Witness Statement

Name: KENNETH GRAY

No.: WITN00491002

Exhibits: **WITN00491xxx**

Dated: 29 October 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF KENNETH GRAY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 October 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, KENNETH GRAY, will say as follows: -

Introduction

1. My name is Kenneth Gray. My date of birth is 19th February 1952. My address is known to the Inquiry. I am a widower with four grown up children: three sons and one daughter, as well as grandchildren.

1.1. I intend to speak about my wife, Sandra Gray, her infection with Hepatitis C and the devastating effect it had on her health and our lives together. Additionally, I will discuss how her illness and subsequent death has affected me.

1.2. I initially made contact with the Inquiry at the hearings earlier on this year where I spoke to a lady called Catherine, to hopefully progress my involvement and tell my story relating to my wife, who passed away on 25 May 2017.

1.3. From the outset, I should mention that about 10 years ago I had a minor stroke, which lead to me suffering some brain damage. This affected movement down my right side but more importantly, makes it difficult for me to remember dates. They are difficult to recollect, including dates such as birthdays etc. However, I am very much able to recall *events* accurately, but datelines become quite difficult, in recollecting chronology issues.

1.4. I am not represented by a solicitor in terms of representation regarding financial matters or other issues, including the inquiry, with the exception of Solicitors Leigh Day, who are assisting me in trying to obtain my wife's medical records. I have not sought medical records from my GP's surgery. I am content for the inquiry team investigators to take my statement. I am content for the Inquiry to approach Skipton to disclose my information to the inquiry.

1.5. Throughout Sandra's illness, which occurred as a result of a blood transfusion at Frimley Park hospital in Surrey, she suffered numerous bouts of Hepatitis C (HCV) related illnesses. She was treated at a number of hospitals, the names of which I will attempt to recall later in my statement.

1.6. I currently live in Chichester having moved here from Hampshire due to financial issues, which were brought about by the effect of Sandra's illnesses. Her medical condition has had a big impact on family life and I had to give up work as a landscape gardener to become her carer, as she needed full time care. This has had a significant impact upon the family finances, which has meant I have had to downsize the large family house to a bungalow.

1.7. Also, I had to give up working and prematurely cash in my pension, for which I had to pay a penalty, i.e. tax owed to the revenue (HMRC). The pension had been earmarked to address mortgage payments.

1.8. Additionally, substantial amounts of money have been outlaid to make necessary building adjustments/improvements to cater for my wife's disabilities. I estimate that over the years in pure financial terms, I have spent something in the region of £500,000. This is a conservative estimate and could actually be a greater sum; it is really difficult to arrive at definitive sum.

1.9. I would also like to say that I have raised the infected blood problem with a number of Members of Parliament, where I have sought their assistance and raised awareness of the issue. During these contacts I have complained about the level of compensation. One MP, James Arbuthnot said *"I can't believe this is true, is it true?"* the current sitting MP, a lady is good and has done a bit for me. However other MPs I have met with have been less than helpful. I feel that this very important issue has been suppressed/ignored by Parliament, with them providing written answers to questions raised by MPs. There has not been proper debate and engagement in this subject matter.

How Affected

2. I am in contact with the Infected Blood Inquiry as a consequence of my wife Sandra Gray being infected whilst giving birth to our first born son in 1979 at Frimley Park Hospital in Surrey. The problems started at this time. Childbirth was difficult and Sandra lost a lot of blood during the birth: she was suffering from anaemia and was given 2 x units of (infected) blood. She told me

that she hadn't given permission for this to occur. I am unsure of the precise day; it may have been the day of the birth or the next day, and it is, after all nearly 40 years ago.

2.1. My wife was infected with Hepatitis C. (HCV) believed to be Genotype 1.

2.2. I do not know the name of the product used

2.3. My wife did not attend a Haemophilia centre.

2.4. At present, I have no access to my wife's' medical records but through Leigh Day Solicitors, I hope to acquire them at which point more information may become available.

2.5. What I am aware of is, that my wife told me she did not give permission for the blood transfusion as she talked to me regarding this, however I have been informed, that the medical records apparently show that she did.

2.6. Information provided much later on when at a second opinion at University College hospital (UCH) London, diagnosed Hepatitis C. Also later information provided by Professor Aftab Allah (Frimley Park hospital) around transplant statistics and survival rates.

2.7. I have found there to be resistance to open, honest and transparent information. To give an example, when we found out about (by accident) the Skipton compensation scheme, they insisted we prove that Sandra had been infected by blood transfusion, as their enquiries suggested this was not the case as the notes were not marked up. We approached our GP who told us they had been destroyed/ no longer had them, so we were unable to progress our claim.

2.8. I attended the surgery on an unrelated matter and spoke to a temporary locum (Australian lady) who made some enquiries and found the notes were on Microfiche and she made a copy for us. Without this stroke of fortune we would have been hard pressed to advance our claim. I do believe that there is some covering up of errors by the whole medical system.

2.9. I think there should have been a properly backed government/NHS campaign to educate people affected as well as the country as a whole, as this a significant problem which potentially affect anyone who required a blood transfusion, for whatever reason.

2.10. On a personal level I wasn't provided any support or signposting to organisations to help me and at this point in time I have not been given the opportunity to participate in any counselling sessions, or have any other contact with a trained professional. The investigators have today, provided me with details of the British Red Cross who are aware of the Inquiry and are providing counselling support. However I am aware of a local organisation St. Wilfred's hospice are offering counselling and I will consider taking this up in the future.

2.11. We were provided with the test results at a second opinion, at UCH London, but it had taken ages for this diagnosis to be identified. When we were referred to the consultant Dr. Ramage he used strange words to the effect of *"We don't expect this sort of thing in Hampshire."* His inability to consider such things, I believe, caused a delay in the diagnosis. I would also say his bedside manner was lacking consideration and empathy.

2.12. The children and myself have been tested for Hepatitis C and we are all clear.

Other Infections

3. Due to Sandra's poor immune system (which was caused by the side effects of Hepatitis C, she suffered various medical problems, including Diabetes, Encephalitis and problems with her spine and neck. Whilst Sandra was not infected with HIV, I only found out that she was clear by

accident, whilst engaging in general conversations with doctors. Whilst relieved to receive this news, it was not what I would call a good communication style by health professionals. I was not even aware that they were testing her for HIV.

Consent

4. My understanding is that my wife was anaemic directly after or during childbirth and was given two units of blood. She told me she had not consented to the blood transfusion.

4.1. As far as I am aware, no information was given prior to Sandra receiving her transfusion.

4.2. I am not aware of any suggestion that my wife was tested for the purposes of research.

Impact

5. My wife was given Hepatitis C via infected blood. The virus ruined her life and her lifestyle changed dramatically. She was confined to the back bedroom of our house; she rarely went out other than to go to hospital and our social life ceased. We felt very isolated, having moved to an unfamiliar area and constantly dealing with the illness, in addition to the financial pressure. Our family life was non-existent as we were always in hospital. I frequently had to travel long distances and spend considerable time on trains. We spent 3 Christmases in hospitals; there were no holidays. I gave up alcohol and I am now teetotal. My wife was the matriarch of the family and all that just disappeared, our whole life was turned upside down. This did not just affect us as a couple, it also impacted on the family as a whole.

5.1. There was a stigma attached to the disease and we didn't feel like we could share with friends until much later. As a family, we kept a lid on the medical issues because we felt embarrassed about the whole situation. However as my wife became more ill, I had no option but to tell people about the infected blood situation and what had happened to us. I took this as an opportunity to make people aware of the situation and educate people. The family as a whole feel very cheated by the events; my middle son is extremely angry at the establishment regarding this set of events. Personally I would like to see someone in the dock, this would be justice, but I don't believe this will happen.

5.2. As previously discussed, the Hepatitis C affected Sandra with other medical conditions including Diabetes, Encephalitis, and the amputation of her big toe.

5.3. The illness resulted in Sandra necessitating a liver transplant, which occurred at the Royal Free hospital. She survived for four years but spent some 3.5 of these years in various hospitals.

5.4. Sandra was fine for about 10-15 years after the transfusion (possibly the late 80s) and then it all began to change. She became ill, listless and had to go back and forth to her GP in Hampshire. After 12 months, a blood test was carried out which revealed a liver issue. She was referred to a Liver Consultant., I can recall he was called Dr. Ramage. Throughout our contact with him (about half a dozen visits) I would describe his care as scratching his head, unable to ascertain what was wrong, and yielding no results. We revisited the GP and secured a second opinion, which is when Sandra was referred to University College Hospital, (UCH) London.

5.5. Within half an hour of our appointment at UCH, tests confirmed Sandra had Hepatitis C. I still can't understand why there had been such a delay in diagnosis previously. Consequently we re-attended the GP surgery and in turn were referred back to the Liver Consultant.

5.6. During a consultation and when discussing the findings of Sandra's, Hepatitis C, the consultant said words to the effect of "*We don't expect this sort of thing in Hampshire*." I was very upset and disappointed by such comments and relationships with him, went downhill from that point.

5.7. There was a drug on the market called Beta Interferon but according to the consultant, it was expensive. I think it would cost somewhere in the region of about a £1000 per month. He agreed to fund this treatment for 6 months, but after 3 months he stopped the treatment commenting on the levels of viral load not being worth it. I was very unhappy about this.

5.8. There was a break in this treatment and I continued to fight and campaign to get Sandra the other 3 months of treatment, which I eventually achieved. From my perspective, this was a financial decision by Dr Ramage and had he continued the treatment for a continuous period, I believe the results would have improved. In my opinion the consultant caused significant expense within the NHS across a number of hospitals, which had to treat her on numerous occasions at different hospitals.

5.9. Gradually over a year, Sandra got progressively worse and we were referred to a Professor at Frimley Park Hospital regarding the possibility of a transplant of the liver. He was a pleasant enough chap, who explained that life would go into decline. As Sandra got worse, visits increased and we were given explanations about the effects of the disease and explanation of the transplant circumstances/issues, including projected percentages of survival/death/recovery rates. He explained that this was a risky operation and one had to be virtually terminally ill to be considered for the operation.

5.10. I should mention that our niece, Sonia Kaufman, née Buxton, was married to Gerald Kaufman. He was an important man in the pharmaceutical industry in the USA and had significant contact/ links to the blood industry. Sonia offered to pay for a transplant in the USA; we would have to pay for the hospital, but he (Kaufman) would pay for the transplant (approximately- $100,000) however we were informed by the consultant that the NHS would not pay for the required aftercare drugs for transplant surgery carried out in the USA. I always wondered if Gerald felt guilty that a member of his family had been affected and that's why he offered to pay for the transplant.

5.11. Eventually my wife was considered to be terminally ill, and the transplant was given the go ahead. She was transported via ambulance on blues and twos to the Royal Free Hospital, London. The start was delayed as the liver arrived late. There were further complications during the transplant, which would normally take about 4 to 6 hours. It in fact lasted all day. Her bile duct was damaged and there were problems with the liver. A new bile duct was created out of stomach lining. I felt she was very ill; the Hepatitis C had contributed to developing Diabetes (type 1- self injecting).

5.12. I would like to mention that pre-transplant, my wife suffered from fluid retention. Her size ballooned from a size 16 to 26, which required over 30 litres of fluid to be removed by drain. It was at this stage that it was assumed she was an alcoholic. The cost of her clothing was bad as she kept blowing up. The strain on our relationship was considerable as she considered herself to be ugly and the effect on our love life cannot be overstated. Then Post-transplant she became incontinent and had to wear bulky pads, which she hated. The last four years were particularly bad as she was hospitalised so much, that our love life became non-existent.

5.13. At one stage she felt so bad she asked me to leave her, which of course I wouldn't do. The dignity issues were quite a strain upon both of us.

5.14. The liver transplant undertaken at the Royal Free Hospital, Hampstead London gave us another 4 years, but in all probability she spent 3.5 years in various hospitals. After her transplant, her Diabetes did improve for a while and at one point she was no longer self-injecting. As a result of the transplant the pancreas began working and produced insulin, she had other medical problems such as osteoporosis and spontaneous fractures of the spine.

5.15. I want to comment on the Liver ward/hospital at the Royal Free. This ward consisted mostly of alcoholics who had only one interest, of popping out next door to the shop to get their alcohol whilst still attached to their drips. The whole hospital was dirty and on occasions I saw human excrement on the floor. The standard of care was appalling with terrible treatment of loved ones. It was disgusting.

5.16. Sandra's window was absolutely filthy, in fact I wrote "Dirty" on the window with my finger. There were occasions when the bed got soiled and she was left lying in it, on another occasions when it happened a member of staff just placed a pad underneath, instead of properly cleaning the bed and providing clean sheets. As she was in an alcoholic's ward, she was treated as an alcoholic and not according to her needs.

5.17. I remember on one occasion on the ward two nurses were having a conversation and one openly commented about Sandra, "*You have to put gloves on, she has got Hepatitis C.*" I was very upset by this and strongly put them straight on the transfer issues of the disease and I expressed that I could hold and kiss my wife without contracting the disease. There was a great deal of ignorance around the disease. I was disappointed with their lack of knowledge regarding the subject.

5.18. I have mentioned that my wife was suffering from other medical issues such as spontaneous fractures of the spine. We owned a caravan in the New Forest and on one occasion whilst we were visiting she was adjusting a hoodie around her head, when she began screaming clearly in severe pain. She had fractured her neck. We had to call an ambulance and the fire brigade to get her into the ambulance and eventually she was taken to Oddstock hospital in Salisbury.

5.19. I would also like to mention that Sandra had spinal surgery at Southampton general hospital. She suffered from Oesteomylasia, she had cement injected into broken discs. This operation worked for a few years, but eventually broke down after a few years.

Consequences of the Liver transplant

5.20. I think to a degree they ballsed up the operation. Sandra developed bedsores whilst at the Royal Free, I had to turn her quite regularly, but I wasn't there all the time, so I believe the attention of nursing care fell short of the expected standard. After the operation, she was in a bed with tilt action. As a result of the surgeon cutting through her nerves she had no feeling in her left leg and she developed a sore on her big toe. This became worse over a period of time. At some point she knocked it and it became gangrenous. They removed the top half of her toe, though this failed to work and address the medical risk and they had to then remove the whole of the toe. The meant she had difficulty in balancing.

5.21. Every time she went into hospital I would always ask for a side room. She was prone to picking up infections, colds and pneumonia, due to her body being immune suppressed. On one occasion at St Richard's Hospital Chichester, I again asked for a side room but due to an outbreak of Norovirus, we were put back. I was constantly seeking the best care for my wife but frequently we were let down.

5.22. During all the times my wife was in various hospitals and especially in London, I always travelled up to see her on a near daily basis. I spent so much time on trains and at hospitals that by the time I got back home, it would be sometimes be 1am. There is also a financial implication for people with short resources. The travelling cost to me was financially crippling, but I had no choice, I had to support my wife.

5.23. Only to reiterate, I had to fight and campaign for a considerable time to have the unused three months of beta interferon reinstated, this was a frustrating time.

5.24. There were many occasions where through no fault of her own Sandra soiled the bed, carpets and converted wet room. She would always be mortified by what had happened and severely embarrassed and would break down crying. The mental and physical impact on both of us was immense.

Treatment/Care/Support

6. Living with this terrible illness and seeing the impact on my wife in particular and on the wider family in general has taken a severe toll on my mental and physical wellbeing. For the last ten years I have suffered from depression. I have not sought treatment and believe I now can manage the problems. I have discussed it with my GP and have been offered tablets, which I declined.

6.1. When we realised the inevitable would happen, we wanted to bring my wife home. The hospital advised us against this and we had to fight to bring her home. We knew what was best for her, to be with her loved ones. Once we arrived back we had various help such as MacMillan nurses come to the house to visit her in the back bedroom, which was set up like a hospital. I remember a nurse who had significant nursing experience and had once held a very high grade position in a hospital who on occasions represented hospitals and patients in litigation, regarding bed sores, (which Sandra had suffered with). His opinion was that all bed sores are preventable.

6.2. Given all the circumstances and considering the effects on our family, I would like to say that I was naïve enough to believe that, as the NHS caused the problem they would have bent over backwards to prioritise her treatment. The opposite of this happened almost an embarrassment to be brushed aside and kept waiting at every given opportunity.

Financial Assistance

7. I found out about the Skipton scheme having caught the tail end of a programme/advert on the radio, which was setting up this scheme for compensation of those affected by the infected blood. We applied, completed all the paperwork and sent it off. After three months of waiting and hearing nothing, we contacted them to ascertain what the current position was. They acknowledged receiving our paperwork, but there was a problem in establishing that she had received a blood transfusion as apparently my wife's medical notes were not marked up.

7.1. Skipton were unwilling to process the claim and essentially the message received was that we had to go and find the evidence ourselves. The purpose of this was to clear up the blood transfusion issue about the medical notes not being marked up, for the claim to progress.

7.2. We approached our GP who told us the records had been destroyed, so we were unable to progress our claim. I attended the GP surgery on an unrelated matter and spoke to a temporary locum (an Australian lady) who made some enquiries and found the notes were held on Microfiche and she made a copy for us. Without this stroke of fortune we would have been hard pressed to advance our claim. I do believe that there is some covering up of errors/closing of ranks by the whole medical system. I should say that without the assistance of the Australian locum the system would have beaten us in terms of receiving any compensation. I have met many people over the years especially at hospitals and found that many people have similar stories to tell.

7.3. To the best of my recollection, Sandra eventually received a lump sum of £25,000 and a monthly sum of about £1000 per calendar month which eventually rose to about £1250 pcm. I believe this was a "take it or leave it" style approach and I believe that she had to sign a disclaimer, to prevent her taking out legal action.

7.4. I found out post-event that if you were a member of the Skipton scheme you could claim expenses, but as I enquired after the event I was informed that claims could not be made retrospectively. This was an unfair set of circumstances: my financial situation was not good, having stopped working. I incurred many travel expenses having to travel to see my wife in hospital in numerous locations in London and the other venues.

7.5. Over the years I have lived like a pauper, I believe that I should receive some compensation. I have lost a considerable amount of money in the region of £500,000. However it would still not balance out the impact, effect and the loss of family life. Whilst on the subject of compensation schemes I don't believe that the five different schemes are the best way to deal with such complex issues. With regard to the EIBSS I don't think it is fit for purpose.

Other Issues

8. When I lived in Hampshire, I remember a story in the local press involving local British Army doctors based in Aldershot, who were taking blood from squaddies based in Aldershot for the

purpose of donating to the National blood bank. It transpires that according to the newspapers they were in fact selling this blood abroad for profit. This does make you wonder whether this criminal activity contributed to national shortages of blood suffered by the NHS and had a direct impact on the authorities importing infected blood

8.1. During my statement I have made numerous references to times when my wife was taken into various hospitals. The below list contains hospitals where she was admitted and received various treatments. This is not a definitive list and there may be others that we visited, but that I have forgotten.

- The Royal Free Hospital Hampstead London.
- Saint Richard's Hospital, Chichester.
- Brighton General, -Brighton.
- Queens Alexander's Hospital, Cosham
- Portsmouth General Hospital.
- Southampton General.
- Oddstock Hospital, Salisbury.
- Frimley Park Hospital, Surrey.
- Northants Hospital, Surrey.
- Bognor War Memorial hospital.
- There are two GP practices we used, they are:
    1) Hook surgery, Reading Road,
    2) SEAL, Medical surgery, Selsey Sussex.

8.2. I consent to the infected blood inquiry using my statement. I don't require any anonymity from the inquiry, I am aware of the Inquiry consent to use my statement form, which I have duly signed.

Statement of Truth

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

Signed

Dated

9/11/18