Not Relevant

Witness Name: Linda Sanchez
Statement No.: WITN0230001
Exhibits: **WITN0230002**
Dated: 15 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF LINDA ANN SANCHEZ

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

I, Linda Ann Sanchez with the input of my daughter Victoria Sanchez, will say as follows: -

Section 1. Introduction

1. My name is Linda Sanchez. My date of birth is GRO-C 1955 and my address is known to the Inquiry. I am a mother of two and currently live with my husband and daughter who has suffered with mild learning difficulties since birth.

2. I intend to speak about and on behalf of my daughter Victoria Sanchez, born GRO-C 1974 and her infection with Hepatitis C Virus ("HCV").

3. In particular, I intend to discuss the nature of her illness, how the illness affected her, the treatment received and the impact it had on her and my family's life together.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My daughter is also present to recall her thoughts and feelings on the events that took place and to assist with the statement. She has also provided a written statement.

Section 2. How Affected

5. My daughter was infected with HCV the day she was born. As she was born she suffered from a condition that required a blood transfusion, due to a Petechial haemorrhage. She had suffered from the condition when she was hours old and after was placed in intensive care.

6. She appeared to be relatively healthy for the first few months until suddenly, she became very ill. She started to suffer from one infection after another and was not eating. She was extremely thin and simply was not a thriving baby.

7. After a series of illnesses, she was admitted to the liver department at King's College Hospital in the early seventies; she was under them for all of her childhood. In charge of the department was Dr. Alexander Mowat, who later became Professor Alexander Mowat.

8. My daughter was continually monitored throughout her childhood. We seemed to be constantly at the hospital seeing various doctors but mainly under Kings College. Unfortunately, her condition was progressively getting worse. At this point my daughter was put onto a steroid treatment as the doctors didn't know what was wrong with. At one stage it was suggested that I may have passed something on to

her which, of course was very upsetting at the time. Obviously, we know now that this was impossible. They knew it was something to do with her liver and diagnosed non-A, non-B liver disease.

9. Even with the steroid treatment her condition only improved slightly. My daughter was extremely thin and caught one infection after another often resulting in hospital admissions. The hospital continued to monitor her but we were told that there was nothing they could do for her in the way of treatment.

10. This continued up until she turned 18 years of age and was referred to the adult clinic at King's College Hospital. In the early nineties she was tested for HCV. The doctors conducted a liver biopsy in 1993 which confirmed she had contracted HCV and that she already had liver cirrhosis which indicated that the virus had been present for many years to have progressed to cirrhosis in such a young person. My daughter was only 18 and she and us were in complete shock at this. I distinctly remember being told by Dr Tibbs that my daughter had between 5 and 10 years to live. This was devastating news.

11. At this time the doctor wanted to refer to her files from childhood but it seemed that her medical records from then were not to be found. Considering I had been taking her to Kings for nearly 20 years this seemed very strange. The doctor did mention they may have been destroyed in a fire. I have also seen her GP records and there are no reports on file from Dr Mowat. I am not sure why there would be no records on file considering she had been under this consultant throughout her childhood and she had many overnight and more prolonged stays in hospital during this time. Considering she has been in and out of hospital since she being a new-born and the number of appointments with Specialists, I find it very strange that there is such a limited amount of stored information from the hospital and the GP surrounding her treatments and the virus.

12. In 1993 we received a letter to confirm that she had been diagnosed with HCV. For the next ten years she underwent a series of drug trials in an attempt to clear the virus. We were given no advice on how to deal with HCV, information about the virus itself, its damning affects or any safeguards that needed to be put in place.

13. The first of these drug trials started in 1993 and the drug being tested was Alpha Interferon. Next, in 1994 my daughter was placed on Interferon and Ribavirin, as the Interferon alone was not working. In 2008 she started on another drug trial for Pegulated Interferon and Ribavirin. Again, this was unsuccessful leading to my daughter being placed on a placebo of Interferon, Ribavirin and Telepavir in 2009. During her final trial in the same year, she was placed on the actual injections of Interferon, Ribavirin and Telepavir, together which cleared the virus in 2010. Dr. Tibbs was her doctor initially and was in charge of her initial trial. Latterly, however, he was succeeded by Dr Agarwal who supervised the majority of her ongoing trials.

14. As her mum I had to inject my daughter with these injections. Depending on the trial it may have been daily or every few days. This process took place between 1993 and 2010. Each trial amounted to up to a year or so out of her life. The treatments caused her to loose so much weight she was like a skeleton; she would have skin rashes, lose her hair and experience severe mood swings. At times she was almost unrecognisable.

15. I can't describe how awful it is to see your child suffer and believe me, I have watched her suffer over the years. When she was on the trials it affected her not only physically, but mentally as well. The trials made her very depressed and it was hard for us as a family to deal with.

16. Once she had cleared the virus we thought her condition would improve but my daughter's health has become progressively worse.

Due to the number of years that she has had the virus, her liver has deteriorated to such an extent that she now has chronic liver disease and chronic cirrhosis. We are all worried about what the future holds for her health and unfortunately it is not looking good at the moment.

17. I have been asked if I was given adequate information to understand and manage the infection, I was told to be careful but at the stage she was diagnosed it was almost too late for that; her childhood was ruined. I do believe however, that there was not much information surrounding HCV at the time when she was first ill. I think that think that doctors did not know much about the disease back then. I think it was all relatively new.

Section 3. Other Infections

18. I do not believe that as a result of my daughter being given an infected transfusion that she has contracted any infection other than HCV. However, I do believe that as a result of her infection she has suffered from a series of other illnesses, which have severely impacted her life, this includes liver cirrhosis. The damage to her liver is so severe that she may have to have a liver transplant in the near future.

Section 4. Consent

19. I have been asked if my daughter was ever treated or tested without knowledge or consent and the answer is no, we have always consented to the treatments.

20. However, it is my belief that we were not fully informed of the risks associated with the transfusion or the consequential treatment.

Section 5. Impact

21. The mental and physical effects my family and I have suffered as a result of my daughter's infection with HCV were and still are profound. During her last treatment to clear the HCV, one of the side effects was depression and aggressive behaviour. This behaviour became so bad that she was referred to a psychiatric doctor. They wanted to stop her treatment at this point. I had to persuade them not to and we would handle the side effects. I knew that we were coming to the end of the line health wise and this may be her last chance. We were desperate. Thankfully, this was justified as my daughter did clear the virus shortly after.

22. As my daughter's parent this was the life that I am used to, I do not know any other life.

23. HCV has led to other serious medical conditions for my daughter. Since the age of nineteen she has suffered from cirrhosis of the liver. This has led to a variety of problems including Portal Hypertension. I recall a time in April 2015 when my daughter started to bleed aggressively, I went into her room and there was blood was all over the bed. The blood on the bed was like coffee brown; I called the hospital immediately and shortly after they arrived. When we went to the hospital they realised it was internal bleeding, this required her to have another blood transfusion. We all, including my daughter thought she was going to go. Can you imagine the sheer worry, stress and anxiety that comes with this sort of situation for her and for us as parents?

24. Except for the transfusion when she was born, this is the only other transfusion that she has had.

25. At the present time my daughter is on monthly check-ups, during her childhood it was every two to three weeks. Back then there was no

transport and it was difficult to travel. It took away her childhood and my chance to experience her childhood. She is now left with cirrhosis and things are a lot worse. It dominated her childhood completely. She has to have an MRI scan every six months with CT scans in-between. They have to check the nodules and growths on her liver to make sure that they are not growing. Now she suffers from a bloated stomach due to water retention, for this she has to take further tablets. There is a huge amount of tablets. The doctors just keep upping her doses.

26. My daughter has also developed a blood clot which has been diagnosed as Portal Vein Thrombosis. We now have to start anti-coagulant treatment which entails further injections into her stomach. This is extremely difficult. I will have to inject her daily. As she has a low platelet count she is unable to have anti-coagulant tablets which are now available.

27. Additionally, has a very large hernia on her stomach caused by the ascites and cirrhotic hard liver pushing the organs forward. We have been told that this cannot be operated on as it would be very dangerous due to the portal hypertension in the same area. This is another thing that we now have to continually monitor. We continue to deal with anaemia for which she now takes Ferratin. My daughter is also having fortnightly blood tests to check her kidney function as she is on Fuerosimide to control the ascites. Just to support her liver she has a daily cocktail of tablets.

28. We believe that all of these side effects are as a consequence of her liver cirrhosis, which was caused by her infected blood resulting in HCV.

29. In 2010 when the drug trial had cleared the virus we thought that the stress would be over but it continues unabated. Hospital after hospital, treatment after treatment. It is never ending, you can never

enjoy life, you can never book a holiday and it always revolves around clinics. We always have to be wary to plan around my daughter's treatments.

30. When we were told my daughter had been diagnosed with HCV it was a very worrying time thinking about my son and people she had played with as a child. What if they had been infected?

31. My husband and I have never been tested; we did not see the point back then, as there was no cure. This is the impact of contaminated blood. It makes me think what if clinicians knew about the risk of contamination. If they did why use it on new-born children?

32. We did not know back then about any contamination and never received any advice. Perhaps we could not have been told back then, as they were unsure of what the virus was or its effects, but I have since heard that there were suspicions that they knew.

33. Our life has revolved around hospital appointments, illness, sleepless nights, worry and the time required to see to my daughter's day-to-day needs. I have had no enjoyment in a lot of things; my son has been partially neglected because our lives have revolved around my daughter, due to her condition and the subsequent treatments. It is not stopping even now; the next step for her is a liver transplant because she is getting to the end stage of her liver disease.

34. The impact it has had on our family life is far-reaching. We have never discussed the infection with anyone, not even my son. It has been really draining; I was always worried about the risk of infection, especially during dinner. In the back of my mind, I would always hope there were no leftovers on my daughter's plate that her brother would want to eat. I was always worried about saliva, back then there was not much information available, so I was constantly cautious about the potential spread of the virus. My next big worry was when my son had

a child and the risk of infection there. Luckily, by this time she had cleared the virus.

35. My daughter has had many opportunities taken away from her; she cannot drink alcohol and feels embarrassed by this. This has impacted her social life, as she does not go on nights out

36. My daughter or us as a family was never subject to stigma, as we never discussed the infection with people. She did tell her close friends but back then, there was such little information that they did not fully understand.

37. My daughter always went to a special needs school so her education was not affected. We did not find out about her infection until later so her school could not have been informed.

38. With regards to work both my daughter and I have been massively impacted as a result of her infection and consequential treatment. She has never even been well enough to have a permanent job. She cannot even shelf-fill in a supermarket because of her lack of strength. She has always been very weak. She has been able to partake in volunteer-work four days a week at a local hospital. I encouraged her to do this so that she feels useful and remained active.

39. Apart from this, she has struggled to find a job with the only employment she has had being at the Benefits Agency. However, they eventually let her go because she could not keep up with the workload due to regular absence whilst attending her hospital treatments. It is very cruel that not even the government can find her a job.

40. My work has also suffered greatly. I have had to leave two jobs because of my daughter's infection, I could not commit to full time

work because of all the treatments. I used to be a legal secretary. My daughter was on and off drug treatments for ten years, so I had to make sure that I could be there for her. I worked extra hours or on my lunch breaks just so I could take days off, to ensure I was there for her treatments. We would have to be at the hospitals all day from 12pm to 5pm; it just drags you down. The doctors act causal, it might be normal for them but it is not normal for the average person.

Section 6. Treatment/Care/Support

41. We have never had any problems in obtaining treatment for my daughter from hospitals, doctors or dentists, the dentist was aware of the infection but we never encountered any problems. I must say that whenever the drug trials came out she was always one of the first to go on them, although this may have been due to her youthfulness.

42. I can confirm that in the past we have never been offered psychological support or made aware of such support in relation to my daughter's infection. There was no specific support for her or for those close to her and affected by the circumstances.

43. I can also confirm that during my interview with the inquiry, we have been informed about the access to the support mechanism that the British Red Cross provide.

Section 7. Financial Assistance

44. Originally, we were never told or knew about any available financial assistance. One day my mother saw an advertisement for the Skipton Fund and notified us. I applied for an ex-gratia payment through them on 2 September 2004, for £20,000, which was accepted. I thought that she would qualify for stage two so I also submitted an application; this was also accepted. There may have been pre-conditions in order

to receive the payments, but I cannot remember exactly what they were. I cannot recall the size of the Stage two payment.

45. Through the England Infected Blood Support Scheme ("EIBSS"), my daughter receives around £18,000 as of April 2018. Initially, this was a lower payment of £12,000. She also receives a monthly top up of £100 from EIBSS.

46. My daughter is lucky that she has had support from my husband and I. If you had no one to help financially the money from the Government is not enough. If you cannot work through no fault of your own but that of the NHS at the time, why should you have to live on the breadline?

47. It is hard enough managing the virus and all the life-changing consequences it carries without having to worry whether you can have the heating on. My daughter is lucky that we have supported her but this has come at the cost of my family losing out financially due to the extra costs involved in providing necessary support for my daughter over the years. I also feel that there is not enough compensation for the lives that have been lost and affected.

48. What price is put on life-long bad health, suffering both mentally and physically, just being able to live a normal life? All through no fault of the people that have been infected via NHS blood transfusions. I appreciate that no amount of money can change the past but it can change the future for those in question and have a great impact on their quality of life for whatever time they have left. I ask; 'What price is put on this'?

49. I feel that in order to receive these payments, we were always the one's having to apply. It always down to us to get the forms and the GP's to sign and fill out the forms. We were never informed of any potential payments or support, if my mother had not told us, we might

have never known about the Skipton Fund. If I had not have applied we would not have received a penny.

50. There is no money that can be put on a life of upset, trauma, depression and worry; there is no price you can put on that. My husband and I are getting older now and I worry who is going to look after my daughter. This is where compensation can really be useful as we can set things up for her.

51. I would further like to state that I feel it is very unfair that Scotland gets double the payments that we have received in England. My family has always lived in London and things are terribly expensive. It is wrong, it should be a level playing field across the entire United Kingdom.

Section 8. Other Issues

52. Finally, I would like to add that my daughter - and I as a prospective grand mother to her child – missed out on the opportunity to experience the joy that should come with a normal family situation. My daughter could have had a family of her own as did many of her schoolfriends if she had had the health and without the worry of passing the virus to a child.

53. She never had the chance to meet someone due to a life of almost continual illness and the consequential treatments, stemming from that transfusion given to her as a new-born baby. This caused my daughter a great deal of distress, sadness and upset. You can never replace these missed opportunities or the sense of emptiness they leave.

54. I have attached a letter **[Exhibit WITN0230002]**. It gives the dates on which diagnosis was made for both the HCV and cirrhosis of the liver.

55. **Not Relevant**

Statement of Truth

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

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

Dated 15 April 2019