13 MAR 2019

Witness Name: Lynne Gane
Statement No.: WITN0055/001
Exhibits: **WITN0055/002-006**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LYNNE GANE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7th January 2019.

I, Lynne Gane, will say as follows: -

Section 1. Introduction

1. My name is Lynne Gane. My date of birth is GRO-C 1957. My address is known to the Inquiry. I am a widow and I retired in 2014. I live on my own and have two children.

2. I intend to speak about my late husband, Jeffrey Nigel Gane, and his infection with the Hepatitis C Virus ("HCV"), which he contracted as result of being given a contaminated blood transfusion. In particular, I intend to discuss the nature of his illness, how the illness affected him and the impact it had on him, our family and our lives together.

Section 2. How Affected

3. Jeff was born on GRO-C 1955. He had Congenital Renal Dysplasia. As a child in severe and ultimately end stage renal failure, Jeff began haemodialysis at age 13. At the time of commencing dialysis, in 1969, very few children had received such treatment. As a result, the training regimes were very strict and the consequences of long-term dialysis on young developing bodies were not fully understood.

4. Jeff adapted to dialysis well and continued his education. He wanted to take up a career in the NHS and qualified as a nuclear medicine technician and radiographer. He was eventually promoted to Superintendent Radiographer in Nuclear Medicine at St George's Hospital in Tooting and ran that department for 24 years (1981-2005).

5. Towards his late twenties, Jeff's bone density results showed that the long-term dialysis was leading to severe bone demineralisation. The prognosis was that should he continue to dialyse he would likely need a wheelchair in the not too distant future.

6. Jeff had been reluctant to go on the kidney transplant programme. As a medical professional, he had a lot of knowledge of transplantations and the failures. He felt that medical science in this area was still developing and there were some very real risks to having a number of unsuccessful transplants.

7. However, his condition and prognosis meant eventually, that he had to consider putting himself on the transplant programme. To prepare for this, he was given two blood transfusions to boost his haemoglobin levels. This was at the suggestion of a friend and colleague who was a renal transplant surgeon at St George's Hospital.

8. These two blood transfusions took place at Dulwich Hospital around late 1985 to early 1986. We believe that it was as a result of receiving

contaminated blood in these two blood transfusions that Jeff was infected with the HCV virus.

9. I am not aware of any advice that was given to Jeff about the possibility of being exposed to infection as a result of these transfusions. I am certain that had he been given such advice that he would not have had the transfusions.

10. Jeff went on to receive a renal transplant on 31st March 1986 at the Royal Free Hospital in Hampstead. After a few settling in issues, the transplant worked brilliantly, until the effects of his acquired HCV began to work against this in around 2003/2004.

11. As Superintendent of Nuclear Medicine at St George's Hospital, Jeff was subject to routine health screening. It was at one such screening that it was discovered that Jeff was carrying the HCV. I cannot say precisely when he became aware of his condition because he didn't tell me at the time. I believe it to have been in 1996. His notes indicate a diagnosis of chronic HCV on 13th June 1996. He later told me of the diagnosis in 1998.

12. I cannot say what information was provided to Jeff. He saw the renal consultant Dr Susan Snowden at St George's Hospital and she may well have provided him with information. As a hospital employee, I am sure that he will have been referred to a haematologist at St George's Hospital and they would have been candid in their patient information as Jeff would have been aware of where to find this information.

13. I was given very limited information about the condition. In 1998, when Jeff told me about it, the HCV was not active. He said that the prognosis was that within a 20-year period, the carrier of HCV would develop either liver cancer or cirrhosis of the liver and liver failure.

14. I cannot say what information Jeff received to manage his condition. He asked for no special provisions around his diet but did stop drinking alcohol. No information was made available to him post-transfusion about the possibility of infection and he was not encouraged to be tested. This is clear as he only found out he was infected by routine health screening at his hospital.

Section 3. Other Infections

15. Very shortly before he died, Jeff was infected with Staphylococcus Aureus, which lead to Sepsis. After his death, I raised the possibility with his renal consultant, Dr Nelson, that he may have been infected by the blood transfusion that he received on 23rd March 2005 **[WITN0055/002]**. Dr Nelson's reply was that it was impossible to say from where this infection originated **[WITN0055/003]**. But as a long-standing medical practioner and dialysis patient, Jeff was very aware of Sepsis and took steps to avoid it. The fact that he ended up with it was therefore very puzzling.

16. Other than the above, I do not believe that as a result of being given infected blood products, that Jeff contracted any infection other than the HCV. I assume that while testing him for HCV or during other blood tests or health screenings, he was at some point tested for HIV and the results were negative.

17. I have never been tested for HCV or HIV. From his own medical knowledge, Jeff judged that it was unlikely that I would be infected with the HCV as a result of him being a carrier.

Section 4. Consent

18. I believe that Jeff was treated with his consent and knowledge. However, I do consider that information about the risks of infection posed by receiving blood transfusions was not given to Jeff, despite

the authorities clearly knowing there were considerable risks involved at the time he had his transfusions. I am sure that he would not have had the transfusions had he known that they posed a risk of HCV infection.

Section 5. Impact

19. For his family, Jeff put on an optimistic façade, saying that although unpleasant, there were treatments possible for the condition. However, in reality, he was profoundly affected by his diagnosis of HCV and his mental health suffered dramatically.

20. By 2002, the 17 years of dialysis and bone deterioration had caught up with Jeff and he had developed Rheumatoid Arthritis. In late 2002, his hip collapsed at work. His right femur had necrosed and worn through the hip socket. Jeff had been in considerable pain for some time but typically fought through it and continued to work. Without a hip replacement, he would very quickly become a wheelchair user. However, he had deep concerns that having a hip replacement would trigger the HCV into activity. The choices he faced were stark. On 21st February 2003, he received a hip replacement. It worked very well and improved his mobility greatly. However, he was still affected by and medicated for the Rheumatoid Arthritis.

21. I have a letter from Dr Snowden dated 24th April 2003 in which she provides some details regarding how Jeff was feeling at that time **[WITN0055/004]**. It notes that he was feeling cold, that he had dry, irritating skin and had felt excessively tired for the previous six months. By this point, Jeff had also lost a great deal of weight.

22. We believe that after the hip operation the HCV did appear to worsen and by late 2003 it was clear that his health was deteriorating. By 2004, it was clear his liver function was compromised and he suffered with an enlarged and hard, painful liver. His haemoglobin was low and

he was very pale. By September 2004, his liver failure was profoundly affecting his health and pallor. He had a negligible appetite and very poor energy.

23. On 9th November 2004, Jeff was seen by Dr Tibbs, a consultant haematologist at St George's Hospital. In a letter dated 13th December 2004, Dr Tibbs outlined the findings of a previous liver biopsy, which showed a lot of fat and fibrosis. He believed that Jeff might have developed cirrhosis since last being seen **[WITN0055/005]**. Dr Tibbs also noted that Jeff's transplanted kidney function was declining quite rapidly. Since the transplanted organ had been very good up until HCV took hold, I am in no doubt that HCV was the cause of its demise.

24. Despite all of this, Jeff continued to work, making the daily 100-mile round trip to St George's Hospital from our home in Kent. He persisted working until January 2005, when his kidney failure meant that he had to stop work to go on dialysis. He was dialysed at St George's Hospital.

25. Although dialysis was a well-trodden road for Jeff, and he would put a brave face on, mentally he was in a low place and he was by then anticipating death. He had made his wishes known to me and had asked friends to keep an eye on our family and me. He had given me details of support offered to widows and family of NHS employees.

26. He was seen regularly by the medical team at St George's for his HCV but did not receive any treatment for the virus. My understanding was that if he were treated for HCV, this would hasten the end of the kidney, so the medical team's plan was to wait for kidney to fail, followed by a period of adjustment to dialysis, before starting the interferon treatment for the HCV. Jeff had an appointment booked and was due to begin treatment four days after his eventual date of death.

27. On or before 23rd March 2005, Jeff contracted a Staphylococcal Aureus infection, which lead to Sepsis. He was very ill and asked to come home. In his letter to me, Dr Nelson says that the hospital were reluctant to let Jeff go home, but that he strongly expressed his desire to go on leave until his next scheduled dialysis. I believe Jeff was firm in expressing his desire to go home because he wished to die at home.

28. On the morning of 25th March 2005, I found Jeff unresponsive and semi-conscious. I called the emergency services and Jeff was admitted to the Intensive Care Unit at Kent and Sussex Hospital. He was placed in an induced state of unconsciousness and was treated for the sepsis. Despite this, Jeff's condition deteriorated and on 28th March 2005, I was asked for permission to end Jeff's life support. Jeff had been very clear in his wishes that life support should not be continued in such a circumstance. Jeff's death certificate records the causes of death as; multi-organ failure, sepsis, chronic renal failure and HCV **[WITN0055/006]**.

29. I have been asked about the mental and physical effects of Jeff's infection with the HCV. Around the time that Jeff learnt of the infection, he became uncharacteristically angry, depressed and withdrawn. He had always been clear that his medical problems should not be a source of pity for him from his family, rather they were his problems alone and he fought to have a normal life. So it was not out of character for him to not want to burden us with the knowledge of his infection.

30. Around the same time as Jeff learnt of his HCV infection, our first son was born. Further, my mother had a GRO-C and required lots of my support, and our daughter was in GRO-C awaiting a GRO-C. Given all this was going on at the time, I was at the end of my tether. There was only so much I could physically cope with

so I can understand why Jeff choose not to tell me about the HCV when he found out.

31. While dealing with the infection, Jeff struggled with his relationship with our daughter. He became quite distant and despite no provocation of her part, he was often unreasonably angry with her. He became increasingly withdrawn from family life and rarely laughed or smiled towards the end of his life. He did not want to see friends or extended family. He did not want to socialise with anyone. He didn't want anyone to see him as he had become. As a result, if I wanted to meet friends, I would meet them away from home.

32. Our personal relationship became strained by the burden of him knowing about the HCV but not telling me. He withdrew internally and our relationship changed. We didn't argue but in 1998, I said to him: "I can tell you have an intolerable burden, you have to tell me what it is because it's destroying you, it's destroying us and I don't want that". I think it was a huge relief for him when he told me. My response was that we just have to fight through this and I tried to support him as best as I could.

33. I felt that Jeff had contemplated suicide, as he would have hated a slow decline into a painful oblivion. He had taken out life insurance and his driving became erratic and frankly dangerous. I think he had contemplated having an accident to give us some life insurance money. I can't imagine why else he would have taken out the life insurance policy.

34. I believe that the disease greatly impacted Jeff's mental health and the quality of our family life together. The HCV robbed us of the original, funny and loving person we had known before the infection.

35. Regarding the physical effects of the HCV, Jeff felt excessively tired and suffered with severe skin irritation and a loss of appetite, all of

which I understand are common symptoms of HCV. From 2001, Jeff's mobility declined dramatically until his right hip collapsed. It is difficult for me to say whether the developing HCV contributed to the increasing symptoms of Rheumatoid Arthritis and pain but it is clear that that as a result of the HCV, his body was compromised in its ability to fight inflammation and disease. Following his hip replacement, Jeff's mobility did improve but his health declined in other ways. He suffered with severe weight loss, hair loss and a poor appetite. By 2004, he had lost 10kg and was just skin and bones. This made it difficult for him to make the journey to work and by the weekend he was exhausted and unable to do anything.

36. I have touched on many aspects of our family life that were affected as a result of Jeff's infection with the HCV. Our relations were profoundly affected. It was as if a light had gone out and the joy of living with him had gone. He tried to carry on but interacted with his family less and less as the disease progressed. I think perhaps he thought if he withdrew it would hurt less when he was gone.

37. The illness impacted me in that I increasingly had to do everything around the house and with the children. Jeff became less and less able to help around the house with decorating, gardening and dealing with admin. As I worked from home at the time, doing part-time work in adult education, I was just about able to cope.

38. Emotionally I felt that Jeff became unreachable and I felt isolated, like I had lost my best friend. We never crossed-words and we got along but a shutter had come down over Jeff.

39. I had worked from home since the birth of our daughter because of GRO-C. It is hard to care for a child with a GRO-C GRO-C and have employed work all at the same time. Most employers

cannot tolerate such regular absence and it is not fair to the children concerned.

40. In May 2004, Jeff asked me to seek full-time work as he felt the family would need my stable income and that he may not be able to work for much longer. Around the same time, my daughter was 16, had had GRO-C and was becoming pretty independent. I was able to get a teaching job at a secondary school. I found this time very tough with Jeff's condition and the difficult working conditions I faced. Teaching was a very demanding job as every weekend and evening I was preparing lesson plans for the next day.

41. I had returned to work to support my husband and my family. Jeff died less than a year later and I was then the main source of income for the family. I had to hold my family together during the very difficult period following his death; dealing with the bereavement administration at the same time as holding down a full-time demanding job.

42. My daughter is fortunate to have had GRO-C, after a period of approximately GRO-C. But as a widow in support of my GRO-C, I had to move our family to London so that she could be nearer the GRO-C and have a degree of independence. To achieve this, I had to change jobs, purchase a property and change my son's school, all of which was difficult emotionally, physically and financially. Had Jeff been with us at this time, we would have been able to handle this very differently and not had to move. It was very emotionally difficult for us to move out of our family home that we had lived in for so long.

43. The impact on both our children has been very profound. Both have GRO-C, some of which I have paid for. My daughter was in the lower sixth form year at school at the time of Jeff's death and found herself feeling isolated because her friends

could not know what it was like to lose a father. I know that her classmates stopped talking to her and she chose to change class because it became so disturbing to her. I don't think she received any help though school, although it may have been offered to her.

44. The difficulties she experienced in her relationship with her father, as a result of his infection with the HCV, still trouble her with feelings of insecurity and not being good enough. To her credit she has made tremendous achievements in her personal and professional life and is a talented writer.

45. My son was in junior school, aged 9, at the time of Jeff's death. His relationship with his father was good but distant, interspersed with bouts when Jeff would shout at him. My son was a typical naughty boy sometimes but he absolutely hated being shouted at and would become very emotional. Jeff wasn't like that before the HCV, he adored his son so it was very out of character. He found it difficult to understand why the hospital had not made his Dad better and was angry for a long time.

46. My son has found schooling very difficult following his father's death, not least because of a persistent level of bullying. He retreated into a world of gaming and fantasy as a means of both escape and communicating with the world. He has tried a few college courses but he has struggled with interactions and work, both because of his GRO-C, morale and confidence. I am still encouraging, helping and financially supporting him at 23.

Section 6. Treatment/Care/Support

47. As an employee of St George's Hospital, Jeff was able to see the appropriate consultants in a timely manner. His renal transplant complicated his condition and therefore treatment for the HCV was not started earlier. Had treatment been started earlier, it would have

caused the failure of the kidney. However, I believe that, had the treatment been started earlier, the liver disease would not have progressed as far as it did and that the chances of successful treatment would have been greater. I believe that by waiting for the kidney to fail and allowing the liver disease to become acute, Jeff's health significantly deteriorated as a result, which contributed in greater part to his death. By the end, his body was so compromised that he had no reserves to fight any infection, especially sepsis.

48. Jeff's HCV status whilst at work at St George's Hospital did not stop him dealing with patients. All nuclear medicine procedures required precautions for sterile handling. Jeff was allowed to attend the school of dentistry at St George's Hospital where they where they were able to cope with his HCV during dental treatment. Appropriate procedures and precautions were also taken at the dialysis clinic that Jeff attended at St George's.

49. Jeff suffered with depression after he found out about the HCV. I could see it in how he withdrew. It got to the point where I said that he should get counselling. I believe that he did, although he never confirmed this.

50. I have received counselling when I felt so overwhelmed by the many things I faced and Jeff seemed so distant. I did not receive any counselling at the time of his death although I could have done so.

Section 7. Financial Assistance

51. Jeff applied for and received two payments from the Skipton Fund. The first of the payments was for £20,000, which he received in late 2004. The second payment was for £25,000, which he received in early 2005 when the disease was seriously affecting him.

52. Correspondence between Jeff and the Skipton Fund confirms that Jeff registered his details with the fund in May 2004 and then completed the application form when it became available to him.

53. I believe that Jeff became aware of the fund through his hospital colleagues. He was able to provide the qualifying evidence from his consultant's statement and faced no particular obstacle in the application process. I don't think that there were any preconditions imposed on the application or the grant.

54. I know that Jeff felt that he must apply for the funds from the Skipton Fund because it was very unlikely that he would live long enough to see any other financial help or a public inquiry into what and how this had happened.

55. As helpful as the funds have been, they are a very poor recompense for a life taken far too young. There was every reason to believe that Jeff should have been able to continue to support his family until his retirement at 66. He died aged 49. The Skipton Funds equate to less than 18 months of his salary back in 2005.

56. Given that NHS and government officials knew that blood products carried a risk of infection before 1985, when Jeff received his transfusion, it is unacceptable that they did not acknowledge what happened until some considerable time later and only set up the Skipton Fund in 2004. It is with regret that, as a supporter of the NHS, I hold this service and the government completely culpable for Jeff's death.

57. I feel that the while the financial support offered by the Skipton Fund has helped those still alive; it has done nothing for those who have already died as a result of infected blood products. It was a calculated damage limitation exercise to which those still alive felt they had no choice but to accept. It has not compensated those who have died

and those who have lost a loved one for the psychological trauma, emotional turmoil and financial hardship they have suffered.

58. I have not received any help from any other funds or trusts set up to distribute compensation. I am not aware of any such funds.

Section 8. Other Issues

59. I have a question that my daughter, as a GRO-C asked: GRO-C

60. When we receive medical products from another living organism, how can we be sure that what we will receive will not harm us? What ethical, medical and moral safeguards do we have in place for the future to protect our patients from the practical and financial pressure that led to blood products being taken from such compromised sources as prison inmates? Will we continue to take blood from people who have been paid for it? What screening processes have or should be put in place?

61. How, in the future, will the NHS and the government change the way it reacts in the face of its own responsibility for such disastrous health outcomes? Will there be a permanent independent review body to oversee the work of the NHS, in the same way this inquiry is doing. We cannot rely on the NHS and the government to provide self-governance. The inconvenient truths of the infected blood scandal have been ignored, covered up and, some might say, cynically delayed.

62. I believe that those infected and affected by infected blood products deserve a much better outcome that they have received to date, one that truly and realistically reflects the harm done to them at the hands of a service they put their trust in.

63. I speak on behalf of my husband and my family. Had he survived, my husband would certainly have given his evidence. The saddest thing is that my husband was saved by dialysis and devoted his working life of over 30 years to the NHS, working alongside colleagues to develop new tests in nuclear medicine for investigations into cancer diagnosis. His last words to me were "this is so unfair". To me, it is criminal negligence.

Statement of Truth

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

Signed GRO-C

Dated 11th March 2019