Witness Name: SUSAN KINGSBURY
Statement No.: WITN0723001
Exhibits: Nil
Dated: 26-03-2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF SUSAN KINGSBURY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 February 2019.

I, SUSAN KINGSBURY, will say as follows: -

Section 1. Introduction

1. My name is SUSAN KINGSBURY. My date of birth is GRO-C 1957 and my address is known to the Inquiry. I was married to Mark Kingsbury for 22 years; I am a mother and a grandmother.

2. I intend to speak of my husband's illness. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

3. Mark was the Managing Director of a successful electrical company. He was a lovely man who was popular with lots of friends, but he was a very private man. We met through work and were married in 1987; we had a son that year too. I have a daughter from a previous marriage. It was in 1987 that Mark told me of his HIV status, both my son and I were tested and found not to be infected.

Section 2. How Affected

4. Mark was born with Haemophilia A; it is a severe form of a bleeding disorder caused by a genetic mutation which does not allow the blood to clot. However, this does not mean that haemophiliacs bleed more profusely than other people, they just don't stop bleeding even with a tiny little cut.

5. Mark's parents found out he was a haemophiliac when he was 18 months old, and was seen by consultants at Royal United Hospitals Bath (RUH Bath).

6. At the age of 3, Mark caught his head on the corner of a table and was taken to RUH Bath. Mark was admitted into care and nearly died that evening from blood on the brain. The consultant advised Mark's parents that he would only live until he was 8 years old.

7. At this point, Mark's parents decided to look for a centre that specialized in haemophilia. After conducting their research, they decided Oxford was the nearest to where they lived, this was the Haemophilia Centre

at the Churchill Hospital in Headington. Mark attended the Oxford Haemophilia Centre for his treatment.

8. Due to Mark's haemophilia, Mark needed plasma transfusions until he reached the age of 10; this is when Factor VIII was produced. Factor VIII is a dried form of plasma that was hailed as a wonder treatment because it only took minutes to infuse into the vein and could be administered at home. Mark told me that life became so much easier as he was able to self-administer, at the age of 11 he said he was the youngest in the country to do so.

9. In 1983, Mark was called to attend an appointment with Dr Matthews of the Oxford Haemophilia Centre. It was at this appointment he was advised he had been infected with HIV from a batch of the Factor VIII products he used. I do not know what information, if any, was given to Mark about his infection.

10. I am unsure if it was at this appointment, but I recall Mark telling me he was advised there was not enough heat treated Factor VIII to treat all haemophiliacs. A decision was made by Dr Rizza, a consultant at Churchill Haemophilia Centre, to give the heat treated Factor VIII to the haemophiliacs with children. This decision was taken without advising those who would be affected.

11. I believe Mark should have been informed he was being given untreated Factor VIII exposing him to the risk of infections. I believe the doctors at the Haemophilia Centre should have been honest about the shortage of Factor VIII and how the decision taken about which haemophiliacs would be given heat treated Factor VIII.

12. Mark seemed perfectly healthy and did not start having any problems until the early-90s; he became fatigued and thrush developed in his mouth and throat. Mark started having infections caused by MRSA, which can only be treated in hospital by transfused antibiotics. At this time, Mark was seen by Dr Christopher Conlon a consultant for infectious diseases at Churchill Hospital.

13. Mark was admitted to the Infectious Diseases ward on many occasions; the worst being an ankle bone infection that would not heal and had to be transferred to Radcliffe Orthopaedic Infirmary for treatment. At this time, Dr Conlon called me to his office to advise me that Mark would likely not live beyond six months as his AZT treatment for HIV was not working.

14. Another hammer blow was dealt when Mark was advised he had been infected with Hepatitis C from the Factor VIII treatment he had received. I cannot recall when or how Mark was informed that he had been infected with Hepatitis C.

15. Mark was infected with HIV, Hepatitis A, Hepatitis B, Hepatitis C and possibly vCJD.

16. Personally, I feel the way Mark was told about his HIV status was at least through a face to face meeting unlike the possible infection from vCJD, which was conveyed to him through a letter! I will never forget the look on his face when he handed the letter to me. I do feel that the nurses at the Churchill Centre were great; they made sure I was immunised against Hepatitis A and Hepatitis B and if needed, they were always available by phone.

17. As I was not with Mark at the time, I cannot comment on what information was given to Mark about living with his infections; I do not recall what information was provided to me. Although, you would have

to live on Mars not to not know something about living with HIV and how you could infect people. We are both fairly intelligent people and had a good understanding of how the infection was passed on. Mark kept it to himself and that is pretty much how it carried on, even when I met him.

18. In 2002, Mark was feeling very ill so I drove him to the Churchill Hospital in Oxford. He was admitted for treatment but seemed very unaware of what was happening. He was given a mental test and during this test Mark pass out and the medical staff could not bring him around; he was sent to Oxford John Radcliffe A&E. It was here we found out his liver was failing due to the HCV; he was in a coma for several days due to the build-up of toxins in his body. Mark was then transferred to Birmingham Queen Elizabeth Hospital under the care of Dr Mutimer, a liver specialist for HIV and HCV; Mark was placed on the liver transplant list.

19. Mark was given a gift of life for 5 more years, although the last 2 years were unfortunately not good. He lived a fair life for 2 years before the Hepatitis C started taking its toll on the transplanted liver. Mark became very ill in 2007 and he never gained back the weight he lost; he was almost skeletal, jaundiced and so very fatigued, but he still had his beautiful smile.

20. Mark died on 8 May 2008 in the Queen Elizabeth Hospital Birmingham due to liver failure caused by Hepatitis C. The doctors tried very hard to save Mark's life using over 50 pints of blood, they could not stem the loss of blood.

Section 3. Other Infections

21. Mark received a letter in September 2004 from Dr GRO-D of the Churchill Haemophilia Centre in Oxford advising that he may have contracted vCJD through an infected batch of Factor VIII between 1980 and 2001.

22. The letter noted that the products were manufactured by the UK Bio Products Laboratory or the Protein Fractionation Centre of the Scottish National Blood Transfusion Service which used plasma pools sourced from the UK. I know this for sure as it is the only letter I have. The letter attached a form that was to be completed if Mark wished to know if he had been infected with vCJD; Mark chose not to know. The effect this letter had on Mark was one of incredulity; I personally thought it was totally insensitive.

Section 4. Consent

23. Mark was tested without his, or his parents' prior knowledge or consent.

24. Mark told me he was treated with untreated Factor VIII without his, or his parents' knowledge, consent and without receiving adequate or full information regarding untreated Factor VIII products.

25. I do not know whether he was treated or tested for the purposes of research.

Section 5. Impact

26. Mark was first diagnosed with Hepatitis A and Hepatitis B followed by HIV and Hepatitis C, he possibly had vCJD. He suffered countless opportunistic infections and the Hepatitis C infection caused Mark to go

into liver failure. In 2003, Mark underwent life-saving liver transplant surgery.

27. Mark began Zidovudine AZT treatment for the HIV. In the mid-90s, Mark was put on a new drug regime called HAART which consisted of 3 drugs, 2 RTI and 1 NRTI. Within 6 months his viral load was lowered and his life in general improved. Mark had been on various HAART therapies including: Abacavir, Lamivudine, Tenofovir, Norvir, Stavudine, Didanosine, Ritonavir, Saquinavir, Nevirapine, Indinavir, Efavirenz, Lansoprazole, Hibiscrub and Oraldene. Mark also started Pegylated Interferon Alfa 2B and Ribavirin treatment to clear the Hepatitis C from his body. It was an awful time for Mark as he became very ill, unfortunately the treatment did not work. To treat the Peripheral Neuropathy, Mark was treated with Gabapentin and Tramadol. Mark was given Tacrolimus and Mycophenolate following his liver transplant.

28. The mental and physical effects of these infections can be described as devastating. I noticed that Mark lost confidence and his ability to concentrate; physically he suffered weight loss due to the HIV drugs which changed the look of his face. Additionally, he suffered from jaundice, hair loss, muscle loss, dry incredibly itchy skin, ulcers, dry mouth, thrush in his mouth and oesophagus, MRSA infections, peripheral neuropathy, pain, ascites, night sweats, severe fatigue, severe diarrhoea, swollen glands, nausea, sore muscles, dark urine, poor appetite, fevers, chills, stomach pain, vomiting blood and opportunistic infections. Furthermore, Mark suffered from depression.

29. Life insurance was not an option as Mark would not attend the medical needed to obtain cover as he thought it would be refused anyway.

30. Mark's infection really started making an impact on his life in the early 90s when he had to attend regular appointments in Oxford to see Dr Conlon as well attending the Haemophilia Centre to pick up Factor VIII and have regular check-ups. As his infection progressed he became very fatigued and was unable to work full time which meant leaving the family business in the hands of company directors, this was difficult for Mark as he felt he was losing touch with what was going on.

31. Mark's HIV status was not known by anyone other than family because of the stigma and reactions of people generally not understanding it.

32. From the late 90s Mark's infection was taking hold of his life as he was in and out of Churchill Hospital being treated for HIV and HCV complications. This time away had a devastating effect on family, as I would accompany Mark it meant that our son, Sean, was left in the care of his grandmother and our friends. Between these appointments and hospital admissions we did have a good circle of friends and a great social life.

33. In 2002, Mark's health took a nose dive. He had been going to work but more often than not, at meetings he would be fatigued and unable to concentrate. When he was at home, he spent most of his time sleeping. Family time was non-existent and our social lives suffered. If it were not for the family business I dread to think how our financial situation would have been; we were lucky in this respect as the business allowed us financial breathing space.

34. In 2003 Mark was admitted to Queen Elizabeth Hospital in Birmingham for a liver transplant. I recall how ill Mark was at this time, He was severely jaundiced, and full of so much water he could hardly lift his feet from the ground. His legs resembled those of an elephant and his stomach was distended. He was so close to death when we received a call informing us of there was a liver available for transplant.

35. With the transplant came a new lease of life for Mark and our family. He was able to return to work with renewed vigour.

36. I think one of the biggest impact's resulting from Mark's infection was on our son Sean, who lost both of his parents at different times throughout the course of Mark's life.

37. Sean was 16 years old when Mark's condition worsened and at the time he was studying for, and sitting exams; I know his school work suffered considering the trauma he experienced in his young life as he watched his Dad struggle and not being able to have the normal 'rough and tumble' boys have with their fathers. This all took a toll on Sean. He spent more time with his best friend's family, but they were happy to have him and to be honest, this made it easier with regards to hospital stays and appointments. I feel like he lost touch with his Dad, but this could not be helped due to Mark's condition. They did become very close 6 months prior to Mark's death and I like to think that they made up for lost time. Sean was working in the family business when it went under; this meant that he also lost what he thought would be his future.

38. My daughter Kelly was living with her father so she was not as affected however, at the time my relationship with her suffered as I was unable to give her the time she deserved. Fortunately, we have a close relationship now.

39. In 2005 Mark decided he could not stand the noise from the traffic outside the house so he wanted to move. We had lived there for 18 years so it came out of the blue but we did move. It was crazy and in hindsight, we should have stayed where we were.

40. For two years Mark was really well but he was suffering from an underlying fatigue. He had lost a lot of weight which he was never able to put it back on and hated looking at himself in a mirror or in a photograph. His illness affected his self-esteem in so many ways.

41. Mark worked within his family business and he was fiercely proud of it. When he was well and able, he worked extremely hard and put his whole self into the business. In the last three years of Marks life he was unable to work full time, he was severely fatigued and unable to concentrate. I recall that Mark would often be found sleeping in his office or he would fall asleep in meetings.

42. The business was going through difficulties which Mark was aware of however, due to his illness he was not fit enough to address these issues. Mark died before the business collapsed and I believe that if Mark had been fit and well, the business would be alive and kicking.

43. We had to make more and more appointments at Queen Elizabeth Hospital in Birmingham. Our family life was again shattered and at this point Sean was spending more time with his girlfriend's family, so we saw little of him.

44. In the last year of his life, Mark was a shadow of himself, however, he always made the best of any situation if he could. He dragged himself into work which was having difficulties; I recall him saying that he felt he had lost control of the company and felt he was not contributing anything. This was a huge frustration for him and added to his sense of isolation. He realised the company was in trouble but did not have the energy or concentration to pull it back, Mark died before the company went under. I believe if he had been fit and well it would still be here.

45. Personally, the impact of this situation was the agony of not being able to do anything about Mark's health other than being there for him,

which I know he appreciated. I pretty much poured my life into caring for Mark, I am sorry to say it was to the detriment of my children, Kelly and Sean. I always went with Mark to his appointments and stayed with him when he was admitted to hospital, this meant that I was away from my children and home many times over approximately 12 years.

46. I gave up work to have Sean, but went back part time for a short period. When Mark's condition worsened, I became his fulltime Carer. Financially we were lucky to have the family business to fall back on. Although towards the end of Mark's life, it was impossible for him to attend to the everyday running of the business and it folded not long after he died.

47. When Mark passed away, I felt incredibly guilty because I had the freedom to do as I pleased. I spent several Christmas days with Mark in the hospital; as I sitting around in hospitals with Mark for so many years I became unfit and gained weight. I was an emotional wreck at times but I had to keep myself together.

48. The worst experience I had with HIV stigma was in 1987, during my pregnancy with Sean. Although I was tested and cleared of HIV, I was given different files with red stickers all over them. When I was admitted to the Princess Anne Wing at RUH Bath, I was put in a separate room with a health warning outside warning people to enter at their own risk due to possible HIV infection! I was not informed that the warning sign was placed outside, people who visited me informed me of this signage. I recall that some of my visitors were not aware of Mark's HIV status and I had to explain the situation. After being informed of the warning sign, I went out and took the sign off my door.

49. Due to the risk of infection, the nurses were unrecognisable as they wore gloves, aprons with masks over their mouths and big glasses covering their eyes. When Sean was born the equipment they were using was faulty, they realised the monitor was not working properly, giving off irregular signals, but they did not change it because of the possible HIV infection risk. I was not HIV+ thought I was made to feel infectious. My treatment by the hospital was unforgivable, I was poorly treated and Sean's birth suffered as a consequence. I have no complaints against the nurses, they said that they were sorry for the excessive measures but that they needed to follow procedure.

50. Due to the faulty monitor, the midwife did not know that Sean was experiencing difficulties, this only became clear when Sean was crowning. The midwife was alarmed; she had difficulty trying to loosen the cord around his neck. When he was born he was a navy blue colour because his cord was wrapped around his neck; he had no pulse but they were able to revive him.

51. Due to regular testing for HIV, I knew I was not infected. This would also have been on my medical records. However, it was made quite clear to me I was not to breastfeed Sean, I ignored this knowing he would be fine.

52. We kept Mark's HIV status to ourselves and family; it was disappointing that one family member decided to tell a friend at our local pub. Our friend told us what happened and he was able to put a lid on it and let us know. We explained the situation and what had happened to Mark and we have always been grateful for his intervention. Fortunately we chose our friends carefully, however you cannot choose your family!

Section 6. Treatment/Care/Support

53. Mark experienced difficulties when seeking dental treatment. He was

treated at the Haemophilia Centre but had to make sure that his appointments were made well in advance, a toothache was not an option.

54. In terms of HIV treatment, when Mark was ever admitted to the Queen Elizabeth Hospital in Birmingham, there was always difficulties getting the necessary HIV drugs; aside from this, Mark did not have issues accessing treatment.

55. Generally, Mark's treatment and care was excellent. There were only a few occasions where this was not the case but this was not related to Mark's HIV status or infections.

56. I have never received any psychological support or counselling; I think it's just a can of worms that is best left.

57. I do not recall whether Mark was offered any psychological support from his treating doctors. Mark became very depressed when he was having difficulty walking and moving around due to a problem with his ankle. I suggested a private counsellor to Mark and he attended about 8 sessions. It definitely helped him through a dark time. When the doctors diagnosed the problem with Mark's ankle his mood lifted. It was an MRSA bone infection which took months to heal as they had to open the skin around his ankle and scrape the bone clear and leave the wound open to heal from the inside out with a seaweed dressing, with of course intravenous antibiotics. Mark was generally an optimist but there were definitely times when a counsellor would have been helpful.

Section 7. Financial Assistance

58. I recall that Mark had a Disability Living Allowance that he had to apply for; I cannot recall how long he was receiving this entitlement.

59. I cannot recall exact details but Mark received £60,000 from either the Terence Higgins Trust or the MacFarlane Trust. I cannot recall the application process but I do believe that Mark signed a waiver stating that the £60,000 was a full and final payment. Regardless, no amount of money can ever cover what Mark went through nor can it bring him back.

60. In approximately 2014, I received £45,000 in 2 payments from the Skipton Fund. I spoke to someone about the Fund over the phone and applied online; I had heard about the payments on a radio programme. I do not recall there being a delay in receiving any payments.

61. I did not have any dealings with any other fund or trust.

Statement of Truth

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

Signed GRO-C

Dated 26 - 03 - 2019