

Witness Name: Paul Hughes

Statement No.: WITN4060001

Exhibits:

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAUL HUGHES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27 January 2020.

I, Paul Hughes, will say as follows: -

Section 1. Introduction

1. I am seventy years old and retired. I previously worked in freight-forwarding. My date of birth is GRO-C 1949 and my address is known to the Inquiry.

2. I am the widow of Judith Margaret Swift, who was born GRO-C 1952 and died 14 August 1994. The certified cause of death was Von Willebrand's Disease and pneumonia, but this was not the whole picture. My wife had been infected with HIV through blood or blood products, and the pneumonia was a complication of AIDS. I intend to speak about my wife's HIV infection and subsequent AIDS, in

particular, the nature of her illness, how the illness affected her, and the impact it had on my family, including our children Laura and Matthew, and our lives together.

3. I confirm I am not legally represented and I am not seeking anonymity.
4. I have today, 25 February 2020, signed a consent form for the use of my statement and I am happy for this to be used in conjunction with this statement once it is signed.

Section 2. How Affected

5. My wife was diagnosed with severe Von Willebrand's disease when she was a young girl. She had an extremely low factor count. She was treated by Dr Mibasham at King's College Hospital in London ('King's').
6. Due to the Von Willebrand's disease, she had persistent difficulties with bleeding in her joints, especially with her left elbow and her right knee. This was treated with home administered Factor VIII concentrate.
7. It is my belief that Judith contracted HIV following the birth of our second child, Matthew, on GRO-C 1984. As with the birth of our first child, the process was carefully managed. Judith was brought into King's the day before the birth was to be induced. This was so she could undergo prophylactic treatment. This went as planned. Matthew was born at approximately 8pm.
8. The hospital decided to keep her in the delivery suite in order to observe her. At approximately 9:00pm all seemed well and I returned home. At approximately 10:30pm I received a call from an unidentified hospital worker, I later suspected it was someone from the cleaning staff, to say that my wife was upset and wanted me to come back to the hospital.
9. When I arrived at the hospital I found my wife in a side room. She clearly had not been properly observed. She was in a state of distress,

extremely cold, and when I pulled the covers back I saw that she was in a halo of blood, as far up as her neck. It was obvious that she had been losing blood and had been doing so for some time.

10. The doctors treated her with large amounts of blood and Factor VIII, as well as Syntocinon. They brought in a machine to pressurise the blood in order for it to enter her system more quickly. I was present during their response and I remember the doctors being nervous and panicked throughout. It was clear Judith was in serious danger.
11. At some point the hospital ran out of Factor VIII altogether. I cannot recall exactly how much Factor VIII concentrate she had been given by that point, but I think it was somewhere around 14 bottles. The hospital arranged for a police escort to try and find some more Factor VIII. My recollection is that they said they could get some from another hospital or a prison.
12. When they returned with the Factor VIII it was not in the form of concentrate, but in clear rubber bags of serum. It was not freeze dried and looked clear in colour. I don't recall any markings on the bags. They gave her this concentrate and eventually managed to stop the bleeding in the early hours of the morning.
13. I clearly remember the doctor saying that with the new product there was a risk of infection. They said they didn't know if it had been tested and might not have been processed to their standards. My recollection is Judith was lucid at this point so they told her that too. However, by that point it was obvious that it was necessary. There was simply no choice in the matter and I was not going to risk her dying that evening.
14. I strongly believe that this is when she became infected with HIV. This has never been confirmed.
15. Judith was lucky to pull through. It was a mistake, not observing her properly and then running out of concentrate. A very unfortunate mistake. But the doctors were always very professional.

16. Judith was allowed to return home three days later. After that everything appeared fine. Shortly after the birth we moved to Milton Keynes.
17. Judith had some trouble with her kneecap due to the bleeding into her joints. At some point between 1984 and 1987, whilst we were living in Milton Keynes, she underwent procedure to remove the kneecap as it had migrated to the right of her leg. This took place at John Radcliffe hospital in Oxford. After the prophylactic administration of coagulants, the operation went as planned.
18. There were other occasions where we had to go to Oxford for treatment, including once with very severe back pain. While she must have undergone multiple blood tests at this time, I do not recall if she was tested for HIV at that point. It is possible that the infection was caused by the later operation, but I think it is more likely it was the incident after Matthew's birth. In any case the infection did not become known to us until 1987.
19. We moved back to South West London in 1987. We received a visit from a woman, I cannot remember where from, who informed us that Judith was positive for HIV. It is possible that Judith had been contacted by phone prior to this visit but I have no knowledge of that. I cannot recall exactly when she would have been tested but she was back under the care of Dr Mibasham at King's by that point so it was likely to have been there. The woman who came to inform us was very pleasant and explained what the diagnosis meant.

Section 3. Consent

20. I can clearly remember the doctors at King's explaining that the emergency blood product they administered after our son's birth may have a higher risk of infection. This was explained to Judith and myself.

As I have stated already, the situation was so dire that the emergency blood product was necessary in order to save her life.

21. In respect of her diagnosis with HIV, I cannot say whether Judith would have been aware that she was being tested for HIV when she provided the blood sample. But I can say that she did not mention it to me and I am sure that she would have had that knowledge.
22. After the diagnosis, we were sent leaflets about the disease from the Terrance Higgins Trust and later the Macfarlane Trust, but I'd just throw them away, I couldn't face it. It was a harrowing time for both of us.
23. I remember having an appointment with Dr Mibasham after this and discussing HIV, so there must have been some follow up or monitoring, but I remember very little. It was not a time I choose to dwell on.

Section 4. Other Infections & General Health

24. As far as I am aware, Judith was only infected by HIV through blood or blood products, and not with Hepatitis or any other infection. I am certainly not aware of her being tested for Hepatitis C.
25. I was tested for HIV following her diagnosis and the results were negative. As far as I can recall the children were not specifically tested for HIV.
26. Other than the Von Willebrand's and conditions associated with the HIV, Judith was healthy. She had a good diet and did not smoke. She had no history of intravenous drug use, and didn't have any tattoos. We had a faithful marriage.
27. I don't recall any problems with other treatments such as the dentist as because of her condition, Judith was normally seen at the dental hospital.

Section 5. Impact

28. It was a massive shock to us both. We must have been given some advice at that time but I cannot remember. It was very topical with extensive coverage in the media at the time but I can only remember the sheer fact of it. At that time there was no treatment, not like there is now. It was a death sentence, that's what people understood. There was nothing we could do. I think our attitude was just 'life goes on'.
29. For years Judith was fine, there was no difference. She was often quite fatigued during the day but had no issues with sleep. She would have some dark days when she would be down and would withdraw into herself but she never needed antidepressants. We saw faith healers quite a few times, but it was as a palliative, not a cure. I found out later that Judith had written poetry as a way of coping too.
30. At one point she did have a small problem with the pain medication DF118. She was in constant pain because of the bleeding into her joints and began to rely on the DF118. However, once she realised there was a possibility she was becoming overly dependent, she stopped.
31. I think we turned our back on the diagnosis. We were in denial, well I certainly was, I got the THT newsletters and just binned them, I couldn't face it. Judith carried on – we had the children after all and she focussed on them and the home. We didn't talk about it much and I was often away with my job.
32. In 1991 Judith's condition began to worsen. She lost weight and started losing her hair. The chronic fatigue persisted and she had no energy. In summer 1993 we were on holiday in Spain and she was very ill with what turned out to be pneumonia. She had to return home and was admitted to Epsom hospital to try and clear her lungs. That was the sign that her immune system was now very weak and struggling to fight off infection.

33. A year later we were due to go back to the same place in Spain. I had rebooked it because Judith had had to go home the previous year. Before we left Judith went back into Epsom hospital with the same condition. I remember asking the nurse whether she was going to be able to travel to Spain, and the nurse saying it would be best to cancel.
34. After three or four days in hospital Judith asked to come home. She knew there was nothing she or the doctors could do. My parents came to help at home with the kids. She was at home for ten days before she died. For the last five days there was a Macmillan nurse that would come to assist at night. I remember us telling the kids that she was going to die, I don't think they processed it at all. Matthew's response was 'who is going to take me to school now?' Laura was thirteen years old and Matthew was ten years old. It was a heart-wrenching time. Watching your wife and the mother of your children as the life slowly ebbs from her.
35. I was woken by the nurse when the time came. I held Judith's hand, and that was it. Dr Thomas, our GP, came over and certified the death. The death certificate just said Von Willebrand's and pneumonia, we decided to keep the HIV off the death certificate. She was cremated, as was her wish, I believe Dr Thomas informed the undertakers of the circumstances of her death but there were not any issues that I remember.
36. In the period after her death I relied on help from my parents and a neighbour. They would make sure the kids got to school and had packed lunches. I had a lot going on at work at the time and would go to Nigeria regularly. I remember this would always upset the kids, me leaving, but did not realise until a little later that they were scared of losing another parent.
37. We decided not to tell the kids that Judith had HIV, even after her death. The only people that knew outside of medical professionals were my

parents, Judith's mother, her two siblings and my two siblings. We did not want the stigma to affect her or the kids. In the 1990s the stigma was awful. I remember my parents being nervous and asking me to be quiet if we discussed the diagnosis in public.

38. I think I was depressed, but I threw myself into my work and into looking after the kids. I made sure I did not have too much time to think about it. I think one of the aspects of HIV is that it gives you the chance to grieve before the event. Judith and I had nearly ten years where we knew she was going to die. I think it did bring us closer in a way and we made the most of what time we could spend together. I used to cry driving to work and it was like I was trying grief that I knew was coming on for size.
39. We were all very close as a family, Judith's passing was very hard on all of us. There were a lot of tears. The children lost a parent far too young, and that means they lost a dimension of their childhood. There's a sadness about it that is still there, both for them and for me. Judith's twin brother took it very badly, he became very dissipated and cut himself off from everyone. My parents took it very hard too as she was close to them.
40. I only told my daughter when she became pregnant in 2017. It was her that encouraged me to speak to the Inquiry. I only told my son after I had decided to speak to the Inquiry at the end of 2019. I think it was the right decision to withhold it from them, such was the stigma at the time of their mother's diagnosis and death. On reflection, I do think we buried it a bit, as a family.
41. There are still times where I will be listening to music or watching a film and I will sit there and cry because it has reminded me of her. You can try and compartmentalise but sometimes that box will re-open and it will make me very emotional. I lost her far too early – she should be here

with me now enjoying our retirement and making a fuss of the grandchildren that she never got to see.

Section 6. Treatment & Support

42. After the diagnosis both of our attitudes were that as it could not be cured, there was no point seeing anyone about it. It would just be a reminder of the death sentence. We felt we would be best trying to ignore it and getting on with our lives.
43. Judith did not have many outward indicators of the infection particularly in the early period after her diagnosis. In the final years of her life her immune system would regularly have difficulty fighting off colds and infections. She would be admitted to Epsom hospital to try and clear her lungs.
44. In terms of counselling after her death, I received some support from the local council. A woman came over to the house maybe four or five times. My first reaction was 'no I'll get through it' but being able to discuss it was actually a real help. She offered to provide the same for the kids, or to do it as a family group, but the kids did not want to. I feel like they did not grieve properly at that time; we did not grieve as a family. Laura and her mother were extremely close and just beginning to build a very close bond, and I think she was affected very deeply. You cannot replace a mother.
45. With regards to counselling after the diagnosis, I don't recall the offer of any or Judith saying that she had been offered such a service for either herself or the family.

Section 6. Financial Support

46. Judith was contacted by the Terrance Higgins Trust. She must have met with them but it was something she did by herself. They agreed a payment shortly before we moved into the address I am still living at. I

do not recall exactly but I think it was £60-70,000. This may be entirely wrong. I cannot remember any specific conditions, but there may well have been a 'provided you don't sue' or similar. There was no other financial involvement that I am aware of.

Section 7. Other Issues

47. I was sad and angry with what happened, but not frustrated with the NHS or the doctors involved. It was a mistake, an accident, they did not do it deliberately. No one is perfect, and the health service is brilliant. They treated Judith very well, and I have had prostate cancer and a heart attack and they have dealt with that very well too. It has not knocked my faith in the health service, but maybe now I tend to ask lots of questions and am more involved when I see a doctor.
48. It was my daughter Laura who persuaded me to speak to the Inquiry. She felt like we owed it to her mother to bear witness to those events and to articulate them, as a tribute to Judith.

Statement of Truth

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

Signed _____

GRO-C

Dated

29/04/2020