

Witness Name: Kathleen Joyce Algie

Statement No.: WITN3109001

Exhibits: WITN3109002

Dated: February 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF KATHLEEN JOYCE ALGIE

1. I, Kathleen Joyce Algie, will say as follows: -

Section 1: Introduction

2. I was born on GRO-C 1947. I am retired and a widow, following the death of my late husband John Kenneth Algie. I live in GRO-C Hampshire in a rented home. My mother, who is 97, lives in GRO-C and I have one daughter, Suzanne, but no grandchildren. I am a Christian and I regularly attend two churches.
3. In the course of this statement I intend to talk about my late husband's infection and subsequent death as a result of his receipt of infected blood products.

Section 2: How affected

4. My husband, John, was born on GRO-C 1940. He suffered from haemophilia A which was severe, although I was never aware that his condition was so serious. In fact, I only learned of this when my daughter was checked to see if she was a carrier of the condition and I saw his records.
5. No-one else in John's family had ever suffered from a bleeding disorder or condition. His mother had created a family tree and, despite their best efforts they could not find anyone who had been similarly affected. He had had a twin brother, Michael, who died while very young, shortly after birth. They were identical twins and Dr Goldman told him that his brother would have been a

haemophiliac as well and that by being born first his brother had inadvertently saved him from potentially having a massive brain haemorrhage. In addition, I am told that John's grandfather died following being kicked by a horse which my daughter speculates might have been exacerbated by haemophilia. However, I had never made this connection.

6. John was first found to be suffering from haemophilia when he was about 14 months old. He had been given a number of injections and his back had gone completely black and blue. He was taken into hospital and diagnosed. I heard John's father say of his two sons, "*Michael was perfect and died, and look what I was left with*".
7. In around 1957 John was sent to private school following which he attended Billingham College to sit his O' Levels. His condition had led to him missing a lot of time at school. At college, he was tripped and fell whilst carrying a large stack of books. At first there were no significant repercussions, however he started to suffer from terrible indigestion and after a period of time it was diagnosed that he was suffering from ruptured intestines. He would have been 21 at the time. He was rushed to hospital and ordered nil by mouth after a major operation. However, he was accidentally given a drink and became so ill that he almost died. He lost his hair and his memory of the time. He was so close to death that the church elders were by his bedside praying for him.
8. He did recover from this incident, however he always had difficulty getting work afterwards. He once applied for a telecom operator job but was not employed because it was 'dangerous'. I could not see the sense of this. He eventually became a driving instructor.
9. It was also at around aged 21 that John had some major dentistry work which resulted in all of his teeth being removed and replaced with false ones. He was getting so many fillings that the dentist decided that it was quicker and more efficient this way. They made him sign to say that if the operation was going well they would remove the top and the bottom teeth. This required whole blood transfusions as he was bleeding so severely.

10. I met John on 12 July 1970, and shortly after meeting we started going out. I recall him visiting me and saying that he had something to tell me. He asked if I had heard of haemophilia. I replied that I knew of it from what had happened to the Russian royal family. He explained that he had the condition and asked me if I cared, to which I replied that it would have been a funny kind of love if it had been affected by that. He asked me to marry him on the spot and I agreed. We were engaged by 16 August 1970, we made our engagement official on 24 August, and we married on 24 July 1971. It was a real whirlwind romance.
11. At the beginning of our married life there was no great impact upon us of John's treatment. As before, he integrated it into his life. My new mother-in-law would always ask me about John's knees, making sure that they were alright, though at the time I was never sure why.
12. During this period of his life John was being treated in Middlesbrough General, as we lived in [GRO-C], with Dr Williams leading his treatment. The treatment used to fit in fairly easily with his life as following a day's driving lessons he would simply go back into the hospital for any treatment that he needed and be back home shortly afterwards.
13. At this time, John was receiving frozen plasma treatment and he used to go to the hospital approximately once a month in order to receive eight bags for treatment. After this I cannot name the medications that he received as John dealt with it all. He saw this as his responsibility.
14. However, at some point during 1977 we went to visit my parents in [GRO-C] and John went into London for a day by himself. When I came back from my day out I discovered that John, having been stuck in London with a ticket that was not yet valid, had decided to stand at the station until his ticket became useable. By the time the train got back into [GRO-C] he had developed a bad bleed into his knee and we had to take him into hospital.
15. I recall that it was always difficult finding a doctor who knew about haemophilia. In many of the places that John went, he knew more about it than the

physicians. I can even recall him lecturing doctors and students around his bed about his condition. This lack of understanding was demonstrated when we got to Queen Elizabeth Hospital ("QEII") where one of the doctors there squeezed his knee and said that the bleed did not look too bad.

16. Following this John was sent to the Royal Free Hospital ("RFH") which was a nightmare of a journey as John was in pain. While there he was provided with little bottles of treatment to be taken back to QEII for them to treat him with. In retrospect, I believe this might have been his first treatment with Factor VIII blood products. I can recall my father, who drove us to the hospital and was such a mild mannered man, driving straight through a barrier marked 'No access to the public' and demanding that they treat him immediately. To their credit they did so.
17. Following this incident John had to be taken into the Royal Victoria Infirmary in Newcastle ("RVI") for a week of treatment. The drugs provided to him were injected via syringe and I could not be in the treatment room. Suzie and I travelled from GRO-C (home), by public transport, every day to visit him.
18. It was while we were there that the doctors announced that from now on John would be home treated for his condition. There was absolutely no discussion about this and we were simply informed by the one of the doctors in Dr Peter Jones' team, that this was how he was going to be treated from now on. I hated the idea, as it was to be me that would inject him. The nurses taught me how administer an intravenous injection, but I never wanted to. It is extremely difficult to put a needle into the person that you love. I can remember the ward sisters insisting that I practice on them. However, I did not love them and so there was no difficulty in injecting them. No matter how much I told them that we did not want home treatment the doctors insisted and eventually John agreed.
19. John was never "anti-medic"; he believed in the doctors and would do as he was told. Despite haemophilia being a condition where it is often said that patients know best, John trusted the doctors.

20. Upon his return home, John was unable to work and for a period of time as he was between jobs. There was no money coming in and this was a difficult period for us. Prior to the holiday he had left one driving school and had intended to go into another, however this job was withdrawn when they discovered how unwell he was. He later resumed employment as a driving instructor.
21. I used to hate having the blood product at home in our domestic fridge. John and I just tried to get on with it, administer the treatments after work and move on. We never wanted our lives to be dominated by the illness. However, the doctors seemed to want him to administer it more frequently throughout the day whenever he had a niggle or a worry. I could just never bring myself to think of John as being disabled, and treating him in this way worried me. While he might have walked a little funnily, he was just John.
22. When administering the drugs, I knew I had to be careful and I had been told about wiping down surfaces and wearing gloves when administering medication during the training given to me by the nurses. I cannot recall, however if I was ever told of any infection risk with the product beyond the normal risks posed by potentially dirty needles and unclean surfaces. As a result of this I always used these safety precautions whenever I treated John.
23. Despite his new treatment, at this time John was pretty healthy. I can recall once that during a driving lesson a pupil had swerved and John had injured his shoulder grabbing the wheel. I received a phone call from the police who were confused by his insistence that they take him into hospital as he seemed fine. I told them *"well of course if he says take him into hospital, take him into hospital"*.
24. His good health continued until 1981. However, on mother's day that year we went out for a meal and afterwards John was very, very sick, although he had eaten the same food as me. He was always a slim man but I noticed that his stomach was a funny shape. The sickness persisted and I took him to our GP who tested him for Hepatitis.

25. I cannot recall precisely what I was told but I was simply informed that John was suffering from Hepatitis. I also cannot recall if we were ever told of the precise strain of Hepatitis that he was suffering from, what it meant or the prognosis; we were just told that he had it. It was not made out to be serious and at the time I was more concerned about selling our house.
26. By this time, we were aware that the blood products John was receiving were from America as they were considerably cheaper to produce than the British plasma he had previously been using. We were given this information at the RVI. We had never been given any choice in relation to the receipt of the new American product as it was simply too expensive for him to continue on his old product.
27. John also suffered from arthritis that was getting progressively worse. I do not know if this is related to his haemophilia, the Hepatitis, the treatment or none of the above.
28. In 1982, John, myself and our daughter moved to GRO-C While here John attended the Royal Free Hospital ("RFH") where Doctor Goldman was his consultant. John was 42 at the time and his health was fair. We were considering trying to buy a post office. The bleeds in John's knees and his arthritis were making it increasingly difficult for him to use the dual-controls in the car and so being a driving instructor was no longer practical. Unfortunately, we were not even allowed to see the books for the post office as the sellers did not think it was necessary for our purchase, therefore the purchase did not go ahead.
29. John's joints continued to get progressively worse. I can remember that while at the RFH we were regularly invited into hospital review days, roughly once a year, in order for the doctors to check up on us and see how the family were coping. I can recall one incident when they insisted that John see a dentist, no matter how often he insisted that he did not need to. Upon going to the dentist John removed his false teeth and presented them to the dentist. He was a quiet man in many ways but often hilarious.

30. I can recall that at these review days John and I would be separated and we would be spoken to separately. We were asked hugely personal questions including things about our sexual activity. I cannot recall if these questions came before or after John's eventual diagnosis of HIV but I do recall we had to fill in a number of forms about types of activity. We were never allowed to discuss this with each other and when we were allowed in the same room we were physically separated on other sides of the table. My daughter Suzanne once noticed that I was low in mood after one such meeting and she asked why I was sad. When I told her what the hospital had asked us, she was utterly furious that we had been asked about such things.
31. In or around May 1988, we were invited in for a seemingly normal review day. It was at the time when we were trying to rent a house from the council and I had hoped that someone from the RFH would be able to write a letter indicating that due to John's health we desperately needed a home, which might be of some assistance. I had prepared and dressed up for the occasion in the hope that this might help. However, when we entered John and I were sat either side of the table. We could not reach each other and we were unable to even hold hands. One of the hospital's social workers, Mrs Riva Miller (who I believe still works there), came in and asked if we minded them filming the meeting. Also in attendance were a doctor and some of the hospital sisters. I was asked a number of questions about what I would do differently if I discovered that John was positive with HIV. I was very angry with them for going on about HIV and AIDS as I simply wanted to talk to them about the house. They continued to ask me a number of questions including what contraception we were using. I was at my wits end, it was so horrible and we could not even hold hands to comfort each other. Following this they turned to John and asked him why he thought I was so upset. He told them off for this. At the end of this meeting they informed us that John had been diagnosed with HIV. I was not particularly surprised, as I had been under the impression for some time that haemophiliacs treated with these blood products might end up getting HIV or AIDS. I have no recollection of being told this before this treatment started.

32. What was a shock however, was that John was being tested for HIV at all, as we had not been informed of this previously. We were told at the meeting that he had been HIV positive for 3 years. Not only this but we discovered from the documentation that the RFH had known about his infection for three years prior to telling us. However, we did not overreact, we simply asked what we could do now. We were given no new information besides them reiterating the safety precautions that I had already been doing in relation to injections and home treatment.
33. Unlike myself, John was absolutely livid with the news. He suspected that, rather than that his blood having been tested retrospectively, the RFH had kept his diagnosis from him for three years. I can recall him saying, "*I could have killed you by loving you*". We had always wanted another child although we had wondered if this was possible as we did not wish to pass on haemophilia. At this meeting, there were a number of things discussed which were unhelpful, including abortions and sterilisation.
34. The whole meeting was extremely traumatic, but for me this was more because they refused to help us with matters relating to the house and not because of John's diagnosis with HIV, which I had assumed he would get.

Section 3: Other infections

35. I am not aware of John suffering from any other infections that HIV or Hepatitis as a result of treatment with contaminated blood products. As noted above, I do not know what strain of Hepatitis he had.
36. I also know that they tested him for TB and the result was negative.

Section 4: Consent

37. As noted above, I do not think John consented to being tested for HIV. We always spoke about his health and I cannot recall him mentioning anything specific. He was aware of the tests for Hepatitis and TB.

38. John regularly gave blood samples, but I do not know if he was ever told why. The RFH also took blood from me which I was told was for the purposes of comparing our bloods. I can recall that I was written to twice, once in 1986 and once in 1987 when the hospital confirmed to me that I did not suffer from HIV. In retrospect I can see that this meant they were testing both of us for a number of years and had been informing me of the results, but not John.
39. Once he was diagnosed with HIV, John was used as something of a guinea pig for different treatments. We knew they could not cure it but they wanted to try different drugs on him. I believe that John agreed to try these new treatments when asked.
40. During the administration of these HIV drugs the treatments were explained, as were the reasons for administering it.

Section 5: Impact

Impact of treatment and illness

41. The practical impact of John's diagnosis was very limited, apart from the nuisance of having to go back and forth to hospital all the time. I was upset at the way the hospital managed his treatment and that it stopped me from doing all that I could for him. Previously I had always done little things to try and help John which had seemed to work. This included giving him paracetamol, putting a little bit of glucose in his tea or giving him some gelatine in the hope that it might help thicken his blood. However, after the HIV diagnosis the hospital instructed me to stop all of this. I do wonder if this was to make it easier for them to test the effect of the new treatments upon him. This was very difficult and I can recall that John and Suzanne always used to drink hot blackcurrant before bed. John liked his with a little bit of gelatine stirred in and it was hard to stop giving him this.
42. By 1989 John's health had deteriorated significantly. I recall that we had a biscuit tin full of colour-coded drugs which were paired with coloured spots on the sheet and list of drugs that I was to administer in order for me to co-ordinate.

43. Mentally, John seemed fine with his treatment and I believe that his faith helped him through as mine helped me. However, he was grumpy at times and I have learned that the illness could possibly have affected his brain. I also think I probably have rose tinted spectacles throughout the entire period. I also got grumpy at times but this felt normal for a married couple. Thankfully his faith stayed strong until the end.
44. John's illness and the treatment he received for it was very trying for us. The HIV treatments he received never seemed to do him any good. I cannot recall any side-effects but he was certainly very ill at the time. We managed to go away on holiday to Portsmouth and he slept the entire time. The RFH began to treat him with hydrotherapy to help him with his joints and in order for this he had to drive 40 minutes every day to attend the hospital. I could not believe that they were making a man with joint problems drive so frequently into hospital. On one occasion, also at the RFH, in early 1989 John was given Penicillin to which he was allergic. He developed a terrible rash all over him and could not walk. He was kept in complete isolation for one week and the food was pushed through a flap in his door. He was quarantined because he had HIV; it was a very horrible experience.
45. His condition worsened over the year and he was given an endoscopy. This treatment would usually be performed in an operating theatre, however due to the fact John had HIV he was treated in his own hospital bed. When I went to visit him he was covered in mucus and I said to them "*in your care he looks like an old man in dirty clothing*". They also bizarrely asked John if he would allow a post-mortem in the event that I died. I have never been able to understand why they asked him this question.
46. Around this time John was diagnosed with AIDS-related complex meaning that he had two of the three conditions associated with AIDS. I never thought there was much point in messing around and so I always treated it as AIDS. Individual doctors and nurses at the RFH were fine but in general the treatment he received there was absolutely rubbish.

47. We had made up a bedroom for John downstairs at home as by this time climbing the stairs had become difficult for him.
48. Throughout all of this John never sought to avoid work. In 1984 he had undergone a six month course at St Lloyds College in Exeter in bookkeeping. He had loved this and now it enabled him to get a job working for the County Council. They were absolutely brilliant and allowed him to work from 9.30am to 4pm filing, and even employed someone to lift things up onto shelves when he could not. He had designated parking and was treated well there. Despite this we could never tell them about his diagnosis with HIV and Hepatitis; we did not tell others due to stigma and a lack of understanding.
49. The loss of John's job as a driving instructor had knocked his confidence as he had been proud of his achievement, and so his new job was very welcome.
50. In November 1989 the County Council suspended him due to absences that he had to take in order to attend hospital. Fortunately, they suspended him on full pay and he remained on this until his death in August 1990. They were absolutely brilliant. They had to respect the rules and suspend him, but they kept him on pay in order to support him and some of his colleagues raised £700 for him.
51. In early 1990 John was transferred to the Mildmay Mission Hospital ("Mildmay"). This hospital specialised in care for those with HIV and AIDS. The Tankerville Ward where John was sent was widely considered to be the place where you went to die. At this time, he really was at death's door.
52. I can recall that the ambulance taking him there was one provided by the St John's charity as there was a general ambulance strike at the time. John was absolutely grey at the time and the doctor would not let us drive him to the hospital and insisted on an ambulance which arrived at 9.30 pm. We set off in convoy to the hospital, and I can remember that the ambulance doors in front of us suddenly flew open and we could see my mother and John in the back of the ambulance with John laughing strapped down in the bed. It was just like "Carry On". At the hospital they put him on a trolley and wheeled him through

and took him to some lifts. He had just watched an episode of "*Hancock's Half Hour*" involving broken lifts and so he joked about not wanting to get in. It was the laughs that got us through that time.

53. John did well at Mildmay. The chaplain there got on well with him and John used to take it upon himself to greet and welcome new patients. Some of the other patients said that they felt it was their fault that they had been infected, but John thought it was his job to be there to support and help others.
54. I can recall that during this period while I was at home, I had a terrible nightmare about his wheelchair being pushed along and John falling out of it; by the time I got to him on the floor he was dead. When I awoke I had to see him and so I got in the car and drove from GRO-C to London in the middle of the night. When I got there I found him in his wheelchair absolutely fine and I placed my head in his lap. All I wanted was for him to hug me but he did not. At that point it felt like I had already lost him a little; it felt as if he had removed himself from family life.
55. Mentally during this late period John seemed fine. I had been warned that terminally ill people were often grumpy with those that they loved and he never demanded our presence. I recall once that we reached the hospital and shortly after our arrival he went next door to play dominoes with one of the other patients. He only seemed aware of his own life which was difficult for me.
56. He also started to make some odd requests, for instance he asked me to bring him a metal plaque that hung on a railway bridge. He was also insistent that we should set the Christmas pudding on fire one year, which is something we had never done before.
57. I remember once, after thinking about the possibility of him dying that I said to him, "*you'll give my love to my Auntie won't you?*". A strange, peaceful look went over his face and he replied "*I will try. I'm going on a lovely journey. I'm going to see mum and dad and Michael*". His faith was helping him and it seemed that he had accepted his death.

58. In February 1990 we brought John home for one night. He had asked, more out of curiosity than desire, if he was allowed to go home and the hospital had organised the trip. This worried me and we had to make up the front room where he had previously slept for him again. The hospital sent a nurse at midnight who was absolutely no help at all. Suzanne and I were shortly to go on holiday to the Isle of Skye where we spent a great deal of time. Whilst he was downstairs John called us both to his bedside and asked us to continue with the holiday and said that if he should die while we were away "*don't hurry back, I'm either being looked after in hospital or I'm in glory*". He did not want to come home to die as he would have been no more comfortable there than he would be in hospital. He had always been around hospitals and doctors and so this was no problem for him. We did not bring him home again. We held John's 50th birthday party in Mildmay and I cooked dinner in the ward kitchen. John also made it clear that he wanted Suzanne and me to buy a home should we be provided with any money in relation to his illness.
59. On 24 July we visited him before going to Skye. This was our wedding anniversary, and John had asked a nurse to get a card and a red rose for me. He was suffering from a chest infection but desperately did not want to have another endoscopy. When we left the hospital I can recall Suzanne saying that she did not want to see her father again.
60. While on holiday I received a phone call from Mildmay saying that I should come back. I knew that John would not want this and so I declined. However, I was called again on the Monday to say that I must come. This was very upsetting as John and I had agreed that he did not want us to come back in such a situation. However, I decided to fly home from Inverness while Suzanne stayed at the accommodation on Skye with someone we knew well. On the plane it was like I met him halfway, me coming down and him going up. When I got to the hospital he was unconscious. I was pleased about this as he would have given me trouble had he known that I had come back, given that we had agreed I would not. The next day I flew back to Inverness.

61. When John was informed that I had safely landed back in Inverness on 14 August 1990, he passed away.
62. John had previously asked that I speak to a funeral director; so his funeral was already planned. My sister insisted on laying out his body and felt it was something that she could do for John. I was happy for her to take care of this as I did not want to. John had to be buried in a lead-lined coffin and in a single grave, which I was surprised by as I had expected cremation. He was buried on 24 August 1990.
63. After his death the RFH had wanted to conduct a post-mortem on John. Suzanne was only 14 at the time but said "*absolutely not*". She felt that he had been a guinea pig enough. Despite our insurances they tried to conduct one anyway but we were able to stop it. I know that the purpose of it would be to provide training to doctors, but there is a limit to what we could take.
64. John's death certificate listed his cause of death as Bronchopneumonia, AIDS and haemophilia. (WITN3109002)

Impact on Suzanne

65. Suzanne had to deal with her father's illness and death being a common subject. I can recall her having to deal with 'AIDS days' at school as well as being told and shown facts about the terrible illness. I do not recall ever instructing her not to tell anyone about the illness, nor can I remember informing her about his diagnosis. She simply knew as she was always around.
66. Suzanne has also developed a hatred of needles that I think came from having to help out with John's treatment. She usually just put the plaster on the wound but even so it is terrible and when she received [GRO-C] [GRO-C] seeing her receive the [GRO-C] really scared me.
67. Fortunately, Suzanne's education did not seem to suffer as a result of her father's death. She was half way through her GCSEs at the time that he died

but she still managed to secure nine As. Following his death, we decided to move to the [GRO-C] so that she could study Gaelic.

68. My own father has only died recently and at the time of John's death I had no idea what it was to lose a father. I have since apologised to Suzanne as I realised that I had not paid her enough attention at the time. As a result of our experiences we are very close and frequently go on outings together.

Impact on me

69. The impact of John's death upon me has been difficult although I do not feel that my experience has been as bad as some. I feel that my faith and my attitude have helped me cope, and that having hope has been extremely helpful. It feels like the Inquiry is asking me to forgive when there is nothing to forgive. I feel that by talking about how having hope has helped me, it may help others.
70. Despite having faith, John's illness and death was difficult. Had I known what lay ahead of us when John asked me to marry him, I do not know if I would have gone ahead with it. If John had asked me "*will you marry me and then give me intravenous injections*", I would probably have said no. It was so difficult injecting someone that I loved and I hurt him badly on occasions.
71. In a way I am relieved for what happened. [GRO-C] [GRO-C] and I am pleased that John never had to see [GRO-C] with the illness, as it would have devastated him. I would not have wanted him to go through that. In a way I attribute this to God's care. As I have mentioned my faith has been very helpful and I could not have coped without God. The treatment and John's health was very up and down but prayers have helped us.
72. In many ways the impact of his death was minimal. On the day that he did not hug me when I was in hospital it felt as though we were no longer married. However, it is harder now seeing older couples the same age as John and I would be now. I can hardly remember being married and this is very difficult.

73. I do miss not having him there to talk to, as while I do not fully believe he is gone, I am not able to communicate with him wherever he is. I wish I could just say, *"Lord please tell Johnnie that Suzanne has done well"*.
74. After his death we just tried to keep living and life went on much as it had done, only without hospital visits. We moved to [GRO-C] in order to support Suzanne's ambitions to learn Gaelic. John had always been interested in moving to [GRO-C] but he had been too frightened to do so due to the lack of medical services on the island.
75. I had to go back to work and had started teaching in a nursery school. I later became qualified to use typing equipment although I was made redundant shortly after this. It is sometimes difficult to see the whole picture while you are going through it but looking back on it I can see how difficult the whole thing was.
76. John had loved my parents and been close to them as he had lost both of his own. While my parents had known about his HIV, I do not know how it affected them. We never discussed it.

Stigma

77. In general, we kept John's condition a secret and did not tell anyone. We had heard about some of the horrible treatment that other infected people had been receiving on the news and the last thing we wanted was for Suzanne to be bullied at school.
78. Around the time that John lost this job in November 1989 we felt that we needed to tell Suzanne's head teacher about the situation. As Suzanne was attending a fee-paying school, we thought the head ought to know about John's change in employment. She had always struck me as a very aloof woman. We met with her and informed her that John was HIV positive. She asked me if Suzanne knew and when I said yes she replied, *"do you mean that this child has been bearing this all this time?"*. She got up, came round the table and hugged me and immediately dropped all the school fees related to Suzanne's education. I was so surprised by this act of kindness.

79. We did, however, face some incidents of stigma as a result of John's diagnosis. On one such incident I had attended a church conference in the new year of 1989. One of the speakers was an older man and following his speech I went up with him to try and discuss my situation. It felt like a safe space and his talk had been helpful. I immediately explained, "*my husband is a haemophilic who is dying of AIDS*" to which the man replied "*oh yes, I have heard of that but not among the Lord's people*". I felt like I had been slapped down.
80. On another occasion, after Suzanne and I had moved to GRO-C (as discussed below), I had a mole on my face that was bleeding. I went to the doctors intending to have it removed but following a phone call the doctor refused to treat me until I had undergone an HIV test. Amazingly, the nurse taking my blood did not wear gloves. My result was negative. When I went to see the doctor I was absolutely livid and asked him when he last had a HIV test, given that he came into contact with significantly more blood than I ever did. He should have known better.
81. At times HIV felt almost like "flavour of the month". Such as when Princess Diana was working with the victims of AIDS and HIV.

Section 6: Treatment, care and support

82. Throughout this entire experience we were never offered any support from the hospital. We were required to attend a meeting for carers and patients of HIV sufferers. This occurred at the Lighthouse in London. I am not really a group person and this meeting was very difficult. I explained to someone that my vows of marriage meant that I was committed to John and I could not leave but that I had never expected to have to go through AIDS with him. I felt that was different from those that were there with partners to whom they were not married.
83. I was never, ever offered any counselling or support on the subject of having to administer the treatment to my husband. I had never wanted to inject him and it is incredibly difficult to put a needle into the veins of a person you love.

84. The help that was provided was very limited. I can remember that a carer was sent to our house, again by the Lighthouse. I think she intended to sit by John's bedside and help him although she only came two or three times and was not much use. I could have used help from someone to clean the house and she clearly did not expect to be doing such things. Another care person came to the house and spoke to us but that never really amounted to anything.

Section 7: Financial assistance

85. We John was alive we received ex gratia payment for £20,000. I believe that this was for Hepatitis and was in 1985.
86. When John died, the Macfarlane Trust told me that I was entitled to £64,000. Of this, £32,000 had been intended for John as the infected person, £16,000 was for me and £16,000 was for Suzanne. This was provided by the government. In order to receive this money, we had to sign to never claim again and we were told never to use this money to buy a house. I cannot recall who communicated this to us but I believe it was in writing. Despite this warning however it had been John's last wish that we use the money in order to put a roof over our heads and so we ignored this advice and put an offer on a home in GRO-C Scottish law binds the buyer to purchase if the offer is accepted but having made the offer the Macfarlane Trust then withheld the money because some of it was Suzanne's and she was underage. As a result of this I wrote to them saying that I would send them the bills for my mortgage payments as it was their fault. I had bought the house based on their promise. I sent the bill to my MP who I believe forwarded it on. Somebody did pay for the mortgage and in the end the money was released. I received John's and my share and they kept Suzanne's until she was 18.
87. I have had to fight in order to obtain the interest on Suzanne's money that was held for her until she was 18 years old. We eventually secured this, however the money was sent via cheque to the bank and I always felt that it should be sent to me as her mother for safekeeping.

88. I also believe that we got some other payments from the Macfarlane Trust, however I do not think that these payments were for much or lasted particularly long. The council have continued to pay John's pension to me despite the fact that John only worked there for four years. I have written to them several times to request they stop this as I feel that they have paid far more than their fair share.
89. I have only become aware of the financial assistance that is available this since the Inquiry began. I had never heard of the Skipton Fund until around September 2018, when somebody that I met at the Inquiry informed me of it. I have found the forms to be mind-blowing and The Haemophilia Society have assisted with the completion of these. However, they are still incredibly complicated and one of the Hepatitis forms needs to be signed by the medical practitioner. John died 28 years ago and his doctor could well be dead or have resigned. I have sent the form to the RFH who have promised that they would get an appropriate professional to sign it but I am yet to hear from them. I knew that John had some strain of Hepatitis but it was never confirmed to me if this was Hepatitis C.
90. I have recently received a lump sum from the English Infected Blood Support Scheme of £20,000 ("EIBSS"). Since April 2019 I have also received an income top up of £1500 monthly.
91. Of all the financial support, EIBSS have proven to be very efficient and fast acting. However, all of the other funds felt as though we are approaching them cap in hand. It always feels as though we are being questioned as to if we deserve this.

Section 8: Other issues

92. Life has gone on a great deal since these events and there have been a great many memories that I have had to drag up to complete this witness statement. None of John's family are alive and so there is no-one on that side of the family to ask about their recollections which I means I purely have to go on my own memories.

93. I have no hopes for this Inquiry as I simply never thought there would be one. I have had a great many difficulties since John died in securing a place to live. I have had to give up my own home due to the cost of the mortgage and move into rented accommodation. I am still being impacted by the events that happened all those years ago and by John's infection. However, I feel that many others have had it far worse than myself. I feel very sorry for those who have spent their whole lives fighting and campaigning for this. I believe that we must not let these events of the past ruin our lives although I know that everyone has a different way of coping.

Statement of Truth

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

Signed

GRO-C

Dated

15th February 2021