knew best and so had no real input in the lead up to the labour and birth of our daughter. He was therefore shocked and desperately worried as events unfolded and struggled to cope with an increasingly sick wife and new baby, whilst trying to work in London. As I have explained previously, I was forced then to return to the care of my mother in Scotland.

58. There is very well documented evidence of the importance of the early days and weeks in the bonding process of a new young family, and, given our geographical separation I still feel deep anger at the destruction for us of that vital time. I struggled to bond with my baby and lost the early weeks with her myself, as others took over her care.

59. It is difficult to explain how very ill I felt constantly and the subsequent feelings of isolation and depression. This obviously had a damaging impact on the personal relationship between myself and my husband, particularly when the outward signs, such as jaundice, had subsided and he felt I should be 'back to normal'. My sense of self confidence had collapsed and with our relationship under strain, and with worries over any future pregnancies given the chances of an affected male child and the obvious risks of contaminated Factor 8, we took the decision to have no further children. It was hugely upsetting, particularly as the advent of Factor 8 had been seen as a major breakthrough in managing near normal life for those children affected to any degree.

60. We then discussed adoption but, he made it clear that he had no interest, and this drove a wedge between us. I felt I failed as a mother and a wife.

61. On my return to Tunbridge Wells, many of the friends who I had come to know through the ante-natal clinic began to keep their distance through fear of infection and worry that their babies were at risk of infection, so my daughter missed out on early contact and play groups with other children. At the weekly baby check clinic in surgery, I was sat away from the other mothers.

62. The traumatic holiday to Spain which I discussed previously and where I was forced to leave my daughter and husband behind, caused a further undermining of our relationship. He is a very social man and felt awkward, restricted and embarrassed by my continuing to be unwell so publicly, especially as there were no obvious physical signs such as extreme jaundice by then. He was impatient that I often had to forego social engagements because I had difficulty in processing certain foods, couldn't drink alcohol or was too tired to get through a social evening.

63. Lack of energy meant that I often was unable to look after the home in the way he wanted, and we couldn't afford domestic help. It was obvious after a while that he felt I was malingering, and we began to draw apart. Further pressure was brought to bear when my sister, who had planned to live with

us temporarily, became infected with Hepatitis B and was unable to move on, as planned, instead also needing support. He found it difficult to relate to me in the experience I was undergoing, and we lost connection as a couple. It was never possible to regain it. He focused heavily on his own career and some years later, we divorced.

64. My own chosen career was blocked. I had begun my SRN training at Pembury Hospital with a clear path in mind. I had planned to complete the training and move on to work in specialist burns treatment at Queen Victoria Hospital in East Grinstead. As I have stated previously, it was made very clear to me by the Nursing Authorities that I would not be welcome to resume any position within the NHS. My husband felt he was being forced to bear the burden of full financial support and was exasperated at my lack of contribution. It was almost impossible to find employment, as disclosure on medical forms meant that no-one wanted to employ me because of my HCV infection but also because, by that time, haemophiliacs had become associated with infection with HIV.

65. Eventually, I took on work as a care assistant via a nursing agency, without disclosing my true health details. This meant that I was not committed to nursing shifts if I had a bout of symptoms.

66. It was also impossible to get any form of health insurance linked to mortgage protection. This has lasted a lifetime despite the written assurances of Haematology Consultants that it was no longer appropriate to exclude me. I have experience of this as recently as the last few years.

67. My fear of needing haemophilia treatments affected me for a long time. Apart from being constantly exhausted (from the effects of HCV) I passed up many opportunities through fear of injuring myself. I remember when the opportunity arose with my husband, to go skiing with some of his work colleagues, I was too fearful of having an injury and possibly being given contaminated factor 8 again. This feeling undermined many choices of recreational activities I had previously enjoyed. I had to give up any thoughts of horse riding and ice skating.

68. The events which impacted upon my health in my twenties had far reaching effects, not only personally and socially but also financially. My opportunities for employment were obviously curtailed for years and with that, any ability to begin to build a pension. I am a determined and strong lady who wanted to work in a field where I could support the health and well-being of others and to this end, I realised that I would have to retrain and become self-employed. I chose to retrain and eventually qualified as a chiropractor at the age of forty, giving me some control over my working practices.

69. Although I am considered recovered from Hepatitis C and am in reasonable health, some of the problematic symptoms have continued throughout my life, very notably the fibromyalgia which is restrictive, flares if I become tired, and is hugely debilitating, sometimes taking weeks for the pain and inflammation to subside . Certain foods are still avoided as my digestive system seemed to change and would never process them again, without me feeling very nauseous.

Treatment/Care/Support

70. Post diagnosis in terms of medical help I was offered a liver biopsy, barium swallow and ultrasound of liver and spleen in addition to regular blood tests. My GP and Royal Free doctor[s] had assured me that the implications of HCV were no more than a bad dose of flu and long term were nothing to worry about. That was not my lived experience given that I continued to suffer from bone and muscle aching, fatigue, nausea and the development of fibromyalgia, as well as hair loss.

71. The only individual who offered me any form of assistance was my Health Visitor who, noting some of these ongoing symptoms arranged to have my two-year-old daughter access to a nursery school place a year ahead of time for two mornings a week. This gave me a little respite from the everyday strain of trying to support family life.

72. During this time, it should be noted that my sister who was also treated with Factor 8 GRO-D later in the same year, also became infected with hepatitis. Due to the fact that she was living with me at this point, I found myself in the untenable situation of having to care for her whilst ill myself. It was literally the sick nursing the sick.

73. With regard to my employer, the NHS, and due to the fact that I fell unexpectedly pregnant towards the end of my first year of SRN training, my intention had been to take maternity leave and return to Pembury hospital to complete the rest of the course. I was unable to fulfil this timeline due to the effects of HCV and when I made enquiries some months later, of the Sister Tutor of school of nursing, as to the resumption of my SRN studies, I was informed by a telephone call that the hospital considered me to be a health risk on the wards and I would not be allowed to resume what had been my chosen career and gain my qualification.

74. At no point throughout my illness and afterwards was I ever offered support/ counselling from either my GP, Dr GRO-D or any of the doctors at The Royal Free. My sister was also refused the opportunity to resume her nurse training upon recovery from her hepatitis illness.

75. For the avoidance of any doubt, I have never undergone any prescribed treatment for HCV; naturopathic treatments which I have taken have treated the infection and stabilised my liver function.

Financial Assistance

76. I received £20,000 from the Skipton Fund approximately 15 years ago and thereafter, nothing until around 2-3 years ago when I began to receive monthly payments of £333.00.

77. More recently, payments have been made through EIBSS rather than Skipton and have increased to £18,772 per year plus a winter fuel allowance of £500.

78. Like my sister, I find the discrepancy between the home nation's schemes reprehensible. Were I paid under the SIBSS, my husband would receive 75% of the sums paid to me following my death; as matters stand, he will receive nothing.

79. This is important because my ability to earn, save and build a pension which we would both have shared in has been severely impacted by my infection; this has led to a direct financial impact upon my husband and it is only right that this loss is recognised.

80. Equally, the means testing of payments to widows and widowers in England feels like another way in which female haemophiliacs are left unrecognised and discriminated against. So little is said of widowers that the fact that they have supported their wives both financially and emotionally through an illness which was thrust upon them by the NHS is easily forgotten.

Other Issues

81. In May 1978, I moved to London with my then boyfriend, later my first husband, where we planned to live and work for approximately four months, until returning to Nottingham for the start of the College Autumn Term.

82. We moved into a flat in Woodside Park, North London which was conveniently close to my maternal aunt, who lived in Barnet with her husband and my GRO-C cousins, GRO-C Due to her long relationship with the Haemophilia Department at the Royal Free Hospital it was thought prudent for me to register with them, as they were familiar with the family history, and since my boyfriend and I were planning to return to settle in Tunbridge Wells after graduation, it was felt that I should form a relationship with the doctors there as it was a main centre for haemophilia.

83. It was there that I first met Dr Eleanor Goldman as well as other senior members of staff. I was happy to give blood samples for research and at some point, during my stay, I was asked if I would be willing to come into the hospital for a full day in order to trial a drug called DDAVP.

84. It was explained to me, that there were good indications that it may be an appropriate drug for use in someone with my level of bleeding problem, as a viable alternative to Factor 8 Concentrate. Any potential problems or dangers involved in commercial Factor 8 and its use were not discussed with me at any time. I was happy to oblige and believe on my arrival I did give signed consent.

85. The drug was injected in the morning, in the haemophilia centre, and whilst I was given a bed, if I wished to rest, I was free to walk about and eat and drink as normal. I was in the department for a full day and during the hours of approximately 9am and 6pm when I left, Blood samples were taken to measure my response to DDAVP. Although I had been warned of potential moderate reactions, I experienced none then or afterwards, which I took to be a positive sign.

86. I do not recall visiting the department again over the course of the summer of 1978. No-one informed me as to the results of the test or advised me that I should ask any future haematologist I may be involved with, to prioritise it as a treatment over Factor 8 Concentrate. It was not something which I remembered to pursue, as I left London in the late August/early September of 1978.

87. As life took over and we organised our return to the South East it further slipped my mind to contact the Royal Free and assumed that when I registered with Dr GRO-D at Pembury Hospital in Kent that he would contact them direct for my records.

88. It strikes me that had DDAVP been given to me in 1982 (as it had been four years previously in 1978) then I would never have been infected with HCV. I am aware that there are a number of other mild haemophiliacs (my sister included) and VWD sufferers who were infected with HCV and HIV between 1978 and 1986 who could equally have been successfully treated with DDAVP rather than contaminated factor concentrates; they would have avoided their infections.

89. I would like the Inquiry to specifically examine why DDAVP was not a treatment method of choice for mild haemophiliacs from 1978 onwards and why blood products continued to be needlessly administered when physicians knew that they carried a 100% chance of transmitting hepatitis and an entirely safe alternative existed.

90. In summing up, I would like to focus on two particular aspects of this scandal; The attitudes of, firstly, the NHS, and secondly, successive governments.

91. Having been infected by completely unnecessary treatment at the hands of the NHS, I, in common with several family members, found myself compelled to defend myself against allegations and presumptions of alcohol and/or drug abuse, when ignorant medical staff of all levels had access to my records. Also, taking into account the fact that my sister and I were described between certain senior doctors as being demanding and ungrateful troublemakers, I feel as let down and cheated as it is possible to feel.

92. My feelings as to the reactions of successive British Governments can be simply stated; rarely, in public life, can there have been a more convincing display of craven cowardice, of an unwillingness to accept and carry out responsibilities, so obvious and transparent that they are not open to debate. It is almost twenty years since the Irish Government, recognising the injustice perpetrated on its behalf, compensated their victims. Yet the British Government has carried on, decade after decade, denying the undeniable, protecting the culpable, and, most reprehensible of all, adding insult to injury

Statement of Truth

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

Signed **GRO-C**

Dated 13/3/20