Witness Name: Carol Patricia Osborne
Statement No: WITN1445001
Exhibits: 0
Dated: 21st December 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CAROL PATRICIA OSBORNE

I, Carol Patricia Osborne will say as follows:-

Section 1. Introduction

1. My name is Carol Patricia Osborne. My date of birth is GRO-C 1947 and I live at GRO-C. I am retired. I met my late husband, Jeffrey William Osborne (Jeffrey) in January 1970 and we married on the 4th July 1970. We have a son, Anthony, born on the GRO-C 1977, as well as three grandchildren and two great grandchildren. Jeffery was born on the GRO-C GRO-C 1948 and died on the 28th March 1992 at the age of 43.

2. This witness statement has been prepared without the benefit of access to Jeffery's full medical records.

3. Jeffery kept a lot of paperwork, including letters written by him, which are still available. The documents have been used in the process of drafting this witness statement.

Section 2. How affected

4. Jeffrey had severe Haemophilia A, he would bleed spontaneously, anything would bring on the bleeds and he had no clotting factor at all.

5. He was diagnosed with Haemophilia at the age of 2. He bruised unusually easily and whenever he had a cut he would bleed continuously, so tests were undertaken which showed he had Haemophilia.

6. Jeffery was treated at St Thomas' Hospital with blood products, and was given Factor VIII from the time it was first introduced. His consultant for his Haemophilia was Dr Savage.

7. I attended hospital appointments with Jeffery from the time I knew him therefore I know that there was never any mention of any risks associated with the use of Factor VIII. Also the documents Jeffery kept confirm this though from early 1983, leaflets published by the Haemophilia Society warned of the possibility of contracting Acquired Immune Deficiency Syndrome (AIDS) but advised haemophiliacs to continue with Factor VIII treatment.

8. As a result of receiving blood products Jeffery was infected with Human Immunodeficiency Virus (HIV).

9. On the 16th December 1985 Jeffery went to St Thomas' for a routine blood test. He was not informed of the reason for the blood test. He was then asked to attend again a few weeks later for a further blood test. Once again, he was not told the reason for the blood test.

10. In January 1986, whilst at work Jeffery was telephoned by the Sister at the hospital and was informed that he had tested positive for HIV. This was a terrible shock to us both and the manner in which he was told of the infection by the Sister over the telephone was appalling. We never thought Jeff would die from this.

11. During the telephone conversation, to my knowledge, no information was provided to him concerning his condition, including no information advising him not to have unprotected sex.

12. Later Jeffrey received leaflets containing advice on how to live with the condition and how it could be spread; however, I do not believe that they were particularly helpful. The advice given in the leaflets was to live a clean and healthy lifestyle, go to bed early, eat healthy, not to share toothbrushes with other people, and not to drink excessively or smoke.

13. Overall, Jeffery received quite a lot of information from the Haemophilia Society, but not much from the hospital.

Section 3. Other Infections

14. I do not believe that Jeffrey had any other infections, as a result of being treated with blood products.

Section 4. Consent

15. As far as I am aware, Jeffery was never informed of the reasons for the blood tests. I recall attending a routine check-up at the hospital with Jeffery and he gave blood samples. This was an ordinary thing to do, neither of us thought anything of it, we assumed it was for his haemophilia condition. Certainly he didn't know he was being tested for HIV.

Section 5. Impact

16. On the 14th December 1989 Jeffery was told by Dr MJ O'Doherty, Senior Registrar at the Haemophilia Centre, that he had PCP pneumonia. As soon as I heard Dr O'Doherty say this I knew Jeffery had AIDS. Dr O'Doherty then confirmed that Jeffery was diagnosed with AIDS.

17. In January 1990 Jeffery was prescribed Retrovir-Zidovudine (AZT).

18. Sometime later he was asked by Dr O'Doherty if he wanted to be admitted to hospital, to be referred to a Hospice (the Lighthouse Hospice or the Mildmay Mission), or stay at home when his condition deteriorated. We were informed that if he stayed at home we would get help and support in Jeff's care, as he was saving the Government money. Dr O'Doherty said to give him an answer when Jeffery next attended the hospital. Jeff and I discussed it in detail, and decided that Jeffery would be best at home in his own surroundings.

19. The tiredness Jeff experienced caused him to become introverted and he said that he just wanted to switch off and be on his own. Also, due to his tiredness he wanted to keep sleeping.

20. At the beginning, Jeffery's condition did not cause him any obvious symptoms; however, once his health deteriorated he suffered from night sweats, diarrhoea, shingles, pneumocystis, dermatitis, chronic fatigue, a cough, shortage of breath, depression and anxiety.

21. Due to his HIV, Jeffery had to give up his hobbies and social events. He enjoyed DIY and car maintenance; however, due to the chronic tiredness caused by HIV, he was not able to perform them. He also missed out on time with our son. He was not able to do many things that he used to do with Anthony, prior to the deterioration of his health, such as canoeing. Jeffery was a canoe instructor at the Club Anthony belonged to. Jeffery would also rarely attend any social events, as he was often too tired, and he felt like he needed to preserve his energy for work.

22. Jeffrey's condition also affected our finances and sense of safety and security. We were constantly worrying about the fact that once Jeffrey's health deteriorated, he would not be able to work, and as he was the main earner, it

would put a massive strain on our finances. We were also aware that we would need to spend much more on laundry (due to his night sweats), travel to the hospital and heating, which was another source of stress. Jeffery was also never able to get life insurance, as a direct result of his illness, which was very worrying to us.

23. On top of that, our home needed a lot of work doing to it at the time, which Jeffery was not able to do, due to his health deteriorating. We were also not able to increase our mortgage so we could move, which was a direct result of Jeffrey's HIV. Therefore, we had to employ people to do all the home maintenance that was needed to our property, which was expensive, so Jeffery had to work as much as he could in order to finance it.

24. Jeffrey's condition was also daunting for his job prospects. He worked as a Principle Administrative Officer for a London Council and he was slowly climbing the career ladder at the London Borough of Tower Hamlets. As he stated in several letters, his illness destroyed his career prospects. He had been working in the Local Government administration for over 20 years, yet he knew it was extremely unlikely that he would be offered a job outside of local authority due to his HIV. He also did not have much opportunity to grow within his own job, as whenever there was an opportunity of a job at a higher role, he would not even consider applying. He thought that taking on a new role would either cause him undue pressure, which he did not need or it would not be fair as he did not know how much longer he would be able to work.

25. Jeffery's condition made us both feel extremely isolated. I recall that soon after he was diagnosed with HIV, adverts were played on the TV showing tombstones in a graveyard, advising about HIV and AIDS, which was very stressful and hard to watch. We could not tell our friends and only our immediate family knew of Jeffery's condition, i.e. Jeffery's parents, my 3 brothers and my mother.

26. Our families showed some understanding initially, but later it became apparent that they had distanced themselves from us and they saw Jeffery's illness as something that they did not want to have anything to do with.

27. Shortly after Jeffery's diagnosis my mother took to soaking the tea cups that Jeffery and I had used in bleach which was extremely unpleasant for both of us. As time went on we were no longer invited to visit my mother and on the rare occasions we did, we were not offered to eat or drink with her. She did not make us meals. On the rare occasions she visited us she would bring an orange with her to eat. We felt less and less welcome when we visited my mother, so we stopped visiting altogether.

28. My husband's parents lived too far away to visit us, and I was unable to drive that distance so we had little contact with them except by phone.

29. We suffered greatly as a result of this isolation, and we were also extremely afraid that somebody outside of our family might find out about Jeffery's condition.

30. It was an extremely emotionally and physically exhausting period of time for me. As a result I experienced severe back problems brought on by the stress associated with Jeffery's condition, the intensive media courage about AIDS and the stigma surrounding the whole issue. I was bed ridden for 5 months, unable to move. Anthony was only 10 years old at the time, and I was not able to care for him or Jeffery during that time. Jeffrey had to take care of me and Anthony, and go to work and he was already unwell.

31. In July 1989 I started work part-time to help pay the Solicitors Jeffery had instructed to make a claim for damages as a result of his condition. Jeffery tried to work, as much as he could, notwithstanding his symptoms, such as chronic fatigue and general weakness. He worked until 6 months before he died and he

had to give up work as he was simply too unwell to function. I continued to work part-time.

32. Jeffrey's HIV had also a great effect on our relationship. After we found out about how the illness is transmitted, we ceased to have any close relations. My husband was too afraid to even give me a peck on the cheek, as he did not want to infect me. This was a very difficult situation for both of us.

33. I also became afraid that I might have been infected. I was offered a test; however, that was not long after my husband was diagnosed with HIV. Due to the stigma attached to this condition, I did not dare to go to any of the local hospitals to be tested. I travelled to St Mary's Hospital in London to be tested, as nobody knew me there. I think I even gave a false name. Thankfully, the test was negative.

34. The effects of Jeffery's illness laid very heavily on me. I worked (part-time), as well as looked after Jeffery and our young son. I was on a verge of complete exhaustion. As Jeffrey's condition deteriorated he was unable to do the most basic functions, as he was too weak. I do not feel we were provided with the necessary support promised, such as a bath board to get Jeffery to the bath to wash him or basic utensils or a bed pan. I ended up buying tin foil dishes in place of a bed pan. It was extremely humiliating and degrading for Jeffrey to do basic things, such as using the toilet.

35. In February 1992 I was at the point of exhaustion my doctor said that I needed a complete rest. It was arranged for Jeffery to go to his parents' home to be looked after to give me a rest. However, his parents were unable to cope and after a week Jeffery returned home, as his parents were threatening to have him put into a local hospital where they lived. As Anthony and I wouldn't have been able to visit or see Jeffery I arranged for him to come home.

36. Christine Harrington, the Nurse Counsellor at the Haemophilia Centre at St Thomas' Hospital, arranged for a 'Buddy' GRO-C to come and sit with Jeffery and make him tea and cut his toenails while I was at work.

37. GRO-C

38. GRO-C

39. When Jeffrey's health deteriorated significantly, we agreed with Dr Driscoll (Jeffery's AIDS consultant) that he would spend his last days at home, rather than in hospital or a hospice. During the final six months of Jeffery's life when he was bed-ridden, we were almost completely isolated. We were only visited around once a month by my brother, but nobody else from our immediate family wanted to see us.

40. Jeffery died 28th March 1992 at the age of 43.

41. Anthony was very young at the time and we decided not to tell him about the seriousness of Jeffery's illness. Anthony enjoyed canoeing and spent a number

of weekends away with his Club. In fact it was probably a couple of years after Jeffery died that I told Anthony the cause of his father's death.

42. After Jeffery died I took on two part-time jobs at the local hospital; I worked in the mornings in one job and in the afternoons in another job, to supplement my income. I would not have had to do that, if Jeffery was around, as he was the main breadwinner of the family. By 1994 I was working full-time.

Section 6. Treatment/Care/Support

43. We were told there was no actual solution to his illness and no other treatment was available.

44. Jeffrey told his dentist of his HIV status and he was refused treatment. He then had to go to the hospital for dental treatment.

45. His doctor also refused to treat him. Jeffery would self-administer his treatments at home. We were not able to travel to the hospital often as he was too unwell, but he still had bleeds, so he needed to be given Haemophilia treatments. The hospital would send Jeff's treatment to him. However, at some point he was too unwell to self-administer the drugs and I was not able to do it so I contacted his doctor and asked for help, but his doctor never came. Therefore, I had to call in an ambulance to take him to the hospital. I am not certain whether the reason for this was Jeffery's HIV, but I believe that it is a possibility.

46. We were offered counselling at the beginning, when Jeffery first found out about his illness; however, we did not find it useful. Jeffrey never went and I attended once, but I found it pointless. It was led by Christine Harrington, referred to above.

47. I also attended a Women's Weekend in the 1990 in Newcastle, which was more informative and more helpful. The conference covered workshops on caring at home, how to have safe sex, money matters, stress reduction, how to deal with

bereavement, preparing for death, and more. It was organised by the Haemophilia Society not the hospital.

48. I am disappointed that we did not receive the help and support needed following the decision to care for Jeffery at home as promised rather than Jeffery being cared for in hospital or a hospice. However for the last three month's of his life a District Nurse visited twice a day.

Section 7. Financial Assistance

49. I believe that Jeffrey found out about the MacFarlane Trust, either through the Haemophilia Society or through the hospital.

50. Jeffery applied for the cost of a washing machine, through the MacFarlane Trust, as he had severe night sweats caused by his illness. However, I am not familiar with the detail of the application process. The washing machine saved me attending the launderette on a regular basis.

51. The MacFarlane Trust also helped to finance the transport to take Jeffrey to his parents' house and back when I had exhaustion and was advised by my doctor to have a complete rest. It also paid for the 3 ¾ hours of home care for Jeffery when the Buddy was no longer visiting Jeff, which cost £30.24.

52. In 1991, the MacFarlane Trust also paid £750 towards our family holiday. Regular payments of £28 per week was also received from the Trust, this was an increase from £15 per week initially received.

53. Jeffrey also received a lump sum of around £80,000, as a result of the Government ex gratia payment to a married man with children.

54. The MacFarlane Trust also supported Anthony financially after Jeffery passed away. He received £69 per month. The support lasted as long as Anthony was in full-time education.

55. About a year ago I received further £10,000 from the Government.

56. I have received a letter from England Infected Blood Support Scheme (EIBSS) stating that I could also apply for the winter fuel payments. I have applied, and received at the beginning of this month a one-off payment of £519 in respect of Winter Fuel Payment.

57. Whilst the financial assistance was helpful, I am rather disappointed with the fact that the funds and schemes failed to take people's personal situation into account. They only took into consideration the difference between married couples, unmarried couples and single people, which entitled them to different payments. However, the Trust did have regard to other aspects, such as whether the infected person or their closest family were also working, whether people were able to support themselves or issues to do with the infected person's retirement.

58. I also receive a widow's pension but as Jeffery died young I was not entitled to his pension until I retired. Further, as I did not pay sufficient National Insurance, nor did Jeffery, I receive a lower rate of state pension than I would have received if Jeffery had reached the age of retirement when he died.

Anonymity, disclosure and redaction

59. I confirm that I do not wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

60. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

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

Signed...GRO-C.........

Carol Patricia Osborne

Dated 21st December 2018