

Witness Name: Kenneth Gray

Statement No: WITN0491003

Exhibits: WITN0491004 WITN0491005

Dated: 14 December 2020

## INFECTED BLOOD INQUIRY

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### SUPPLEMENTARY WRITTEN STATEMENT OF KENNETH GRAY

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4th March 2020.

I, Kenneth Gray, will say as follows: -

#### Section 1. Introduction

1. My name is Kenneth Gray. I make this statement to supplement my original statement to the Infected Blood Inquiry dated 29 October 2018 (WITN0491001). My personal details are known to the Inquiry and remain unchanged.
2. I do not want to be anonymous because I consider that it is important that my story is told.
3. I am not legally represented for the purpose of providing a witness statement to the Infected Blood Inquiry.

4. The Inquiry Investigator has explained to me the 'right to reply.' I understand this to mean that any significant criticism I have made of a medical professional, or other person the Inquiry considers necessary to inform, may be contacted for the purpose of responding to the criticism.
5. I intend to speak about information I have received recently, and believe to have uncovered, concerning the periods prior to, during and subsequent to the death of my beloved wife Sandra Gray on 25 May 2017.
6. This statement relates to the research I have undertaken since my wife's death, and to the conflicting medical advice that we were given regarding the availability of a pharmaceutical drug that might have made a difference to her condition and to Sandra's lifespan and chances of survival.
7. My recollection of exact dates may sometimes be hazy but I have endeavoured to recall all events with as much accuracy as possible.

## **Section 2. How Affected**

8. My wife Sandra underwent a liver transplant at the Royal Free Hospital (London) in May 2014. On the day of her release from hospital my wife suffered an aneurism and was immediately taken back into hospital from where she was not finally discharged until August 2015.
9. Sandra spent approximately 15 months in hospital from the time of her initial admission until her discharge. After this very protracted stint in hospital, my wife continued to receive regular medical check-ups at Queen Alexander Clinic in Portsmouth every 3 months. At those appointments Sandra was seen by Dr Aileen Marshall and Dr Thorburn.

10. Approximately 3 months after the time of her transplant, in or around August 2014, Sandra and I began to be told by her treating clinician Dr Marshall (Drs Marshall and Thorburn worked at the Royal Free Hospital in London and also at the satellite clinic in Portsmouth) that there was a new drug which apparently demonstrated a 95% effectiveness for curing Hepatitis Genotype 1. I do not recall being told the name of this supposed wonder drug at that time; merely that it was in existence though not currently available.
11. At every subsequent clinic visit, Sandra and I would ensure to inquire about the availability of the drug, only to be told by Dr Marshall that it was not yet available and was awaiting approval by the National Institute for Health and Care Excellence (NICE). Dr Powell, who also treated Sandra at the Queen Alexandra Hospital, would often defer our expectations until the next appointment due in 3 months, stating that perhaps the drug would be available to us then.
12. Sandra and I attended the clinic for quarterly check-ups on 3 or 4 occasions, only to be told that the drug was not yet available but perhaps it would be on the following occasion. We continued to hold out hope in this possibly miraculous prospect, spurred on by the information given to us by our clinicians Dr Marshall, Dr Powell and Dr Thorburn.
13. During the period of these reoccurring quarterly clinic appointments, my wife was very susceptible to contracting infections due to her poor, immuno-suppressed condition. Sandra was frequently admitted back into hospital with an infection and sometimes she would even contract further infections from the hospital itself.
14. There was rarely a period of more than a fortnight where she could settle at home before needing to be re-admitted in order to deal with these infections. I became very frustrated at the fact that Sandra was refused entry into the isolation ward of the hospital, when this clearly would have benefitted her.

15. However, despite the seriousness of her condition, there was a relatively brief period of respite of around 8 months (between roughly August 2015 until the beginning of 2016) when Sandra seemed to be recovering well and could have benefited from any new applicable course of treatment. During this time Sandra and I continued to be told that the wonder drug previously alluded to was still not available.

16. Once this brief window of well-being began to subside, Sandra's recurring infections returned and, at the start of the Summer of 2016 Sandra had to be taken (by wheelchair) back to the clinic in order to receive medical attention. At that time we were told that, although the aforementioned drug was now available, Sandra's weakened condition made it ill-advisable for it to be administered.

17. Without adequate treatment my wife's condition continued to decline and she succumbed to her illness and died on 25 May 2017. In the wake of Sandra's death, I took an avid interest in the work and progress of the Infected Blood Inquiry and I therefore endeavour to attend as many oral hearings as possible.

18. In May 2019 at the headquarters of the Infected Blood Inquiry at Fleetbank House in Central London, whilst in attendance at the Inquiry hearings, I had a brief encounter and conversation with a man who had not been known to me hitherto. The information relayed to me during this short conversation had a profound impact on me and, had I known it during the course of my wife's life, might have drastically altered the tragic outcome that was her death.

19. I do not know the name of the man but I am able to provide a detailed description. GRO-A

GRO-A

GRO-A

 I believe

that, given these unique characteristics, this person's identity is likely to be known by the leadership at the Inquiry.

20. During a lunchtime break from the Inquiry's work, I conversed with this man and related to him the story of my wife's treatment with a particular focus on the drug that eluded us, but which I believed could have helped.

21. The unidentified man also told me about his personal medical history and involvement with the inquiry. [REDACTED] GRO-A

[REDACTED] GRO-A

[REDACTED] GRO-A I know that the man was a haemophiliac who was infected with HCV through transfusions of Factor 8 concentrate. The man told me that his HCV eventually cleared.

22. In response to me telling him about my wife's experience of being refused the unnamed HCV medication, the man told me that he had received what sounded like the same drug on the NHS. The man also stated that the drug he had received was part of a 3-month course of treatment and that, similarly, it was able to effectively treat 95% of HCV Genotype 1.

23. Furthermore, the man told me that he believed the drug was available both on the continent and on the NHS. Although I do not recall the man telling me the name of the drug, on a balance of probability, I believe we were talking about the same drug that had eluded Sandra in the past.

24. Unable to forget the implications of this conversation and after prolonged reflection at home by myself, I later raised this issue with a Mental Health Nurse at the Queen Mary's Hospital where I received bereavement counselling; I believe her name was Lynn Pratt (although it might actually be Jane Pratt, I am unable to definitively recall). I provided a full account of my wife's medical history and shared the information that the unidentified man had given me and Ms Pratt

conducted a search based on the parameters that I had provided. I exhibit the printout results of Ms Pratt's search at **WITN0491004**.

25. Ms Pratt's search resulted in her locating a pharmaceutical drug named Sofosbuvir, sold under the brand name Sovaldi. Ms Pratt told me that the drug was manufactured by an American pharmaceutical company and, following approval for use by the European Medicines Agency on 22 November 2013, became available for use in 2014.

26. Following the conversation with Ms Pratt, I went home and googled 'Sovaldi'. The drug costs \$1000 USD per pill. Assuming only one pill is taken per day, and no other drugs are taken in combination with it, the full cost of a 3-month course of treatment would be approximately \$90,000 USD.

27. If this is indeed the case then the ramifications are disastrous. My wife received two £25,000 lump sum payments, as well as £1000 monthly payments from the Skipton Fund. At the time of her death there was in excess of £60,000 sitting in a bank account that would have been capable of funding vital treatment. I would have moved heaven and earth with no hesitation in order to secure further precious time with my Sandra, including travelling abroad to procure the medication.

### **Section 3. Other Infections**

28. I do not believe that Sandra received any infection or infections other than HCV as a result of being given infected blood products. Please see paragraph 3 of my first statement in relation to my wife's infection.

### **Section 4. Consent**

29. Please see paragraphs 4, 4.1 and 4.2 of my original statement in relation to my wife's original infection with HCV.

## **Section 5. Impact**

30. I cannot overstate the devastating impact that the information I have received has had on me.
31. Following my initial encounter with the unknown man at the Infected Blood Inquiry (in or around May 2019) I experienced many sleepless nights over the course of many months. I have replayed the conversation I had with the man over and over in my head, torturing myself with the thought that the key to Sandra's salvation and survival was out there the whole time, and that my inability to find it constituted the final nail in her coffin.
32. I still hold onto the suspicion and guilt that I could have done more to procure better, more effective medical treatment and medication for my wife. I hope that this additional statement to the Infected Blood Inquiry may save others from similar torment.

## **Section 6. Treatment/Care/Support**

33. I did not initially seek any bereavement counselling or therapy in the wake of my wife's death and I was able to manage well enough at first, that is until I heard about the possibility that this possibly life-saving medication might have been available all along. That thought broke me and without the very helpful counselling that I have received I would have been left completely bereft and unable to cope with my depression and the consequent feelings of guilt.
34. I cannot stop wondering whether the consultants I have mentioned above wilfully withheld details of a beneficial treatment or were simply

negligent in failing to prescribe it. In my more cynical moments I tend towards the former.

35. In general, I believe that Sandra encountered resistance to being prescribed a potentially life-saving drug due to financial considerations and austerity measures. Although it is possible that medical considerations informed the decision, I feel that the medical establishment and Sandra's treating clinicians missed an opportunity to save her during her window of wellbeing in late 2015/early 2016. I believe that at this time she would have been well enough to endure the course of treatment.

36. I have discussed with the Inquiry Investigator the existence and contact number for the counselling and psychological support service the British Red Cross is running in collaboration with the inquiry. The Inquiry Investigator has provided me with a card and I will consider calling them.

#### **Section 7. Financial Assistance**

37. Please see paragraphs 7 – 7.5 of my original statement for a full account of the financial assistance that Sandra received.

#### **Section 8. Other Issues**

38. For the avoidance of doubt I wish to categorically state that, regarding the specific details of medical treatments and/or prescribed medication, none of the issues enumerated in this statement are to be confused with the course of Ribavirin that Sandra received as detailed in my original statement.

39. Further, I attended the Infected Blood Inquiry hearings on 24 – 28 February 2020 hoping to encounter the same man I had met before.

During those hearings, experts were relaying general information pertinent to the inquiry's work.

40. As I listened, the panel of experts discussed a drug that was used to treat Hepatitis C. The experts stated that the drug was rationed due to limited availability. Ironically, one of the experts giving evidence was Aileen Marshall, one of my wife's treating clinicians. I believe the experts may have been talking about Sovaldi.

41. I exhibit a handwritten note containing these questions composed by me prior to my attendance at the hearings on 24 – 28 February 2020 at WITN0491005

42. I would have liked to have known answers to the following questions:

- a) When in 2015 did NICE approve Sofosbuvir?
- b) When in 2016 did the NHS start using it?
- c) Was it manufactured abroad? If so, where?
- d) Was it available privately and/or could it be purchased from abroad?
- e) Why was it not available to NHS patients en masse to address infections caused by the NHS?

43. I imagine that I will have to wait until the next hearings in order to get further details.

**Statement of Truth**

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

Signed GRO-C

Dated 14-12-20