

Witness Name: Janet Smith  
Statement No: WITN1523001  
Exhibits:WITN1523002-4  
Dated: February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JANET SMITH

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I, Janet Smith, will say as follows:-

#### Section 1. Introduction

1. My name is Janet Smith, date of birth **GRO-C** 1955 and I live at **GRO-C**  
**GRO-C**
2. My son, Colin Smith Jnr, date of birth **GRO-C** 1982, died on 13.01.1990 at the age of 7 after being infected with HIV and Hepatitis C through contaminated blood products. Colin was the youngest of our four sons.
3. This witness statement has been prepared without the benefit of access to my late son's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

## Section 2. How Affected

4. Colin was diagnosed with severe Haemophilia A at around four months old. My sister's GRO-C and when she noticed a bruise on Colin's knee she suggested we have him tested.
5. He was tested at the Royal Gwent Hospital and as soon as he was diagnosed as a haemophiliac he was transferred to the Heath Hospital in Cardiff.
6. Colin first had Factor VIII when he was around twelve months old. There is now shown to me marked **WITN1523002** a page from Colin's clinical notes dated 21 July 1983 where it is noted that he was a known haemophilia "Not Treated". There is then a letter from Professor Bloom (**WITN1523003**) following a clinic appointment on 28 July 1983 which confirms that Colin had an IV injection of one bottle of 250 units of Factor VIII concentrate following a head injury. I believe that this is the first time Colin received Factor VIII (ie. just after Professor Bloom had identified him as a Previously Untreated Patient).
7. We were told absolutely nothing about Factor VIII. There was no discussion of risk, and there wasn't even a discussion about the difference between Factor VIII and Cryoprecipitate. The nurses had to tie Colin up to keep him still so they could inject him with Factor VIII. It was very difficult for me to have to watch this.
8. When we first met Professor Bloom we totally trusted him. He called all of his patients his 'boys' and we thought that this was a sign of how much he cared about them. He was a specialist so we trusted him with Colin's health. He was very keen for us to transfer Colin's care to him.
9. Colin was about two years old when Professor Bloom came down a corridor and told us that he had HIV. He didn't even take us into a room; he just told us a corridor in front of other patients. After he saw how upset we were, my husband and I were moved into a private room. We were told absolutely

nothing about prognosis, other than 'this year will be vital'. He told us there was a new drug available called AZT but there could be difficulties in obtaining it and that he might have to send away for it. We also were not told anything about the possible routes of transmission. We didn't understand how serious it all was.

10. Colin was started in AZT in late 1988.

11. It wasn't until we started seeing the Tombstone adverts on TV that we realised Colin's illness was very serious indeed. We were kept in the dark by the hospital. I believe that more information should have been made available to us.

12. I found out three years after Colin's death that he had also been infected with Hepatitis C. We had a letter through the door telling us to be tested for Hepatitis C as Colin had also been infected with that and they couldn't be sure which infection had killed him. We were not told prior to that that Colin had been tested for Hepatitis C so the letter came as a huge shock.

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

13. I am not aware of any other infections that Colin may have been exposed to.

### **Section 4. Consent**

14. I had no idea that Colin was being tested for HIV or Hepatitis C. Colin was a PUP (Previously Untreated Patient). There is no doubt that they treated and tested him for the purposes of research.

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

15. Colin adored school and a lot of the children there were wonderful with him. If he had to go to school in his wheelchair then the children would all want to

help push the chair. If only the parents had been as understanding as the children, it would have been much easier for us.

16. It took us a long time to get Colin back into school because they wouldn't let him in without a full time nurse. This was because of his diagnosis and the fact that he was on AZT at this time and needed a nurse to dispense the tablets.
17. Colin had to leave school when his health deteriorated. He frequently suffered from chest infections. It was only after Colin's death that I found out in his medical records that he had suffered from pneumonia twice and they also suspected that he had meningitis. I cannot believe this information was kept hidden from his parents.
18. One night Colin was in bed with his brother, Daniel, when he had a really severe nosebleed. The hospital was worried if Daniel had got blood on him but they said he didn't need to be tested for HIV. They did tell us that we should burn the mattress. It was only at this time we realised the severity of it all.
19. Colin was rarely left on his own at the hospital. Either my husband or I were there. This had an obvious impact on our other three children who had to spend a lot of time with other family members, away from their parents.
20. Colin had grommets fitted at Gwent Hospital in 1983/84. He was such a brave little boy. He never complained about his illnesses or feeling unwell. He used to love drawing, but at one stage all he would draw were headstones. Colin never asked what was wrong with him or if he was going to die, but I suspect that he knew. One day when he had a row with his brother he said 'you're going to miss me when I'm gone' and another day he said 'you can have all of my toys'.
21. We tried to keep Colin's infection a secret. However, there was another local haemophiliac who was also infected with HIV, so as people knew that Colin

was a haemophiliac they put two and two together. The abuse we suffered when people found out about Colin's infection was horrendous. We had crosses scratched into the front door, abusive phone calls in the early hours of the morning and one morning I had to get my husband to quickly paint the side of the house as someone had painted 'AIDS DEAD' on the side wall. Colin was just a little child; he didn't deserve any of this.

22. We lost a lot of friends. The people who lived across the road who we knew well suddenly wouldn't speak to us anymore. Parents moved their children out of Colin's school and crossed the road when they saw us coming. We were known locally as the "AIDS family" and were forced into isolation. In the end we became hardened to it. We knew we had nothing to be ashamed of but it still hurt. We were proud of our kids and refused to move for as long as we could protect the boys.

23. Out other boys were also bullied at school about their brother's infection. Other kids shouted "your brother's got AIDS" or "AIDS kids" at them. They tried to keep this from us at the time as they wanted to protect us.

24. My husband was unemployed for a period during Colin's illness because no one would give him a job as they knew we had AIDS in the family. As soon as Colin died he suddenly became employable again. He has now been in the same job for 20 years.

25. When Colin was very ill we told the hospital that we were taking him home as we didn't want him to die in hospital. The doctors tried to stop us but we wouldn't take no for an answer. Professor Bloom said that no one with AIDS ever died at home.

26. Colin passed away at home on 13.01.1990 at the age of seven. A copy of the sheet from his medical records which confirms his cause of death as 1(a) PCP Pneumonia (b) AIDS due to contaminated Factor VIII infusion (c) Haemophilia is now shown to me marked **WITN1523004**.



27. The devastation of having your child on your lap, watching the rise and fall of his chest and waiting for it to stop is absolutely heartbreaking.
28. There were no problems with the funeral arrangements because fortunately the funeral director was brilliant. All of the ward staff from the hospital came down for the funeral as they all loved him. He was an amazing little boy.
29. After Colin's death my life fell apart. My husband and I almost divorced. Instead of our grief uniting us we found that we could not talk about it. I went into my own little world and listened to Elton John's song "Sacrifice" over and over again. The boys lost us for a year and had to fend for themselves.
30. Daniel left a shrine in his bedroom (which he shared with Colin) and wouldn't let us touch or get rid of anything. Daniel goes to the cemetery with us once a week, but my two eldest sons can't go to the cemetery; it is too difficult for them.
31. Daniel really struggled when he got married because he wanted Colin as his best man. At the wedding both him and his wife had something of Colin's sewn into their wedding outfits so he could be there with him.
32. When you've got four boys your heart is in four pieces. So when you lose one of your children, you lose a part of your heart. We still talk about Colin everyday. His pictures are all over the house. The first place our grandchildren want to go on Christmas morning is to the cemetery to take Colin his card and presents. They never got to meet him but he is still a big part in their lives.

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

33. After Colin died we all got counselling from the hospital. They were really good with us, especially with Daniel.

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

34. We have had some dealings with the MacFarlane Trust but found that they never got in touch with us about assistance; the onus was always on us to go looking for help.

35. We received the Stage One and Stage Two Skipton Payments.

**Section 8. Other Issues**

36. I just want justice. I want them to admit what they done to my son and for people to be held accountable for this.

**Anonymity**

37. I do not wish to remain anonymous.

38. I want to give oral evidence to the Inquiry.

**Statement of Truth**

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

Signed.....

Dated

**Statement of Truth**

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

Signed GRO-C .....

Dated 27-2.19