SUPPLEMENTARY

Witness Name: Linda Sanchez
Statement No.: WITN0230003
Exhibits: **WITN0230004-WITN0230007**

Dated: 22nd January 2020

INFECTED BLOOD INQUIRY

SECOND WRITTEN STATEMENT OF LINDA ANN SANCHEZ

I provide this further statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 January 2019.

I, Linda Ann Sanchez, will say as follows: -

Section 1. Introduction

1. My name is Linda Sanchez. My date of birth and my address are known to the Inquiry. I have provided a written statement to the Inquiry, dated 15 April 2019, in which I spoke about and on behalf of my daughter Victoria Sanchez. (See WITN0230001). She was infected with Hepatitis C ("HCV") at birth and passed away on 22 June 2019 in Spain. Her death certificate is exhibited in this statement **[Exhibit WITN0230004]**. The cause of death was acute liver failure.

2. I am providing this further statement in order to speak about the events which led to her death and the impact this has had on my family and I. I am also adding some details which support my

previous statement, some of which I have been able to remember since then and others that I held back to protect my daughter's feelings.

3. My daughter and I initially wished to remain anonymous in order to protect the privacy of our family but particularly that of my daughter. However, since she has now passed, I have asked for her and my identity to be disclosed, as I want her story to be told and for people to know about her life.

Section 2. How Affected

4. As previously stated, Victoria received a blood transfusion shortly after birth. Victoria spent the first few months of her life in a hospital and was allowed home in early 1975. However, it wasn't long before she was back in hospital. It was setback after setback, usually with unknown fevers, flu-like symptoms, listlessness, problems with feeding etc. Victoria was tube-fed on and off for most of her first year. During this period, she was close to death on many occasions. In fact, we had her christened in hospital, as we thought she was going to die shortly after.

5. Doctors had no answers as to what was causing those various problems, so she was referred to the Paediatric Liver Department at King's College Hospital ("KCH"), London. Obviously, they must have realised it was a liver problem, but I cannot recall this being discussed with us at the time. At this point, it was a case of monitoring and testing, and I was often asked to attend other clinics so that doctors could examine Victoria. She had at least one liver biopsy in this period. We were simply told that she had a "liver disease".

6. Victoria remained exceedingly thin as a baby and young girl with bouts of general ill health. It came to the point when she was put

on steroids (Prednisolone) as a last resort, to try to stabilise her condition. This went on for some time until I was told to gradually wean her off them.

7. In around the late 1970's, Victoria was diagnosed with non-A non-B Hepatitis, but I was never told this had anything to do with blood, or how this could be acquired. Nor was there any mention of the potential serious risk that it posed to her wellbeing. Unfortunately, as mentioned in my first statement, no records are available from either KCH or her GP for some unknown reason.

8. This pattern of monitoring continued throughout Victoria's childhood, with visits scaling down to eventually once a year. Victoria continued to have bouts of bad health which resulted in many hospital admittances for various infections. She remained thin with no appetite, suffered joint and bone pain at times and itchy skin, especially on her torso.

9. I do not know whether HCV was known or identified during this period. I suspect it was known of in the later years of Victoria's childhood from articles I have read, but we were not told anything at the time.

10. When she was referred to the Adult Liver Clinic at KCH, the treatments and liver biopsies became more intense and she was diagnosed with HCV. A liver biopsy at this time found cirrhosis was already affecting Vicky's liver.

11. Although we were not given much information on the infection or how to manage it, we were told to be careful of Victoria's blood, not to share toothbrushes and ensure cuts were quickly covered etc. This advice was a little late coming as we had already lived with the dangers for eighteen years!

12. We were never offered any test for HCV as a family. It was never suggested that we should have one and to date it has never been

discussed by Victoria's doctors. I suppose their stance was, it was up to us to ask for it and we never did. However, I believe we should all have been tested when Victoria was diagnosed, and closely monitored, as we had all been in physical contact with her without taking any preventive measures for years prior to her diagnosis.

Section 3. Other Infections

13. I do not have anything to add to my previous statement regarding this Section.

Section 4. Consent

14. I do not have anything to add to my previous statement regarding this Section.

Section 5. Impact

15. The mental and physical effects my family and I have suffered as a result of my daughter's infection with HCV and her resulting death are profound.

Impact before HCV diagnosis

16. I myself was little more than a child when I was put into the position, through no fault of my own but which we now know is through the fault of infected blood, of caring for my daughter through many years of illness, as I was only nineteen when she was born. Seeing her so close to death on so many occasions was extremely distressing for a young mother.

17. Throughout her childhood, I had to take her to Kings College hospital in Denmark Hill every month. It was a long journey from Kent. We did not have a car at the time, so the journey entailed

taking three buses which took two to three hours each way. This was very tiring for both of us, but we didn't have a choice.

18. These appointments always included blood tests. These are tricky with any child, but Victoria had very small veins, so it became very difficult for blood to be taken. As a result, sometimes doctors resorted to taking blood from her neck. This was very upsetting for her and I.

19. This way of life became normal for us, but it shouldn't have been like that. We should have enjoyed Victoria's childhood, but that was impossible. The contaminated blood had seen to that.

20. During this period Victoria also had a bone marrow test, which was extremely painful for a child. I do not recall the reason this was done, but presumably the doctors were looking for reasons for the problems she had.

21. As you can imagine, this whole situation was very stressful and mentally draining. It really was a lot for a young family to deal with.

22. We always had to be aware of what we could do in the way of activities, as we never left Vicky out and tailored things around her which were not strenuous. As a result, I think my son suffered a lot for being second place, as everything had to revolve around Vicky. Even simple family outings like cycling or dog walking were out of the question as Vicky never had any stamina. Consequently, we would avoid these types of activity as a family.

Impact after HCV diagnosis

23. When Victoria was diagnosed with HCV, we realised we had a major problem on our hands. It was very worrying to think that throughout her childhood, she had been, and still was, potentially capable of passing a very serious virus to family members and

friends. I felt so guilty, but decided not to tell anyone. As there was no cure at that time, it would have caused them too much worry and stress.

24. The risk of infection made us completely paranoid; even cutting Vicky's nails became a worry. We tried to make light of it for her sake but every scratch, paper cut etc., was a major headache. We worried about saliva as well, as I had read this could carry the virus. I understand now that this is a really small risk, but at that time I was worried about anyone drinking from her cup and sharing plates of food.

25. The fear of contamination did put an unintentional barrier up between us all. If Vicky picked up someone's glass and drank from it, I would say: "You have that one, Vicky, and I'll make X another drink". We always had to be on our guard for situations that arose. We tried not to make her feel ostracised, but it was a strain. At this point, we were also extremely worried about our son and not knowing if he could have been infected.

26. When we were offered a trial treatment, we thought we should take the opportunity for a cure, as we were well aware Victoria had had the virus for a long time by then. I remember that we were told it was the most difficult strain to cure.

27. As mentioned in my first statement, Victoria underwent several trials before clearing the virus. Each of them took a year out of our lives, between the length of the trials and the recovery periods. We were constantly in and out of hospital, with appointments at least once a month.

28. The trials were very difficult for her and for me. As her mother, it fell on me to have to inject my daughter and look after her when she couldn't even get out of bed. She suffered so much with having the injections, which were usually given in the fatty area above her

knee. They often resulted in tiredness, breathlessness, rashes, feeling moody and miserable. I also had to cut her beautiful thick dark hair short on the first trial. It never had a chance to grow again, because it went so thin with every trial. All of this was heart-breaking and difficult.

29. The last trial which eventually got rid of the virus was particularly harrowing, with Victoria suffering through some bad episodes mentally. She was so weak, wheezy and breathless that she couldn't walk without help; she was so tired all the time and had fainting episodes. Another side effect of the trial medications in Vicky's case, was a reaction to bright sunlight. We soon learnt to keep her out of the sun as a little exposure seemed to burn her skin bright red and cause a temperature. This went on for a number of years but did gradually improve back to normal.

30. We thought that, with the virus gone, it would be a question of convalescence and starting life afresh. How wrong we were.

31. Initially, Victoria regained a lot of her former "health", although this was never good health or even health as the average person would expect. Between 2012 and 2015, she was relatively well, although every little cold and infection resulted in a week in bed. Vicky was also suffering badly with extremely cold hands and feet with her hands being particularly painful. We still had to attend regular hospital appointments with the usual tests.

32. Victoria always wanted, and deserved, a "normal" life and it looked like this was now possible with the eradication of the virus. However, some aspects never changed. For instance, having children was never an option for her, as she was never well enough, and it was always a worry that the virus would return or would be passed onto her child.

33. In April 2015, Victoria said she felt unwell, so she went to bed early. In the early hours, she called out and I went into her room. She had vomited on the bed, but it did not look normal; it was what looked like a huge patch of brown coffee grounds. An ambulance was called and she was taken to hospital where she continued to lose blood. It turned out to be bleeding from the portal vein. She nearly died and had a prolonged stay in hospital. After this, she underwent "banding" on the vein several times.

34. Since this episode, her health went downhill with various problems, including extreme tiredness, anaemia, fluid in the abdomen, portal vein thrombosis and umbilical hernia, amongst others. At this time, it also became apparent that Victoria was suffering from hearing loss, which resulted in her needing hearing aids. When I queried whether the hearing loss could have been caused by her treatment, I was told that it was unlikely. However, I have since read an article by the National Center for Biotechnology Information website that this can be a side effect **[Exhibit WITN0230005]**.

35. The large number of tablets and injections she had, generally had an adverse effect on her health, even though they were necessary to maintain a level of health she could live with. For instance, I believe Victoria's teeth started discolouring as a result of her medication. Vicky seemed to be increasingly suffering with bruising. Any slight knock would turn into a massive bruise. Bruises seemed to appear for no reason as well. This may have been due to a low platelet count as Victoria had a very enlarged spleen.

36. She had to have regular MRIs and CTs, which were always harrowing, as we knew they were looking for early signs of cancer. The endoscopies were also very unpleasant and something Victoria dreaded. This was the story of her whole life: test after test, examinations, hospital appointments and more blood tests.

37. Obviously, Victoria could never drink alcohol. Although she got used to it, it was depressing for her to not have a drink when she met with friends, attended parties, holidays, family gatherings like weddings, christenings and other events.

38. Over the last two years, we had been very careful with her diet, which was low salt, not too much fluid, low carbs and more protein, amongst other things. In addition, she was only able to eat small amounts of food before it would cause "retching". This had always been the case, although we don't know the reason for this. It was depressing for her as she was able to enjoy the taste of food for the first time after clearing the virus.

39. As mentioned in my previous statement, Victoria developed ascites (swollen abdomen due to fluid in her abdomen). This was very upsetting for her. It was uncomfortable and embarrassing; people used to ask her: "when is it due?", as it did look like she was pregnant. The ascites also caused a number of painful stomach aches, which often meant she had to rest in bed. I think this enlarged stomach hindered her balance, as she recently had two nasty falls. One of them resulted in her cutting her nose open. She bled excessively due to the blood thinners she was taking, and therefore required several hospital appointments to dress the wound. This left a nasty scar.

40. The daily injections Victoria received into her stomach for her portal vein thrombosis were also a very unpleasant experience for her, as her stomach was distended due to ascites. Anticoagulation tablets were unsuitable as Victoria's platelets were so low. Her stomach became so black and blue that it was becoming increasingly difficult to actually get the injections in, but she bravely did it. Thankfully, after three months of treatment for her thrombosis, her platelets increased slightly and she was started on anticoagulation tablets at the beginning of June 2019.

41. A common side effect of cirrhosis and ascites is an umbilical hernia. Victoria suffered from this type of hernia over the last two years. She felt very down. It was quite prominent in the left side of her already swollen abdomen. Even though she was very petite, we had to start buying larger loose-fitting clothing in patterned material to accommodate her stomach and disguise the "lump" which was limiting and depressing.

42. Her doctors were well aware of her hernia and much enlarged spleen. **(Exhibit WITN0230007)** I asked if they could operate on her, but was told it would be too risky to do so in that area of her body. I regret taking this at face value at the time, and not really going into the reasons why it would be dangerous. I now blame myself for this, in case it could have changed the outcome. In fact, looking back, I realise that we were given no information of what situations could arise from her problems, or advice on how they should be dealt with in the case of an emergency.

43. Victoria's health seemed to be deteriorating, especially in relation to her ongoing tiredness and pain and, more recently, mental confusion. I made our concerns clear at every appointment. Nevertheless, the various doctors she saw never really responded to our concerns and a "watch and wait" policy was adopted. A letter from one of the gastroenterologists at KCH to her GP, dated 5 March 2019, states that Victoria was "well in herself" but that she had also been "given the red flags to attend ED ever in case of haemorrhage" **[Exhibit WITN0230006]**. Victoria had three-monthly appointments at KCH in addition to two or three weekly appointments at the Princess Royal hospital.

44. Despite all this, on a personal level, things were looking up and with the increased money from the England Infected Blood Support Scheme ("EIBSS"), life was looking more positive. With our help, Vicky had recently been able to move into a small apartment. I think

this was the first time she felt like she had a "normal" life and was so happy.

45. However, the contaminated blood has taken this promised life away from her. All of the problems which arose from her infection with HCV resulted in Victoria's death at the age of forty-four.

Events leading to Victoria's death

46. On the 20th of June this year Victoria went on holiday to Spain with her boyfriend. The hernia was a bit uncomfortable, normally it would settle but this time it did not go away and was causing her some discomfort on and off all day. In the evening, she started being sick. A doctor was called and she was sent to hospital. The hospital staff in Spain were made fully aware of her problems and were provided with her prescription list. Her partner was told that her platelets were very low. The hospital gave her a transfusion of platelets and said she needed an emergency operation, as the hernia had strangulated.

47. My husband and I took the first flight out and arrived shortly before they took her in for the operation. We went through everything with the doctor again. He said he would never contemplate an operation on someone with her problems but that they had to go ahead, as she would die without it.

48. Whilst waiting for the operation, she said to my husband: "I don't want to die, Daddy". I told her not to be silly, that she would be fine. We could never imagine that twenty-four hours later, she would be dead.

49. The operation seemed to go smoothly. She was carefully monitored all day and released to the general ward after twelve hours. We stayed with her until late and she seemed ok, just a little tired. The doctor told us she would be able to go home in two days. We were

so happy at this news that we left the hospital that evening, planning to stay on in Spain and finish the holiday with her.

50. When we arrived in the morning, we thought we would find Victoria well on the road to recovery, sitting up and having breakfast. However, this was not the case. As soon as we saw her, we thought she looked a little yellow, so we spoke to a nurse. The nurse said they had called a doctor, who arrived five minutes later. He said a liver specialist had been called, but that Victoria might have to be transferred to a different hospital (presumably with more expertise).

51. I asked Vicky if she had slept and she said: "Not much". I asked if she wanted to speak to Richard her partner and gave her the phone. She called him but she must have sounded strange, as he asked to speak to me again. He asked if she was ok. I told him she wasn't too well and that a specialist had been called. After this, Vicky said her legs felt numb; I touched them and asked if she could feel it and she confirmed she could, so I told her it must be dead legs from laying down for so long. A few minutes later she touched her head and said it felt numb as well. Within seconds Victoria started breathing deeply, so I called a nurse who took her blood pressure and immediately called intensive care. Victoria seemed to be turning more yellow in front of our eyes.

52. When the intensive care doctor arrived, within a minute or so, she looked at Victoria, then turned to us and said: "I don't think I can save your daughter". We were in such a state of shock; we couldn't take in what just happened. Victoria started rasping and was rushed away to intensive care, but it was all too late. The doctor explained that her liver had failed, which in turn had caused all of her organs to fail. She likened the failure of the liver to a bomb exploding throughout the body. This all happened within an hour of our arrival at the hospital.

53. Victoria died at 11am on 22 June 2019. To look down and see our daughter dead, her beautiful face and body turned the colour of mustard with liver failure, but with her beautiful brown eyes still bright, is a sight that will haunt us forever. We were and still are in utter shock and disbelief. She was dead within two days of leaving for her holiday. We could never have imagined the way it all unfolded so quickly.

54. Victoria was cremated two days later in Spain. We took our daughter home in an urn. My husband and I are desolate, broken hearted and inconsolable. We are also so angry. Why our precious daughter? We go to sleep thinking of it, going through every step. We then wake up still going through every step that led to her death and thinking we could have changed it - if only we did this or that or asked this or that...

55. It is a living nightmare and we spend most of the day in tears at the loss of our daughter and the injustice of it all. I still cannot think it is real, even though she died in front of us. I still think she is going to walk in the room. She used to ring or message me several times a day when she was not with us, so every time a message pings on the phone, I think it is her.

Section 6. Treatment/Care/Support

56. Despite the early damage to her liver and ongoing health problems, Victoria was never offered a liver transplant. Doctors at Kings had mentioned that it was something they may consider in the future but as I understand it, a place on the transplant list or a transplant is offered according to a MELD or UKELD score, regardless of the circumstances of your liver damage and Victoria was probably borderline. However, the Spanish doctor, who treated Victoria until she passed, said that she would be top of the list for a transplant in Spain, given her health conditions. Whether this was true is

unknown, but that is what he said. If this is true, it is another bitter blow for us that she was not offered a transplant in the UK.

57. Victoria, in my opinion, should have been offered a transplant as her condition could only go further downhill. There was obviously no chance of a natural improvement. Surely, she should at least have been on the list? However, nobody ever suggested it to us before March 2019. I believe she should have been on the priority list, as she was young and the cause of her cirrhosis was not her fault, but the fault of the NHS and Government. My family and I feel very bitter. She should not have been put in such a position. It should have been dealt with.

58. Essentially, the "waiting and watching" policy adopted by her doctors at KCH killed her. I would like answers as to what they were waiting and watching for.

59. I would like to comment on the medication prescribed for Victoria to treat her HCV. She was treated with various combinations of Alpha interferon, Pegylated interferon, ribavirin and telepavir. I understand that these drug combinations are no longer in use as they are now considered unsafe. In comparison to current treatments in relation to the duration of the course and the side effects experienced by patients, they are as different as night and day.

60. Perhaps more consideration should be attached to the suffering, both physical and mental experienced by those who underwent treatment with the old combinations of drugs. Indeed, it was not something that stopped once the course of medication was completed. For many, too many, the long-term side effects are still evident in their everyday lives – this was very much the case for Victoria.

Section 7. Financial Assistance

61. The financial assistance provided by the Skipton Fund and later the EIBSS was a great help towards everyday expenses as, up until then, we had funded ourselves. However, even as the payments went up, it would never have been enough to live independently in London. With her bad health and work incapacity, Victoria would never have been able to obtain a mortgage to finance the purchase of a home. In addition, obtaining assisted housing in London was impossible.

62. I also find it unfair that, as her mother and carer for over forty years, I am not entitled to any financial assistance now that she has passed. If she had been married, her spouse would be entitled to receive financial assistance from the EIBSS. I do not understand the rationale for this distinction. It makes me feel that Victoria's life is worth less because she wasn't married or in a civil partnership? Victoria was lucky inasmuch as my husband and I were always able to support her financially. However, this was of course at a cost to ourselves.

63. No amount of money will ever soothe the grief of losing our daughter. Nevertheless, I believe some financial help should be made available to those whose lives have been devastated through something that was no fault of their own.

Section 8. Other Issues

64. To lose a child is something no one can comprehend unless they have experienced it themselves. To lose a child in the way we have, after forty-four years of care against all the odds is so unfair. The contaminated blood killed her. It took forty-four years but it eventually killed her. It is manslaughter of the worse kind.

65. Victoria died in front of us and we could not stop it. No one should have to watch their child die in such a horrific way.

66. The outcome we have is so cruel. My daughter did not deserve to have her life taken and we do not deserve to have to live the rest of our lives consumed with guilt and grief.

67. My daughter was a beautiful innocent person who proudly spent nearly twenty years doing voluntary work at her local hospital, ironically the same hospital that gave her infected blood, as her health did not enable her to find a paid job. She was so brave. She was loved by everyone. She was tolerant and was well aware of her limitations, but was happy and content with the life she had.

68. Victoria had been through so much pain and anguish but she never really complained, she just tried to make the best of the situation. She should not have had to!

69. From this in June 2018;

70. to this in June 2019.

71. Forty-four years old. The Government must take responsibility.

Statement of Truth

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

Signed **GRO-C: Linda Ann Sanchez**

Dated 22rd January 2020