

Witness Name: Mary Heath

Statement No: WITN3341001

Exhibits: WITN3341002-7

Dated: 11/11/19

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF MARY HEATH

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 July 2019.

I, Mary Heath, will say as follows: -

#### Section 1. Introduction

1. My name is Mary Heath. My date of birth is [GRO-C] 1943 and my address is known to the Inquiry. I am affected by my husband's infection with Hepatitis C. I intend to speak about my husband's infection with Hepatitis C. 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.

#### Section 2. How Affected

2. My husband's full name was Robert Charles Heath. He was born on [GRO-C] [GRO-C] 1943 and died on 17 January 1993, following a 2- year battle against Acute Myeloid Leukaemia.

3. He was infected with Hepatitis C by blood transfusions at the induction period to his treatment for Leukaemia. I presume this must have been at Whipps Cross Hospital, when he had a Hickman Line inserted for his Leukaemia treatment. Hepatitis C is listed as a cause of death on his death certificate, a copy of which is labelled as Exhibit **WITN3341002**.
4. We were married in May 1969 and we had 6 children together. At the time that Robert died, our youngest son was 9 and our oldest daughter was 21. Our children are now in their 30's and 40's.
5. Robert had his own surveying company at Lincoln's Inn Fields and I think it was the stress of his work, coupled with a recession at the time, which may have caused the Leukaemia.
6. Robert was diagnosed with Acute Myeloid Leukaemia in February 1991. The diagnosis followed an incident when he cut himself shaving and it bled more than usual. He also developed a bad mouth ulcer.
7. He went to see our GP, Doctor Franklin, regarding the above. Doctor Franklin had personal experience of this type of Leukaemia and as a result sent Robert for a blood test immediately that same day.
8. The results were returned the same day, and Doctor Franklin rang us that evening and told Robert that he needed to go and have a bone marrow sample taken. It should be noted that a positive Leukaemia diagnosis can only be made through a bone marrow sample. The sample was taken the next working day.
9. Robert went to have the bone marrow sample taken at Wanstead Hospital. He took the day off work to go and have the test. The sample was taken by a Registrar from Doctor GRO-D's team, who was the Consultant Haematologist for Wanstead and Whipps Cross Hospitals.

10. The results of the bone marrow sample came back the same day and Robert received a call from Doctor GRO-D. He said that he needed to see us and that evening we went to see him at Wanstead Hospital. He told us that Robert had been diagnosed with Acute Myeloid Leukaemia. We discussed the diagnosis and treatment options, how many courses of treatment he would need etc.
11. 2 days after we received the diagnosis from Doctor GRO-D Robert was admitted to Whipps Cross Hospital for the insertion of a Hickman Line. The Hickman Line needed to be inserted before his chemotherapy treatment for the Leukaemia could begin.
12. A Hickman Line is a central venous catheter that is used for the administration of Chemotherapy. The Hickman Line needed to go in through a major vein. Robert was given blood products as his whole chest became bruised following the insertion of the Hickman Line.
13. After the Hickman Line was inserted, he was transferred back to Wanstead Hospital the following day to commence chemotherapy treatment. If successful, it was hoped that the chemotherapy would result in remission and that a bone marrow transplant could then take place. He had around 3 courses of chemotherapy at Wanstead, each course lasting approximately 6 weeks, with a few weeks in between for recovery.
14. During the chemotherapy, Robert was given blood products. He had numerous transfusions of blood, platelets and packed cells, all necessary due to the negative effects of the chemotherapy on his blood and bone marrow. The transfused blood supported his system whilst his own bone marrow was not functioning.
15. The recovery periods were necessary between chemotherapy courses to enable his white cell count (lowered by the chemotherapy) to return to an acceptable level, where infection could be fought. Robert's white cell count was often so low during treatment that when we visited him

we were required to wear gowns, masks and gloves, and we were prevented from touching him, in order to limit his exposure to infection. A couple of photographs showing visitors wearing protective gear are labelled Exhibit **WITN3341003 & WITN3341004**.

16. In April 1991, Doctor GRO-D referred my husband to Doctor Goldstone at University College Hospital for a bone marrow autograph with the prospect of a bone marrow harvesting in June 1991, after the second consolidation of chemotherapy.
17. Robert was in remission at this point. He had his marrow harvest on the 8 June 1991. At this time, his blood tests showed that he had abnormal liver function tests and was Hepatitis C antigen positive.
18. He was referred to the liver unit at the Cromwell Hospital where he had a liver biopsy on the 6<sup>th</sup> of August 1991. The biopsy showed a very severe active Hepatitis C virus related disease. He was very ill at this time with the effects of acute Hepatitis. He had severe nausea, headaches, jaundice, cold sweats, pale stools and dark urine. The Hepatitis prevented him from having further chemotherapy for his Leukaemia at that time.
19. He was prescribed Interferon immediately, commencing on 3 mega units, 3 times a week. This continued until his liver function returned to normal around the end of September. The Interferon was stopped and his next course of chemotherapy commenced on the 3<sup>rd</sup> of October 1991. He relapsed during this course of chemotherapy and the doctors could not decide whether the relapse was caused by the Interferon, which reduces platelet level, or the Leukaemia. It took him 2 months to get over this course of chemotherapy.
20. It was around July/August 1991 that we were told that Robert had contracted Hepatitis C from the blood products that he was given during his treatment. Doctor GRO-D gave us the diagnosis. He told us during one of the normal general consultations he had with Robert.

21. The consultations happened once a week when Doctor GRO-D would visit. Robert was so ill at this time with the symptoms of severe Hepatitis, but we were unaware how serious this was.
22. We were told that they were trying to isolate which product was responsible for the infection and that screening of the blood products had since commenced in September 1991. There was not a lot of importance attached to the Hepatitis C diagnosis by Doctor GRO-D at that time, and the diagnosis did not make Robert or myself panic. I think that the medical profession did not know a lot about Hepatitis C at that point in time.
23. We were not really given any information by Doctor GRO-D to understand and manage the Hepatitis C infection. Because of the Leukaemia, the main focus was getting Robert into remission, so nothing was really said about the Hepatitis C. As I said before, not a lot of importance was attached to it.
24. Doctor GRO-D did not give us any advice about the risks of others being infected as a result of the infection. There is nothing that I can recall that he said to us, nothing that stands out in my mind. I'm not quite sure whether he told us to be careful sexually.
25. Robert did not have at any time tattoos or piercings. I think that he only ever had one other blood transfusion during his life and this was as part of treatment he had for a complicated tibia and fibula break in around 1966-67. He was in his early 20's at the time. His leg was put in plaster, but the fracture became unstable and he had to go back into hospital as he had developed an infection. He went back into hospital and had pins inserted. I think that at this time he had a blood transfusion, but I can't be 100% certain. He was at Whipps Cross Hospital for this.
26. Wanstead Hospital closed down at the end of 1991 and in early 1992 Robert's treatment was continued on the Charity Ward at Whipps

Cross Hospital. I'm not sure how many courses of treatment he had at Whipps Cross. There is a photograph of Robert holding up a card during his treatment at Whipps Cross which is labelled Exhibit **WITN3341005**.

27. The chemotherapy treatment took place over the period of 1991 and part of 1992. Robert did not return to work after he started his treatment.

28. By February 1992, the Hepatitis C was again rampant so Robert was re-started on Interferon (3 mega units, 5 times a week) plus Transretinoic acid. This regime continued for several months, but he was now having severe systemic side-effects from the Interferon. He had severe pain in his joints, knees and ankles which had become very swollen. His knees had to be drained and he had severe cramps which caused him a lot of distress.

29. A letter from Doctor Goldstone to Doctor GRO-D on 9 March 1992 stated that because the harvested bone marrow had a considerable amount of Hepatitis C onboard, the ablated regime with which an autograph is done is liable to allow the Hepatitis C to go haywire and may damage his liver irretrievably. In my opinion, this is exactly what happened and contributed to his death.

30. Robert was in remission in May 1992. In August he relapsed and had another course of chemotherapy.

31. In October 1992, he was again in remission. He had several episodes of sepsis which were treated with antibiotics. This caused severe diarrhoea for several weeks. He was very frail after all of this treatment.

32. I remember that year we had our family Christmas party early, as Robert was expected to receive the bone marrow autograph close to Christmas. I remember that at the Christmas party he was already

looking jaundiced. I have a photo of him at the Christmas party which shows this and is labelled Exhibit **WITN3341006**.

33. He had more bone marrow harvested at the end of October 1992, and an autograph was booked for November 1992 at University College Hospital under Doctor Goldstone. He tolerated the autograph really well until 25 days post-transplant at which time he started to develop veno-occlusive disease of the liver, became more and more jaundiced and finally encephalopathic from hepatic failure, and terminally had a large haematemesis and melaena 51 days post-transplant.
34. Robert experienced extreme hallucinations and nightmares leading up to his death, which I attributed to his liver failure. The night before he died, he was vomiting blood and he became very confused with hallucinations. My sister in law would stay with Robert during the day at the hospital and I would go in at night. The night before his death when I went in, my sister in law told me that he was not well and that he had taken a turn for the worse.
35. He was vomiting blood and seemed very confused, he was also trying to get out of bed. The nurses put up the cot sides on his bed to prevent him from falling out. He was rambling on and on about how he was a property developer and he was buying property in all parts of the world. He went on talking all night.
36. Doctor Goldstone's Registrar at University College Hospital asked to see us and told us that Robert was not going to make it. He said that no matter what they did, they couldn't save him. Robert had gone through so much pain in the last couple of years that I wanted his death to be as painless as possible. I called Robert's sister and brother and they came to his bedside for the night.

37. Robert died from a large haematemesis on 17 January 1993, the day after we were told that he would not survive. He passed away 51 days post-transplant after a horrendous few weeks.

38. Doctor GRO-D told me that Robert died from Hepatitis C, not the Leukaemia. Robert's liver was put under a lot of stress from the chemotherapy, and the Hepatitis C progressed his liver failure which ultimately caused his death.

39. I was tested for Hepatitis C twice after Robert died. I thought to myself that maybe I had contracted it because of my contact with Robert. For example, I had to flush through his Hickman Line every night. Someone told me that you cannot contract Hepatitis C sexually, but I'm not certain about that.

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

40. As far as I am aware, Robert did not receive any other infection from the blood transfusions besides Hepatitis C.

### **Section 4. Consent**

41. I do not believe that Robert was tested or treated without his consent, without being given adequate or full information or for the purposes of research.

42. We were told that Robert would be given blood products as part of his treatment for Acute Myeloid Leukaemia. It was a do or die situation, he needed to have the transfusions as part of his treatment otherwise the Leukaemia would kill him. We left it in the hands of the experts.



## **Section 5. Impact**

### **Physical and mental impact of Hepatitis C and the treatment**

43. What Robert went through physically and mentally throughout his treatment for the Leukaemia was horrendous.
44. An impact of the Interferon treatment was that his knees and ankles became very swollen and he experienced severe cramps.
45. The Hepatitis C complicated, interfered, interrupted and delayed Robert's Leukaemia treatment. Who knows what the outcome would have been had he not contracted it. I believe that the Hepatitis C and its treatment caused him to have severe systematic effects, nausea, vomiting, headaches, temperature, diarrhoea, cramps, swollen joints, jaundice, pale stools, dark urine and a huge amount of pain which was only relieved by Diamorphine.

### **Impact on Family Members**

46. I cannot differentiate the impact of the Hepatitis C diagnosis and treatment on our family from the Leukaemia diagnosis. It was a traumatic period in our lives.
47. I feel that my children coped well with their Father's death. I think that the trauma they experienced made them good teenagers and young people, and I did not have any problems with them.

### **Stigma**

48. Stigma in telling the outside world about the Hepatitis C infection did not really apply to us, as Robert was already unwell with Leukaemia and the Hepatitis C was ancillary to that. As I mentioned before, there was not a huge amount of importance attached to the Hepatitis C by

Doctor GRO-D and it seemed that people just didn't know a lot about it.

### Financial Impact

49. I cannot differentiate the financial impact at the time of the Hepatitis C diagnosis from the financial impact of the Leukaemia diagnosis. However, in my opinion the likelihood of Robert's early death was dramatically increased by his Hepatitis C diagnosis. The financial implications, not to mention the mental and physical ones, of being widowed at 49 with 6 young dependent children is hard to quantify.

50. As I mentioned before, Robert was unable to work during his treatment for Leukaemia, which was prolonged and interrupted by contracting Hepatitis C from the blood products.

51. Our house was paid for by Robert's life insurance policy. During Robert's illness, because he was unable to work, he put his company in the hands of others and it was put into liquidation when he passed away. His assets paid for his debts. I had a young family, so I had to go back to work which was very difficult when you are trying to support a young family.

52. At the time that Robert got sick I was planning to go back to work, but because of his illness I could not.

53. I went back to work as a nurse within a year of Robert's death. As I had been away from the workplace for the past 14 years raising my family, it was necessary for me to undertake a back to nursing course. I initially worked as a nurse in the community before commencing a role in school health.

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

54. As the focus of Robert's treatment was his Leukaemia, and he received Interferon for the Hepatitis C, I do not believe that Robert faced any difficulties or obstacles in obtaining treatment, care and support as a consequence of being infected with Hepatitis C.

55. No counselling or psychological support was made available to Robert and our family for either his Leukaemia or Hepatitis C diagnoses.

## **Section 7. Financial Assistance**

56. I have not as yet applied to any of the funds for financial assistance.

57. I became aware that I could apply for financial assistance through the funds recently set up by the Hepatitis C Trust. I can't remember how I initially contacted the Trust.

58. Sam from the Trust sent me links to 2 websites, one being the Inquiry and the other one being EIBSS. I submitted an Expression of Interest in giving evidence to the Inquiry, and downloaded the forms for EIBSS from their website to complete them.

59. I have not yet completed the forms for EIBSS as they are very complicated and it is not clear to me what information they want me to provide. I consider myself to be an educated person, however the forms are extremely confusing.

60. I telephoned EIBSS as I was confused about what information they require to be added to the forms; whether it is Robert's information or mine.

61. In addition to this, they require me to submit Robert's medical records. I have received the medical records from University College Hospital, however, Whipps Cross Hospital, which is now part of Bart's Health, have not as far as I understand retained any of Robert's medical records.

62. With the GP records, I initially applied to Primary Care Support England for them earlier this year, but was told that my utility bill was almost out of date and to forward another one. In response, I sent another utility bill dated the 27<sup>th</sup> June 2019. I received a letter back from Primary Care Support England in July stating that they required a certified copy of Robert's will. This letter is labelled Exhibit **WITN3341007**. I have now learned that his GP records relating to his death are non-existent. I received a letter from Primary Care Support England stating that as of 23<sup>rd</sup> of August 2019, he is eligible for a pneumococcal and shingles vaccination plus a pulse check. There is no record of his death.

63. I obtained a certified copy of his will at a cost of £60.

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

64. My purpose for giving this statement is to tell my family's story and how it has been affected by the NHS's use of contaminated blood.

65. I believe that the NHS should be held accountable for its use of contaminated blood.

66. In comparison to others suffering daily with complications, such as HIV following transfusions of infected blood, I do not believe that I have been badly affected. However, Robert's early death has had a huge financial, physical and mental impact on the lives of my family.

**Statement of Truth**

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

Signed \_\_\_\_\_  

GRO-C

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Dated 11/11/19