

Witness Name: Jean Black
Statement No.: WITN2092001
Exhibits: **NONE**
Dated: 17th December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JEAN GAGE BLACK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 3rd December 2018.

I, Jean Black, will say as follows: -

Section 1. Introduction

1. My name is Jean Gage Black, I live independently and I am a retired nurse and my date of birth and address is known to the enquiry.
2. I intend to speak about my husband, Reverend David Charles Black (Deceased GRO-C 2003). His certified cause of death was Hepatocellular Cancer in transplanted liver, Hepatitis C, transfusion of blood products and Haemophilia. In my account I will include, the nature of his illness, how the illness affected his quality of life, the

treatment/care/support received and the impact it had on myself and our family.

Section 2. How Infected

3. David had a congenital blood condition Haemophilia A, mild to moderate. To the best of my knowledge David was diagnosed soon after birth and from early childhood to adulthood only received treatment in relation to his Haemophilia when he required a tooth extraction or due to accidental injury.
4. His first treatment was at approximately 5 years old, I believe due to a fall with a injury that did not stop bleeding and required medical attention.
5. David was provided with GP care in the 1970's by Bishopbriggs Health Centre, in 1985 by Dr J Hill in Lanark Health Centre and finally in May 2002 until he died, Dr Hood, Alloa Health Centre Marshall, Alloa.
6. Almost all matters for his health tended to be dealt with the Haemophilia Unit at Glasgow Royal Infirmary. Additional health care was provided at the School of Dentistry in Glasgow, where David was treated infrequently for dental work with products provided by Glasgow Royal Infirmary.
7. It was difficult to pinpoint when he was infected with Hepatitis C however, by 1979, David had developed elevated liver enzymes, a sign of Hepatitis infection as deemed in the Penrose Inquiry.*ref (Penrose executive summary page 11) Prior to the 1980's his quality of life was good until it was recognised by 1985 that he had NANB hepatitis .

8. In 1987 on a holiday to USA he was found by Lawnwood hospital, Fort Pierce, Florida to have Oesophageal varices, a significant symptom of liver disease. Followed by regular care/follow up for liver deterioration in the 1990's caused by hepatitis C. Resulting in a liver transplant in 1996. In the years after surgery, Hepatitis C caused deterioration in the new liver and developed cirrhosis, which in turn led to Hepatocellular cancer from which he died on the 31st October 2003. The Penrose Enquiry concluded that David acquired Hepatitis C from treatment with blood or blood products by the NHS in 1960 's , that time frame being compatible with the fact that the disease typically takes around 20 years from infection to develop. *Ref The Penrose Enquiry Final report executive summary page 11
9. Blood products used for treatment initially was AHG an early NHS concentrate and later Cryoprecipitate. I am unaware of early childhood treatments and most of David's care/treatment was at Glasgow Royal infirmary, until David's work as a church minister led to missionary work in South Korea in 1968-1970. He did not require treatment in South Korea, however on the way back home he came back via Palo Alto California, where he did have some blood products for a kidney stone, I believe it was cryoprecipitate. He also received a number of products throughout the life at the Glasgow Royal infirmary. My recall on the dates and names of the products and batch numbers is unknown and will be in the medical records. In the initial Penrose enquiry there were no medical records available. However Frank Maguire with Thompsons Solicitors was able to obtain a copy of records held at the School of Dentistry in Glasgow that contained some detailed information and later records from Strathcarron Hospice.

Section 3. Other Infections

10. I have no awareness of any other infection David contracted other than Hepatitis C..

Section 4. Communication and Consent

11. In the late 1970's my husband's experience of communication processes were minimal on the risks of blood products and infection in the early in the diagnosis. However, this improved as medical understanding of Hepatitis C was clearer.
12. In 1996 as a result of the Penrose enquiries investigations, David's own liver once removed, was discovered on laboratory examination to be cancerous. That information was not communicated to my husband. Apparently due to an oversight. This was a communication failure in relation to the detection of cancer and had an impact on David's choice of Hepatitis C treatment post surgery. During the inquiry we received an apology for this omission from the Edinburgh Royal Infirmary Transplant unit. The amazing circumstance is, if at the time they had known before the transplant about the cancer, another liver would not have been given to him. The transplant gave him seven more years of life.
13. I am not aware of them treating or taking blood without my husband's knowledge.
14. I don't have any strong views about how the results of the tests were communicated to David.

Section 5. Impact

15. Following diagnosis of Hepatitis C in 1987, and the resulting liver damage David's quality of life deteriorated, with frequent visits to the hospital with spontaneous bleeds, alongside fatigue limiting his day to day activities. Anxiety and stress was a factor due to limited information available on Hepatitis C at the point of diagnosis. Stigma

and David's fear of infecting myself impacted my husband's emotional health. Prior to his transplant in 1996 his failing liver resulted in ascites (swollen abdomen) and dyspnoea affecting his breathing this resulted in several months of intensive family support for daily living activities.

16. David's health improved after his transplant until 2002 when he felt the need to retire due recurring health issues as a result of the Hepatitis virus still being present in his system and affecting his new liver. In May 2003 a diagnosis of liver cancer was given and David's health rapidly decreased, dying in GRO-C 2003. This period was particularly difficult due to the finality of prognosis and his distress of not seeing his grandchildren growing up.
17. The Financial impact of his ill health prompted my husband to retire earlier than planned .

Section 6. Treatment/Care/Support

18. This section excludes treatment and care for his Haemophilia A and focuses on treatment, care and support for his Hepatitis C and resulting liver cancer diagnosis .In May 2003, he was diagnosed with cancer of the liver and by October 2003 he had tried approximately 6 months of treatment with I believe Ribavirin for the Hepatitis C. However the doctors at Edinburgh Royal Infirmary recommended that the treatment be discontinued due to the severity of side-effects resulting in incomplete treatment for his Hepatitis C .
19. He was offered this treatment prior to transplant, but the information on the side effects and quality of life caused him to decline treatment back in the early 1990s. In 1996, information was communicated that it would have been contraindicated prior to a liver transplant.

20. I am not aware of any other treatments that could have been offered for Hepatitis C. Most of his treatments consisted of treatment for his deteriorating liver .
21. There were no difficulties or obstacles in obtaining care and support. We are grateful for the care and support that he did receive, particularly with the transplant at the Edinburgh Royal. David did not require any psychological/counselling support for his diagnosis of Hepatitis C .

Section 7. Financial Assistance

22. I received attendance allowance for David between June and November 2003.
23. In November 2003 I was informed of financial support through Thompson Solicitors and Frank Maguire pre Penrose Enquiry.
24. I received 3 lump sum payments from the Skipton Fund. On the 13th November 2003 I received £25,000, on the 19th October 2004 I received £20,000 and on the 1st May 2013 I received a further ex gratia payment of £25,000.
25. There was no process for me about applying for assistance. Skipton contacted me, I had some paperwork to sign but there was no big application.
26. There were no difficulties and obstacles in applying for financial assistance
27. There were no preconditions imposed on the making of an application for financial assistance

28. I have no more comments about the various trusts and funds and the amount of financial assistance received.

Section 8. Other Issues and Information

29. I understand that Thompsons Solicitors are retrieving David's medical records and I will be given a full opportunity to review these .

30. Post transplanted liver David participated in research at Glasgow Royal infirmary, he was invited to give blood so they could monitor the blood clotting levels and liver function before and after transplant .

Statement of Truth

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

Signed

GRO-C

Dated: 16.2.19