

Witness Name: Mary Evelyn Grindley  
Statement No: WITN2336001  
Exhibits: WITN2336002- WITN2336008  
Dated: 26<sup>th</sup> February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF MARY EVELYN GRINDLEY

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I Mary Evelyn Grindley make this statement true to the best of my knowledge and belief and will say as follows: -

#### 1. Introduction

1. My name is Mary Evelyn Grindley. I am nearly 70 and I have a son, a daughter-in-law and two small grandchildren. I am a retired teacher and I gave up teaching in 1991 to look after my husband John Wellham Grindley. He was a severe haemophiliac (Haemophilia A – 0/0 clotting factor in blood) who died on 13<sup>th</sup> June 1994 aged 41 from AIDS having been infected by contaminated blood products He was also co-infected with Hepatitis C.
2. I was the eldest child of my parents. I had a younger brother who was two years younger than me. I had a fairly happy childhood until the age of seven, when my mother developed breast cancer. We were a happy family, my

brother and myself, but when mum developed breast cancer and became ill and died when I was 10, everything went downhill from there. I became my brother's carer and had to look after him. Although not forced not, I tried to clean, wash and cook at this tender age as my father was not at all practical and also had elderly parents living across the road to care for. My father seemed unable to get or accept help. I am very surprised we were never taken into care.

3. My father was an intellectual and was working all the time (five and a half days a week) so we were basically neglected as children (not intentional – father couldn't cope), which meant that I grew up very quickly. My mother's death had a serious effect on me psychologically and I developed at the time what they now call selective mutism. I was not even allowed to go to my mother's funeral and my father never allowed us to speak about my mother, so I think this is what caused my mutism.
4. I did in fact pass the 'eleven plus' test to attend the local grammar school but the teachers and my father agreed they would prefer for me to go to the local secondary modern school because I would cope better, I then went onto further education to do GCSE's and A-Levels. Eventually, I went on to a Teachers Training College.
5. My mutism meant that although I spoke some at home ( I felt inhibited though), I could hardly speak at school or in other situations. It was a real trauma to speak to anybody, but I gradually came out of this due mainly to the teachers at school and particularly the English teacher who encouraged me to participate in discussions about literature (which I loved) and read or recite poetry in front of the class. I think that the reason I suffered from selective mutism was because having been told not to speak about the situation at home, my mum dying, I felt I could not speak about other things as well.
6. My father worked as a production manager in a factory, but he never went to University and had always wanted to. Instead, he fought in the war and was at the liberation of Belsen Concentration Camp. I think this badly affected him. I know that he helped survivors of the Concentration Camp get away from the camp and escorted them and the nurses up to North Germany where they

then went on to Scandinavia. I think maybe my father suffered from posttraumatic stress disorder after the war. One can only imagine the horrors he saw and what he might have had to do but he hardly spoke of it.

7. When I was in North London at the Teacher Training College, I would sometimes go back at weekends to visit my dad and I did eventually go back and live with him initially when I was teaching in Ipswich after I had finished the Training College, before getting my own flat.
8. I moved to London initially in 1968 to attend Teachers Training College, which was a real shock to me having come from the slow pace of life in Suffolk. I had never experienced the Underground before and London was very busy and different to Suffolk. However, I found Teachers Training College very liberating and a good experience.
9. In 1971, I went back to Suffolk to teach at a Primary School on the outskirts of Ipswich. I then moved to another Primary School where I stayed for about 7 years until I married John.
10. I met John whilst I was still at the Teacher Training College. He was the brother of somebody I had become very friendly with. He was younger than me, about 3 ½ years younger. I was invited by his sister to go to her parents flat for the weekend. That's where I first met John. He was home at the time from his College. He was at Lord Mayor Treloars School in Alton in Hampshire. He went onto be the Head Boy there.
11. I then began to visit John's sister quite regularly and she used to invite me to her parents' flat in South East London for weekends. Sometimes John would be there and sometimes he wouldn't be. When my sister-in-law got married in 1975, I carried on going to John's parents flat to see him. After that, I started to visit him at his flat and we would go out together as far as we could although he couldn't walk very far at the time because of his Haemophilia but he was able to drive.
12. We decided to get engaged on Silver Jubilee Day, which was in 1977, and we were married in Suffolk the following year.

13. When I married John, I only did Supply Teaching from 1978-1991 so I could look after my young son and also John if he was off work with a bleed.

## **2 How Affected**

1. John was in a wheelchair when we met so it was obvious there was something wrong. I think when he was about 18, which was before I really knew him, he had a serious operation in which they broke his legs and reset them, and he was eventually able to walk a little bit. When I met John, I had no experience of Haemophilia at all, but I believe that I was drawn to him because of his strength. A lot of Haemophiliacs have the most tremendous strength because of their constant fight for life and for survival. I distinctly remember a mouth bleed John had which would not stop. After treatment with Tranexamic Acid which didn't work, the roof of his mouth was stuck with super glue.
2. During his childhood John spent a lot of time (at least half) in Evelina Children's Hospital at Guys' on Great Maze Pond, London SE1 9RT. I know he had two serious throat bleeds which nearly cost him his life. He therefore lost much time from school. He was very intelligent and when he did attend school, a Special School (Charlton Park School, SE London), he became increasingly frustrated by his lack of educational opportunities particularly in the Sciences which he had particular interest in. John was very glad to go to College. He did get some CEs but the school didn't offer GCSEs.
3. When I was staying in John's flat, he would sometimes have bleeds and I would go with him to the Hospital where I would see other Haemophiliacs there as well. I remember one Haemophiliac who could not be helped at all. He had what they call "inhibitors" and he was thriving on the floor in agony. These experiences made me aware that Haemophilia was a very serious thing. I became used to John always being at the Hospital or being treated.
4. John's time at the Lord Mayor Treloars School was before I met him. However, I know that this was a very happy time of his life. I know that he learnt to be an Electronics Engineer there and took his City and Guilds certificate. I also know that he had some good friends there and many of them were Haemophiliacs.

5. When I first met John, he was regularly going to the Hospital to receive treatment with Cryoprecipitate. He was one of the first then to go onto home treatment, well before we were married. This was very liberating for him and gave him much more freedom. John was one of the first to use the Factor VIII product. I know he had this initially at St Thomas' Hospital, Westminster Bridge Rd, Lambeth, London SE1 7EH, and then continued with the treatment at home. John was very keen to treat himself at home and it enabled him to go to work and hold down a job. He still had to have a lot of time off because of his condition but the home treatments enabled him to drive and get about more independently.
6. John was working in a small Electronics Firm in Brockley, South East London. It was a family firm and he was well liked there even though they knew of his situation. He was not paid for the time he had off work, but they were OK with him having time off when he needed it for bleeds or trips to the Hospital. Eventually, Statutory Sick Pay came in after we were married. Up until then we were struggling financially with a small child.
7. We got married in 1978 and I moved to London. Although it would have been better for me to stay in my teaching job in Ipswich, we decided it would be better for John to stay under the care of St Thomas' Hospital and the Haemophilia Centre there. When I first moved to London, we couldn't find anywhere to live so we ended up living with my mother-in-law and father-in-law for around a month, which was very difficult because my mother-in-law and I never really got along. Eventually we got a Housing Association flat in GRO-C It had one bedroom.
8. I became pregnant about five months after John and I were married, and I stopped working just before my son Tim was born. When I was pregnant, we knew full well that if I had a boy, he would be fine but if I had a girl, she would have been a Haemophilia carrier. We decided at the time that we felt that science would advance so much by the time, if we had a girl, she was old enough to have children that Haemophilia could possibly be detected and cured by then. However, I was very upset by a lady doctor at St Thomas' Hospital when at eight months pregnant I attended an antenatal appointment.

She was very angry with me at having a child with a Haemophiliac. I had an Amniocentesis for Spina Bifida at about 16 weeks but nothing was found. The sex of the baby was found then but we didn't want to know.

9. When Tim was born, we were still living in the small flat in GRO-C I felt a bit isolated at the time because I hardly knew anybody in London. As my son started to grow up, I used to take him to Playgroups and Mother and Baby Club and I began to feel happier in London.
10. John did what he could in terms of playing with Tim and looking after him. There were lots of things that he couldn't do, for example, he couldn't teach him to play football. He was quite good at changing nappies and doing practical things that didn't cause him any danger. We used to take Tim out together to the Park and to Museums. John was a really good father to Tim but it became more difficult for him after his HIV diagnosis.
11. John was diagnosed as HIV positive in November 1986 but looking at his medical records recently it is clear that the Doctors knew that he had it earlier. Whether John knew before this date and didn't tell me, I am not sure but I think it unlikely as we were very close and discussed everything. He already knew years before that he Hepatitis C, then called Non A, Non B. When the first English Haemophiliac died from the virus, I think in April 1983, I was with John at an AGM of The Haemophilia Society. I think it was announced then but I don't think the condition was called HIV or AIDS back then I think it was still called HTLV3.
12. That day completely changed my life. I remember standing up at the meeting because I wanted a second child at that time and I asked what the implications of this disease, virus, or whatever it was would have on our potential for having children. The answer I was given on the day by the Haemophilia Society was that, "we don't know, we don't know enough about this at all." We were advised to put having children on hold.
13. John and I went home and talked about what we had heard that day and decided from then on that we couldn't think about having another child in case this virus was passed on to either me or the child. We also decided, in order to

be safe, that we would have no intercourse at all which is very difficult for a newly married couple. Nobody knew for sure whether or not the condition was sexually transmitted at the time but we both felt that our son should have at least one parent alive if we had anything to do with it. We had only been married for three or four years at this time. The thought of no more children nearly broke me.

14. From the time of that meeting in April 1983 we changed our lifestyle. John had his own crockery, cutlery, towel etc if though he was not HIV positive at the time, we assumed that he would be because of the number of donors needed for Factor 8. We didn't kiss each other or cuddle. The threat of imprisonment for transmitting the virus to another was also in our minds at this time. This was in the News.
15. I believe that day was the first time I had heard about the condition of HTLV3 but we were already aware of problems with Hepatitis that people were reporting all over the country. Initially, we had been concerned about infection with Hepatitis B and Non A, Non B. I remember writing to Ronald Reagan in America in 1980 about this and also to Margaret Thatcher a year or two later to ask if anything could be done about blood products coming from America, which were, we were told, the source of the infected blood. We were told that these blood products were from 'down and outs' in America who were selling their blood for money. Over the next few months in 1983 to 1984 the issue was all blown up in the press and the Government were trying to bring AIDS to people's attention. There was a television advertisement with the slogan, "Don't die in ignorance, don't die of AIDS" or something along those lines.
16. We tried to keep ourselves informed as much as possible and if there was a program about HIV or AIDS, we would watch it. John did a lot of research and we collected some cuttings from the press and newspaper articles as well as we wanted to be as informed about this issue as possible.
17. I remember Edwina Curry, I think she may have been Minister of Health at the time, made a very cutting remark on TV. I can't remember exactly what she said but it went to the effect that anybody who contracted HIV was not a

Christian. I was extremely angry about that. She was implying that you only caught AIDS if you were immoral in some way. This really upset me. I wrote to her as well at the time and the appalling response I received is exhibited before me at Exhibit WITN2336002. It says:

*"I understand that you take particular exception to Mrs Currie's reminder about good Christian people not catching the disease. She had in mind merely that, for most people, a responsible and caring way of life should protect them and their loved ones from the threat of AIDS in future."*

18. In terms of John being diagnosed with HIV, I recall that he had a couple of negative tests at the Haemophilia Centre at St Thomas'. It was in 1986 that we had a formal diagnosis. I recall that John had a blood test, which I believe was in November 1983, which was a kind of patch test to the arm, whereby they put tiny amounts of antibodies into the blood stream rather like an allergy test. I don't know exactly what they put but in John's arm but there were about half a dozen different things to see if the arm would swell up. This would be an indication of whether or not the body had some kind of immune system to deal with it. I remember that John's arm blew up very badly and I have kept a picture with the arm blown up. This is exhibited before me at Exhibit WITN2336003. It was a shock to see this but I remember thinking that I was pleased that it proved that he had some kind of immunity to what they were testing for. I believed at the time that this meant that John would be OK.
19. As a child John's parents always sought treatment for him as soon as possible travelling frequently by public transport to hospitals and visiting him when he was an inpatient. As I have said, John spent a lot of his childhood in hospital. I think he was treated with whole blood and later with cryoprecipitate. He had some deterioration of joints and was in a wheelchair until his operation which I have mentioned. After this he started on Home Treatment his health was reasonably good. His Haemophilia was stable and under control with fewer bleeds. He was on prophylactic treatment three times a week, which he would administer himself at home. He was on this treatment for about ten years from 1976 before he was diagnosed positive. Once John had a positive test result for HIV, I was also called in for a test.

20. This was horrible and very frightening. I didn't really think there was any chance of my catching HIV because I believe we had stopped intercourse three years prior to the test so I just assumed that I was negative. This turned out to be correct but being tested was not a nice experience and it made me feel that I was in a high-risk group. The test was an ordinary blood test carried out at St Thomas' Hospital Haemophilia Centre. Over the next few months I was tested a few times for HIV and didn't test positive. I was not aware that I was tested for Hepatitis C as well, until very recently when I went through John's medical records for the Inquiry. I also had a couple of HIV tests after his death as I nursed him closely both in St Thomas' Hospital during his opportunist infections (as there were not enough nurses to give him the attention and care he needed) and at home after discharge. I also had a Hepatitis C test at my insistence. Very fortunately I escaped the viruses unlike many others.

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These events are etched on my memory.

21. I want the Inquiry to be aware that some confusion has arisen as a result of my getting John's medical records some years ago. It appeared in the notes that John was possibly diagnosed with HIV well before he was actually told that he had been diagnosed positive. Exhibited before me at Exhibit WITN2336004 is a letter dated 24 July 1991 from John's AIDS doctor, Dr M O'Doherty in which it is clearly stated that:

*"He undoubtedly had his HIV infection between 1980 and 1981 and has therefore been positive with haemophilia for at least 10 years."*

As far as we were aware, there wasn't a proper test for HIV in 1981 so I am not sure how this could have happened.

22. John never talked to anybody about his diagnosis initially. We had few friends and kept ourselves to ourselves. It was a period when he appeared to be quite well and there were no obvious signs of HIV or AIDS so he carried on with his work and his prophylactic treatment and we decided there was no reason to tell anybody at that point. I think the first person I remember telling was my

son's teacher when he was around 7 years old. I was working at the same school at the time and I can't remember how the conversation cropped up but I remember this person was very sympathetic. At the time, we had no conception of how long John was going to live. Most Haemophiliacs who were diagnosed with HIV thought that they would die within a few years so I think I was concerned at the time about the effect on my son of losing his father so early.

23. I remember one day my son Tim did not want to go to school because John was really unwell. It was only a cold at the time but I think this was around the time we had started talking to Tim about what might happen to his Dad. We had Tim watch television programmes with us about AIDS because we wanted him, as hard as it was, to know as much as he could about the situation. This caused Tim to become quite anxious and not want to leave his Dad when he was unwell.
24. I think Tim must have been six or seven when we told him that his Daddy was seriously ill and that he might die. Tim was an intelligent child and we felt it was better that he should know the truth as far as he could understand. Some relatives thought it would be better if he went to boarding school, away from the situation but we didn't want that and we couldn't afford it anyway. At this point in time, we had been told that people who had been infected with HIV normally survived around 18 months to two years.
25. I don't think anybody really knew what we could expect at this point. There was some kind of test that they did at the Hospital then to test the level of immunity left in the body to diseases or infections. I think it was called the T-Cell count. That was a sort of general indication of how the illness was progressing in a patient.
26. I remember one incident when there was some kind of mistake over this and John's T-Cell count and immunity seemed to have dropped very quickly to almost nothing. Tim was around eight years old at the time and we never really went on holiday other than down to West Sussex to a caravan that the Haemophilia Society used to have because it had a fridge for John's treatment. Also we stayed with John's sister who lived in GRO-C to use her

fridge because it was difficult with hotels to store treatment. I had decided to take Tim on holiday to Butlins on my own and then I heard that John's immunity had gone down to almost nothing and I didn't want to go on holiday and leave John because I thought something might happen whilst we were away.

27. Fortunately, the next time he was tested, his T-Cell count had gone up again and I never really knew the reason, whether it was a mistake or not, but John was still OK at this time.
28. At this stage, I think John had still not told anybody about his infection. In those days, it was something that you very much had to keep a secret. The reason for the secrecy was due to the stigma attached to AIDS and HIV, which was exacerbated by the kind of television advertisement shown at the time. Certainly the stigma made me feel like a second class citizen. We often had to lie to people and they became suspicious.
29. One experience of this was when my son Tim was about eight years old and we moved back to GRO-C from GRO-C into a house with two flats. We were on the ground floor with a communal door. There was a young couple living there and they must have heard somehow about the connection between Haemophilia and AIDS and they had found out that John was a Haemophiliac. I don't know how they had found out but I was coming out of my front door into the hallway one day and the young woman upstairs was coming down the stairs with her child in the pushchair. We opened the doors at the same time and she suddenly backed up the stairs with the pushchair shouting something to the effect, "Your husband's got AIDS, your husband's got AIDS!" or something like that. This was actually before John had been diagnosed positive so I was able to say to her that he hadn't got AIDS. However, the woman went into hysterics and wouldn't speak to me. The next thing I knew they had moved out and got a transfer to another flat.
30. This was horrible because first of all I wouldn't have wanted anybody to have moved out of their home on our account. However, at the time people thought that you might catch AIDS off door handles. She obviously thought that she might be at risk of catching it and that is why she moved out. In fact, around

that time, even we were still using our own separate cutlery and mugs just to be on the safe side.

31. After this lady and her family moved out, another woman with a small child moved in upstairs (we lived on the ground floor). Over a period of three years she began to harass us constantly. Again, she must have found out about John. She falsely reported John to Social Services for abusing (physically) Tim. We were visited by them but found to be wrongly accused. She also smashed John's car window (we saw her do it). There were several other incidents and the beat officer was regularly calling to see if we were safe. Eventually, with the help of the police, the Housing Trust moved us to a brand new house in GRO-C where we had no trouble.
32. Prior to living in this flat in GRO-C we lived in a two-bedroom ground floor flat in GRO-C. We also had trouble there with the teenage son of the upstairs neighbour who for some reason threatened to kill John on the telephone. He somehow got our number (not sure how he knew).
33. We were generally quite cautious around this time because so little was known about the risk of infection and transmission. We were particularly cautious over food or throwing things out if they were out of date, making surfaces clean, washing our hands properly and trying to keep the place as clean as we could.

### **3 Other infections**

1. We were warned about the 'theoretical risk' infection with VCJD but John had already passed away by the time the Haemophilia Society sent us any information about that risk in 2001. Exhibited before me at Exhibit WITN2336005 is the letter I received.
2. As far as he knew John 'only' had HIV and Hepatitis C. His two opportunist infections were Pneumonia peculiar to HIV and Cryptosporidiosis (he was down to about 5 stone at the end).

### **4. Consent**

I do not believe that John was treated or tested without his knowledge or consent or without being given adequate or full information or for purposes of research. John had a close relationship with Professor Savidge and I believe that, despite his brusque manner (he was very rude to me on occasions), he had the best interests of his male patients at heart. John was not the sort of person to just accept what he was told or not told without question. He was constantly asking questions about his treatment and tests. He would take back Factor VIII batches if felt dissatisfied with them. He also had a good relationship with his AIDS doctor, Dr Michael O'Doherty who told me when John was dying that 'he was searching the world for a drug for John'. He was a doctor with great integrity.

**5. Impact**

1. It was extremely difficult for John to talk to his family about what he was going through. In fact, it was only a couple of years before John died when he started to become seriously ill and started to lose weight and his T-Cell count was coming down that he decided to tell people that he had HIV. He wanted to tell everybody more or less at the same time so he basically wrote a list of all the people that he wanted to tell and he just rang them up and told them over the phone. This must have been incredibly difficult for him.
2. If I remember rightly, he told his father well before his mother because I don't think his mother would have understood. I think his mother was the last person he told.
3. John had to tell his Managing Director at work because he was having a few problems and people were starting to become suspicious. John was starting to look ill and was having time off work, becoming more and more tired. John had a problem with one work colleague who had somehow guessed what was happening and word got around at work. On one occasion, someone pinned a horrible notice to the stockroom door, something to the effect of, "Danger – Watch Out It's Mr Grindley" and they would not allow him in. Another notice

pinned on the staffboard said "Danger: Government Health Warning – Mr Grindley can seriously damage your health!" and it had a skull and crossbones on. This was awful. The notices are exhibited before me at Exhibit WITN2336006.

4. I think that John was quite angry at the time but he wasn't the kind of person to lash out or hit back no matter how badly he wanted to. As far as I remember, we didn't have any bad reaction from family or friends when he told them. I think it was more shock and a lack of real understanding of what was going on. I think a lot of people including John's mother and sister went into total denial about the whole situation.
5. This was an incredibly difficult time for me because not only was John becoming progressively more unwell, I then had my own father become ill in Ipswich and he died only eight months before John. Then John's father died two months after my father died. It was an incredibly difficult time because I had to leave John to deal with my father's death even though he was in hospital.
6. It was a relatively short period of time between John becoming seriously ill and passing away. John had to give up work two years before he died because he was falling asleep in the afternoons and it was getting more and more difficult for him to drive home from work. At this point, he was working for the same firm but they had moved to Sevenoaks in Kent and it was a much longer journey. John was starting to feel that he couldn't cope with driving home. Apart from that, he wasn't too bad. He had started to go off his food a little and wasn't eating that well. Things went seriously downhill really about eight months before his death.
7. John was on antiviral drugs called Retravor which, because he was in work he had to pay for. This is something that annoyed us intensely, that he had to pay for his own drug to cure a condition that he had been infected with by the NHS through contaminated blood. He had to pay because his firm paid him until his death even though he didn't work for the last two years.

8. John was diagnosed with Hepatitis C about two years before his death, in or around 1992 but he knew many years before that he had Non A, Non B Hepatitis. He knew he had an enlarged liver I don't think there was effective testing for Hepatitis C before this time. By this stage, John already knew he was dying so it didn't make an awful lot of difference to us. It was just one more thing for us to deal with. It is difficult to know whether or not the Hepatitis C had any kind of profound affect one way or another.
9. In the two year period before John died, I had already given up teaching, John had given up work, and we were both home together. Physically, John had become like an old man. He had to walk with a stick and to my mind he looked about 80 years old when he was only 40. This was just a period of waiting. Occasionally we would go out for dinner because John's appetite was waning and he didn't fancy the food that I cooked. He would occasionally come out shopping with me and was still driving up until a few months before his death but we went out one day and he decided 'on the spot' to give up driving. For a while, he would be OK in the mornings but then by the afternoon he would be sleeping again.
10. I remember during this time period that we made an appointment with Tim's Headmaster. We never told the Headmaster specifically what was wrong but we told him that John was terminally ill and that we didn't know how much longer he was going to live so that the school could be prepared. We did this in agreement with Tim just so they were aware of the situation.
11. My son Tim will provide his own statement to the Inquiry giving details of his experience of what happened. From my perspective, I saw him go into denial. He knew well enough what was happening but he basically carried on as normal as far as you could tell.
12. Growing up, Tim always knew that his father couldn't play football or do any physical activities with him but they used to do a lot of other things together, for example, playing board games, chess and Lego. Tim was aware that Dad

couldn't be kicked or punched. Overall, they had a good father son relationship.

13. It was so difficult to tell what the impact of John's illness and death was on Tim. He didn't exhibit any particularly bad behaviour or real difficulties with schoolwork or anything like that.
14. John made his own funeral arrangements. When he gave up work, he had no real idea of exactly when he would die. He went into the Undertakers and told them exactly what was wrong with him, which is quite remarkable I felt. He paid for his own funeral and told them exactly what he wanted so they would know the nature of the beast that they were going to have to deal with and they were extremely grateful for this. They said they never had that happened before, that anybody with HIV had come forward to tell them. He also in the two years before he died made his will and sorted out all of his affairs so it was less for me to worry about later on.
15. I think that John did this so that things would be easier for me and so that I wouldn't have to face these kinds of problems when he was gone. John even found the music he wanted for his funeral, he found the poems (because he wrote poetry) that he wanted. We even timed the music exactly how he wanted it. John had also gone to see the Rev Tanner, Chairman of the Haemophilia Society, to conduct his funeral, which he agreed to do.
16. It was when we were planning John's funeral that I remember him lying down on the couch and crying for the very first time. John was an incredibly strong person and I never known him to cry, it was totally out of character. He said, "I don't want to die." And I said "I know you don't." I didn't know what to say to him.
17. In the eight months, before John died he went downhill really quickly. It was really after his father's death at Christmas in 1993 when John started to become seriously ill. I think his father's death was a turning point for John because we all went to see his father in Hospital and John said to his father, "See you soon Dad."

18. I think it was February 1994 that John went into St Thomas' Hospital with Pneumonia. It was the AIDS form of Pneumonia and he was in there for a while but he did come home again after about a month. He must have been on antibiotics of some form at that time.
19. I remember when he was in St Thomas' at this time, he was in a single room on his own. There was also a single room next door to it. Two asylum seekers were brought in on hunger strike. In order to keep them together the staff wanted John to move into the general ward. John refused to be moved.
20. I think it was just before Easter 1994 that John was taken into St Thomas' Hospital again with serious diarrhoea and sickness. This was diagnosed as Cryptosporidiosis. He was hardly eating at this time and became doubly incontinent. St Thomas' couldn't really cope with his condition as they did not have adequate nursing staff. I was constantly sending Tim to school and going straight up to St Thomas' and helping to nurse John on the ward because they were unable to cope. Unfortunately, at this point, Tim was left to fend for himself at 14 much of the time, for which I still feel guilty about. Through Barnardos, we had arranged for Tim to go to a lovely family at Biggin Hill for some respite from the situation but it proved difficult as the journey on school days was long and he was sometimes late. I think he occasionally got detention even though we had explained the situation to his school. Tim was unhappy about this so he didn't go anymore but we have stayed in touch with the family.
21. The staff from St Thomas' Hospital Haemophilia Centre would come up regularly to visit John. There was one nurse in particular, called Christine Harrington, who was absolutely marvellous. John had known her for many years down in the Haemophilia Centre as she used to visit him at the weekends. Also, another nurse called Jo Hurst who was with John's mother and myself when John died as she had just left St Thomas'.

22. John was comfortable in St Thomas' with familiar staff and towards the end expressed a wish to die there but prior to this, a few years earlier he had visited St Christopher's Hospice in Sydenham, SE London and thought initially he would like to die there. This was on his notes. St Thomas' then sent him home with little warning in an ambulance with other people which took hours because we lived the furthest away. When he arrived home (I was not allowed to go with him) he nearly collapsed and I had difficulty getting him upstairs to bed. He was weak and fragile and no immediate nursing care had been arranged.
23. It had been arranged with St Thomas' Hospital that John would come home and that the GP would visit. However, I think that the GP was reluctant to come or didn't have much experience of dealing with AIDS. After two weeks of struggling to cope with John on my own at the same time I had to look after my son and get him to school and run the household, I decided to call the GP. He eventually did come but he wasn't much support. He sent a nurse but she just bought incontinence pads and didn't do anything else. I was therefore left to look after John and this carried on for six weeks during which I was just totally exhausted. John and I were still sleeping in the same bed as we had no other bed or anywhere else for me to sleep. It was awful sleeping next to John knowing he was dying.
24. Eventually nurses from the local Hospice were called in. I presumed that the GP must have made a referral. They helped me nurse him for a few days then it was decided that he needed to be in Hospice care. They took him into St Christopher's Hospice in Sydenham.
25. John was in St Christopher's Hospice for two weeks where they were absolutely marvellous. They took care of his pain and he was still being treated for his Haemophilia because that's what he wanted. They allowed me to come in every day and the last four days before his death, they allowed me to sleep there with him. Various relatives took care of Tim at the time. I didn't wash for four days and had practically no sleep but they knew that was what I wanted and they were very supportive.

26. The day before John died, his sister and my brother-in-law and even our niece and nephew came to visit. I also managed to persuade my son to come and see his Dad at the end, partly because I didn't see my mother when she died and I knew that Tim needed to say goodbye to his Dad. Also a group of about six visiting doctors to the Hospice on that day, visited him in his room with my permission. John would have wanted that. I think he was the first AIDS patient at St Christopher's Hospice.
27. On the last day, John's mother was there and so was another nurse from St Thomas' Haemophilia Centre. We willed him to go and we were all together at the end when John passed away peacefully on the 13<sup>th</sup> June 1994.
28. I remember a tremendous sense of relief when John died, that his pain was over. They then left me alone in a room with him for a while and I never seen anybody dead before and unfortunately he didn't look very peaceful. His head was to one side and he looked as though he was in pain. I was upset by this. When I left the room, I was ok. I gathered myself together and I remember worrying about what they would put on the death certificate. I don't think John would have been too worried about what they wrote but my first thought was for my son. I told them I didn't want HIV or AIDS on the death certificate. Initially, they offered to put Haemophilia on it but I did not agree to this because he didn't die of Haemophilia. In the end, they just put pneumonia on the certificate, which in fairness is what finally killed him.
29. After John died, I went to stay with my mother-in-law for a day or two because she did not want to be alone. I think I was so exhausted at that point and I hadn't slept for days. My brother-in-law came to help me with the funeral arrangements and we more or less got everything done within a day because John had been so meticulous about it.
30. My son Tim decided that he wanted to go back to School. I think I must have rang them up to tell them what had happened. I remember feeling in limbo until the funeral. Tim GRO-C in the period between John's death and

funeral soon after he returned to school.

GRO-C

GRO-C

31. It was a very big funeral. I think there were well over 100 people there, perhaps more like 150. John's firm virtually closed down for the afternoon. The Managing Director came and most of the other staff, about 30 or 40 people. The funeral went just as John had planned, with the music and the poems that he wanted. I had written out a piece about John's life and how he felt about things and that was read out by the Vicar. AIDS wasn't mentioned at the funeral but I think that everybody knew how and why John had died.
32. John was a stamp collector and a lot of his friends from the stamp club came. I remember it was an extremely hot day in June and one of the more elderly members of the stamp club unfortunately passed out just after the funeral.
33. Because I only had a small house, we had to have the reception at a Hotel near the Crematorium and most people came to that. I remember waiting on the funeral cars and being concerned that John was a bit late for his own funeral.
34. My son Tim came to the funeral. I said that this was up to him entirely but he wanted to come. He had attended my own father's funeral 8 months before and that was also his choice. I was very glad he came and had the opportunity to say goodbye to his Dad.
35. John's funeral was at Elton Crematorium (Falconwood) in South East London. His ashes were scattered with his father's at Honor Oak Cemetery, Forest Hill, South East London.
36. My initial feelings after John's death were of great relief that he was not suffering anymore. His life had been full of suffering from day one and I just felt relieved that his battle was over and that he was now at peace. Things did not really hit me for the first few months after he died as I tried to make myself incredibly busy and make things as 'normal' as possible for my son but things

became very difficult for me and I struggled to cope with my loss. I am still under a psychologist currently for depression and panic attacks.

37. I took on a lot of courses and a lot of classes to try and fill my time. I took a course in City and Guilds to do some voluntary teaching and numeracy teaching for adults. I did several adult education classes on each day of the week. I did a German course, a choir course, and an art course. I think that I was overdoing it in order to fill my time so I couldn't think about what had happened.
38. I did not have the self-awareness to realise at the time I was overdoing it and I became extremely stressed and anxious. Because of this, I began to see a psychologist regularly at Beckenham Hospital, a lady called Doctor Geraldine Muleady. She was fantastic to me. She saw me on a regular basis and this was a great help. I had seen her prior to John's death after trying to get counselling for myself when none was available elsewhere. GRO-C John also saw her once or twice. She was among the few psychologists specialising in AIDs at the time. I also remember being offered a couple of counselling sessions at St Christopher's Hospice where John died but that didn't continue, although John and I had had a little at St Thomas' with Chris Harrington. Years later, I received some counselling from Joanna Fenning and some from another counsellor from Greenwich Council.
39. Around 18 months after John died I was asked by an ex-colleague of mine who was in charge of a state Nursery, attached to the school I had been the regular supply teacher at before giving up to care for John, whether I would temporarily take over the Nursery. I hadn't intended to go back to teaching but at that point, I thought I might be ready. I managed two terms then I suffered a breakdown in the classroom in front of 25 three-four year olds. Fortunately I had a nursery assistant who helped me out of the classroom after I collapsed with a parent left in charge for a few minutes. This was around the time when my son was coming up to take his GCSE's, which was very unfortunate for him because he basically had to look after me as well. At this time, it was impossible for me to get out bed for days on end. I remember Doctor Muleady

came out to the house to see me. It took me a long time to get over that breakdown, years and years really. I felt guilty at the time and still do that Tim had to cope on his own as well as with me.

40. It was a very slow recovery and I lost all confidence in myself. My self-esteem was very low (and still is at times) and I couldn't take on anything that involved responsibility. I still had extreme difficulty getting up and out of bed and even getting dressed and ready. Doctor Muleady had encouraged me before John died to think what I would like to do after he died. I said singing and travel.
41. I have done some travelling in Europe both with Tim and sometimes with friends which I really enjoyed. I am unable to travel now due to ill health. Also I did take up singing after John died. I had and still have singing lessons. I have been told that I could have been a professional but came to it too late. I joined an opera group at the suggestion of my first singing teacher and have sung in many staged opera productions (amateur). It has been great to be on stage in character. It has been a good form of escape especially when you are singing and acting at the same time. I have sung mainly chorus but have done some small singing and acting roles. I have also been a member of a group which went far and wide entertaining in Care Homes etc. Currently, I still sing in an Operatic Society which does stage productions, go on singing courses and attend master classes. I go to Morley College in London once a week to an advanced singing class and do voluntary work (singing) once a week in a Care Home. Singing has been my salvation. It has been my immense joy and I have made many friends.
42. However I feel I have lost so many things in my life and the whole situation has affected me beyond measure. I have lost the love of my life and been left to bring up my 14 year old son alone. I lost my career as a teacher and have not been able to work since because of bad depression. I am still devastated by not having a second child. Since my son left home (now married with two small children) I have lived alone. It is very lonely with only the four walls to talk to. There is nobody to confide in, to make me a cup of tea, or care for me

when I am ill, although my family help as much as they can and have been a great comfort which is much appreciated.

43. I think people must think that maybe after all these years have gone by that I would somehow forget what had happened. In fact, John's death has permeated every area of my life and affected every area of my life. First of all, I lost the love of my life and he is not here any more. In some ways, AIDS brought us very close together. We could talk about anything. On the other hand, we were denied the opportunity to have a proper marriage. John and I were like brother and sister for most of our marriage. I lost the child that I wanted but never had and Tim lost the opportunity to have brothers and sisters.
44. In the past John and I had to live in very bad housing with some very antisocial neighbours who caused endless difficulties for us at a difficult time. This was because John's illness meant he was never able to get life insurance and because of that we couldn't get a mortgage. This meant that we had to live in low standard social housing in deprived areas. I lost my entire career as a result of John's illness. Fortunately, I now live in a decent home in a nice area with good neighbours. This is due to the help of Susan Daniels, former freelance Financial Advisor. I still have a mortgage but I am content here.
45. I am still very angry about certain specific things that have happened to me. I am very angry about the lack of support that I received towards the end of John's life - particularly from Bromley Social Services who did absolutely nothing for us and completely ignored my pleas for help. I am still cross about the lack of help during the six-week period that John was at home in between him coming home from St Thomas' and going to St Christopher's. I had practically no support from the GP or from any nursing staff that should have been provided. I was left completely on my own to deal with my dying husband also having a young son to look after.

6. **Treatment/Care Support**

1. John and I were 'happy' about his treatment at St Thomas' until he had his two opportunist infections when the hospital couldn't cope with nursing him. Not enough staff and as already stated I nursed him some of the time there.
2. Also, as already stated, I had inadequate help when he came home to die until he went into St Christopher's Hospice.
3. I am still angry about John having to pay for his own treatment. It was a disgrace that he was made to pay for his own AIDs drugs when he was infected with by the NHS.
4. I am very angry that Bromley Social Services did nothing to help us and completely ignored our pleas for help when we asked for it.
5. John had several visits from an occupational therapist a couple of years before his death. She assessed him for physical aids that could help him with things like getting into the bath etc.
6. There was a complete lack of support available to me and my son after John died except what I received from Dr Mulready. I went to the GP about a year after John died and he told me 'to get over it'. The MacFarlane Trust was little help practically or emotionally.
7. John received dental treatment at Guys' Dental School. When he was HIV positive the dentists treated him in spacesuits and passed instruments through a hatch.
8. I also visited Guys' Dental School on occasion for emergency treatment. I told them my husband was HIV positive but that I was negative. The student called over the dentist in charge. He barely looked in my mouth and told me there was nothing wrong when I was clearly in pain. I complained to the School and there was an investigation and hearing which I attended but it was his word against mine. I believe he didn't want to treat me because of the situation. My

own dentist was happy to treat me always and I did get treated a day or two later on that occasion by my own dentist.

## 7. Financial assistance

1. For the first four or so years, after John died, until my son went to work, I did receive regular payments from the MacFarlane Trust. After that nothing, as they only gave payments to disabled widows or widows with children. Years later, they introduced an income top up scheme. As it was means-tested and I strongly disagreed with 'going cap in hand' I have refused to apply so I have had nothing since about 1998-9 when my son left school.
2. I have had several grants from the Honeycombe Trust (money left for widows to help them back to work, learn to drive, education etc) to go on singing courses but the last few times my applications were refused because they wanted me to be means-tested.
3. I have also in the past year received payments to pay for visits to the same psychologist as many years ago, Dr G Muleady as she only has private patients. This funding has been from the English Infected Blood Scheme. I have also received one Winter Fuel payment from them which is not means tested.
4. John received two ex gratia payments for the HIV, one was £60,500 and the other was £20,000.
5. I had to fight hard for the two ex-gratia payments from the Skipton Fund known as Stage 1 and Stage 2. They initially turned me down two or three times before I was eventually accepted with the help of a doctor at the haemophilia Centre at St Thomas'. I think his name was Dr Bevan. I received three payments, one of £20,000, one of £50,000 and one of £10,000. Most of the money I have received from the HIV and Hepatitis C ex gratia payments have gone towards the deposit and mortgage balance of my house. Now I live on my teacher's pension such as it is, my ordinary state pension and an annuity from John's work pension (20 years with the same firm).

6. The regular level of financial support available to widows like me is completely unsatisfactory, especially when the MacFarlane Trust was first set up and in subsequent years when nothing was available to most widows. I have heard of extreme hardship, homelessness and even suicide. When you take into account what we have lost, in my case my own career and income and our ability to get a mortgage etc. it is disgraceful that widows like me have been made to feel like charity cases having to repeatedly ask for money and being denied. Even one-off payments have been denied for specific items.
7. I went to see Martin Harvey, when he first became Chief Executive of The MacFarlane Trust, to get some regular help for all widows, not just myself. He asked me what my late husband did. I told he was an Electronics Engineer. He then said 'Do they not have any charitable organisation that can help you?' I walked out in disgust at his response.

8. **Other Issues**

1. John and I have campaigned on various issues related to blood products. I started in 1980 writing to Ronald Reagan and Mrs Thatcher directly (no response). - I have written to various MPs and Health Ministers including Kenneth Clarke over the years. Copies of some of this correspondence is Exhibited before me at Exhibits WITN2336008. I have also campaigned generally on an individual basis. I have campaigned for Recombinant Factor VIII to be introduced and had a question asked in the European Parliament about the VAT on Recombinant Factor VIII. Recombinant Factor VIII has, of course, since been introduced but the issue of justice and adequate compensation has been ignored and also, until now, a proper Public Inquiry, which I have also campaigned for. I gave evidence at the Archer Inquiry but little came of it.
2. Still nobody has admitted any kind of blame and we have not had a real or meaningful apology or compensation for the situation. I am pleased that all of these years of campaigning have now resulted in a public inquiry although

many of the victims of the contaminated blood scandal died years ago and I can't see any excuse for having left this for so long.

3. Some years ago now, I attempted to become involved with some litigation against the American Pharmaceutical Company who produced the Factor VIII product and were then being taken to Court in America by the victims for compensation. I tried to pursue this and there was an English Law firm dealing with it from this side of the water. Initially, I had to try to obtain John's medical records for the litigation. There was a time limit to getting these records and I had an awful job trying to get hold of them. Eventually, I sent what I could get hold of to America together with John's treatment diaries. Initially I had a letter from the American Lawyers saying they thought that we might have a case. However within a few weeks of that letter, I received a second one to say that because John had died in England and because his death was 10 years prior to the claim, I was "out of time", which meant that I couldn't pursue the case. Initially I was extremely upset by this because I had promised John I would do my best to get some kind of justice for him.
4. I want the Inquiry to know how much difficulty I had getting some of John's medical records. When I initially approached St Thomas' Hospital, I was told it was all too long ago and that the records had probably been destroyed. In fact, I was able to obtain some of John's treatment records through the National Haemophilia database. Unfortunately, they were sent to St Thomas' for security reasons and I had to go to St Thomas' to collect them. When I arrived there, I had an unfortunate incident with the Director of the Haemophilia Centre, Doctor Savidge, who had been John's Doctor. Unfortunately, instead of keeping our conversation private in a closed office, this Doctor decided to open the medical notes in the reception area and talked in a very loud voice about the contents while people were passing by. This greatly upset me and I took the notes away and went to a toilet and cried for about two hours afterwards.
5. There were two very significant things in these notes, which had been written by John's AIDS Doctor. At one point, the note said that it was thought that John had contracted HIV in approximately 1981 although he was not tested

and proved positive until November 1986. I believed this was because there were not reliable AIDS tests before that point. The other thing was that there had not been a test for Hepatitis C until approximately two years before John died. John had been tested at this point and was positive. However, the notes from John's AIDS Doctor said that he felt that John had Hepatitis C since 1969, which was when John was very young in his late teens. This was confirmed by a letter from the Haemophilia Database dated 22 May 2003 which is Exhibited before me at Exhibit WITN2336008.

6. I felt all along that I never failed John in life and I tried to be the best wife I could under the circumstances. I know he loved me and he told me near the end what a good wife I had been. However, I have failed him in death because I haven't been able to get justice for him and the thousands of others who have died or are still alive, many of whom I know personally or the widows who I know or don't know.
7. I know that John would want me to try and be happy. He didn't want me to cry after his funeral and I didn't but I have cried buckets since and still do. He said when he was ill that he wanted me to grieve for him for a year and then forget him, perhaps remarry with his blessing. Well, I have learnt that is impossible. We still have no closure, no admission of wrongdoing; everything has been swept under the carpet and no one listened. The blame, I believe, is threefold.
8. Firstly, I blame the American Government at the time, for allowing prisoners, drug addicts and the homeless, to give blood in return for payment, which caused the transfer of the virus in the first place.
9. Secondly, I blame the American drug companies, who continued to send out their stockpiles of un-heat-treated blood products (Factor VIII) knowing that they had heat-treated available, all because of the greed for money.
10. Thirdly, I blame Mrs Thatcher and the British Government, especially Mr Kenneth Clarke, for refusing to withdraw American Factor VIII, despite it being known as a potential danger when haemophiliacs in American and England had already died of AIDs. They refused and denied there was a problem

because they believed to do so would cause mass hysteria about AIDs among the general public. This left Haemophilia doctors continuing to hand out Factor VIII and haemophiliacs who had no choice but continue being treated or treating themselves in order to stay alive.

11. At last we have a proper Public Inquiry and I have every faith in Sir Brian and his team to establish the truth and that we will get justice for our loved ones.
12. Lastly I would like to pay tribute to my husband. John had the most phenomenal strength and courage. It was a great privilege to care for him and nurse him. Every day I think of him and hope one day we will be reunited.
13. I commend to you several people who have helped me through the many difficult years. Joanna Fenning (counsellor), Susan Daniels (Financial Advisor to the MacFarlane Trust, Liz Cox (Barnados), Dr Mike O'Doherty (my husband's AIDS doctor), Chris Harrington and Jo Hurst (John's nurses) and Dr Geraldine Muleady (my psychologist). Lastly but not least, my family and friends who have supported me throughout, particularly Christine and Richard Purr, who temporarily fostered Tim for a short period, John's sister Patricia and her husband Bruce, for helping me and including Tim in their family holidays, and John's cousins, Rita Anthony and Susan Morgans, for their help and support.

**Statement of Truth**

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

Signed **GRO-C: M E Grindley**

Dated 26/2/19