

Witness Name: Tiffany Stewart

Statement No.: WITN4652001

Exhibits: **WITN4653002**

Dated:

## **INFECTED BLOOD INQUIRY**

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### **WRITTEN STATEMENT OF TIFFANY STEWART**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 August 2020.

I, Tiffany Stewart, will say as follows: -

#### **Introduction**

1. My name is Tiffany Stewart. My date of birth and address are known to the Inquiry. I am the daughter of Mark Stewart who suffers from Von Willebrands Disease ("VWD") and who was infected with HCV; I also suffer from VWD and have been subject to covert HIV and HCV testing throughout the early part of my life. I intend to speak about my own experiences as a VWD sufferer as well as the impact of my dad's HCV infection and the deaths of my grandfather (Angus Stewart Sr) and uncle (Angus Stewart Jr) who were also VWD sufferers who died from HCV infection.

## **How Affected**

2. My dad has provided a statement to the Inquiry **[WITN100001]** and a separate statement has also been provided by my aunt which discusses my uncle, his infection with HCV and his ultimate death **[WITN1001001]**.
3. My dad, my uncle and my grandad were all treated at the Royal Free Hospital by Professor Kernoff and Professor Tuddenham and were all given FVIII in the early 1980s. My dad's statement sets out that he was infected on 12 May 1981, my grandad was infected on 11 January 1980 and my uncle was infected on 1 December 1980. Each of them were infected on their first exposure to FVIII concentrates – all had previously been treated with either cryoprecipitate or fresh frozen plasma.
4. My dad has also set out the reasons why he believes that he, his brother and his father were part of a study on virgin patients which was run by Christine Lee under the supervision of Professor Kernoff. The study was reported in the British Journal of Haematology on 22 October 1984 **[WITN1000024]**.
5. My dad, grandad and uncle were all mild to moderate sufferers of VWD and did not need to be treated with concentrates – this can be seen from the fact that my grandad was nearly 42 before he first received concentrates.
6. My grandad died of HCV induced liver cancer on 2 September 2002 and my uncle died of the same cause on 28 December 2013. My dad's life has been ruined by his infection with HCV and the failure to even give him his diagnosis for decades.
7. I am not only affected by the terrible experiences of my dad, my grandad and my uncle, I am also personally affected by VWD and haemophilia treatment.

8. I was born in 1992 and I was diagnosed with VWD at 5 weeks old; I was treated with heat treated, plasma derived VWD concentrate for the first time when I was four years old.
9. My dad has gone into some detail at paragraphs 62 and 63 of his statement, in relation to my possible exposure to vCJD. I have to rely on my mum and dad's recollection of these events because (thankfully) they kept what was happening from me.
10. As I understand it, when I was 12 I was supposedly seen by Professor Christine Lee and she had a discussion with me and my dad about how we had been exposed to vCJD through the concentrates we had been treated with. I was not present at any such discussion and my medical records confirm this.
11. Instead, I believe that my mum and dad did meet with Christine Lee but without me and they were clear that they did not want me to be informed about any exposure to vCJD. I further understand that hospital staff reluctantly agreed that the information could be withheld from me until I was 18; again, this is confirmed in my medical records.
12. Later, in 2010 and following a review by the Royal Free, Professor Tuddenham confirmed that I had actually never been exposed to vCJD **[WITN1000031]**. This was yet another mistake for which the Royal Free apologised.
13. I have now learned that throughout my childhood, I was being tested for HIV, HAV, HBV and HCV; I was obviously not in a position to give my consent to these tests and my parents knew nothing of them.
14. From a complaint my dad made to the Royal Free on 19 March 2020, the relevant history of my treatment can be taken from the Royal Free's response of 15 April 2020 **[WITN4653002]**:-
  - a) I was diagnosed with VWD at the age 5 weeks old and appear to have been given an HBV vaccination some time prior to July 1993.

- On 1 July 1993, I was seen at the Royal Free and a sample of my blood was taken to see whether the vaccination had been effective;
- b) On 4 August 1993, the same sample of blood taken on 1 July was sent for HIV and Hepatitis testing without my parents' consent;
  - c) A further blood sample was taken on 9 February 1999 and again, I was tested for HIV and Hepatitis without my parents' knowledge or consent;
  - d) Again, a further sample was taken on 14 February 2007 (when I was 14 years old) and I was again tested for HIV and Hepatitis without my or my parents' knowledge or consent.
15. It can be seen from the Royal Free's letter that they accept that these tests were undertaken without consent but they have refused to tell me who ordered the tests or what reason there was for them being undertaken.
16. The tests that were carried out on 14 February 2007 are particularly interesting because they were carried out on the same day that the Royal Free realised that my Dad was HCV positive [WITN0644020]. My own view is that, as a result of this realisation, they tested me again to see if I had been infected – I do not think that this was a valid reason to test me but even if it was, it was done without my (or my parents') consent which is clearly wrong.

### **Consent**

17. Neither my father, grandfather nor my uncle gave informed consent to being treated with factor concentrates; I do not believe that they were told about the enhanced risks of concentrates nor do I believe that they were given the option of continuing with cryoprecipitate.

18. I believe that they were treated with concentrates purely for the purposes of enrolling them into Professor Lee's study; this is leant some weight by the response Professor Lee provided to my dad's witness statement [WITN0644004-5]. At paragraph eight of this statement, Professor Lee says:-

*"The treatment for 'VWD' was formerly with cryoprecipitate as the early plasma concentrates did not have sufficient VWF. It was not until the mid-1990s that treatment with large pool concentrate became possible because of the improved 'VWF' content. DDAVP (also known as Desmopressin), a treatment only used for mild to moderate 'VWD' came into use from around 1981."*

19. If concentrates were known to be ineffective in VWD patients and were known to carry a certain risk of infecting the patient with NANB hepatitis, then what possible reason could a doctor have for giving them to my family? Particularly when there was a sound history of treatment with cryoprecipitate and there was a synthetic alternative available.
20. Equally, I know from my dad that neither he nor my grandad or uncle could have consented to being included in any medical study because none of them knew anything about it.
21. By the same token, my dad did not consent to being tested for HCV because he did not know, until decades later, that he had even been tested.
22. Turning to my own circumstances, I did not, as a child, consent to being tested for HIV or HCV and nor did my parents consent on my behalf – they could not have done because they did not know that I had been tested until my dad obtained copies of my medical records.
23. This testing could have caused me serious problems in later life outside of a medical context; at the time these tests were undertaken it was difficult or impossible to obtain certain types of insurance as a result of

merely being tested. Until my dad began to investigate my medical records, I never even knew that these tests had been carried out on me.

### **Impact**

24. Dealing first with my family, I was robbed of the chance to properly know my grandad; he died whilst I was still young. My uncle's death was horrific – I was old enough to know what was happening as he went first through his transplant, its failure, cancer, chemotherapy and then an horrific, painful death. It was bad enough knowing this was happening to my uncle, but I was terrified knowing that it may also happen to my dad.
25. The impact on my dad of finding out that he was infected with HCV was appalling. One moment, we had a happy, loving family life and the next, my dad was gone and so was our family.
26. My dad's world fell apart; he went from being in a successful high paid job to barely being able to work and ultimately, to moving away from our family home. To top this off, when my dad started investigating and complaining about our family's treatment he was branded mad and delusional.
27. Our family life will never be as it was again and will never be as it should be.
28. The impact of my treatment has been bad but I have been lucky in that my mum and dad have shielded me from so much. Instead, mum and dad had to carry all the worry and fear for six years that I had been exposed to CJD or that I might start developing symptoms. I am a mother now and I can start to imagine how terrible it must have been for my mum and dad to keep this a secret.

29. I'm so pleased that I was not told that I was (mistakenly) believed to have been exposed to CJD as I think it would have destroyed my life in the same way that it has for so many other people who have given evidence to this inquiry.
30. As to testing me without consent, I didn't find out about this until recently and I don't understand the reasons for it. At the time I was being tested, the products being given to me were heat treated and (I believe) high purity so I can't see why there was any need to do it unless they thought I would become infected with HCV through my dad but even then, that doesn't explain why I was tested for HIV.
31. Aside from being confused about the testing, it obviously diminishes my trust in the people who have treated me – there seems to me to be no reason not to just be honest about things. If my haematologists had wanted to test me and there was a good reason that they explained to my parents then I'm sure they would have given permission.

### **Treatment/Care/Support**

32. Dad has talked in his statement about the lack of support and care he has received – his care from childhood has been a pattern of mistakes and lies.
33. I think one of the worst parts of his treatment was that they tried to make out that he had mental problems and was delusional when he realised what had been done to him, his father and his brother. I think this is absolutely unforgivable.

### **Financial Assistance**

34. Dad receives payments from EIBSS but I don't know the details of what category he falls into or precisely how much he gets.

35. What I do really want to say about financial assistance though is that it is completely wrong that the partners of people infected are so poorly supported. I know that in Scotland, if my dad was to die then my mum would continue to receive 75% of the payments that are being made to him but because we are in England, she will get nothing.
36. I think it would give my dad some comfort to know that my mum will be provided for after he has gone.

**Statement of Truth**

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

Signed GRO-C

Dated 30/9/2020