Witness Name: K NEWPORT
Statement No: WITN3382001
Exhibits: WITN3382002
Dated: September 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KAREN NEWPORT

I, KAREN NEWPORT, will say as follows:-

Section 1. Introduction

1. My name is Karen Newport of GRO-C Essex, GRO-C My date of birth is GRO-C 1967. I am married and have one child named Ryan (aged 25) who suffers from Haemophilia A. I currently work full time in Human Resources.

2. I make this statement in relation to my late father, Mr David Farrugia, who passed away on 3 April 2012, aged 69. As a result of receiving contaminated blood products, my father was infected with Hepatitis C.

3. I also have two uncles named Barry Farrugia and Victor Farrugia, both who passed away as a result of being infected with HIV via contaminated blood. My father was the last of my family to pass away from infected blood.

4. My mother, Madeline Farrugia is also giving a statement to the Inquiry. Her witness number is WITN1215001 and details my father's medical history.

5. This witness statement has been prepared without the benefit of access to my father's full medical records.

Section 2. How infected

6. My father suffered from moderate Haemophilia A with a clotting factor of 3%, the same as my son. He was initially treated with Cryoprecipitate and then Factor VIII Concentrate.

7. My father was first treated at the Royal London Hospital in Whitechapel, where my son currently gets treatment for his Haemophilia.

8. When my father turned sixty, he took an early retirement from the London Underground and moved to Cambridgeshire where he was treated at Addenbrookes Hospital.

9. I cannot pinpoint exactly how frequently my father received Factor VIII treatment; however I know that he was not keen on using Factor VIII. This was because my father was a highly intelligent, well read man who knew that these products were being imported from the US originating from drug addicts, homosexuals and prostitutes. Therefore he often refused treatment and instead used home remedies to treat himself, such as applying ice packs on bleeds. I believe that this is part of the reason why my father did not contract HIV and why he lived until the age of sixty nine.

10. Any information my father knew about the risk of being exposed to infection through blood products was sourced by his own means. As far as I am aware, no hospital ever mentioned this risk to him, although he may have confronted the hospital about this directly.

11. As a result of receiving Factor VIII concentrate, my father was infected with Hepatitis C.

12. My father never really discussed what he was told on diagnosis with me and I didn't find out straight away that he had been infected with Hepatitis C. In

general, my father kept a lot from me as he was trying to protect me. To a certain extent I can understand him, but I wish he had told me more.

13. As Dad got older, I became more involved in his hospital visits and treatment. At the time I lived five minutes away from him. My mother was unable to administer his injections, so I learnt how to do it. My dad allowed it when my son was born as he knew that one day I would have to do it for Ryan. This was after his Hepatitis C diagnosis.

14. When I was administering Factor VIII treatment on my father, he was so fearful that he might transmit the disease to me. He ensured that I wiped everything down, which I would have done anyway, but it was that fear in him that made him extra cautious about it. I do not know if he learnt about the risk of transmission from the hospital or if he just knew about it.

Section 3. Other Infections

15. One Christmas, my father got a letter stating that he may have been exposed to vCJD through contaminated blood products. Our family had planned to gather for Christmas and I recall how much that letter impacted him. It was another thing to worry about. He still managed to joke about it; he would grow a tail.

Section 4. Consent

16. I do not know if my father was tested or treated without his consent or knowledge.

Section 5. Impact of the Infection

17. During the 1960s, my father spent a lot of time abroad. He went to Italy and nearly lost his life after being stabbed. He did everything he should not have done and he never allowed his Haemophilia to become an obstacle in his life.

He wrote memoirs about his journeys around the world, although he never managed to finish it.

18. My father was an adventurous and spirited man. Whilst he was in Italy, he ended up in prison and they had to write a letter to my grandmother saying he would not be home for Christmas. There are pictures commemorating his time in the army where he had black eyes. Eventually the army found out that he had Haemophilia and kicked him out. That side of my father was very amusing; he was quite the character. Whilst in Brazil, he got into a fight and experienced an awful nose bleed for which he had to have stones put up his nose. He lived his life to the full and was a man with many stories to tell.

19. In the final years of his life, my father's health deteriorated. He lost all of his energy and vigour, was always tired and struggled to cope with his fatigue. I feel that my father knew that he was dying, although he never explicitly said this to me. Relatives had known this and mentioned it to me at his funeral.

20. On the night of his death, at 2am in the morning, I received a phone call from Hinchingbrooke Hospital saying that my father was not in good way and requesting that I come to the hospital as soon as possible. I drove there immediately, praying that he would be alive when I got there. When I arrived my mother was with the police. At first I didn't understand what had happened; my father had been rushed to hospital by ambulance and had died before I got there.

21. On his death certificate, the cause of death is listed as Hepatitis C.

22. My father was put on a course of Interferon and Ribavirin treatment to clear his Hepatitis C. It was supposed to last for a year but, due to the side effects, he was unable to complete the course. He then wanted to try the Interferon again but died before he could. I do not believe that the hospital ever discussed the possibility of getting a liver transplant. I recall that Angela Farrugia, my dad's sister, looked into this further but by then my dad was too ill.

23. The side effects of treatment were too much for my dad. He spent a lot of time in bed and was extremely depressed.

24. I married on 5 June 2010 whilst my father was on Interferon treatment. He made it to my wedding, thankfully, but was so ill that he was unable to stay for the reception. His body was unable to cope – he felt nauseous, had constant itching and his energy was completely drained. My mother said that the Interferon whacked the life out of my dad and he had to give it up.

25. Whenever my father needed to have dental care, or wanted a routine appointment with his GP, he would have to wait until the last appointment of the day. I understand that hospitals have protocols to follow but that does not make patients feel less stigmatised. I feel that they had very little compassion back then and people automatically assumed that my father was a homosexual or a drug abuser. That was simply not the case; innocent people were negligently infected through Haemophilia treatment, blood transfusions and during child birth. People did not ask for this and therefore they do not deserve to be treated this way by hospitals.

26. In terms of my father's social life, in his later years, he no longer attended our family barbeques and did not want to go away on holiday with us. My parents were supposed to go on a cruise together over Christmas but my father was too ill to fully enjoy the on-board activities and entertainment. My mother ended up spending a lot of time alone. In fact, on Christmas Day my father stayed in bed all day.

27. This was not how my father used to be. He was the life and soul of the party when he was younger. He loved drinking and socialising when he wasn't suffering from ill health. In addition to this, we would always go away on holiday, for example, going to Ireland for fishing trips and Cornwall. It was difficult to see him change from the person he was.

28. I lost my father which devastated me and my family. I also had to care for my mother after his passing and although I feel sad for her, it was quite a stressful time to live with her, particularly given her mental state and that I was

a newly wed. She would often GRO-C start screaming and crying. I tried to convince my mother to go for counselling sessions, but she refused as she felt she could only speak to me. She therefore only vented to me which was tough as I had my own feelings to cope with.

29. On top of that, my mother was unable to handle all of my father's affairs so I had to do everything – close his bank accounts, deal with his pensions and bills and cancel a holiday that had been booked prior to Dad's death. My husband said that I never had time to grieve because of this.

30. Meanwhile, alongside caring for my mother and dealing with the aftermath of my father's death, I maintained a full time job and had to care for my son who suffered from Haemophilia. It was very tough to juggle, but somehow I managed.

31. After my father died, I took my mother home from the hospital. We then collected my father's death certificate; however there was a delay in receiving it as my father died during Easter. This meant that the funeral had to be delayed as well. When the time came, the funeral home refused to embalm my father's body. They would not dress him or touch him and this caused uproar in my family. He was cremated in a shroud. My mother was shattered as she had prepared a suit to dress him in, however they outright refused. We could not convince them otherwise, despite several attempts by my cousins and me. He was not cremated how he should have been. This is one example of how the stigma impacted my family.

32. To further demonstrate the stigma surrounding Hepatitis and HIV, when my uncle Victor was dying of AIDS, somebody had sprayed the words 'AIDS SCUM' on his house walls so my father went around to clean it off for him. It was heart breaking for my uncle and family.

33. As a family, we were all quite close, aside from ordinary family rifts. My cousins lost their father at the age of fourteen after which, their step mother did not wish to care for them. In consequence, some of my cousins ended up

in children's homes which had a serious mental impact on them. To lose their dad's at such a young age, and to get no support afterwards messed with their heads. On the other hand, I was lucky as I had my father around for a long time.

34. My mother was not in a good condition at all. She was severely affected by the loss of my father and had a breakdown. She dealt with the funeral arrangements and was quite good at it. She went to the local Co-operative who helped. Unfortunately on the day of the funeral, my mother was extremely shaky and unable to cope. My entire family kept their eye on her.

35. Thereafter her mental health did not improve and my mother moved in with my husband and me for a year. Prior to my father's death, my mother never drank alcohol, but suddenly she started drinking to cope with her loss. She still drinks now.

36. My mother currently lives ten minutes from me, so she is able to care for herself, but she has never really come to terms with Dad's death and cannot accept the way in which her husband and brother in laws died. I try to visit her as much as possible, but there are days when she refuses to get out of bed.

37. The loss of my dad also had a massive impact on Ryan. I often worry about my son.

38. Since my father refused treatment knowing the risks, we never treated my son with blood products until his teenage years. I remember that my son had his first major accident when he fell off his tricycle and smashed his face. My mother who cared for Ryan whilst I was at work, rang me screaming as the bleeding would not stop. He had also cut the back of his mouth. Despite that, my father would not allow me to give my son recombinant Factor VIII and instead told me to give him ice cream and he would be alright. This was absurd at the time as my son was bleeding everywhere. I doubted myself and wondered what I was doing leaving it like that, but my dad was right and, with time, Ryan healed. This demonstrated just how worried my father was about Ryan being exposed to the risk of infection.

39. As Ryan had Haemophilia, my father advised him not to get a physical job and to use his brains instead. He encouraged Ryan to go to university rather than being a labourer as he knew exactly how the Haemophilia would impact him, having lived with the condition himself.

40. Ryan only had my father to guide him – he was someone Ryan could relate to. Amongst my cousins and their children, between all the men, Ryan was the only one to be born with Haemophilia. For that reason, Ryan would always contact my dad and ask for advice. They spoke to each other all the time and he was a fantastic role model and mentor to Ryan. Now Ryan had lost that and is left with a massive hole in him. The hospital has never been enough to guide Ryan and he always trusted my father more than any medical professional.

41. I had to tell Ryan his grandfather had died over the telephone as people had started posting their condolences on social media. I didn't want Ryan to find out that way so I wanted to tell him myself first. Ryan broke down and I do not think he has ever gotten over the death of his grandad. My father will never see Ryan get married; he will never see his great-grandchildren.

42. When my mother and I were clearing out my dad's belongings, I discovered a letter written by my father to my son for his eighteenth birthday. In it, my father described that he did not think he would not live long enough to witness my son turn eighteen. He wrote that he was so proud of my son and was apologetic for passing on such a horrible bleeding disorder. He advised my son not to allow his condition to hinder him, not to let it become his weakness. I am so appreciative that my son has this letter. A copy of the letter is now shown to me marked **WITN3382002.**

43. In terms of work, my boss was very understanding and allowed me to take a few weeks off to deal with my father's funeral. After that I was back to work whilst my mother was left at home alone. I got on with life as well as I could which is something I adopted from my father. He never took time off either,

even if he had a bad bleed. On a number of occasions my father went into hospital for a bad bleed and as soon as he could, he was back to work.

44. My son also has this work ethic. He is a successful manager. As advised by my father, my son does not allow his Haemophilia to get in the way of his life, and my son is doing very well in his life. He is due to purchase his own home with his girlfriend and I am so proud of him for this.

Section 6. Treatment/care/support

45. My mother did not get offered counselling or psychological support in consequence of what happened. I feel she should get counselling now but she would rather talk to me than to a stranger. She feels that I am the only one who understands her.

46. I was not offered any counselling.

47. My son had counselling for a year due to his own anger issues. He lashes out sometimes and gets into fights, much like my father did.

Section 7. Financial Assistance

48. My mother informed me that my father received a lump sum of £20,000 from the Skipton Fund and a further £10,000 a couple of years ago. I do not know the exact dates.

Section 8. Other Issues

49. I do not understand why this had to happen to my father. My father only had mild to moderate Haemophilia, which did not require him to get frequent treatment. My dad was smart and knew he didn't need the blood products; therefore he refused treatment whenever he could. My uncles were not like that; to them, Factor VIII was a godsend and whenever they had bleeds, they would receive Factor VIII, feel instantly better and be able to return to work.

My father would rather use up his holiday leave and recover naturally than use Factor VIII.

50. My son is now 25 years old and was diagnosed with Haemophilia A at birth. He has had a tough time dealing with his Haemophilia. He started a new drug for treatment this year which he takes weekly. In the 1970s the hospital introduced Factor VIII as a new wonder drug, yet it did more harm than good. Who is to say that the same will not happen to Ryan? Once again, Ryan and I have to blindly put my faith in the doctors and take what they recommend on board.

51. Somebody should be held accountable for what happened. People deserve to know who was behind this scandal. Furthermore, the cover up of the issue is unacceptable. I look on the Tainted Blood Facebook page at posts that there were obvious risks in the blood products and feel that people should have been informed of this at the time.

52. If my father went to hospital for a bleed and the hospital said that he could have Factor VIII but there was a risk of infection, my dad would have refused. I understand that this was not possible in emergency situations where the patient required life saving treatment, but where the patient's Haemophilia was mild or moderate, they should have been given the opportunity to provide informed consent.

53. Without the Public Inquiry, I never would have realised the sheer scale of the issue. It was clear that people were lied to. They knew how bad the risks were, but no matter who their patients were - children, the elderly or the vulnerable, they didn't seem to care. As a result families were torn apart. Children were orphaned at a young age, parents lost their children. This could all have been avoided had they not wanted to save costs.

54. More and more people have come forward every year saying that they were impacted by contaminated blood and even today there are people dying from

infections. The Public Inquiry had given people a voice to finally speak about their experiences.

55. I do not believe that this Inquiry is about monetary compensation, but particularly for those infected who are still alive, they should have some form of financial support in order to enjoy the remainder of their lives in peace.

Anonymity

56. I do not wish to remain anonymous and I understand that this statement will be published on the Inquiry website. If called, I am willing to give oral evidence to the Inquiry.

Statement of Truth

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

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

Dated 24/9/19