

Witness Name: Louise Hughes

Statement No: WITN0238001

Exhibits: WITN0238002 - WITN0238003

Dated: 8 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISE HUGHES

I, Louise Hughes of GRO-C make this Statement for the benefit and assistance of the Infected Blood Inquiry relating to the circumstances surrounding the death of my late husband.

1. My late husband Steve tragically died arising from receipt of contaminated blood products on 21st November 1995. My late husband was aged 38 years at the date of his untimely death.
2. He suffered from severe Haemophilia A with a Factor VIII level of less than 1%.
3. I believe he initially received his Factor VIII replacement therapy treatment at the Royal Sussex County Hospital and subsequently under the care of Professor Geoff Savidge at St. Thomas's Hospital, London.
4. Despite his disability, Steve was a Chartered Accountant, and worked with an accountancy firm for the entire duration of his working career. I met Steve, on moving to work at the same accountancy firm in 1986. I am also a Chartered Accountant. We started dating in 1987, and subsequently bought a home together and married. We were successful in our profession, and had a wonderful life together, with many holidays and a great social life.

5. I knew that Steve was a haemophiliac. When we started to go out he informed me that he didn't know his HIV status. I assumed as it was so long after it was known that haemophiliacs could have contracted HIV, that it was unlikely he was HIV positive. But I was wrong.
6. On 31st October 1990, Steve was telephoned at work, by the Haemophilia Centre at St Thomas' Hospital and informed he was HIV positive. His CD4 count was low, and they wanted to treat him. As you can imagine this was devastating news. I arrived home to find him in tears, he believed I would leave him. Despite the shocking news, I knew that I loved Steve, and would stand by him. We both believed that this would mean a limited life. We also decided to keep this information to ourselves, only letting Steve's mother know. My own family only knew the day before Steve's death 5 years later.
7. We kept this secret due to the stigma attached to HIV.
8. I was unaware of any offer of support and knew very little of how the virus would progress. I was not offered an HIV test. No advice was delivered nor indeed was any support provided of a psychological nature to us. I assumed that we could not consider ever having children.
9. He was also HCV positive, this was disclosed later, but again we had no knowledge of the progress of this, and received no support regarding this diagnosis.
10. I sought out an HIV test after Steve's death, which thankfully was negative. After attending a meeting for the inquiry, I realised that people were only recently diagnosed with HCV. Steve was also HCV positive and I realised I probably hadn't been tested for this, so I was only tested for this a few months back, again thankfully this was negative.
11. Steve's health was generally good for 4 years. Immediately after diagnosis, Steve was put on AZT, which I believe was a trial drug. It did result in muscle wastage, but otherwise he carried on his life as normal. He was once hospitalised with salmonella poisoning and did have tummy bugs on a few occasions. Because of the severe

nature of his haemophilia, he suffered from bleeding in his joints. This resulted in his joints wearing out, and he had a successful hip replacement operation in St Thomas'.

12. At the start of 1995 a series of infection started.

13. Firstly he had an infection in his other hip joint, which necessitated a two month stay in hospital. He had part of the bone removed, and returned home wheel chair bound, and on morphine tablets.

14. About 6 weeks later he was back in hospital with a lung infection, which I now understand was a common HIV infection, of pneumocystis carinii. We were warned that this was serious, and he received a few treatments, and was told that the final treatment was the last they could give him. However his health seemed to stabilise, and he even started to walk again. We took a short break in August 1995, and Dr Tabrizi gave us a letter in case of hospitalisation. I **attach** a copy of this letter to this statement [Exhibit WITN0238002]. This showed the precarious state of his health at this point.

15. However he felt well enough to start to go back to work.

16. At this stage Steve's spleen was not working correctly, and his platelet count was low. This is a very serious situation for a haemophiliac as it helps in blood clotting. I understood at the time that this was due to the treatment he had just received for the lung infection. I have now been told this is indicative of rampant Hepatitis C infection. He was receiving infusions of platelets. He also had a great deal of pain in his elbows, which were damaged due to the bleeds into the joints. But no reason was ever found for this pain.

17. On 21st September he was admitted to St Thomas' Hospital for a splenectomy. This was a truly traumatic time. This is outlined in the details **attached** to this statement [Exhibit WITN0238003]. But in short, he was admitted to an understaffed and chaotic ward, where infection control was lax. An inappropriate place, both from a sterile and isolation perspective, for a person with a compromised immune system. Steve contracted MRSA, which I was told by a nurse was on the drains inside his body. He died from septicaemia and consequential impact of multi-organ failure.

18. All the time Steve was in hospital, I continued to work full time, though with flexible working thanks to an understanding employer. During the last period of hospitalisation I spent many nights at the hospital, finding a bed in the nurses' home, or on a discharge ward, or a side room next to the main doors, so would be woken every time someone went through the doors.
19. Subsequent to Steve's death, I complained to the Hospital Authorities in connection with the lack of sterile environment and I had three meetings with various Departments but in essence no-one bothered. These meetings occurred after I realised that Steve had staphylococcal auras and in essence, that that was the causative factor for his death.
20. It should be noted that Steve's cause of death is set out on the Death Certificate as: -
1. Multiple organ failure
 2. Septicaemia
 3. Methicillin Resistant Staphylococcus Aureus
 4. Haemophilia
21. Steve's death hit me very badly. I was traumatised by the final period he had in hospital. I attempted to find answers as to why MRSA infection had occurred in my husband, whose immune system was so depleted. As I had been informed that MRSA had been found in the drain tubes, I knew that there was a hygiene issue.
22. After his death, I suffered severe exhaustion and it became necessary for me to re-evaluate my life. I gave up working full time, I had been an Associate Partner in an accountancy firm and at the date of Steve's death I was aged 32. There were many career options available to me. I intended to take 6 months sabbatical, but started to work for myself out of our home. My income was much reduced over the level of income that I previously achieved, but I needed the time to come to terms with Steve's death.
23. I believe that if Steve had been in good health and I had remained within the accountancy firm concerned that I would have been a partner in that firm or a similar

type Firm. I have lost out significantly in financial terms in relation to income, pension rights and that loss has continued to this day as I have not achieved earnings expected at this stage of my life and career. My income as an Accountant generated from my own home is lower than I would have achieved if part of a multi partner firm.

24. I have never really overcome Steve's loss.

25. There were compensation payments from the McFarland Trust and Skipton Fund. The later only being paid out in the last few years when widows could claim, we were previously unable to. I only heard of the Skipton Trust change of heart through a third party, I was not contacted.

26. To this day I have never received any psychological support from St. Thomas's arising out of the tragic events that occurred. The only support that I have received was from the McFarland Trust, with a women's weekend away, which was most helpful. It was here that I learned of new medication which was transforming lives. I realised how close Steve's death was to the introduction of this treatment. In fact I now know it was being trialled in 1995, but Steve did not benefit from it.

27. The issues that I would like to see addressed by the Inquiry are as follows: -

- a. Why Steve received a contaminated Factor VIII concentrate?
- b. Why were Factor VIII concentrates imported from the United States into the United Kingdom where the plasma utilised in the manufacture of those products was derived from high risk donors?
- c. Could the circumstances of death of Steve have been avoided by more sterile or a greater approach to isolation to minimise risk of transmission of various opportunistic type infections?
- d. Why was Steve informed over the telephone that he was HIV positive, and that his diagnoses was not discussed with him at his normal doctors meetings
- e. Why did Steve not survive to avail of the HAART treatment options that would have prolonged his life that were either then available or in contemplation at the date of his death? It should be noted that in 1996, the statistical detail was available to substantiate the success of this treatment that prolonged the

lives of many people with AIDS. Why did Steve not receive that treatment or if it was reasonable for him not to receive it preceding his death, why was he not assisted to live as long as feasible to avail of that treatment which was then in contemplation?

- f. Why has the level of recompense both to people infected with HIV and/or Hepatitis C been so low in comparison to the loss that they sustained in financial terms?
- g. Why has it taken so long for this Inquiry to be established in that it is now more than 35 years since the date of Steve's infection? It would have been better if that detail that will be disclosed by this Inquiry had been available for consideration by Steve during the course of his lifetime.
- h. Why has the Government not routinely tested people who had blood transfusions during the period of concern, or their partners. Why are GP's not warned of this link and the symptoms?

28. I believe the story ought to be told as to why this health catastrophe occurred. I wish to deliver evidence in public as I believe Steve's story needs to be told, and I have now decided to stand up and go public after years of silence. The circumstances of Steve's loss and the period leading up to his death have left an indelible mark upon my life, my personality and my opportunities

29. My prayer for this inquiry 'He will bring light to what is hidden in darkness and will expose the motives of the heart' 1 Cor 4:5.

Statement of Truth:

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

Dated the 8 day of May 2019

Signed:

GRO-C

Louise Hughes