

Witness Name: Sophie Smith

Statement No: WITN1527001

Exhibits: 0

Dated: March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SOPHIE SMITH

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I, Sophie Smith will say as follows:-

#### **Section 1. Introduction**

1. My name is Sophie Smith. I was born on the GRO-C 1975 and I live at GRO-C
2. I am married with two children who are 12 and 13 years old. I am self-employed and work with my husband.
3. I write this statement on behalf of my late father, John Michael Anthony Dinkel, born on GRO-C 1942. He died at the age of 48 years old on 15 August 1991, as a result of cerebral toxoplasmosis.
4. This witness statement has been prepared without the benefit of access to my late father'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**

5. My father had severe Haemophilia A. He suffered throughout his life. As a child, he had quite a lot of time off from school because of his Haemophilia.

6. I am not sure when my father first received FVIII treatment. However, I recall that my father was taking it when I was a young child. All my life, he used FVIII concentrate.
7. He was mainly treated at the Royal Free Hospital (RFH). I do not know the names of his treating doctors.
8. I believe my father was infected with HIV and Hepatitis C (Hep C) as a result of being given contaminated FVIII, from which the HIV subsequently developed into AIDS.
9. I believe my father was told that he had HIV in the late 1980s. I was fairly young at the time and so I was not really given much information.
10. I do not know what information was provided to my father. I believe he did not tell me or my sister much about the infection as he wanted to protect us.
11. I do not know if my father was provided with adequate information to help him understand and manage the infection. I think the information back then was all kept between the doctors.
12. I believe that if it was known earlier that my father had contracted HIV, it should have been provided to my father and he should have been informed of the risks beforehand.
13. GRO-C I believe at some point my father was told about the risks of others being infected.

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

14. I am not aware if my father was infected with any other infections from the infected blood products. However, he suffered from cerebral toxoplasmosis, which I believe is connected to a low immune system caused by the HIV.

#### **Section 4. Consent**

15. I believe that my father was treated and tested without his knowledge as he would not have known that the FVIII was infected.

16. I believe that if my father was told about the risks involved with the blood products, it would have given him the choice to either accept or decline FVIII.

17. I believe that my father was treated and tested without being given adequate or full information.

18. I do not know if my father was tested for the purposes of research. However I believe from various articles and information that I have read that the government knew the blood products were infected and still offered them as treatment to haemophiliacs. In this way, it could be seen that the patients were treated as guinea pigs under a 'hope for the best' scenario. I also understand that the blood product was taken from high risk donors in the US who were paid for their blood and therefore no incentive to reveal any imperfections in it. These high risk donors (drug users, prisoners etc) should never have been given the option to provide blood product to be used to treat haemophiliacs and others in need of blood transfusions.

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

19. After my father's diagnosis he became less and less mobile and needed more time in bed. He was distracted and in a lot of pain. I think my parents were having a terrible time but kept it from us. I became aware that he was infected with HIV when I was about 13/14 years only by accident when visiting him in a different hospital in Hove. He was in a particular ward, it was such a weird and frightening place where everyone was extremely sick. He looked terribly terribly sick and I was told afterward that this was a specialist ward only for patients with HIV.

20. I believe my father suffered from **cerebral toxoplasmosis** as a result of the infections. He also suffered from brain fits. In the last few years of his life he

had seizures. I believe the infections were getting worse. I used to lie in my bed upstairs from his bedroom and hear him moan and groan and cry out with pain and delirium. I will never forget those sounds. It breaks my heart.

21. I believe my father received AZT for the HIV. I recall that my father did not like the treatment. I do not know if my father faced any difficulties or obstacles in accessing such treatment. I do not know if there were any other treatments that ought to have been made available to him at the time. I do recall my father tried alternative therapies in order to ease his pain.

22. I believe the treatment had a mental and physical effect on my father. He spent a lot of time in bed and was constantly sick. He also lost his appetite and lost weight as a result.

23. I do not know if my father's infected status had an impact on his treatment, medical or dental care for any other conditions.

24. There was definitely a stigma attached to HIV at the time. I believe my parents had a good circle of friends. However, I believe it was the way the media portrayed the infections which made it awful. I believe it was a difficult time for my parents to cope with it.

25. The infections that my father suffered impacted on me physically, mentally and emotionally on my private, family and social life. It diminished him and it was so so sad to see him so ill. I remember at school if someone cut themselves and bled, the others would run away saying 'argh stay away you might give me AIDS' There was a sick panic about the condition that no-one really understood and came to all sorts of conclusions. I just kept quiet and didn't tell anyone my father had HIV. I still struggle to tell people that he died of AIDS because of the stigma around it and the horror that it is.

26. We kept my father's infections very quiet and private. I did not tell anyone. My parents told their close circle of friends and no one else.

27. The way that my father was infected was scandalous and horrifying and it affected the whole family. It should have been avoided.

28. Before my father was diagnosed with the infections he was happy and working full-time. His Haemophilia did not affect him. However, after his diagnosis he had to give up his job. I believe this caused a financial impact as a result.

29. When my father was very sick in his last year, I was doing my GCSEs. I don't know how we all got through it. I just soldiered on. Although I did complete my exams, it was utterly hideous and I cried a lot of the time.

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

30. I do not know if my father faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with the infections. I know my parents spoke to the MPs and councils about the scandal and they joined a campaign. I also know that various trusts were set up at the time, but I was not involved in any of it.

31. I believe that my father may have received some counselling, but I am not sure when. I was not offered counselling. I believe it may have helped to talk about it if I had received some counselling. At the time no one was talking about it, it was brushed under the carpet by everyone including my mother. No one reached out such as the authorities to help or talk about it. I believe they did not talk about it as they did not want to treat the FVIII and they knew that they were culpable and didn't want the scandal to get out.

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

32. I believe my father received a lump sum payment from the Macfarlane Trust in the 1991 litigation. I believe it was approximately £60,000. This covers not even a fraction of the earnings he would have brought in had he been able to carry on working a normal working life until retirement. I believe that he was also asked to sign a waiver not to seek compensation from the NHS in the future. They were told that there was no point in joining a class action. This rings huge alarm bells in terms of the authorities hoping for to cover up the

true horror and extent of the infected blood that was brought into the UK - like they were paying people off to shut up and not look into it any further.

33. The payout was later increased by public demand and they received a further sum. However, I am not sure how much this sum was or when they received it.

34. In the last 2-3 years we were made aware of a fund available to relations of those that were affected as a result of the contaminated blood products. I received a sum of £5,000. I believe it was from the Macfarlane Trust. I believe the application form was relatively straight forward. I only found out about this as my friend sat next to a CEO of the Trust and they had a conversation about it. The person told her to tell her friend to get in touch. We did not get a letter to inform us of this and it was not offered to us. We just got it by chance.

#### **Section 8. Other Issues**

35. I believe this whole scandal has been dealt with in a dreadful way. The Inquiry opening, last year was an eye opener as I did not know it was such a broad issue and that so many people were infected and affected as a result. It really highlighted the fact that it is a huge scandal. No one seemed to have known anything about the infected blood products until much later. It all looks quite suspicious and there really needs to be someone held accountable for it. It should not have happened. So many people died and it is shocking.

36. We were dealing with our own father's death but going to the Inquiry made us realise it has happened to so many other people.

37. I lost my dad when I was 16; he was only 48 years old. He never got to see me pass my exams, go to university, become a grown-up. He never met my husband or my children. They never met their grandfather and will never know how wonderful he was. He should not have died in this way. It is not fair that what he was taking to keep his Haemophilia at bay killed him. It was a terrible terrible time and I watched my father die. The irrevocable impact of this effects my everyday life and the emotional debt can never be repaid. I am

pleased there there is an inquiry as the truth should out and all these thousands of affected people should get some answers.

Anonymity, disclosure and redaction

38. **NOT RELEVANT**

39. I do not mind giving oral evidence if it is considered to be helpful by the inquiry.

**Statement of Truth**

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

Signed. **GRO-C**

Dated 28/3/19