

Witness Name: Catherine Mary
Alexandra Burchell
Statement No.: WITN0835001
Exhibits: WITN0835002
Dated: 18 July 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CATHERINE MARY ALEXANDRA BURCHELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 March 2019.

I, Catherine Mary Alexandra Burchell, will say as follows: ~

Section 1: Introduction

1. My name is Catherine Mary Alexandra Burchell (née Harvey). My date of birth is GRO-C 1973 and my address is GRO-C, Dorset GRO-C.
2. I intend to speak about my late brother, James Marcus Alexander Harvey (Jamie). In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our family.

Section 2: How Affected

3. Jamie was born on GRO-C 1966. Jamie developed renal failure around the age of 11. During his treatment for renal failure, while on dialysis, Jamie received blood or blood products that were contaminated with hepatitis C. I

am not entirely sure where he would have received the contaminated blood, but it likely would have been at the Norfolk & Norwich Hospital or Addenbrookes Hospital in Cambridge. I do not have access to Jamie's medical records at this stage, and given that Jamie received several transfusions and blood products during the 1980s it is very difficult to track down the exact location or date that he received the contaminated blood.

4. I do not believe my parents were given any information or advice about Jamie's risk of being exposed to infection before his first treatment. My parents dialysed him at home during the 1990s and they were not informed of any risks at that stage either. My mother is 82 and in good health but my father sadly died in 2010 from sepsis following bowel cancer surgery.
5. Jamie was informed approximately 20 years after his first treatment for renal failure that he had hepatitis C. He was told by the renal team at Guy's Hospital, where he was a renal patient and where he dialysed three times a week. Jamie had a good relationship with his medical team there and I am sure he would have been informed in the proper manner, and results and tests would have been communicated directly to him as he would have been an adult at this stage.
6. I have no doubt that Jamie received the infection from contaminated blood. Jamie was in poor health from renal failure and never took illegal drugs or had any adult relationships.

Section 3: Other Infections

7. I am unaware of Jamie receiving any infections other than hepatitis C.

Section 4: Consent

8. I believe that Jamie would have provided consent to be tested and that he was given adequate information when he was told that he had hepatitis C.

Section 5: Impact

9. Jamie was always an optimist which was amazing given his medical problems. However, the hepatitis C was a difficult matter to deal with: he suffered physically, mentally and emotionally from it. He struggled with depression that was caused by the lethargy and exhaustion that came with the disease.
10. Jamie's hepatitis C progressed to liver cancer which in turn spread to his lungs with secondary lung cancer. Jamie died on 28 June 2012. I exhibit Jamie's death certificate [WITN0835002] which lists his causes of death as hepatocellular carcinoma (a type of primary liver cancer), hepatitis C and end-stage renal failure.
11. Jamie's hepatitis C was treated with Interferon. His GP did complain about the costs of the drugs. I am unaware of any difficulties he received from the hospital.
12. Jamie suffered the full spectrum of side effects with Interferon: headaches, exhaustion, depression, difficulty sleeping. Jamie went through two rounds of Interferon and neither were successful.
13. The worst side effect of Interferon was the loneliness and isolation. He felt so unwell that he was unable to go out and consequently his social life dwindled. Having struggled so much with the ill health caused by renal failure there was not a lot of strength left to fight hepatitis C.
14. Jamie endured horrendous cancer treatment due to the contamination. The consequences of all the treatment made him desperately unwell, physically weak and mentally distressed. This was horrendous for him and terrible for the family to witness. Jamie had tried so desperately hard to be the strength for our mother when our father died. My mother was incredibly worried about how she was going to financially support both herself and my brother and consequently had to sell her house. My other two brothers were living abroad

when Jamie became very, very unwell, I had a young child and my mother was suffering from terrible anaemia which required chemotherapy. At the time of Jamie's death, my brother was in intensive care at St Thomas's and my mother was an inpatient at the Hammersmith Hospital. My brothers left their young children and flew back to the UK and I left my child with my parents in law to try and manage this terrible situation. My mother physically recovered but she lost her first born child.

15. Jamie was a huge loss on our family, especially so soon after my father's death. He was the glue that held us together, he was funny and kind, and patient and so interested in our lives and seeing us all together. The impact of the contaminated blood caused so much destruction, the death of a son, the death of an uncle, the death of our brother. My daughter never met him, she missed out on ever knowing her uncle and my now 8-year-old son cannot remember him. It is a devastating loss. He is missed by his mother and siblings every day.
16. As a family there was no stigma. Jamie was Jamie, and the hepatitis C did not change any relationships within the family. Outside the family it was not something that was discussed, not because of any shame but Jamie was not prone to discussing his health with anyone other than his closest relatives.
17. Jamie was unable to work due to his illness. Instead he wrote poetry which was published. Even travelling on the underground to the hospital for dialysis became a painful battle.

Section 6: Treatment/Care/Support

18. I don't believe Jamie faced difficulties in obtaining treatment. This may have been because Jamie was already a long term patient at Guy's Hospital.
19. I am not sure if Jamie was offered counselling. This is not something he would have taken up as he was a deeply private person who would not have been comfortable talking about his illness.

Section 7. Financial Assistance

20. Jamie was left some funds by his maternal grandmother and was able to live off this along with benefits. During Jamie's lifetime, Jamie also received the stage 1 Skipton Fund payment of £20,000. I cannot provide any detail about the process of applying for financial assistance as Jamie's father would have completed the paperwork for him but unfortunately Jamie's father has passed away.

21. His estate received the EIBSS stage 2 payment this month. He was unaware of this funding during his lifetime. This payment would have been made available to him once the liver cancer diagnosis had been confirmed. Unfortunately no one informed him of this funding. It is tragic that now only after his death has the payment been made. The money would have made life much easier for him. He would not have had to struggle to take the underground for renal and cancer treatment but would have been able to take private transport or a taxi. This payment would have also allowed him to more easily have access to a social life, without which his depression spiralled.

22. Access to these funds has not been easy or straightforward. The trusts and funds were never clearly explained to him.

Section 8: Other Issues

23. I attach Jamie's death certificate as evidence of his hepatitis C contamination.

Statement of Truth

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

Signed

GRO-C

Dated

18 JULY 2019.