Witness Name: Barbara Milne
Statement No: WITN4580001
Exhibits: None
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BARBARA MILNE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 September 2020.

I, Barbara Milne, will say as follows: -

Section 1. Introduction

1. My name is Barbara Milne. My date of birth is GRO-C 1947 and my address is known to the Inquiry. I am a retired nurse and live on my own. I am a widow and I have one son, Chris, who has also given a statement to the inquiry (W3379).

2. I intend to speak about my late husband Ken Milne's infection with HIV and Hepatitis C (HCV). In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him our lives together.

Section 2. How Affected

3. My late husband Ken was born on GRO-C 1948. He was diagnosed as a haemophiliac as a small child. His mother had been a carrier of haemophilia as her father, Ken's grandfather, was a haemophiliac. I remember being told that he died during the flu epidemic in 1957 as there were a shortage of hospital beds and he was unable to receive treatment for a throat bleed.

4. Ken had no siblings and I remember his mother saying that she wouldn't have had any children if she had known what it would be like for Ken living with haemophilia.

5. Ken had severe haemophilia A with less than 1% clotting factors in his blood. He would have known about his condition very early on in his childhood as he suffered from frequent joint bleeds and had to spend a lot of time in bed as a result.

6. Ken had to be tutored at home for his primary education as the local primary school would not take him, due to his haemophilia. When he was around 10 years old, he was sent to Lord Mayor Treloar School to continue his education. He was there until he was around 16 years old and he completed his O-Levels there.

7. He then went to his local school in Crawley to do his A Levels. He did very well and got A grades in Chemistry and Maths. He received a place at the University of Kent in Canterbury to study Chemistry in September 1965.

8. I met Ken in the January of 1966 on the medical ward at Canterbury Hospital when he came in with a bleed. I. was working there as a nurse at the time. I remember he was treated with whole plasma and pain killers when he came in with a bleed. He would regularly pop back and forth into hospital when he had a bleed as the University sick bay was unable to deal with his condition when he was living on campus.

9. Initially, the Hospital wasn't too keen on our relationship as they didn't really like nurses forming relationships with patients, especially ones that were regular patients like he was. However, they ended up being very supportive and I remember the ward sister would call me if Ken had gone back into hospital and would tell me to come and visit him. It was a little weird that they became so supportive as I knew another nurse who was dating a patient and their relationship was frowned upon.

10. In 1968, Ken graduated with a first-class degree in Chemistry and started working at the Civil Service Patent Office in London. He spent his entire career with the Civil Service.

11. In January 1969, we got married. I felt like I really knew what I was getting myself into with regards to his haemophilia as I was a nurse; nothing really felt like a surprise and it was all very normal for us. My parents loved Ken and he got on well with them too. We had no friction in the family. We went on to have our son, Chris, in 1976.

12. When Ken started working in London, he was under the care of St Thomas' Hospital. His treatment had switched from whole plasma to cryoprecipitate and it meant that it could be administered at home. This was vast progress. However, as we didn't have a freezer, I would have to store the cryoprecipitate at my parent's house and go and get it if he had a bleed. The cryoprecipitate needed to be thawed out and then set up in a drip and would take some time to administer. I remember we used to hang it up on the curtain rail while he was having the drip. I can't remember exactly where we got the cryoprecipitate from and whether it came from London, as we lived some distance away in Herne Bay.

13. I believe Ken was still under the care of St Thomas' Hospital when Factor VIII became available and I remember him coming back home with boxes of Factor VIII bottles. Factor VIII was life-changing and it meant not having to rely on the frozen cryoprecipitate which was a huge process to

administer. Now all you needed to do was inject yourself with a bottle of Factor VIII which you kept with you.

14. I remember if Ken had an elbow bleed, he would be so stiff he couldn't even feed himself. However, whatever bleeds he suffered, he just got on with things and never made it into a big deal. With the Factor VIII, he was able just inject himself if a bleed happened and this made life much easier. This gave us the opportunity to travel abroad and we visited my sister who lived in Australia for the first time.

15. Ken had always been very involved in the Haemophilia Society. I believe he began getting involved with the society before it even became the Society and played a big role in making it into a proper society as opposed to just a group of affected people. This all started either while he was at university or just after he had left, and his friends John Prothero and Clive were also very involved.

16. They all stayed very involved in the Haemophilia Society and good friends until they all passed away. I think his mother may have had some involvement in the society before it became the proper Haemophilia Society and this may have influenced his involvement.

17. I'm not sure when Ken became Vice Chairman of the Haemophilia Society but he held the position for a long time. Reverend Tanner was the Chair and I remember John Prothero also had a senior position. Ken used to go to World Haemophilia Federation meetings abroad in countries including Costa Rica, Brazil and Madrid and generally travelled quite a lot on society business. I think the Haemophilia Society had monthly meetings in London which he would attend after work. Because of his involvement with the society, he was very knowledgeable about what was going on in the Haemophilia world.

18. In 1985, Ken was under the care of Dr. Mark Winters at Margate Hospital. Around this time, there was some understanding that Factor VIII products may be infecting some users with HIV and an HIV test became available. I

am unclear as to who suggested Ken should get tested for HIV but I'm sure if he knew it was an option to get tested, he would have wanted to know if he had HIV.

19. One day in 1985, Ken came home and told me he had tested positive for HIV. He had had no symptoms at all at this point. We were obviously upset by this news but had to get on with our lives. We did adjust our lifestyle and love making stopped.

20. He had always dealt with his own treatments so nothing changed in that sense. We didn't get much more advice really and it was down to us to educate ourselves. I remember there was a lot of media coverage about HIV and its dangers at the time and it was very 'in your face'. This didn't faze us and we tried to continue our lives as normal as possible.

21. When Ken was diagnosed with HIV in 1985, HCV had not been identified and I believe they were still referring to it as Non-A Non-B Hepatitis at this stage. Ken never had any symptoms of HCV as far as I'm aware and it was only after his death that I discovered he had also been infected with HCV, which had damaged his liver.

22. His death certificate had included liver disease or liver failure as a cause of death. I'm not sure if Ken knew about the HCV before he died but it was not something he shared with me, I think he would have told me.

23. When Ken was diagnosed with HIV, testing Chris and I wasn't suggested. However, when I had an operation in 1986, I told the surgeon that Ken was HIV positive and he wanted me to get tested. I tested negative for HIV. Chris has not been tested but he was never exposed to any risk of infection so would never have required testing.

24. Ken had an operation on his leg to straighten his tibia as he had damage to his knee joint, due to the bleeds caused by his haemophilia. This was in the late 70s or early 80s and I'm unsure if he had a blood transfusion for this operation. Other than the very slim chance that Ken was infected as a

result of a blood transfusion, it is pretty clear that Ken was infected with HIV and HCV through the large amount of Factor VIII product he used. He had no tattoos or piercings and there was no other way he could have become infected.

Section 3. Other Infections

25. I do not believe Ken was infected with any other infections apart from HIV and HCV.

Section 4. Consent

26. I do not believe Ken was ever tested or treated without his knowledge or consent. Ken had a good relationship with both haemophilia centres he was treated at. Due to his involvement with the Haemophilia Society and the knowledge he had, I think he would have been very involved in his own care.

27. I do not believe Ken was ever part of any medical research or trials and he would have told me if he had been.

Section 5. Impact

28. Although we tried to continue our life as normal, whenever Ken got a cold I would think 'is this the beginning of the end?', and that was not an easy thing to contend with. However, it was just a passing thought and then I'd move on and try and live for the day. For a long time, he didn't have symptoms and seemed well.

29. After Ken was diagnosed, I told my friends about his diagnosis. No one reacted badly to the news or treated us any differently as a result; I must have had very good friends. When we were in Australia visiting my sister, I told my sister about Ken's diagnosis and there was never any stigma towards Ken from her. He was just the same Ken as always, whether he

had HIV or not. We made the decision not to tell our son, Chris, about Ken's diagnosis as he was so young and we asked everyone we told to do the same.

30. I also shared the news about Ken's diagnosis with the GPs at the practice I worked at as a practice nurse. The GP practice where I worked was also where we were registered as patients. It didn't affect my role or how I was treated in any way. Of course, I didn't tell any of the patients as they would have been terrified, even though I think it would have been a great learning tool to share Ken's experience.

31. We shared the news about Ken's diagnosis with his mother but she seemed to just blank the information. When Ken was dying, his mother claimed that we had never told her about Ken having HIV. This was not true as we had informed her about it and asked her not to tell Chris. However, I think she just didn't want to know about it and never spoke about it with us until he was dying.

32. Chris was around 13 years old when he found out about his father being infected with HIV. I remember at the time there was some discussion on the radio about no fault payments for those who had been infected with HIV. One day, when I was dropping off Chris to his school in Canterbury, he asked me whether his dad was involved in the payments and whether he was infected. I was absolutely floored by the question but I said yes. I remember he just said "okay, bye", and trotted off to school like nothing had happened. We had never said anything to Chris about HIV or what was going on, but he wasn't stupid and had obviously picked up on our conversations.

33. The first time I really noticed things starting to go wrong with Ken's health was when he had colitis. He was treated at St Thomas' Hospital with barrier nursing. The colitis never really cleared up and he had issues with his gut until he died. Although he did have this bout of sickness, he kept going and did not go badly downhill health wise until the summer of 1993, the year that he died.

34. In the August of 1993, we went to Canada as a family. I remember Chris was 17 and we weren't sure if he would want to join us on the trip but he said he did. We knew it would be the last family holiday with Chris before he left home but we didn't know that Ken's death was so imminent. Ken was unwell while we were in Canada but he managed quite well. I remember he would fall asleep on the coach when we were travelling from place to place.

35. After we returned from Canada, Ken was only able to go back to work for a day before having to be off sick. He had so much wrong with I remember a nurse friend joking, "we are waiting for Ken to become pregnant because that's the only thing he hasn't had!". He had shingles, steroid induced diabetes, he was on a nebuliser for some kind of pneumonia, bad mouth ulcers, ongoing colitis and towards the end of his life, he was diagnosed with lymphoma and had issues with his brain which caused him to be very confused. One medical issue he did not have was Kaposi's sarcoma which was common amongst those with HIV complications.

36. Ken kept going to the Haemophilia Society meetings until he was extremely unwell and was very involved with everything that was going on with the Society. He was even on a BBC program called Nationwide which Dr Jones also appeared on. I think he may have been involved in other press on behalf of the society. Ken was also involved with meetings with government ministers and the Blood Transfusion Service to promote self-sufficiency in blood products.

37. I remember in 1993, when Ken began to get very unwell, the Society was in crisis and there was a lot of infighting going on. A fraction of the Society members were trying to remove David Watters, which they eventually did. Ken didn't agree with this and fought David Watters's corner.

38. I was resentful of the fact that Ken spent so much time during his last few weeks attending Haemophilia Society meetings and events and working on society matters, when he could have been spending that time with the

family. Especially when Ken's health was deteriorating, I could see the writing on the wall and wanted him to spend more time at home. Because of this, I wasn't really too involved with what was happening with the Society.

39. After Ken started going downhill health wise, we were able to manage at home for a long time as I was a nurse and able to care for him. We didn't have any external help like carers coming in. We moved the bed downstairs as Ken couldn't manage the stairs. I think I was also able to switch off from how bad things were due to my nursing experience.

40. Ken would see Mark Winters very frequently and had so much medication that he was taking around 23 tablets a day. He used to spend hours sorting out the pills he had to take for the week.

41. One night, Ken seemed very confused and disoriented and when I went to the bedroom, it seemed like he had suffered a fit. I called for an ambulance and he was taken to the hospital in Margate. After this stay in hospital, he came home for a weekend but went back into hospital soon after.

42. Ken was in a bad state when he came home for the weekend and Chris told me that he didn't want to see his dad like that again. Because of this, I made the decision for Ken to remain in hospital and did not attempt to bring him home again. I remember discussing this issue with Dr Winters and he agreed. Even though I knew Ken wanted to die at home, I had to put Chris's needs first as he was the one that was going to live on.

43. Ken died in hospital on the GRO-C 1993, 8 years after finding out he was HIV positive. We had been told that 8 years was around the maximum length of time most HIV sufferers would live, following diagnosis.

44. I remember that initially his death certificate had listed liver failure or liver disease, lymphoma and haemophilia as the causes of his death. However, the registrar told me to get haemophilia removed off the death certificate as if it stayed in, it would go to the coroners for examination and it would

end up being in the papers. Dr Winters removed haemophilia as a cause of death on the death certificate upon my request, after this conversation with the Registrar.

45. HIV or HCV were not mentioned on his death certificate and I was only made aware that he tested positive for HCV, after his death. When I saw liver failure on his death certificate, I did assume HCV. I have not applied for copies of Ken's medical records but these may shed more light on when Ken tested positive for HCV.

46. Although Ken suffered greatly as a result of the HIV and HCV, he never understood why people complained so much about the Factor VIII treatment. He believed it gave him a normal life for a long time and he was grateful for it, despite everything else that followed. He was able to travel and was not tied to being close to home or a hospital all the time. He always said that any treatment was better than no treatment. However, I understand why people are angry about what happened and in hindsight, maybe things could have been done differently.

Section 6. Treatment/Care/Support

47. Ken did not struggle to get the treatment that he needed and he always had a good relationship with his doctors and the haemophilia centres he attended. However, when Ken was dying, he was refused a place at Canterbury Hospice as he was HIV positive.

48. I'm not sure if Ken was offered counselling following his diagnosis.

Section 7. Financial Assistance

49. I am aware that Ken applied to the McFarlane for a payment and received £20,000. I remember that he had to sign a waiver which said that we would not bring a claim against the Government for any further payments

in order to receive this payment. I believe the sum was based on the fact that we were married and had a son. It was paid in order to give us the opportunity to buy a house as we were unable to get mortgage insurance at the time. I think he was also funded to buy a laptop which he needed for his work with the Haemophilia Society. As far as I am aware, he did not receive any monthly payments.

50. Around 3 or 4 years ago, Chris applied for a lump sum on my behalf as a cause of Ken's death was liver disease as a result of HCV. The Trust paid me a sum of money but I cannot remember exactly how much this was.

51. Although Ken had applied for early retirement a few weeks before his death, the application had not been filed before his death as the woman in charge had been on holiday. Because of this, Ken died in service and I received his full civil service pension. I also receive my own pension and this has meant I have been financially stable since Ken's early death.

Statement of Truth

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

Signed GRO-C

Dated 08/10/2020