Witness Name: Laura Jane Gould
Statement No: WITN1657001
Exhibits: 0
Dated: October 2019

INFFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LAURA JANE GOULD

I, Laura Jane Gould will say as follows:-

Section 1. Introduction

1. My name is Laura Jane Gould. My date of birth is the GRO-C 1980 and I live at GRO-C with my husband and two daughters GRO-C 13, and GRO-C 11. I am employed as an Administrative Assistant at a special needs school.

2. This impact statement is made in relation to my older brother, Stuart Michael Blake, (Stuart) who was born on the GRO-C 1978 and died on the 29th May 2006 at the age of 27.

Section 2. How Infected

3. Stuart was diagnosed with severe Haemophilia A at the age of 13 months. As a result he was treated with blood products and contracted Human Immunodeficiency Virus (HIV) and Hepatitis C (HCV).

Section 3. Impact

4. When I was born Stuart had been diagnosed with Haemophilia and I was not very old when Stuart was diagnosed with HCV and HIV. So I do not remember not knowing, I always knew Stuart was unwell, I do not remember being told about Stuart's illness; I only remember always knowing of it. I did not understand what his condition meant or the impact on our lives as I was too young at the time. HIV means nothing when you are 6 or 7 years old.

5. When I was young, I spent a lot of time at Great Ormond Street Hospital and later at the St Thomas' Hospital because of Stuart's illness. My peers were involved in activities whereas I spent a lot of time at hospitals, a lot of time in a train or car or taxi or so it seemed.

6. Stuart also did not get to do many things that his friends were able to do, such as cricket, rugby or football due to the Haemophilia.

7. When we were in primary school mum came with us to ensure Stuart was fine and whether he needed any injections. Also if Stuart was involved in an activity trip or holiday organised from school I would go a long as well with Mum and Stuart. This was because Dad had to work so there was no one to look after me. She was the only one who could treat him for his Haemophilia, due to the precautions that were needed to be taken due to his HIV and HCV, no one knew of his condition. It was a different childhood.

8. As a teenager I was not one to cause trouble, I had to be quiet and good as my parent's attention, quite rightly, was on Stuart. This was just how it was, it wasn't a conscious decision. I believe that if this was not the case, I could have become a different person.

9. My parents were amazing, growing up I did not understand the full impact of his condition because they were very protective and tried to prevent Stuart's condition affecting me. For example, we were not allowed to watch certain episodes of 'EastEnders', as the story line involved a character with Acquired Immune Deficiency Syndrome (AIDS). They tried to protect us from the negativity and stigma.

10. It was not until I started hearing about HIV and AIDS on the news and in the press that I began to understand the severity of Stuart's condition.

11. Stuart's condition remained private, it was never revealed to anyone outside our immediate family, as it was his choice whether to tell anyone or not, it was his news to tell. I never even told my boyfriend (now husband) who was one of Stuart's friends about it, it was Stuart who told him when Stuart was ready to do so; he took him to one side and told him. However when Stuart's health declined towards the end I had to tell my employer, with Stuart's permission, as I needed their support when I was visiting him in St Thomas' Hospital

12. Stuart went through a very cross stage in his teenage years, he was very angry and distant as well as rebellious. It was very bad at times, and I recall one specific instance, when he attacked our mum because of his anger. That was very hard to watch.

13. He also hated school, he didn't see the point of it due to the uncertainty of his illness and how long he would be around, he did not think that it was important for him to get any education. To him it was a waste of time and energy even though he was very clever but he wasn't academic. He always felt different and he didn't like that.

14. When we went on holiday, he always had a bag full of medications and letters from the doctors to take with him, which he found embarrassing, especially when bags were searched at security. It was also distressing, as he did not want people to know about his condition, but the medications made it obvious that

there was something wrong with him. He never went on a 'lads' holiday because of this.

15. In the late 1990s when Stuart was in his early 20s he had a mini stroke at our family home. I was bedridden with flu and an ambulance was called. I remember vividly having to flag down the ambulance while very poorly with the flu. He was put in a horrible ward, away from everybody and it was always like that. The medical staff would not take proper care of him; they were frightened of him and the care was not personal at all.

16. In about 2000 or 2001, when I was in my late teens or early 20s, Stuart had his second mini stroke/seizure at night. I was looking after Stuart at the time as our parents were in Australia as our father had a contract to work there. Stuart lived in his own flat but he didn't seem very well that day. My grandparents had visited him and said he didn't seem right so I told him to come and stay with me that night. I called an ambulance as Stuart couldn't speak he was just making very strange noises and his eyes were wide and terrified. The ambulance took us to the local emergency hospital rather than his treating hospital St Thomas'. They didn't believe me when I was telling them he had had one of these episodes before. I am certain they thought he had been taking drugs or had drunk too much.

17. Once the staff at the hospital found out he was HIV positive; they were very disrespectful they did not want to have anything to do with him. They did not want to help him and they treated him dreadfully. I tried my hardest to get them to listen to me and to contact St Thomas' for his records. We were waiting in casualty and I asked them to take him to St Thomas', nobody paid attention to him until he had a serious nose bleed and all hell broke loose. His blood splattered everywhere. At that point, I became very cross with them and I told them to give me gloves so that I could clean up the blood. I didn't want them anywhere near him; they were worried about the blood, not Stuart.

18. He was eventually transferred to St Thomas' but they put him in a room in the mental health ward on the top floor, which was very unpleasant and distressful, There were also signs over the door to his room advising that protective clothing must be worn at all times and there was constantly someone screaming or shouting out due to their mental illness.. I do not believe that he should have been treated like this. It made me very angry as he was only poorly due to an infection given to him, he should have been treated better than that. He was there for a couple of weeks and I had to come in and wash his hair, because the staff would not do it for him. He was a young lad who was there through no fault of his own.

19. I believe everyone assumed that he was a drug-user, and that is how he contracted HIV, which was very unfair. Either that or that he was gay; stereotypical views.

20. I went with Stuart on a number of general appointments, it was normal going to the hospital and attending appointments, we spent a lot of time there.

21. When our parents were living in Australia, Stuart went to visit them for six weeks. He really enjoyed it, but it was also rather stressful, as he was not able to obtain travel insurance because of his condition.

22. Thankfully, I had the opportunity to have Stuart at my wedding, which I was very grateful for. He was an usher but he had to wear different, more comfortable clothes, linen, which made him stand out from the guests. Clothes hurt his skin, so he didn't want anything too tight or stiff. He also used to get very hot. During the wedding I had to make sure that the photographer took pictures of him and me together, because it was unlikely he would be with us much longer, so it was important for me to have the picture as a memory when he was gone. It was really upsetting for me, as this is not something that a bride should be thinking of on her wedding day. I treasure that photo.

23. Stuart was a brilliant golfer, regardless of his illness, I used to caddy for him. Also my eldest daughter and I are learning to play golf in memory of him. I find it very hard knowing that we will never get the chance to play with him and have that bond with him.

24. Stuart was also a football fan, an Arsenal supporter but he had only watched them on TV with Dad. The Willow Foundation charity arranged a ticket for Stuart to attend an Arsenal match however, he never got to go and enjoy it as he was too poorly to go. He was in a hospice at that time. Bob Wilson did come to visit Stuart at the hospital though.

25. The period of time before Stuart's death was particularly difficult and distressing for me, as I witnessed the extent of his mental and physical decline. The illness affected Stuart's brain and he became more childlike and lost some of his bodily functions; not something you should see your big brother go through.

26. I recall one time that we attempted to take Stuart to the town for a walk. I had to hold him by his arm because he was so frail and at times he would shout because his illness affected his mental health. It was difficult for all of us, because we wanted to enjoy the time with him as a family.

27. He had carers visit him at his home as he wanted to live independently but these were just strangers.

28. Everything went downhill when I was pregnant with my first child. I gave birth in GRO-C 2005. I was so grateful Stuart managed to hold on to see her. The pictures of him meeting her are precious but you can see how very poorly he was. Stuart's health deteriorated and he was admitted into hospital in January 2006.

29. The hospital was awful. The staff did not take proper care of him. They were not even able to position him properly on the bed, so they left him without caring about his comfort. He was unable to lift his head up. He was later moved to the

Isabel Hospice in the Welwyn Garden City which provided great care. It wasn't straight forward getting him transferred there as they were used to dealing with patients with cancer, not his illnesses. However we fought for it and they took him in. he never wanted to go into a hospice as he knew what that meant; death. However, once he was there the care was wonderful and he was able to relax. They were able to see him as a special case and understood the need to treat him so.

30. At the time, I was suffering from a combination of having postnatal depression and anxiety caused by the worry of my brother's health. I visited him at the hospice daily, which is not something a new mother should do. I feel guilt for not being the best mother for my daughter during that time, whilst also not being the best sister for my brother.

31. Watching Stuart die was horrific. He was my big brother. It was a slow and very painful decline to death and we could do nothing to help him. We took pictures of my baby daughter with him in the hospice bed. I wanted memories of her with him. They should have been happy times but instead she was sitting on his bed while he was unconscious and he was just skin and bone. We, my parents and I were able to be with him night and day during the last week of his life and we were all together as we watched him take his last breath.

32. After he died I was adamant he wasn't to go to the hospital morgue next door. We promised him he wouldn't go back into the hospital and the hospice agreed to keep him in a separate room until the undertakers came to collect him the next day.

33. He was not treated with respect even after he died. The staff at the undertakers refused to embalm Stuart because of AIDS being written on his death certificate. This made me very angry. Even after his death he was being treated badly. . As a result of this, the whole process was very rushed and we were not given the time with him to say goodbye. He died on Monday the 29th May 2006, a bank

holiday, and as Stuart was not embalmed his coffin was closed on the Wednesday. His funeral did not take place till the 12th June 20016 but we could not see him again. It was very distressing.

34. It is also very upsetting to see how Stuart's illness affected our parents, particularly our mother. She felt, and still does, a great sense of guilt, as she injected Stuart with Factor VIII whenever he needed it. She felt she was to blame for his condition as it was passed from her as she was the carrier and she injected him with the infected product albeit she only administered him with a product which should have saved him, but instead it killed him.

35. Our whole family always wondered about how Stuart would have been if he had the chance to live his life without being ill. It was difficult to live with Haemophilia, but HIV and HCV made his and our lives very harder.

36. We were never offered any counselling in relation to Stuart's illnesses until after his death. The counselling was at the Isabel Hospice and was bereavement counselling. I found it very useful, as it helped me to deal with being a new mother and losing my brother.

37. I stopped going to counselling sessions when I became pregnant with my second child. This was also about the time when I gave an interview, which was later given to the British Library Project as part of their Oral History of the NHS. . I had to re-tell my brother's story, I found it very difficult and painful, so I went back to the Hospice to have some more counselling sessions, which also proved to be very supportive and helpful.

38. I find it very upsetting that my daughters have been deprived of their uncle, and I know how much of an uncle he would have been due to his fun and bubbly personality. He never met my youngest daughter, and I struggle with that concept of GRO-C not knowing Stuart, she hears about him but she never had the chance to meet him.

39. At the moment I feel I am losing connections with Stuart which is very upsetting. I had to have my cat of 19 years put down recently, and I found it very upsetting and distressful as my cat was another connection to Stuart which I have now lost.

40. I am angry and devastated that I have lost my big brother and my girls denied their Uncle.

Anonymity, Disclosure and Redaction

41. I confirm I do not wish to have anonymity and that I understand the statement will be published and disclosed as part of the Inquiry.

42. I do wish to be called to give oral evidence if I can assist the Inquiry.

Statement of Truth

I believe that the facts stated in this Witness Statement are true.

Signed...... GRO-C

Laura Jane Gould

Dated:...17/10/19...........