

Witness Name: Terri Kuman  
Statement No.: WITN3326001  
Exhibits: [WITN3326002 –  
WITN3326005]  
Dated: 25 August 2022

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF TERRI KUMAN

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#### Section 1. Introduction

1. My name is Terri Kuman. My date of birth is  My address is known to the Inquiry. I live in  Surrey with my son, daughter and grandson. My husband, Cem Kuman, and I met in 1984. He died in 2010.
2. Cem developed Hepatitis C (HCV) as a result of one or more blood transfusions. He was diagnosed in 1994.

#### Section 2. How Affected

3. Cem was diagnosed with beta thalassemia major and began getting regular transfusions at the age of three [WITN3326002].
4. Cem and I met when he was 18, and at that time he was getting monthly blood transfusions. He was treated at Kings College Hospital. I started going with him to appointments soon after we began dating; he had initially tried to hide his thalassemia treatments from me.
5. Cem had several health conditions, including thalassemia, arthritis and diabetes. He managed his conditions diligently.

## HCV Diagnosis

6. In 1994, Cem was experiencing bad night sweats and had acute pain in his side. He was very in tune with his health, so he knew something wasn't right and requested to be seen at the hospital. Cem was then admitted through the haematology department because his temperature was so high.
7. When he was first admitted after about a week, doctors believed Cem had a kind of infection that came from sheep, which I believe was called klebsiella. After about a week I was getting angry because he kept having awful chest pains, it was actually his sugars dropping but we weren't aware of this at the time. However, while in hospital, doctors performed liver function tests and scanned Cem's liver, which showed he had an abscess. The abscess was drained, and a few days later he was discharged. Cem lost a lot of weight in hospital and he kept holding his chest like he was having a heart attack. Cem was in there for around a month and after about three weeks a doctor mentioned in passing that Cem had tested positive for HCV. It was then brushed under the carpet.
8. For a long time after his hospital admission, nothing happened. Cem knew one of the doctors from the haematology department as he was the doctor that measured Cem's iron levels in his liver (Dr Adrian Bomford) so we kept pushing, trying to understand what had made Cem so ill. Eventually, one of the doctors told us it was because Cem had HCV. Cem asked him what that meant for his life, and the doctor simply said that it was nothing and that it might not cause him any problems. The only thing the hospital did was arrange for Cem to have yearly liver scans.
9. No information was ever given to Cem about the risks of blood borne diseases through blood transfusions either before he and I met or during the time we were together. I know this because if he had been informed about these risks, he

would have told me. In fact, I asked Professor Bellingham at Kings College Hospital about any risks associated with thalassemia and blood transfusions before Cem was diagnosed with HCV because we were considering having children. He told us that as long as Cem continued managing his conditions well, he should live as long as me. Looking back, this would have been a perfect opportunity for him to mention Cem's elevated risk of blood borne diseases.

10. Cem was never given information on the cause of his HCV infection, either. He was never even told by a doctor that his HCV was caused by the blood he was given. He found this out through speaking with other people with thalassemia.
11. We were not informed about what HCV was, how to protect others from infection, or how to manage the condition at the time of Cem's diagnosis. I read a leaflet when he was on treatment and I was shocked; I had no clue HCV could be so serious. Cem would say it was like living on a ticking timebomb. I couldn't believe we had never been told anything about HCV by doctors apart from being told he could have Interferon treatment.

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

12. Before preparing this statement with my solicitors, I believed that Cem had only ever been infected with HCV. However, upon examination of Cem's medical records, my solicitors discovered that he was infected with Hepatitis B (HBV) in 1979 [WITN3326002]. I am certain that Cem was not aware that he had ever tested positive for HBV. Discovering so many years later that he had been infected with HBV and was never told just makes me feel more strongly that there has been a big cover up of this scandal, I don't even feel shocked anymore.

### **Section 4. Consent**

13. Cem – and Cem's parent's while he was a child - consented to him being given blood transfusions as he understood them to be lifesaving treatment for his thalassemia. However, Cem was not fully informed of the link between transfusions and blood borne diseases. He believed the transfusions were totally safe and necessary. The only risk he was ever made aware of was the reaction he could have if the blood was transfused too quickly.

14. I believe that Cem was also tested for HCV without his consent or being given any information. He definitely didn't know he was being tested for HCV because they just came back after 3 weeks and told us he was HCV positive.

#### **Section 5. Impact**

15. The impact of HCV on our lives has been huge. Of course, the most significant impact has been the loss of my husband, a man I had been with since I was 14 years old. However, even before Cem died, HCV ruined our lives.

16. Shortly after his HCV diagnosis (as a result of the liver abscess hospitalisation), Cem developed separation anxiety and could not go anywhere without me. I couldn't even leave him alone at the house, we had to do everything together. He made me his safe zone and couldn't manage being without me in case he had a medical emergency. Cem's struggles with his mental health are recorded in several letters contained within his medical records [WITN3326003].

17. In 2004, Cem went on Interferon treatment to clear his HCV [WITN3326004]. Unfortunately, the treatment was stopped because didn't work to clear the infection [WITN3326005], and it negatively impacted his thalassemia and his heart. While Cem was on treatment, he regularly ended up in resus. Professor Thein, one of Cem's doctors, told us Cem would die if he remained on treatment so it was abandoned and HCV treatment was not discussed with us again.



18. For a long period of time, we knew Cem had five nodules on his liver. No one ever explained what these nodules were or what it meant for him. In 2009, we were told Cem had liver cancer. He had three rounds of chemo. At first, we were told that the chemo had worked to clear the tumours in Cem's liver, but then it all changed.
19. Just before Cem was due to come home after a chemo treatment, we were told he had caught a superbug called c.diff. I took him home and shortly we got back, Cem's skin went yellow so I took him back to hospital. At hospital, they decided to give Cem a stent. After the procedure, I was told that Cem had sepsis. This information didn't come easy, I had to chase the doctor down the corridor and demand to be told exactly what was causing him to be so unwell.
20. Cem was taken to ICU that night (24 April 2010). He was then moved to a ward the next morning. I'd managed to go home for a quick shower when his mum called me and told me to rush back. When I arrived, he said "I'm dying" and I told him he wasn't. They called me in and they were trying to tell me what had happened, I asked if they could do anything and they said they could drain his lungs but it would prolong the pain. I didn't want him to suffer so I asked the doctors how long he had left and they said six weeks or six months. I just told the doctors I didn't want him to suffer. He died that night, on 25 April 2010.
21. I stayed in the hospital with Cem in the days before he died. He was eventually put on a ventilator so I had to sleep in the car park outside; he couldn't bear for me to be away from him even then. My cousin had been looking after my children, and she brought them to the hospital when we knew he was going to pass away. I worry a lot about whether it was right that I let my kids be there when their dad died.

22. What has happened to us has led to a mistrust of the government, the NHS and doctors. None of my family have had COVID vaccinations as we just don't trust the doctors or the government, I believe they lie. I never felt like this before Cem was infected, I would have just gone along with things like vaccines like a sheep. I just think if they're capable of what they did to my husband then what else are they capable of. The evidence is there in black and white and they still won't admit it. Even the way they cover COVID in the news, the government only puts out what it wants people to see. It is the same with the Infected Blood tragedy, they barely put anything about it out there. But I think if they ever give compensation they'll make sure it is plastered everywhere, they just put out what they want. I believe no one will ever be held accountable for this, I wish they would be. No amount of money will ever bring back my husband or undo what has happened to us.

Impact on myself and my children

23. Due to Cem's separation anxiety, I had to stay with him at all times. This inevitably impacted my ability to work, socialise and parent my children. Every time Cem was in hospital I had to stay there with him. It was very hard to juggle childcare during these periods.

24. I now have severe OCD and PTSD as a result of what we've been through as a family. I have always struggled with OCD, but it got much worse after Cem died, and my mental health has continued to decline since then. I take medication, but unfortunately my life is still very limited by my mental health. For a long time after Cem's death I couldn't go into any hospitals. Even now I struggle, and I try to do all appointments over the phone.

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27. Cem's health issues also impacted my children's schooling. They were off school for a year after he died. When they returned, they couldn't cope in normal classrooms. My  . I think they struggled to be without me.

28. My  to be apart from me. Even going through it when Cem was ill, it was so difficult to get her and her brother into school at the time. My anxiety is also through the roof on every single thing, I can't even get out the door. My  has to come everywhere, I can't go anywhere on my own.

29. I had no assistance from social services with my children while they were growing up. I haven't had support from family, either. I am very close to my mum but she could never really get her head around Cem's separation anxiety which meant I couldn't rely on her for emotional support.

### Stigma

30. I started visiting hospitals with Cem when we were teenagers, and most of our experiences were good. However, when Cem was moved to the hepatology department at Kings when he was diagnosed with HCV, it was a different feeling entirely. They didn't tell us enough about Cem's condition. The doctors were dealing with a lot of drug addicts at the time, and I feel he was treated as they were treated, with a lot of stigma from the doctors. In appointments I would announce that Cem had caught HCV from contaminated blood and would watch doctors' faces change.
31. Cem also experienced stigma from the Turkish community due to his thalassemia. He had no other family members with thalassemia, but it was fairly common within the community. Once at a friend's barbeque, a family friend said (about a man her daughter was dating) "I'm not going to give a daughter of mine to someone who's going to die from thalassemia". He knew he would experience worse if his HCV status was revealed. He did not tell many people about his HCV, just close family and friends he made in hospital who also had thalassemia and HCV.
32. He always felt worse about the HCV stigma than any thalassemia stigma. Once, when I was eight months pregnant, we were in a café in West Norwood and Cem had a diabetic hypo. When the ambulance came, the paramedic asked about Cem's conditions. I told him about diabetes, thalassemia and HCV. The paramedic then said "oh, I wish you told me before, so I could have put gloves on". He then asked if Cem had taken any drugs. He later apologised but incidents like that had a lasting impact.



## Finances

33. Cem's HCV had a huge financial impact. When we first moved to our current home, we considered buying it from the owner but we were unable to get any insurance due to his condition.
34. Cem was not able to work for most of his life because he was ill. He lost out on the chance at having a career because of his health. I also had to give up my work as a hairdresser in the late 1990s because it was too hard to keep working with Cem's appointments, care needs, and separation anxiety. I tried doing some hairdressing work privately, but it was impossible to maintain.
35. When Cem was on Interferon treatment, he tried to get disability benefit. He was so unwell the DWP assessor had to come and do the appointment at our home could barely hold his head up. The assessor declared him fit to work. That night he ended up in resus in A&E. We then had to go to the tribunal to overturn that decision and thankfully he was signed off work indefinitely. I am disappointed he was treated this way, and wish the assessor had known more about the impact of conditions like HCV.

## Section 6. Treatment/Care/Support

36. In 2007, Cem was referred for a short course of psychotherapy [**WITN3326003**]. The therapist tried to help him with his separation anxiety. Unfortunately, by the time his counselling was stopped, he was still unable to be without me, even for short periods of time. We really had to push to get him access to psychological support, and it was disappointing that it was stopped abruptly as he had significant mental health struggles and was getting a lot out of his therapy sessions [**WITN3326003**].

37. I was referred to IAPT talking therapy last year through my GP but unfortunately, I was told that I was not ready for therapy yet and so not a suitable candidate.

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

39. A long time after Cem's HCV diagnosis, a friend he met at the hospital came up to us and said "did you get anything from the Skipton?" He then explained to us what the Skipton Fund was, and we got the doctor to sign the forms for us. I remember it being a long process before we were approved. Cem received two lump sums from the fund. He didn't go on to receive monthly payments. I only managed to get monthly payments sorted a long while after Cem died, around the time that the Inquiry started. I never received any backdated payments for the period we were without them.

40. I feel it's wrong that Cem was not immediately put on the monthly payments after receiving the lump sums, and that we now cannot access any backdated payments.

41. Everything about the financial support schemes has always been very hushed. No doctors ever mentioned it to us, we had to find out on our own. Feeling like doctors were keeping things from Cem negatively impacted his mental health.

## **Section 8. Other Issues**

42. I want the people responsible for this scandal to be held accountable to try to heal some of the harm done. I see what happened to my husband as murder. My life has been ruined. My kids' lives have been ruined. These are the knock-on effects of Cem being given contaminated blood. I am not an angry person, but this makes me very angry. Cem tried so hard to manage his conditions and managed them well. What I find hardest is that people knew about the blood being contaminated and didn't warn him. I don't think that those people should get away with it.

43. I don't trust anything I watch on the news or what doctors tell me as a result of what happened to Cem. I feel that if they could do that to Cem, they can do the same to me. Maybe some kind of acknowledgement of the past could help me and others like me to move forward.

44. I want this scandal to be publicised better too. Not enough people know what happened to Cem and others who were given the infected blood. Their stories deserve to be told. This is why I would like to see a public acknowledgement of the harm caused.

## **Statement of Truth**

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

Signed .....  
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Dated ..... 25.8.22 .....