

Witness Name: GILLIAN BAYLISS

Statement No: WITN5234001

Exhibits: WITN5234002

Dated: November 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GILLIAN BAYLISS

I, Gillian Bayliss, will say as follows:-

Section 1. Introduction

1. My name is Gillian Bayliss. I was born on GRO-C 1946 and I live at GRO-C GRO-C Nottinghamshire GRO-C. I live alone and have done so for the last 25 years. I have a daughter and three grandsons in my life. I have another daughter and a son that I haven't had contact with for 27 years.
2. My husband, David Stanley William Bayliss (born on GRO-C 1946), was co-infected with the Human Immunodeficiency Virus (HIV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on 17th July 1995, aged 48.
3. This witness statement has been prepared without the benefit of access to my husband's full medical records.

Section 2. How Affected

4. David had mild Haemophilia A, diagnosed in the late 1960s/early 1970s. David was under the care of Professor Preston, Dr Makris and Sister Joy Farnsworth at the Sheffield Haemophilia Centre at the Royal Hallamshire Hospital (RHH). I remember David had an accident/went through a pane of glass at work some time during the early 1970s and had treatment at RHH. I believe that he may have become infected then as he very rarely needed treatment.
5. I think that David was treated with Cryoprecipitate initially and then Factor VIII (FVIII) Concentrate. I do not believe that David was told of any risk to him of infection before he had treatment. David was tested for infection without his knowledge, consent and without adequate information. He was told that he was infected with HIV and HCV (known then as Non-A, Non-B Hepatitis) by one of his doctors (I do not remember whether it was Dr Makris or Professor Preston) at a routine visit to the Haemophilia Centre in May 1984. I remember the date because I had just lost my mother.
6. No information was given to us to understand and/or manage the infections. I remember David called me upstairs after his appointment and told me that he had a disease that was going to kill him. I replied 'It won't!' as I have always been a fighter. David was a very private person and didn't want to talk about it beyond that. However, I am certain that he was not provided with the information and the help and support we both needed. David changed after receiving this terrible news. He was frightened of the unknown and became chronically depressed. There were at least five occasions on which my husband tried to overdose on tablets.

Section 3. Other Infections

7. I am not aware of anything other than HIV and HCV.

Section 4. Consent.

8. As stated, David did not consent to testing before being informed of the results. His bloods were taken at his appointments that he thought were for his haemophilia levels.

Section 5. Impact

9. David was often ill with chest infections, tiredness/fatigue, sickness and diarrhoea. He also suffered with insomnia, night sweats and general overall weakness.
10. Our lives (David's, mine and that of our daughter) were profoundly affected by the behaviour of other people when they became aware of David's illness. My son said his Dad should be shot against a wall. My oldest daughter never came home. We lived in a village and David's mother blurted it out in the doctors' surgery even though David had told his parents not to breathe a word. Friends never came to our house again and we were treated like lepers. My daughter was bullied at school and that has had an impact on her whole life. We were on our own trying to deal with this. HIV/AIDS was known as the gay plague. When news about it came on the television, I would turn it off.
11. David worked until he could work no more, finally having to give up in or around 1989. We used what was left of his savings and the £23,000 payment from the MacFarlane Trust (MFT) to live on right up until David died. This included all our bills and our mortgage repayments. There was no financial help offered to us at all during this time. It was a case of just dealing with everything on our own.

12. My husband became a grandad in 1989 and, again, in 1993. He tried to enjoy the time he had left with his little family but there was always a black cloud above us. We all had to try so hard just to keep going.
13. As David's death loomed closer, we were told that he would not be permitted to remain at home and would have to be hospitalised but after a lot of upset and distress, we were finally informed that my daughter and I could care for him at home. We took it in turns to sleep in order to provide around the clock care. Watching what this man had to go through and watching him take his last breath was soul destroying and something we will never come to terms with. I loved him to death and he would have only died in hospital over my dead body.
14. I refer to Exhibit WITN5234002 being a copy of David's Death Certificate listing Bronchopneumonia and Acquired Immunodeficiency Virus (AIDS) under cause of death (alongside Haemophilia A).
15. Because AIDS had caused David's death, we were told that David had to be cremated creating more distress. We, again, won our right, this time to have David buried but he nevertheless had to be placed in a sealed glass unit inside his casket. We should not have had to fight and be left with all this upset at that time to get what we wanted and what we felt was the dignity David deserved. The casket cost a fortune and I struggled to pay for the funeral. I had to sell our home and move into rented accommodation because I couldn't afford to live there after David's death.

Section 6. Treatment/Care/Support

16. David was prescribed AZT. The AZT treatment resulted in David's muscles wasting away and he was left unable to walk. He was given steroids and antibiotics regularly and the antibiotics gave him constant thrush.

17. David had a liver biopsy without a general anaesthetic. They sent for me because he was in agony from it and we thought he would die from the pain. It was cruel. David also had unsuccessful Interferon and Ribavirin treatment.

Section 7. Financial Assistance

18. We had no financial assistance other than the £23,000 MFT payment. We paid for a walk-in shower and other items David needed, to make his life a little easier, ourselves. David was even turned down for disability benefit because he managed to drag himself around a local market under the scrutiny of a benefits assessor notwithstanding that he had to stop very many times along the way.

Anonymity, disclosure and redaction

19. I do not wish to apply for anonymity.

Statement of Truth

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

Signed.....

GRO-C

Date.....

28-11-20/20