

Witness Name: Paul Harry Leah

Statement No: WITN3018001

Exhibits: 0

Dated: May 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF PAUL HARRY LEAH

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I, Paul Harry Leah, will say as follows:-

#### Section 1. Introduction

1. My name is Paul Harry Leah. I was born on [GRO-C] 1970 and I live at [GRO-C]  
[GRO-C] Cheshire, [GRO-C]
2. I make this statement regarding my younger brother, Daniel Philip Leah, who was born on 23<sup>rd</sup> September 1971 and died on 19<sup>th</sup> August 1992, aged 20 years old.
3. My mother, Margaret Madden, has also made a statement, which I refer to as 'WITN1364001'. I also have one elder brother, [GRO-B]
4. This witness statement has been prepared without the benefit of access to my late brother's full medical records.

## Section 2. How affected

5. Daniel was a severe haemophiliac. I believe his haemophilia was explained to me when I was about 7 or 8 years old. I always knew Daniel was poorly since he was a child but did not really understand what was wrong. My brother, [GRO-B] and I used to get into scraps as children but we knew we had to be careful around Daniel. I remember Daniel being very frustrated about his haemophilia, breaking down and crying about not being able to join in in the games that my brother and I would play, such as climbing trees or play fighting. Daniel would want to join us when we played but, often, we would not let him as we did not want him to get hurt.
6. The three of us brothers shared a room but had different beds. I remember Daniel regularly waking up in the night in a lot of pain and crying quietly trying not to wake me or my brother. He would be holding onto whatever was hurting him (such as his arm or his leg), rocking backwards and forwards crying to himself; he suffered in silence for the sake of his family.
7. A simple knock or fall could lead to a bleed in his joints, which meant very regular visits to Pendlebury Children's Hospital (PCH). My mother used to take [GRO-B] and I with Daniel in the car whenever she took him to hospital for a bleed, which would happen about twice a week.
8. At PCH, Daniel was given Factor VIII Concentrate (FVIII) to treat his bleeds. He later started to receive FVIII at home. I remember being taught how to administer FVIII to him when I was as young as 7, mixing liquid with powder, putting on a tourniquet to pump his veins up, putting the solution into a syringe, checking for air bubbles, before injecting it to him. The FVIII was kept in the fridge at home. Daniel probably received FVIII almost every day. At the time, this treatment seemed fantastic, as it meant fewer hospital visits, but it was frightening to administer. I was more scared to inject him than he ever was receiving it.
9. In or about 1982, when Daniel was 12 years old, he had knee operation which was complicated by Daniel's haemophilia; during the operation he lost a

significant amount of blood. I was told that, during the operation, he had "died" on the operating table but the doctors were able to revive him. Daniel recovered quite well after his operation. He was having FVIII and blood transfusions at the same time. We thought that, after this operation, Daniel would be able to walk and run and live as much of a normal life as he could.

10. I do not know exactly which FVIII batch infected Daniel but, in my mind, I have always believed that he was infected during this knee operation. I believe this because, although he received lots of FVIII throughout his childhood, he received a particularly large amount of blood products during and after this operation. There is no way I can know that for sure, but that is the way I have always seen it.
11. I think it was around the time of this operation that I started to notice that my parents were constantly arguing and fighting. Being young, I just switched off to it and hid out of the way. Now, I believe that the strain on their marriage was caused by their having to deal with Daniel's health problems. These marital issues eventually led to my parents splitting up and my father moving out. When this happened, I moved in with my father whilst Daniel and GRO-B stayed with my mother.
12. Before being diagnosed with HIV, my brother was very ill for some time with large red scabs all over his chest and torso; I remember the doctor told us it was chickenpox. It was my mothers' disagreement with the doctors at PCH over this diagnosis that led to my brother being taken to Newcastle General Hospital for a second opinion. He remained under the care of Newcastle General Hospital for the rest of his life. It was there that he was diagnosed with shingles. At the time, we did not know it but this was brought on by Daniel being infected with HIV.
13. My mother then went to live in Newcastle, where she had nowhere to live and ended up living above a pub. She did this so that she could be nearer Newcastle Hospital, where Daniel was being treated for his Haemophilia. I

remained with my father in Manchester. After my mother and brothers moved away, our relationship became more distant but I would regularly visit them.

14. In or about 1985, when I was around 15 years old, both my parents sat me and [GRO-B] down after one of Daniel's hospital appointments. We were told that Daniel had the AIDS virus. At the time, I had no idea what AIDS meant.

15. I found out that Daniel had Hepatitis C some time later. I believe the doctors were trying to drip feed us information about the infections rather than just telling us everything at once.

16. I do not believe that my parents were given any information or advice beforehand about the risk to Daniel of being exposed to infections from contaminated blood products.

17. I do not believe my parents were given adequate information to understand and manage Daniel's infections either.

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

18. I do not know whether Daniel had any other infections.

### **Section 4. Consent**

19. I believe that Daniel was treated and tested without his and my parents' knowledge.

20. I do not believe that Daniel or my parents were given adequate information about the products he was using. The medical professionals never gave him options; my parents just took doctors' advice as it was given. The doctors pretty much did as they pleased.

21. I feel as though Daniel was used as a guinea pig. I believe that he was tested on, although I have not seen medical notes which confirm this.

## **Section 5. Impact of the Infection**

22. The news of Daniel's infection with HIV had a great affect on our relationship as brothers. Growing up, my brothers and I had shared baths, food, drinks and clothing. When we were older, we shared the same bottles or glasses of alcohol and we also shared cigarettes. Things were completely different after Daniel received his diagnosis with AIDS, as I was told that Daniel's condition was very infectious. I was told to stop administering FVIII to Daniel in case I came into contact with his blood and, from that point our relationship was affected as I did not want to share anything with him.
23. Looking back, I feel incredibly guilty for how I reacted to Daniel's infection. I was scared to even touch him as I was frightened of catching it. As a result, there was always that barrier between us.
24. There was an enormous stigma surrounding HIV at the time of Daniel's diagnosis which affected the whole family. I believe my parents told a few people in our area about Daniel's infections and I began to notice that everyone was avoiding Daniel and the whole family. Parents would not allow their children to mix with us. I used to feel like people were always looking at me and talking behind my back. Even the teachers at school treated me completely differently; an example of this was that I was made to sit on the floor for school pictures when all my classmates were allowed to stand. Soon I had no friends at school at all.
25. At its worst, the stigma in our local area was so bad that my parents' properties were actually vandalised and we were subjected to outright harassment. We had red crosses painted on our front door on numerous occasions. On another, our windows were smashed during the night, waking us all up. We received many nuisance phone calls at random times of the day and night. People would also send all sorts of tradesmen to our door when we hadn't requested them: taxis, fire engines, carpenters, even undertakers. I believe they did this to bother us and try to drive us out of the area. Both my



father in Manchester and my mother in Newcastle were subjected to this treatment.

26. After Daniel's diagnosis with AIDS, I began to act up and went off the rails. I started to get into fights in and out of school because I was so fed up. This led to me moving out from my Dad's house and moving in with my mother and brothers as I needed a new start. Unfortunately, after years of living away from my mother, our relationship had deteriorated significantly. I also had difficulty fitting in at school near my Mum's house. In the end, I moved back in with my father.
27. Daniel's infections had a profoundly negative impact on his mental state. Growing up was already very hard, what with the severity of his haemophilia. The discovery that he also had HIV and Hepatitis C was devastating.
28. I know that Daniel was taking some tablets for the HIV but I do not know what they were. He was receiving the treatment at a hospital in Newcastle. Whatever treatment Daniel was receiving, made him violently ill. He was sick all the time, had headaches and no appetite. I believe it was a trial drug that they were experimenting on him. He was at home with an oxygen tank. He was dying.
29. Daniel also suffered physical effects as a result of his infections; after he was diagnosed with HIV, he began to suffer from recurring shingles and had the most horribly painful sores all over his body; they would cover the whole of his torso and be very painful for him. It was difficult for him to carry on living a normal life.
30. I would regularly travel from Manchester to Newcastle to visit my mother and Daniel. As time went by, from about 1987 onwards, I would notice Daniel's health begin to deteriorate. Every time I saw him, he looked thinner. His cheekbones started to stick out and he became very bony. Towards the end of his life, he was almost like a skeleton and needed to use an oxygen tank to breathe.

31. Shortly before 19<sup>th</sup> August 1992, I visited him for the weekend at my mother's house for what turned out to be the last time: he was the thinnest I had ever seen him.
32. In the early hours of 19<sup>th</sup> August 1992, days after travelling back from spending the weekend with Daniel, I was staying at a friend's house in Manchester when I received a call from my girlfriend Nicola. She told me she had received a call from my mother who had told her that Daniel had died. I was shocked as I had been with him only days before. When I realised it was true, I was mad with grief. I got into the car, collected Nicola, and we travelled together to the hospital in Newcastle. When I arrived, I went into Daniel's room to see him lying there almost like he was asleep; his eyes were open but there was no twinkle. My mother and her friends were all there, and we stayed until we were made to leave by the hospital staff.
33. The doctors at the hospital referred to my brother as a 'body', which I found very upsetting. They told me that his body would be dropped off at home that night. I asked which home, and they said 'Stockton', not Manchester which is where he had grown up and which he always felt was his home. Later that night, the van arrived with Daniel in it. They carried him in and put him under the window like a window box. We could not even open the coffin because it had been sealed shut; I believe that this was to prevent the risk of anyone coming into contact with his body and catching HIV.
34. I decided that I wanted to make sure that Daniel was taken home to Manchester so he could be buried there. For that reason, I measured the coffin, measured my mother's car and managed to fit Daniel's coffin into it. I had to remove the back seats to do so. We then set off on the 219 mile drive home and took him to my father's house. After that, my mother arranged everything else as per Daniel's wishes.
35. Daniels' infections and subsequent death had a huge impact on me physically, mentally and emotionally on my private, family and social life. I feel now like my life has been a complete waste of time because my brother is

dead. My life was ruined by his death. After he died I turned to drink and my life fell apart.

36. My son was born in 1991 when I was 21, just before Daniel passed away. Nicola, my wife, later gave birth to our daughter. If I did not have Nicola and my children, I do not know what I would have done with myself. It was only the fact that I had a family to look after that has made me get back on track.

37. My children do not know about what happened to my brother. I have kept it from them as I do not want them to know how hard it has been for us as a family. I feel like the stigma carried on after Daniel's death and I do not wish people to know I am the brother of the person who died of AIDS.

38. Daniel's condition has truly affected my life and still affects me until now. I wish that I had died instead of my brother. All of this has been shut out of my mind because it hurts me and upsets me to think about it.

#### **Section 6. Treatment/care/support**

39. I have never received any counselling or psychological support. I just switched off everything regarding Daniel's death in my head and everything he went through and moved on. I have not spoken to many people about it.

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

40. Daniel was involved in the 1991 litigation and received some money. I do not remember how much he received but I felt as though it was hush money at the time.

41. I have never received any financial assistance arising from Daniel's condition and, as far as I know, neither have my parents.



## **Section 8. Other Issues**

42. I loved Daniel no matter what and AIDS took his life away. His condition tore our family apart. The loss of my brother has ruined my life.
43. No amount of money is going to bring my brother back. I believe the government should be held responsible and whoever caused this should go to jail. They must answer for what they have done. This should never happen again.
44. I want justice for people who were affected by this scandal. I want this inquiry to bring closure for everyone that has been affected.

## **Anonymity**

45. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the inquiry.
46. I do not mind giving oral evidence to the inquiry.

## **Statement of Truth**

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

Signed.....

**GRO-C**

Dated 22.5.19