Witness Name: Diana Jones
Statement No.: WITN6651001
Exhibits: **WITN6651002**
Dated: 26 August 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DIANA MARY JONES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 16 August 2021.

I, Diana Jones, will say as follows: -

Section 1. Introduction

1. My name is Diana Jones. My date of birth is GRO-C 1937 and my address is GRO-C. I live with my husband of 60 years, Dr Phillip Jones. Philip is a long retired GP.

2. I am the mother of four. Two girls and two boys. Timothy ("Tim") Jonathan Jones, my third child born GRO-C 1967, sadly passed away in 2008 aged just 41. I intend to speak about Tim's infection with hepatitis C ("HCV") as a result of receiving infected blood products. In particular, the nature of his illness, how the illness affected him, the treatment received and the impact it had on Tim, our family and our lives together.

3. I should point out that memories fade but along with Philip, I have tried to respond to the questions asked by the inquiry as best as I can. Also, after Tim had become an adult, although we remained close and

regularly saw each other, he shielded us from a lot of what he was going through and so I just did not know a lot of detail in the first place.

Section 2. How Infected

4. My mother was born in 1900 and I can remember her telling me stories about the family being 'bleeders'. She recalled that her mother died of TB and her father died when she was 9. She also remembered being told about her mother's dentist in Grays, Essex, who refused to treat the family because they were 'bleeders'. In all these stories, the word 'haemophilia' was never mentioned.

5. Phillip and I had our first child, Christopher, in 1964 GRO-C GRO-C. Both children were healthy and happy. After a brief two year gap, we had Tim in 1967. Our fourth and youngest child, Sarah, was born 2 years later.

6. When Tim was young he used to bruise a lot. When he first started school he would often come back with bruises or a lump on his head. On one occasion he cut his gum and the blood just kept dripping from his mouth.

7. Phillip, who was a local GP for over 50 years, decided when Tim was about three years ol,d to take him to Llanelli Hospital where he was seen by Dr John Davis. Dr Davis did something to stop Tim's gum from bleeding, but I cannot recall what exactly he did. There was certainly no suggestion of haemophilia at that time.

8. When Tim was aged 12, in 1979, we went to Heath Hospital in Cardiff for an appointment with Dr Bloom. At this time I believe we must have suspected that Tim was a haemophiliac owing to his persistent bruising.

9. I remember Dr Bloom was the kingpin at the Cardiff haemophilia centre; he was world renowned and respected by everyone, he was 'God'. Dr Bloom tested us all I and found that I was a carrier of haemophilia GRO-C

GRO-C Tim was diagnosed with mild haemophilia A, which partially explained why it took so long for him to be diagnosed, as he rarely had problems. Christopher was not a haemophiliac and Sarah was not a carrier.

10. After his diagnosis, Tim was referred to Morriston Hospital, nearby in Swansea. There was a very small haemophilia centre there at the time. Morriston Hospital provided Tim with tranexamic acid, which was to be administered a few days prior to him having any invasive procedure.

11. Tim was also told that he could self-inject factor VIII if he had a bleed, though Phillip would always do this. Between 1979 and 1981 there were no incidences which necessitated Tim to receive clotting factor.

12. Then, in May 1981, Tim was out crabbing with his friends. He was climbing a fence when he fell and fractured his arm. I received a phone call from the nearby swimming pool and sent GRO-C running around to tell them he had haemophilia.

13. Tim was taken to Glangwili Hospital where he was kept for 10 days. He received factor VIII product every day during his stay. When he was discharged from hospital he appeared jaundiced and generally unwell. He was not readmitted to hospital because this subsided after a few days.

14. We used to keep Tim's factor VIII bottles in the fridge to use as and when he needed it. On average he received factor VIII maybe once every 3 months. This was generally whenever he had a bleed in the joint or a particularly bad bruise. I do not recall any writing on the labels.

15. On one occasion when Tim was 16, around 1983, he came running home with a black, swollen right eye. He made some excuse for it but told his Dad years later that someone had punched him. When he got home we laid him on the sofa and put ice on it but the swelling persisted. He was being physically sick with the pain, though typically he didn't complain one bit.

16. Phillip took him to Morriston Hospital where they stuck a label on the end of his bed that read 'No Aspirin' due to his haemophilia. When we visited again the next day Tim hadn't received any factor VIII whatsoever. It hadn't occurred to the hospital that he should receive it as a haemophiliac with a badly bruised eye.

17. Phillip was allowed to administer a dose of factor VIII to Tim once we flagged this to the doctors. I can remember Phillip showing one of the doctors at the hospital how to inject the factor product. Tim was then referred to Singleton Hospital in Swansea, in which they had a specialist eye department. He was kept at Singleton Hospital for 10 days where he received factor VIII and was attached to a drip. His eye was badly damaged and he did not regain any eyesight in that eye until about 5 years later and that was only partial.

18. In 1985 or 1986, I received a phone call from Morriston Hospital informing us to return a batch of factor VIII because it could be contaminated. They didn't specify what exactly the factor product could be infected with. At the time there were 10 to 12 bottles in the fridge and some of the batch had already been administered to Tim.

19. After leaving school, Tim struggled to find any work. His employment options were limited by his haemophilia and his eye, which meant he couldn't perform manual or physically demanding jobs. He also had very few qualifications and had struggled academically at school because of his dyslexia. All this meant he found work difficult to come by.

20. In 1987, Tim was accepted to St Loye's College in Exeter to study food preparation and cookery. He registered with the local haemophilia centre at Exeter Hospital and was under the care of Dr Lee. During his course he used to wear a metal wired glove to help prevent any cuts when he was chopping in the kitchen. Nothing was known about his HCV the at this time, that he must have had. It's quite disturbing to think that he was working in kitchens with the associated risks.

21. After completing his 6 month course and gaining a diploma, Tim decided to stay in Exeter. It was during this time, around the late 1980s, when Tim was diagnosed with HCV. He did not tell us this directly at first, though he told his two sisters who relayed it back to us. I do not know specifically when this was but I would say that it was during the early years of him living in Exeter.

22. We learnt later from Tim that he was initially refused treatment for his HCV. The treatment was said to be very expensive and, as a result, it had to be approved by an 'ethics committee'. However, Tim was eventually accepted for treatment, which I know included interferon

23. After completing the treatment, I believe that Tim had cleared the HCV. We did not see much of him but by the end of the treatment he was very frayed and upset. He struggled to cope with life. His mental health began to worsen and he showed signs of depression and paranoia. We were unaware of any potential side effects connected to the treatment that he received. If Tim was informed he did not tell us but this was not unusual. Tim liked to keep things very much to himself once he had become an adult.

24. We used to go and visit him in Exeter whenever we could. He was often cheerful and tried to put on a happy face. He was affectionate and tactile. I remember him putting his arm around me a lot. Despite this, Tim's appearance began to deteriorate and we became increasingly worried about him.

25. I remember one day in particular when we went on a picnic. Tim was looking nervously around a lot and seemed to believe that people were watching him. It was like he was paranoid. It was around this time that Sarah, our youngest child, told us that Tim was being harassed by his neighbours in Exeter. Tim was shouted at and jeered by people saying he had AIDS, presumably having learnt about his haemophilia.

26. Every time we visited Tim in Exeter he appeared to have declined further. He just didn't seem like the same person. He was also mixing with a bad crowd. He was unemployed and began hanging around with the wrong people. I remember one day receiving a call from Dr Lee saying that he was concerned having seen Tim walking around the town with a black bag and he was clearly in a bad state. We were obviously extremely worried about him.

27. In December 1996, I sent Tim some money so he could come home to visit us for Christmas. Then, on Christmas Eve around 11pm, we received a phone call from a gentleman at Cardiff station telling us that Tim was there. He was being looked after by the staff in the station as he was in a state of distress. There were no trains available for him to get home to us and he had no money. They said they would keep him inside away from the Christmas Eve crowds of revellers, as he was unable to cope with it.

28. Sarah and her then husband, went to Cardiff and picked him up. He had all his things wrapped up in black bin bags. He told us that had an anxiety about mould. He didn't sleep at all that night, instead just pacing around his room. He couldn't join us for Christmas dinner. He preferred to eat on his own. It was all very upsetting to witness.

29. By this time, it was clear to all of us that Tim had a quite severe mental illness. We rented Tim a flat near to us in early 1997 but it wasn't suitable, it was a room with shared facilities. So Phillip wrote to the council. The council found him a flat but this was in a really bad area that is still renowned for drugs. Tim moved in there in mid 1997. He remained there for the last 10 or 11 years of his life.

30. Phillip drove Tim to Cardiff haemophilia centre every Wednesday for physiotherapy. Tim's ankle had been damaged over a number of years as a result of regular internal bleeding. Cardiff had a physiotherapy pool which Tim used to enjoy using and he was friendly with the

physiotherapist. We later learnt that Tim had told his physiotherapist that he was buying painkillers off the street to manage the pain in his ankle.

31. In hindsight I believe Tim became addicted to painkillers whilst still in Exeter. We knew he was buying painkillers off the street when he returned to live in Wales but we didn't realise the extent of his addiction.

32. On 31 August 2008, a Sunday afternoon, the police came around to our home at around 3pm. Phillip had been due to collect Tim and bring him round for dinner as we did every Sunday, at 4pm. The police asked if my son was Timothy and then said he had been found dead in his flat by his friend Greg.

33. Greg had a key and used to call round to see Tim regularly for a cup of tea. Greg said that he came in and found Tim sat up leaning on his bed. It was clear that he was not alive.

34. Tim's cause of death was recorded as 'I) Poisoning with combination of drugs morphine, methadone, venlaflaxine, diazepam, buprenorphine and alcohol, II) Haemophilia. Accidental death was recorded in the sense of it being the unintended consequence of a deliberate act. I enclose his death certificate as exhibit **WITN6651002**.

Section 3. Other Infections

35. Tim did not receive any other infections from the use of blood products, as far as I am aware.

Section 4. Consent

36. I am unable to say whether Tim was treated or tested without his consent once he became an adult.

37. When Tim was treated as a child, Phillip and I may not have given explicit consent to treat Tim but we would say that our consent could rightly be

said to have been implied. We simply accepted that it was the right treatment and that was that. We had and have no issue with that.

38. Phillip and I were not informed of any risks associated with factor VIII blood products prior to Tim receiving them. Whether it would have made any difference, I am really not sure as there was no alternative to Factor VIII.

39. I think that had we known the risks when Tim broke his arm we maybe would have declined Factor VIII and accepted that the recovery would have just taken longer. However, I believe that when Tim badly damaged his eye, he had no choice but to receive factor VIII product for his recovery.

40. I would be shocked to learn that the clinicians knew about the risks of infected blood and continued to administer Factor VIII without explaining the risks. If they did know I feel that we, as Tim's parents, should have been informed.

Section 5. Impact

41. I believe that Tim's diagnosis with HCV was the catalyst for the decline in his mental wellbeing. We were much more worried about his mental health than his infection with HCV. We saw him change drastically; he went from being a cheerful person who was always out with his friends to a depressed and deeply troubled man.

42. After his diagnosis, Tim did not have another girlfriend. When he first moved down to Exeter he had a lovely girlfriend from Swansea who used to go and visit him. After being diagnosed with HCV he kept himself clear of others as he was worried about infecting girls through sexual contact.

43. A number of factors contributed to Tim's mental health issues, from his interferon treatment and pain in his ankles to the abuse he received from

his neighbours in Exeter. However, on reflection I feel that his HCV diagnosis was the final straw and triggered his mental illness.

44. Another issue that is connected to contaminated blood that I would like to highlight, GRO-C as a carrier of haemophilia, decided not to have children. She went to meetings about HIV/AIDS in the mid to late 80s when she would have been of an age to be thinking about becoming a mother. She knew of the risk of treatments for haemophiliacs. I think the effects of all of this on carriers of haemophilia has not been fully acknowledged. GRO-C suffered as a result of this when she should have been able to have children of her own but for the risk of contaminated blood products.

45. Phillip and I are close and we have stuck together throughout all of this. Our primary concern when Tim was young was for his employment prospects as they were hindered by his haemophilia, his eye damage and also dyslexia. Then, after his HCV diagnosis, we became increasingly worried about Tim's mental health. All of this was terrible to witness.

46. After Tim's death, Phillip and I found it extremely difficult. We didn't know how to go on. We both struggled for a long time and I don't think we will ever get over it.

Section 6. Treatment/Care/Support

47. I understand that Tim was initially refused interferon treatment by an ethics committee owing to the costs involved. However, he was later accepted for the treatment and I believe it was successful in clearing Tim's HCV infection. Though, I do not know this directly. Tim never told me personally. HCV is not on his death certificate and so it must have been cleared.

48. Tim received counselling and psychological support for his depression but not specifically in connection with his HCV diagnosis. He also spent

a fortnight in St David's Psychiatric Hospital in Carmarthen for depression in August 2003.

Section 7. Financial Assistance

49. Tim was informed about the Skipton Fund by The Arthur Bloom Haemophilia Centre at the University Hospital of Wales, Cardiff. The Arthur Bloom haemophilia centre wrote to Tim and intimated that they would support his application. We hold this (undated) letter in our records.

50. Tim applied to the Skipton Fund in July 2004 and received a payment of £20,000.

51. My son Christopher recently informed us of 'levelling' payments to bring payments for Welsh HCV sufferers in line with those received in Scotland. We may consider applying, not for ourselves but maybe for other family members to benefit. After all, they lost their brother and uncle. Tim should have had it before he died. We have also lost the son that could have helped us in our old age.

Section 8. Other Issues

52. I would like the Inquiry to establish what happened. Those people who knew what they were doing and did nothing, have got to live with it.

Statement of Truth

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

Signed GRO-C

Dated 26th August 2021.