Witness Name: Edna Frances Hodgkins
Statement No: WITN3889001
Exhibits: WITN3889002 - 004
Dated: December 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF EDNA FRANCES HODGKINS

I, Edna Frances Hodgkins, will say as follows:-

Section 1. Introduction

1. My name is Edna Frances Hodgkins. I was born on the GRO-C 1929. I live at GRO-C Berkshire, GRO-C with my son, Robert Hodgkins. My husband passed away in 1998.

2. I make this statement in relation to my son, Robert. His date of birth is the GRO-C GRO-C 1968. Robert was infected with HIV, Hepatitis B, C and D as a result of being treated with Factor VIII (FVIII) blood products.

3. I am aware that, Robert, has provided a statement to the Inquiry, **'WITN0009001'**.

4. This witness statement has been prepared without the benefit of access to Robert's full medical records.

Section 2. How Affected

5. Haemophilia runs on my side of the family, on my mother's side. My maternal grandmother had five children, two boys of which had haemophilia. My cousin

Ken, who was my age, died in the 1990s as a result of haemophilia. My sister is not a carrier of haemophilia. I have two daughters, GRO-A GRO-A As a result, Robert was diagnosed with severe Haemophilia A at two and half months old. It seems that all the boys in our family have had haemophilia, which is incredibly rare.

6. In 1947, I went to the hospital GRO-A and we had blood tests in order to see the likelihood of us being carriers. The doctor told me that the likelihood of me being a carrier was incredibly low. I didn't realise I would pass haemophilia on to anyone.

7. When Robert was born, he was perfect. After about 24 hours I noticed some swelling above his left ear. I spoke to the nurse and she told me not to worry about it as lots of babies suffer from swelling. When Robert was only a few days old and still in the hospital, a sister came around whilst I was feeding him. She said that the umbilical cord was supposed to come off after 10 or 11 days, which it hadn't and in those days you weren't able to go home until the umbilical cord had fallen off. She gave it a tug and it started to bleed. The sister went on to put some talcum powder on the wound and walked away. The next morning at 5:30am, I went to feed Robert and he was still bleeding!

8. I told the nurse about haemophilia on my side of the family and the nurse said 'no that only runs on the girl's side.' She had no idea about it at all.

9. The paediatrician came to the ward and gave Robert an injection of Vitamin K in his heel. I was told to feed him only when he wanted it. They put us in the NICU unit. Whenever he cried someone would come and get me and I would go and see him. This was at Wexham Park Hospital.

10. I stayed in the hospital for about 10 days and I was told that they wanted to keep Robert in longer. As long as I was there to feed him, I could leave and come back to the hospital however I pleased.

11. Whilst we were at the hospital, they made arrangements for us to have proper blood tests. They wanted us to go to the Hammersmith Hospital to have the

tests and they made the arrangements for us to go there when he was about two and half months old. At that time, mothers were not allowed to stay with their children at the hospital. I was surprised to be allowed to stay with him, so had nothing prepared. We left Robert there and came home. We returned after a couple of days. The nurses apparently fought over who got to feed him because he was so good.

12. Dr Roberts treated Robert at Hammersmith Hospital and Dr Pitney was his paediatrician. We were told 'well your son is a bleeder and he will be for the rest of his life. Not to worry though, there are treatments.' It was a huge shock to us. We were told to become members of the Haemophilia Society and that we could get more information from the Society. I don't think any of us spoke in the car on the way home. My daughters were waiting outside the house for us, hoping for good news. We told them the results and they just said 'don't worry, we won't let anything happen to him'.

13. You wouldn't know from looking at Robert, that he was a haemophiliac. He always looked so healthy and was very active. We had no problems until he was around ten months old.

14. Robert started treatment with FVIII concentrate when he was four years old. I received no information about the risks of treatment which he received at Hammersmith Hospital. He did not have the treatment prophylactically; we had to go to the hospital every time he had a bleed to get treatment. I remember them having it in the needle, to which I said 'that's not enough!' It was only then, that we were told that it was a new treatment from America which was freeze dried. They never spoke to my husband or I about any risks, or what it was. It was only when I questioned it that they only told me it was a new treatment.

15. Robert was diagnosed with Hepatitis first. When Robert was about six years old (mid 1970s), we went to a steam fair and I remember he had an ice cream. When he got home he was very ill, vomiting and in a lot of pain. I couldn't think what would help him or how to get some nutrition into him. The doctor came but he didn't know what to do either. I started to feed him baby

food, because it was a puree. It was later that my husband noticed that Robert's eyes had started to go yellow and eventually he ended up in hospital. It lasted about six weeks and he lost about a stone in weight. We took him to Hammersmith Hospital again, where he was eventually tested and we were told about his Hepatitis infections.

16. Robert was diagnosed with Hepatitis B and this was when discussions of Non A Non B Hepatitis started.

17. When Robert was 15 years old (in or about 1983) there was a documentary on the BBC, which spoke about the people in America being treated with blood products and being infected with HTVL-III (HIV). It was only after this that Robert was called into Hammersmith Hospital and was tested for it. When Robert turned 16 years old, they called him in alone to give him the news that he was infected with HIV. Dr Howells had taken Robert's bloods along with all the other Haemophilia patients under his care and had the blood samples shipped to America to have them tested.

18. I also received factsheets about AIDS from the Haemophilia Society. Copies are exhibited at **'WITN3889002'**.

19. I didn't go with Robert into the meeting with Dr Howells and I didn't want to ask him if he was infected or not. I spoke to Dr Paul, and explained that I couldn't bring myself to ask Robert. I was told that because Robert was over the age of 16, they couldn't tell me. From my understanding he had been exposed to it, but I didn't really understand what it meant. After Robert had found out in the meeting, we didn't speak in the car on the way home and I just couldn't ask him myself.

20. It wasn't until we were at my daughter's house for lunch a few months later, that he overheard us talking and we asked if he was infected. He replied yes and confirmed his infections.

21. I continued to take Robert to his hospital appointments until he was transferred to the Oxford Haemophilia Centre. I did not go into his appointments with him; I would sit outside in the corridor.

22. Robert started treating himself with FVIII at the age of 13, but received treatment prophylactically from when he was about 8 years old.

Section 3. Other Infections

23. Robert received a letter from Churchill Hospital in the early 1990s which stated that he has been treated with a batch of FVIII concentrate, which had been contaminated with the blood of someone who had died of vCJD. The letter stated that he was at risk, but there was no further communication regarding this.

Section 4. Consent

24. I believe Robert was treated and tested without being given the full information and without my consent and knowledge. I found two letters from Hammersmith Hospital dated, 16 February 1981 and 13 March 1981 which state that his blood tests show some mild abnormalities. Is it possible that Robert was being tested for infections, without our knowledge. Copies of the above letters are exhibited at **'WITN3889003'**.

25. Looking back I am not sure that Robert was tested for the purposes of research. However, looking through a letter that we received from Hammersmith Hospital, dated 4 July 1983, it states the following: '....we would like to offer an opportunity for our patients with haemophilia to be seen at the haematology clinic. Regular medical check-ups, with appropriate blood tests and x-rays could be done at this clinic, and it would also provide a time for any new problems to be talked over with the senior medical staff, and any necessary investigations to be arranged'. It was possible that they could have been testing Robert for the purposes of research, as they had some knowledge that something was wrong. I exhibit a copy of this letter at **'WITN3889004'**.

Section 5. Impact of the Infection

26. I felt very confused and upset when I found out that Robert was infected with Hepatitis. It was so difficult when he lost all that weight and couldn't eat. It was slightly better when we got him onto the pureed food.

27. When I found out that Robert had been infected with HIV I was shattered. It was an incredible shock. We didn't know a lot about it, it's all become a bit of a blur now. We were at my daughter, Christine's house and we just didn't quite know how to deal with it all. We had no idea how to handle his illness, it was all fatalistic and there was nothing I could do. I just tried my best to look after him.

28. We never really spoke about Robert's infections at home. There was nothing we could do. We just knew we had to carry on. I lost belief in the system and what medical care was. I felt utterly betrayed.

29. My husband and I were not particularly social people. I always had friends around here, but Robert's infection never really impacted our social life.

30. I used to be a secretary, but Robert being born a severe haemophiliac (and then later infected) meant I had to be home most times in case anything happened. I was always clear about what was going on with Robert in all of my jobs and made it clear that he always came first.

31. I have not suffered any stigma surrounding Robert's infections. We never hid it, because we didn't feel like we had to. We didn't directly tell anyone, but it wasn't something we hid either. The hospital never gave me any advice on how to handle infections, therefore I felt it wasn't necessary to tell the school. Robert never received any specialist treatment or care at school.

32. I know that Ivan, my husband, spoke to Robert about his infections and the impact of them. I believe that Ivan was a rock for Robert, because I was at work a lot of the time.

33. I lost my husband in 1998 and so I was Robert's only carer. It was difficult to cope with looking after Robert and Ivan. It was a lot to handle.

Section 6. Treatment/care/support

34. I don't feel I would have benefitted from having any psychological support. Ivan and I got through it together; with the help of our family. I was never offered any psychological support or counselling from anybody in a professional manner.

Section 7. Financial Assistance

35. I was not contacted or referred to any schemes when Robert was a child and did not receive any financial support when it came to handling Robert's infections. It was only when Robert was an adult that he received financial support.

36. I would like to rely on my son's statement in relation to the financial assistance as I do not know what he has received.

Section 8. Other Issues

37. I would like the Inquiry to find those responsible for this terrible trauma. Someone needs to be held accountable for what they did to my son.

Anonymity

38. I do not wish to remain anonymous.

39. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.... GRO-C

Dated.....19th December 2019