

Witness Name: [REDACTED]

Statement No.: W0560

Exhibits: none

Dated: /07/2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF [REDACTED]

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 January 2019.

I, [REDACTED] will say as follows: -

#### Section 1. Introduction

1. My name is [REDACTED] but I am known as [REDACTED]. My date of birth is [REDACTED] [REDACTED] and my address is known to the Inquiry. [REDACTED] I work in [REDACTED] [REDACTED] I am making this statement principally to talk about my brother, [REDACTED] B [REDACTED] In particular, the nature of his illness, how the illness affected him, the treatment he received and the impact it had on him and our lives together.
2. I have requested that my name and the names of my family members be anonymised in this statement. I have also requested that any identifying details be redacted. I do not want other members of my family to be identifiable when my statement is published. This is a matter of family privacy.
3. I have had to estimate the dates of some events by reference to key moments in my life, such as which house I lived in and what job I was doing at the time.

I have remembered these details to the best of my ability. I have indicated throughout where a date is an approximation.

4. I am not legally represented.

## **Section 2. How Affected**

5. **B** was born on [REDACTED]. He has severe haemophilia and was infected with HIV through blood products. He is still alive, though suffering from the effects of his infections.
6. There are three other members of my extended family who were infected with HIV. Each of them died from their infections.
7. **C1** was my cousin. He was born on [REDACTED]. He was a haemophiliac and was infected with HIV through blood products. He went on to develop AIDS and died in around [REDACTED].
8. **C2** was another cousin of mine. I am unsure of his date of birth. He was a haemophiliac and was also infected with HIV through blood products. He died in 2017.
9. I also have a second cousin called **C3**. He died shortly after **C1**, also due to HIV infection through blood products. Sadly, his wife was infected through him before they knew he had HIV. She also died.
10. I am [REDACTED] older than **B**, so I can recall his early years. He was in hospital with a bleed when he was around 1 year old. This is the first time I remember him being really unwell.
11. He was treated at what was then, the [REDACTED].  
[REDACTED].
12. I was one of [REDACTED] siblings. It was very difficult for my mum to manage all of the childcare duties as well as looking after **B**. My mum was not able to go to the hospital all the time because of this, so I used to take him.
13. I spent a lot of time looking after **B**. This included going to the hospital daily, feeding him and changing him as well as playing and spending time together. I remember the nursing staff at the hospital told me that I did not have to be there, that they could take care of him. I told them that he was my brother and I wanted to be the one looking after him. This was during [REDACTED].  
[REDACTED]

14. When **B** was around 2 or 3 years old he would get very bad bleeds in his joints. He used to cry a lot, in pain. When this happened, he would go in to the hospital and they would do an assessment. If it was a small bleed he could have some treatment that day and then be sent home. If it was more serious he would be kept in for several days' treatment.
15. At some point, while **B** was still fairly young, our mum learned to administer the factor VIII treatments at home. I remember he used to have sharps boxes for the used home treatment needles. Despite this, he still had to go to hospital every couple of months when he had particularly bad bleeds. When **B** was old enough to go to school, I used to collect him sometimes when he was in a wheelchair due to the bad bleeds in his ankles.
16. I remember in around [REDACTED] my mum told me that **B** had been infected with HIV. I have trouble remembering this conversation. I cannot remember where I was when I was told, though I do recall being on my own. I think my mum said that **B** had been infected through factor VIII. I do not know if he was infected through home treatment or while at the hospital.
17. I remember feeling devastated upon hearing the news. I was terrified that **B** was going to die and it caused me to have very bad anxiety. I was upset for him and for my mum.
18. My mum found it very difficult to talk about. I know that she discussed it with a priest at the church and he said that she should tell us what had happened. It took her a few months between finding out and telling me and my siblings.
19. My parents found out that **B** was infected when the hospital called them in to share the information. They spoke to one of the doctors at the haemophilia unit. All they were told was that **B** had HIV and that if he had a bleed they must take precautions not to get infected.
20. The precautions included burning things that got blood on them. I remember this in particular because of a time that [REDACTED]  
[REDACTED]  
[REDACTED]
21. It was left to my parents to tell **B** that he was HIV positive. My view is that they should have been supported in giving that information to **B**. It was a terrible shock for my parents and it should not have been left to them to do this alone.



22. There should have been counselling available right from the start. I would have liked there to have been an expert there with them when they told [B] that could answer his questions. My parents also needed more education about HIV.

23. I do not recall any information being given to me about the risks of others becoming infected within the family home.

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

24. I believe that [B] was infected with hepatitis B and C through blood products. I do not know the details of this.

25. I understand that [B] had routine interferon treatment for hepatitis C but I am not sure if he was cleared of the infection.

26. When I was [REDACTED], all our family were vaccinated for hepatitis B.

### **Section 4. Consent**

27. It is clear to me that [B] was tested without his knowledge. When my parents learned that [B] had HIV, it was a complete shock to them. It was not something that they were aware of before it happened.

28. When the results were communicated to our parents, [B] was not given any information about his infection at all, nor was he told that he was infected with HIV. This information was kept from him by the medical staff and it was left to my parents to tell him, which took several months.

29. The hospital should have told [B] that he had HIV so that he could be given treatment, support and information. Those with expert knowledge should have been made available to him to answer his questions.

### **Section 5. Impact**

30. In around [REDACTED] [B] was at university. My mum, my sister [REDACTED] and I went to visit him. [REDACTED] C1 [REDACTED], our cousin, had died and we wanted to tell him face to face.

31. I think I have blocked out the memory of this conversation. I remember going to tell him but I cannot remember the conversation itself. It was a traumatic moment for me and I think that this has had an impact on my recollection.
32. Shortly after this, B became very unwell and had to leave university. When he recovered, after about a year, he [REDACTED]  
[REDACTED].
33. I remember around about that time he had his first girlfriend. It got to the point where he felt he had to tell her about his condition. They were together for around 12-18 months but she was not able to cope with the fact that he had HIV. She was scared of becoming infected. They split up [REDACTED]
34. B subsequently met [REDACTED] [REDACTED] [REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]
35. I think it was very difficult for B to tell the people he was starting a relationship with that he had HIV.
36. The stigma that surrounds HIV has made things very hard, both B and for the rest of the family.
37. Our dad used to go to an Ex-Servicemen's club and I recall someone saying something very unpleasant about what they would like to do to people with HIV.
38. I also remember the adverts that used to be on the TV about HIV. They had tombstones in. When B got HIV, I did not think he was going to live. I was convinced he would die. Me and my family had so much anxiety about him because of this and the way it was talked about in the media played into that.
39. My sister [REDACTED] went to the local pub with B when he was very unwell. He had lost 2.5 stone in weight and had bald patches on his head. Someone at the pub said to [REDACTED] something along the lines of *"It doesn't take a genius to work out that your brother has HIV."* They knew he had haemophilia and they made the link.
40. I remember, even in the nursing profession people would make negative comments about people with HIV. The stigma was coming from all angles. When I have had my own medical care in the past, for severe anxiety it was



made worse by knowing of [B] condition but I felt unable to disclose this to medical staff.

41. When my cousin, [C1], was in the [redacted] for a minor operation, someone had put the theatre list up on the wall out in a public area of the ward. It said on the list that he had HIV. Anyone could have seen that. I was really upset by it. I was shocked that they would put it up on the wall for everyone to see.
42. There was a lot of hatred and fear directed at people who had HIV. As a family, we tried to keep it all to ourselves. We also did not discuss it because we did not want to upset each other. It was too emotional. My family did not share [B] HIV status with people outside of the family.
43. In the 1980s, many people thought that you could get HIV from touching or kissing. There was a lot of ignorance around. I remember going to my GP and telling him that [B] was HIV positive and he said, "Oh, is he a drug addict?" People would often jump to conclusions like this.
44. [C1] was the first of my family to become seriously unwell. At the time, the ambulance staff used to use gloves when they were dealing with someone with HIV. The way they dealt with [C1] was very insensitive.
45. To me, that seemed to say that you could get HIV from someone just by touching them. I do not blame the ambulance crews for that. It was the fault of the people who were making the policies and procedures that the staff had to follow. This was totally wrong, in my view. It made people who were dying feel terrible.
46. When [C1] became unwell, I felt like I could not discuss what was happening to him with others because there was so much ignorance around HIV in the general public, which was reinforced by the media campaigns.
47. In around [redacted], six months after [C1] died, I had a breakdown. I had been to see him not long before he passed away. He was [redacted] but he looked much older. He was so weak that he had to be nursed on the ground floor. Seeing him like this and the pain of his death were a big part of what led to my breakdown.
48. Shortly after this, I was diagnosed with [redacted] as were my sisters, my brother [redacted] and my mum. In my opinion, the stress of [B] health

problems and the impact it had on my family contributed directly to our mental health issues.

49. After [C1] died, staff at the hospital told my family to prepare for [B]'s death. They said he would probably die. During this period, [B] was in and out of hospital regularly with pneumonia. His T cell count went down to 0 which indicated that his immune system was seriously compromised.
50. However, in around [REDACTED] a new drug was introduced. It was unlicensed at the time but [B] was able to take it anyway because there was not much else they could do for him. I do not know the name of the drug or any of the details.
51. [B]'s health picked up from this point on. Within about 6-12 months he looked much better. He gained weight again and his hair grew back. His health and general well-being improved greatly.
52. [REDACTED] he moved [REDACTED] into the countryside. Part of the reasoning for that was about maintaining privacy. [B] never really discussed how he felt about his illness. He kept it to himself when he was going through it.
53. Despite [B]'s recovery, his health complications did not end. He still goes to the [REDACTED] regularly. [REDACTED]  
[REDACTED] He has internal bleeding and so he goes in to get the blood vessels capped off. This is a recurring course of treatment.
54. The internal bleeds in his ankles caused serious disintegration. [REDACTED]  
[REDACTED] While he was in hospital for this he picked up an infection [REDACTED]  
[REDACTED].
55. Earlier this year [B] was told that [REDACTED]. He is still having tests done on this.
56. [B]'s whole life, ever since he was a baby, has revolved around going to hospital appointments and treating conditions that have come up. It has had a big effect on his quality of life. It is stressful for [REDACTED] too because she does not know if he will have to give up his job. [REDACTED]  
[REDACTED] I feel that they are under a lot of strain.

57. B was working in a good, [REDACTED] job but he was very run down and tired all the time because of his health issues. He changed careers in order to reduce the stress on his health.
58. My cousin, C2 died in [REDACTED] from medical issues related to his HIV infection. He was very seriously ill prior to his death. He had become blind in both eyes because of infections that his weakened immune system was not able to fight off.
59. This has had a significant effect on B because out of all of our extended family who have had HIV, he is the last one still alive. He does not show it but I believe that it has had a stressful impact on him and [REDACTED]. I think it makes him wonder what is in his future.
60. C2 tended to keep himself to himself. I am aware that he has made comments about whether haemophiliacs were being used as guinea pigs. He made some comments to my sister, [REDACTED] about them being infected with CJD. He was very paranoid about that.
61. I believe that C2 stole his medical records from the hospital before he died. I am not sure where these records are. I am not sure what is included in the contents of these records.
62. C3 was a second cousin of mine. He was married to a woman named [REDACTED]. He became infected with HIV through blood products without his knowledge. His wife then became infected through him. They both died from the infection [REDACTED]
63. I am left wondering how long he went without knowing he had HIV and what could have been done for him had he known.
64. The stress of these events has had a major impact on me. I have had to give up my job on three separate occasions because I simply could not go on. I nearly lost my home at one point. I only avoided this because my parents helped me with my mortgage while I was ill and could not work.
65. I was married and although my husband knew what was going on in my family, it was never anything we discussed between us.

## **Section 6. Treatment/Care/Support**



66. I am not sure whether [B] received any counselling later in his life. I know that he was not offered it when he received his diagnosis.

67. I understand that a charity supported him [REDACTED].

68. I have been on one counselling and support weekend [REDACTED]  
[REDACTED] Other than that, I have neither been offered, nor received, any support.

69. I think there should have been counselling available on an individual basis for everyone in our family from the time when the infection was first identified.

70. I have been informed of the British Red Cross telephone counselling line which has been established specifically for those taking part in the Inquiry. I understand that they are available should I feel the need to talk to someone and that I may be signposted to local services if this is appropriate. I will consider whether this is an opportunity I would like to take up.

## **Section 7. Financial Assistance**

71. I know that [B] received some money from the Macfarlane Trust [REDACTED]  
[REDACTED] I do not know any of the details about this.

72. As you would expect, I do not know anything about potential financial payments to [B]. This is a private financial matter and only he would be able to answer these questions.

## **Section 8. Other Issues**

73. I would like the Inquiry to establish whether more could have been done to protect the UK's factor VIII supply. In particular, I am concerned about reports I have read in the news about reliance on dangerous materials derived from paid blood donors, including drug addicts, in the USA.

74. I would like the people who were infected to get justice. I think there should be compensation for those who were infected as well as the children of those who have died from their infections.

75. I understand that there have been different levels of payments made to those affected who live in the different nations of the UK. I think that this is unfair. You should get the same regardless of where you live and it should be dealt with centrally, not in piecemeal fashion.

76. I hope that the Inquiry will bring about greater awareness of what happened to people. Even now, there is a stigma around HIV but I hope that the Inquiry will help to change that for the future.

### **Statement of Truth**

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

Signed

A black rectangular box redacting the signature.

Dated

17.8.19.