

Witness Name: Agnes McNeish

Statement No.: WITN2677001

Exhibits: **NONE**

Dated: 19th December, 2018

INFECTED BLOOD INQUIRY

First Written Statement of Agnes McNeish

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Agnes McNeish, will say as follows:

Section 1. Introduction

1. My name is Agnes McNeish. My date of birth and address are known to the Inquiry. I am a pensioner. I intend to speak about my late husband Robert Donaldson McNeish. In particular, the nature of if his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Section 2. How Affected

2. My husband was Robert Donaldson McNeish better known as Bobby. I first met Bobby when I was seven years old and despite a few years apart we were married in 1973. Bobby was not just my husband he was my best friend. Bobby was my soul mate and since his death there has been no other man in my life. Bobby was infected with contaminated blood and as a result he contracted hepatitis C and HIV. He died of hepatitis C on the GRO-C 1994.
3. Bobby had haemophilia type A this was a very severe form.
4. Bobby received factor 8 blood products for his haemophilia.
5. Bobby attended the haemophilia clinic at the Old Royal Infirmary, Edinburgh. The haematologist that Bobby was under was Doctor Ludlum. I know it was Doctor Ludlum because if we were going on holiday Bobby always had a letter from him to say that if he had a bleed he was only to receive British blood. It said he was not to receive American factor 8 as it was from drug addicts and he would be at risk of infection.
6. Bobby started getting factor 8 blood products sometime between 1973 and 1984. I cannot be any more specific.
7. Bobby received a batch of contaminated factor 8 blood products at some point at the haemophilia clinic during 1973 and 1984.
8. It was normal and routine for Bobby to receive factor 8 blood products for his haemophilia but I do not believe he was ever informed of the risk of being exposed to infection.
9. Bobby was infected with hepatitis C and also HIV.

10. In 1984, I cannot be more specific, Doctor Ludlum sent a letter asking for Bobby to attend at the haemophilia clinic at the Old Royal Infirmary. Bobby went to see Doctor Ludlum and he told him that his blood had been tested and he had contracted HIV. Doctor Ludlum said one batch of factor 8 that Bobby had received had been contaminated. He told him that the person that had given the donation had been homosexual and had HIV. A few years later Bobby went to see his own Doctor about his skin being very itchy. His own Doctor was Doctor Reed at the Trannent Medical Practice, Edinburgh. His own Doctor referred him back to Doctor Ludlum at the haemophilia Clinic. Doctor Ludlum told Bobby that he had hepatitis C as well as HIV.
11. In relation to the HIV, when Bobby was told he had this infection Doctor Ludlum did provide him with some information. He told him that we would have to use protection when having Sexual Intercourse as he could pass the infection on to me. I remember Bobby telling me this. I do not know what other information he received about this infection. In relation to the hepatitis C he must have been given some information about spreading the infection because he told me that he could not share a toothbrush and could not share a cup with another person. Bobby always had his own towel and was conscious not to share towels with anyone else.
12. I do not know if adequate information was provided to Bobby to understand and manage the infection. I do not think the Doctors really knew themselves very much about the conditions.
13. Bobby was told he had hepatitis C a few years after being told he had HIV. I do believe that they must have known he also had hepatitis C at the time they discovered he had HIV. If this is the case Bobby should have been told earlier. That said, Bobby might have been told that he had both infections at the same time and only told me about one in an attempt to protect me.

14. I do not have any views about how Bobby was told about his infections. Doctor Ludlum spoke to Bobby personally about his condition I was not present at the time. When Bobby told me that he had HIV he told me that he had directly asked Doctor Ludlum how long he had left to live. He had been told he would not live any longer than ten years. We were both devastated.
15. I was not present when Bobby was told he had HIV and hepatitis C so I do not know what he was told about the risks of others also being infected by Bobby's infections. I do know that after he had been told he had HIV we always practised safe sex by using condoms. Bobby would not let anyone else drink out of his glass or cup. He would always have his own towel and toothbrush. He must have been told to not do so there would be a risk that he could pass on his infections.

Section 3. Other Infections

16. I do not know of any other infection that Bobby received other than Hepatitis C and HIV.

Section 4. Consent

17. I do not believe Bobby was tested or treated without his knowledge.
18. Bobby had a rare blood group I believe it was O positive. He would often give his blood willingly so I believe he would always give his consent to his blood being tested.
19. I do not know if Bobby received adequate information about being treated or tested.
20. I do not know if Bobby was treated or tested for the purposes of research.

21. When Bobby contracted the HIV and hepatitis C it ravaged his body. His skin was a yellow colour. He was always very tired and lethargic. He seemed to be constantly itching his skin. Mentally Bobby was always a positive man. He would say that medical research would eventually come up with a cure for his condition. I believe he always lived in hope. The treatment Bobby was given changed him completely. He became a different person. He was often moody and very nippy. His positivity had gone.
22. I don't know of any further medical complications or conditions that resulted from the infection. Bobby's physical condition just deteriorated until he was eventually bed bound.
23. The last five years of Bobby's life his health was very poor. He could no longer work. He was in a lot of pain and rarely left the house. He was admitted to hospital in April, 1994. Bobby did not want to die in hospital so he was allowed to come home. He was given only days to live. Bobby was bed bound and was not able to eat. He died at home on the GRO-C 1994.
24. Bobby was on a lot of medication in the form of tablets. He would take many tablets a day. I cannot say the names of the tablets he was taking as he was very private when it came to medication. I know that he was given interferon at some point. Bobby would inject the interferon into his stomach twice a day.
25. I do not know if Bobby had any difficulties or obstacles in accessing any treatment.
26. I do not know whether there were any other treatments available for Bobby. He did not say to me that there were any other treatments available so I assume there were not.

27. When Bobby started to take the interferon he was a changed man. His personality altered, he would become quite moody and nippy. This was not like him at all. He was constantly tired and very lethargic.
28. I do not think that Bobby's infected status impacted upon his medical care. He did not however go to his local dentist. If he needed any dental treatment he would go the specialist dentist at the Old Royal Infirmary. I do not know the name of the dentist who treated him.
29. The impact on Bobby of being infected with HIV and hepatitis C ultimately cost him his life. He was very ill for many years particularly in the last five years of his life. We would often go out to socialise with friends and family at our local club but Bobby was not fit enough to go. Family would always come to us to visit. [REDACTED] GRO-C [REDACTED] GRO-C had been infected with Hepatitis C and his brother Tom had contracted hepatitis and HIV. Tom was in the same ward as Bobby at the Royal Infirmary. It was ward 23. Tom died five weeks before Bobby so Bobby knew that he himself did not have long to live. This was why he wanted to come home he was adamant he did not want to die in hospital like his brother. He suffered terribly in the last two years of his life. He was the colour of mustard and just skin and bone.
30. The impact of losing my husband has devastated my life. He was my best friend and I have been on my own for over twenty years. When Bobby first told me that he had been given only ten years to live I was devastated and as every year past I was more anxious as I knew time was getting closer to me losing him. In the last ten years of his life as he became increasingly unwell I had to take a lot of time off work to look after him. We had to sleep in separate beds in the last two years of his life as he was in a lot of pain and discomfort if I touched him. Clearly there was no sexual relations between us after that. Throughout his illness I was constantly worrying about him. It made

me very anxious and depressed as there was nothing I could do to help him. There is nothing worse than seeing someone you love suffering.

31. Bobby was a very private person and did not want anyone to know that he had been infected with Hepatitis C and HIV. There was and still is a stigma attached to the conditions. He did not want anyone to think he was a drug addict. As such we didn't tell anyone other than close family members. It was almost like a dirty secret. I did tell my place of work about Bobby's condition. I worked in the St Andrews Hospice at the time as a pastry cook in the kitchen. Robert didn't use his own towels or cups as it could only be passed on by body fluids, the gowns and masks were only for a few days until things were made clear. I felt terrible at the time but I went to see Doctor Ludlum at the Royal Infirmary and got tested. I was all clear but didn't get back into my place of work for three weeks. Such was the stigma surrounding Bobby's conditions. When Bobby was ever admitted into hospital all the doctors would gown themselves up and put masks on. I remember they would make me wear the gowns and mask. It was ridiculous because I lived with him at home. Did they think I gowned up at home. It just made you feel as if Bobby was dirty and unclean. I was heartbroken for him.
32. Bobby and I didn't really have many friends we tended to socialise with family. Bobby's family were very supportive as GRO-C had also been infected and the family rallied round.
33. The last five years of Bobby's illness before he died he was unable to go to work. He obviously lost his wages and had to go on benefits. Bobby was very private about his finances so he did not really discuss them with me.
34. I took a lot of time off work when Bobby became very ill. I needed to be there to look after him. I obviously lost out on wages. I eventually went part time.

Section 6. Treatment/Care/Support

35. I do not believe that Bobby faced any difficulties or obstacles in obtaining treatment or care in consequence of being infected with hepatitis C and HIV. I'm sure he would have told me if he had.
36. I know Bobby did not go for any sort of counselling or psychological support throughout his illness. I do not know if it was offered to him but I don't think it was because I think he would have told me.

Section 7. Financial Assistance

37. I believe that Bobby found out he was eligible to receive financial assistance from the haemophilia clinic at the Royal Infirmary. I do not know who told or exactly when he found this out.
38. Bobby did receive a lump sum of £20,000. I cannot remember when he received that, it was a long time ago. I know we used the money to buy our council flat. I believe this was from the MacFarlane fund. I know he started to receive a monthly payment but I have no idea how much he received. I believe this was also from the MacFarlane fund.
39. I cannot remember how Bobby applied for financial assistance.
40. I do not know if he had any difficulty or obstacles that he faced when he applied for financial assistance.
41. I do not know if there were any preconditions imposed on the making of the application for financial assistance.

42. Bobby did not tell me how much money he received on a monthly basis so I do not know how he felt about the amount he received. I know he was grateful for the £20,000 as it helped us to buy the council flat.
43. After Bobby died I did receive a one of payment to go towards his funeral. This was to the amount of £1,000 pound. Five years ago my son told me that I may be entitled to some financial assistance and I contacted the Skipton fund. I received a payment of £20,000. It was five years ago but I cannot exactly remember when. Not long after this I received another lump sum of £50,000 from them. In 2016 I began to get a monthly payment of £2,312.50. This is from the Scottish Infected Support Scheme.
44. The process of applying for financial assistance I found to be relatively straight forward. I was sent out some forms and I filled them in and sent them back.
45. Not long after Bobby died I contacted the MacFarlane Fund to inform them of his death. They told me that even though I was Bobby's widow I would not be entitled to any financial assistance as I did not have any dependent children. I did not receive anything until 5 years ago. It was my son who had seen something on his computer and told me to contact the Skipton fund. If he had not I would probably have never known about any funds. Once I contacted them I found no difficulties or obstacles in obtaining the funds.
46. I do not believe there were any preconditions imposed on the making of an application for financial assistance.
47. I am very grateful to receive the money I have got because I do not need to struggle financially to pay my bills. Although it seems a lot of money for what Bobby would have earned its probably less than that. To be honest no amount of can compensate for the premature death of my husband. I would give it all back just to have him with me again.

Section 8. Other Issues

48. I am in possession of Bobby's death certificate. This clearly states that he died of hepatitis C. I can produce this in evidence to the enquiry team if need be.

Statement of Truth

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

Signed GRO-C

Dated 21.3.2019