IRO

Witness Name: Margaret Vaughan

Statement No.: WITN3156001

Exhibits: WITN31560002 – WITN31560007

Dated: August 2019

6.9.2019.

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARGARET VAUGHAN

I, **Margaret Vaughan,** will say as follows:-

Section 1: Introduction

1. My name is Margaret Vaughan and my date of birth is GRO-B 1937. I reside at GRO-B I have two sons. I am retired, having been a hairdresser. I have remarried since I lost my husband as a result of his infection with contaminated blood.

Section 2: How Affected

2. My late husband, Robert Thomas Emery, who was known as Bob, was born on GRO-C 1936. We married on 4 October 1958 when we were both in our early twenties. I was an apprentice hairdresser and Bob worked in the men's outfitting trade.

3. When we got married, I knew that Bob had haemophilia A, but I did not know much about it. Bob and I always understood that Bob's haemophilia was classed as severe. Bob instructed solicitors to litigate in relation to his infection with HIV and in connection with this a Preliminary Medico Legal Report was prepared, based on review of his medical records (the "Report") [WITN3156002]. The Report notes that his haemophilia was

described as mild on 26 June 1963 but was described as severe on 24 February 1968.

4. For the first few years of our married life Bob was reasonably well but following this he started to get bleeds more frequently and had to go to the Churchill Hospital in Oxford more often. Bob was under the care of Dr Matthews and Dr Rizza in the Gibson ward, which became like his second home. He had an excellent relationship with the staff there. When Bob died, they sent flowers with a message that said "*not only just a patient, a friend*".

5. In 1975, Bob and our friend Martin Shaw set up a petition to get treatment for haemophiliacs at Northampton General Hospital, which was our local hospital. As a result of this campaign, the Northampton local group of The Haemophilia Society (the "Northampton Group") was born; with Bob as chair and Martin as secretary. Their petition was successful, however, only minor bleeds could be treated at Northampton General Hospital. Bob's bleeds were bad so we usually had to travel to the Churchill Hospital in Oxford and he continued to have many admissions to the Gibson ward there. Travelling to Oxford was difficult as Bob would be in horrific pain. He had inhibitors and one bad knee, although he also had bleeds elsewhere in his body. The inhibitors rejected the treatment which meant he needed more treatment than other haemophiliacs. It was like living on egg shells. When our sons were small we would have to take them with us to the hospital.

6. Bob once had a bleed when we were away when the plane on which we were travelling came down severely. On another occasion he had a bleed when a fish hook went into his finger. Once, when we were on holiday in Exeter, he had a bleed into his stomach and an ambulance came and took him to hospital in Devon. I had to travel back and forth from Exeter to Devon to visit him.

7. In the early days there was no treatment when he had a bleed. However, when we were married in 1958 treatment was available. The Report states that Bob first received Factor VIII on 1 August 1975. I am not sure

whether this is correct, as I know he was receiving treatment from when we got married. I do not know what treatment he was receiving at that time.

8. Bob started home treatment with Factor VIII on 11 January 1978. The Factor VIII for home treatment was sent from the Churchill Hospital to Northampton General Hospital, where Bob would collect it. He used approximately four bottles per month. He injected himself with the treatment. However, if he had a bad bleed we had to go straight to the Churchill Hospital.

9. We were never told that there were any risks associated with Bob's treatment with Factor VIII products. I note that at page 5, the Report states as follows:

   "16. Do the records contain any evidence of warnings being given to the client of the dangers of Factor VIII or Factor IX in the context of AIDS and, of so when?

   No.

   17. Do the records contain any evidence of warnings being given to the client of the dangers of hepatitis in the context of AIDS and, if so when and to what extent?

   No."

10. Bob was diagnosed with HIV in the 1980s. We were both tested for HIV at the same time and I remember going to the Churchill Hospital to get the results. It would have been Dr Rizza or Dr Matthews that we saw, but I think it was Dr Matthews. He told us that Bob was HIV positive and I was not. I do not recall what year this was, however the Report notes that the first blood test that produced an HIV result for Bob was taken on 8 August 1985. It was tested on 29 August 1985 and initially produced a negative result but it was immediately retested on the same day and produced a positive result. The Report indicates that there was a letter from Bob in

late 1985 wishing to know his AIDS result and that the records indicate that he was first informed on 15 February 1986.

11. I cannot remember what else we were told at the time Bob was diagnosed, but I do not feel that we were provided with enough information.

12. Shortly after Bob was diagnosed, a social worker, Mrs Fletcher, came to visit us. She gave us a book on safe sex but did not talk about it, she just left it on the table. It was very crude. I am not sure how many times she came to visit but it was more than once. On each occasion she asked Bob if he was drinking a lot of alcohol. At the time we did not understand why she was asking this. On reflection, I presume she was asking because she might have known what could happen to Bob, or that he had Hepatitis, although we were not told that. She did not provide any counselling.

Section 3: Other infections

13. As described below, Bob died as a result of infection with Hepatitis C. However, he was never told that he had Hepatitis C.

Section 4: Consent

14. I believe both Bob and I were tested for HIV at the same time and we knew we were being tested. However, the Report suggests that there was a delay between Bob initially testing positive and him being informed. I do not remember having to chase for the result.

15. As Bob was unaware he had Hepatitis C I do not know if he consented to being tested. Perhaps, if Bob had consented to being tested he might have sought to find out the result. He was always very adamant that he would not pass anything onto anybody else, and he took precautions to protect his family.

Section 5: Impact

16. Our lives changed from Bob's diagnosis with HIV onwards. We went from being a happy family to a very scared and worried one. We were devastated. From then on we lived like brother and sister. Bob was

terrified of passing HIV to me. He had his own towels and toothbrush that were not to be used by anyone else. We carried on and made the most of the life that we had been dealt.

17. In those days, HIV was something that you could not talk about. There was such a lot of stigma and it was like a dirty word. The impact of that was terrible. People are more open nowadays, which is a good thing.

18. When he was diagnosed, Bob became a very worried man. He worried about me and our sons and he wanted to make sure that we would be okay. He had some very bad days on which, if I had to go out, I would come back to find him just sitting in the house. On other days, he would go out to do things with The Haemophilia Society ("The Society"). He also liked going to house sales to look at old furniture or, if he was well enough, he loved to be in his garden.

19. As the years went on his moods became changeable. He had good days and bad days, on some he would be happy and on others he would be down and slightly depressed. I also noticed that his handwriting changed.

20. Bob never received any treatment for his infection with HIV. The only treatment he received was for his haemophilia.

21. I was very worried following Bob's diagnosis; I did not know anything about HIV other than what had been in the papers. We both kept the worry of Bob's diagnosis away from our sons as much as possible. They knew their father had haemophilia and hated seeing him in pain. I believe they must have realised that Bob had HIV, particularly when he was becoming very unwell and he was so protective over sharing things with them, but we never really talked about it.

22. In early March 1990, Bob had a fall in our garden and he was admitted to the Gibson ward in Churchill Hospital in a lot of pain. When I was visiting him there one day I noticed that his stomach was very swollen; he looked as if he was nine months pregnant. I asked the nurse what was wrong and she told me not to worry, everything was okay. I do not think I even knew at that time that he had Hepatitis C. He was then transferred from the

Churchill Hospital to ward 5F in the John Radcliffe Hospital in Oxford ("John Radcliffe").

23. Bob was put under the care of a liver specialist, Dr Joanne Trowel. Dr Trowel said to me, "*If I were you I would go home and put your husband's affairs in order*". This was a big shock. I really do not know how I managed to drive back to Northampton from the John Radcliffe.

24. When I came back to the John Radcliffe, there were lots of doctors and microbiologists around Bob, trying to find out how to help him. Bob said "*If you can't help me, bugger off*"." Our son, Miles, was graduating that week and I took pictures of Miles' graduation into the John Radcliffe to show Bob, as he was too ill to attend. In the liver ward, he was in a room completely on his own but we were never told why. I lived there for a week with Bob.

25. Bob died on 11 April 1990 at the John Radcliffe as a result of infection with Hepatitis C. We were not told that was what was making him so ill, just that he was on a liver ward. Hepatitis C had never been discussed with me, only HIV. Hepatitis never seemed to be mentioned. I cannot remember when Hepatitis C was first mentioned to me in connection with Bob. Bob's death certificate does not mention Hepatitis C, it says hepatorenal failure and haemophilia.

26. When Bob's body was returned from the John Radcliffe to Northampton, the family were not allowed to see him. It knocked the family for six. Bob's sister was away on holiday when he died and she wanted to say goodbye. This was very difficult for us and I felt the stigma of it all.

27. Our eldest son Miles, was 25 and our youngest, Damon, was 23 when Bob died. GRO-C

GRO-C

28. I still worry about the possibility of having been infected. I worried when I met my husband, Dennis, and was tested for HIV and Hepatitis C at that time. When I had to go into hospital for a hysterectomy, I worried about

going into hospital and asked the doctor again for tests for Hepatitis C and HIV. This brought it all back; everything that Bob and I went through.

Section 6: Treatment/Care/Support

29. At page 5 of the Report in answer to the question "*Do the records show that the client has received AIDS counselling and if so when and to what extent?*", reference is made to a visit on 7 January 1990 "*to discuss HIV protection and collect blood sample from Mrs Emery*". This cannot be referring to a visit from Mrs Fletcher as she did not take any blood. I do not recall Mrs Fletcher taking my blood during her visits. As stated above, Mrs Fletcher did not provide counselling. There is also a reference to a letter dated 10 January 1990 offering *"support, friendship and counselling*", this was only a few months before Bob died, however, I cannot remember Bob receiving any such letter.

30. We were not offered counselling or any other psychological support. Counselling or psychological support would have been very helpful had it been offered.

Section 7: Financial Assistance

31. When Bob died, I received money for Bob's funeral from the Macfarlane Trust. I did not have to contact them for this, it was just sent to me. I think Bob may have received something from the Macfarlane Trust when he was alive, but I do not have any details about this.

32. Bob did not receive any payment from the litigation which he raised as a result of his HIV infection while he was alive. I continued the litigation after Bob passed away, as can be seen from the letter from our solicitor to me dated 5 October 1990 providing an update [WITN3156003]. Bob worked very hard on the litigation and tried to help people. I recall I received a settlement as a result of this litigation but I cannot remember how much.

33. Paul Giogrande, Consultant Haematologist, from the Haemophilia Centre at the Churchill Hospital, helped me to complete the application forms for the Skipton Fund in 2011. I cannot recall precisely how I became aware

of the Skipton Fund but the Macfarlane Trust may have provided my details. I believe the Skipton Fund contacted me and I had to prove I was eligible for the payment. I received the £20,000 basic payment and a further £50,000. On the application for the stage 2 payment, Paul Giogrande states that Bob's post mortem report "*states very clearly that this man had established cirrhosis and ascites*" [WITN3156004].

Section 8: Other Issues

34. Bob retired aged 46 as a result of his frequent bleeds, and did a lot of work for others with haemophilia. He was very generous and thought a lot about others. He went to conferences of The Society and a lot of events at The Society's head office and even went on trips abroad with his work with The Society.

35. In connection with this work, Bob had a lot to do with those that were infected and people would come from all over to meetings of the Northampton Group. He was very proactive within the community. He used to go around and visit people in their homes and make sure younger people with haemophilia were ok. In later years, we held the meetings of the Northampton Group in our bungalow. I have found a letter within Bob's papers which suggests that he assisted members of the Northampton Group with the HIV litigation process [WITN3156005].

36. I have within my possession a report prepared by Dr Aronstam, Consultant Haematologist, for J Keith Park & Company which comments on the treatment of haemophilia and testing for HIV in the 1980s [WITN3156006]. I also have a document which sets out the chronology of haemophilia and AIDS. It is noted that in 1976, 58 cases of Hepatitis had been recorded.

37. When Bob died, the local newspaper reported his death [WITN3156007], and it noted that he campaigned for compensation for those who had been infected with HIV as a result of blood plasma. I have kept this article in my wallet since Bob passed away.

38. I took up the role of chair of the Northampton Group following Bob's passing. Martin's wife, Rosemary, took up the role of secretary after Martin passed away, also as a result of infection with Hepatitis C. We have organised many events to raise money for those with haemophilia. Haemophilia has been in my life forever and it still is. I continued running The Society and fundraising in Bob's memory until recently, when Rosemary and I stood down.

39. The community is still living with the impact of this scandal. I attended a funeral in June this year of a member of the Northampton Group's son who died as a result of contaminated blood.

40. I feel that that people who let contaminated blood be used should be held accountable for their actions. Contaminated blood should not have been brought into the UK and it should not have been used. It has given many families a lot of grief and worry and has changed their lives forever. Being involved with the Inquiry is making me relive these events 29 years later, but I am doing it for Bob. We were kept in the dark. I feel like having all of this outstanding means that Bob is not being allowed to rest in peace.

Statement of Truth

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

Signed GRO-C

Dated 6 · 9 · 2019 .