

Witness Name: Brenda Thewlis

Statement No: WITN1783001

Exhibits: WITN1783002-003

Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BRENDA THEWLIS

I, Brenda Thewlis will say as follows:-

Section 1. Introduction

1. My name is Brenda Thewlis. I was born on the GRO-C 1956 and I live at GRO-C
GRO-C
2. I am married and I have 3 children and 2 grandchildren. I am currently working as a receptionist.
3. I make this statement on behalf of my late brother, Trevor Orwin. He was born on the GRO-C 1959 and died on the 6 June 1996 aged 37 as a result of Pneumonia.
4. My mother, Irene Orwin intended to make this statement initially, but sadly she passed away on 5 July 2018.
5. This witness statement has been prepared without the benefit of access to my late brother'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 Infected

6. Trevor was diagnosed with severe Haemophilia A. He was always in and out of hospital and lost a lot of time at school. In his childhood Trevor received other FVIII clotting products such as plasma. He always received some sort of treatment for his Haemophilia since he was a young child. Trevor was also treated with Factor VIII concentrate (FVIII) to treat his bleeds, but I do not know when he started this treatment.
7. My elder brother also had Haemophilia and both he and Trevor were always at the hospital being treated for bleeds. My elder brother died when he was 17 years old. His death was not related to receiving contaminated blood products.
8. Trevor was mainly treated at St James Teaching Hospital in Leeds (STH). He was treated there as a child and as a young man. He was under the care of Dr Swinburne for many years. She was a lovely doctor and she spent a lot of time with Trevor and my other brother. When she retired, a Dr McVerry took over. I remember my mother never had a good word to say about Dr McVerry's abrupt manner. That's when Trevor moved his medical care to Bradford Royal Infirmary (BRI) around the late 1980s/early 1990s.
9. As a result of being given FVIII, Trevor was infected with HIV and Hepatitis C (Hep C). A blood test on 27 March 1996 confirmed that Trevor had Hep C, which was approximately 4 months before his death. A copy of the blood test is exhibited at **'WITN1783002'**.
10. I believe that Trevor was not provided with any information or advice beforehand about the risk of being exposed to infections when using FVIII.
11. Trevor's death certificate states that he died from HIV, Bronchopneumonia and Haemophilia A.
12. Six members of my family had Haemophilia and they were similarly infected with HIV. In the late 1980s, my uncle Stephen, suddenly collapsed and had a stroke. He was kept in isolation and all the nurses were wearing protection.

There were quite tight measures around him when they were keeping him in and it became apparent to my mother (his sister) that he had HIV. Stephen died in 1988. After this, Trevor and the other members of my family who had HIV all found out that they were infected with HIV. Dr McVerry was the doctor who diagnosed my family members with HIV. My cousin, Eileen Burkett is the daughter of my uncle Stephen and I believe she has already made a statement to the Inquiry.

13. I believe that Trevor was not provided with adequate information to help him understand and manage the infection. I believe that information should have been provided to him and/or my parents earlier. I believe there was a 6 month gap between him being tested and being told of the results.

14. Dr McVerry told Trevor that he tested positive for HIV in a very abrupt manner. He was insensitive and unsympathetic towards him. I think they should've discussed the results properly; had a one-to-one consultation and had a care plan to see how Trevor was going to manage the infection.

15. I believe Trevor was not provided with any information about the risks of others being infected as a result of the infection. However, because 6 family members found out at roughly the same time, I believe the doctors knew that there were risks involved.

Section 3. Other Infections

16. As far as I know, Trevor did not have any other infections other than HIV and Hep C.

Section 4. Consent

17. I believe that Trevor was treated and tested without his knowledge and consent. I don't believe that he would've been aware that he was being tested for HIV or Hep C. I believe he would've thought he was being tested for Haemophilia, a routine check but not for anything else.

18. A medical record dated 3 August 1988 is interesting as it shows that some form of testing was going on. A copy of this letter is exhibited at 'WITN1783003'.

19. I believe he was definitely treated and tested without being given adequate or full information.

20. I didn't realise it at the time, but in hindsight, I believe Trevor was tested for the purposes of research.

Section 5. Impact of the Infection

21. Trevor suffered mental effects as a result of the infections. He became worn down and realised he wasn't recovering quickly enough. He decided to move in with my uncle and aunty in GRO-C My uncle had HIV too so they were able to have discuss the infection together. My parents then decided to move to GRO-C themselves. I think he dealt with what he had quite well. He got on with life as he knew he had no choice.

22. Trevor had a lot of open wounds on his leg, like boils. I think it was as a result of HIV or Hep C as he didn't have issues like that when he was younger.

23. He caught pneumonia twice. The first time he was treated for it and responded quite well. The second time however was fatal. He was treated in BRI and a week later he died. He said he wanted to go home, as he was well aware that his time had come to an end. Whilst at the hospital he shouted across the room saying 'stop giving me treatment that is not working'. We were relieved that he was allowed to go home for his last few days.

24. I was married at the time so I didn't live at home with Trevor. However, when I visited Trevor and my parents, they had a lot of frustration and anger about Trevor contracted HIV but was not told about it. They were angry that he was given blood products which were suppose to make his life easier, but instead gave him a death sentence. My mother never swore but she started to swear a lot when she found out that 6 members of her family were diagnosed with HIV.

25. I don't know what treatment Trevor received for his HIV. I believe Trevor had Interferon treatment for the Hep C infection. However, I don't know when he started it.
26. I don't think Trevor faced any difficulties or obstacles in accessing treatment. The medical staff at BRI treated him pretty well.
27. I don't know whether there were treatments which I consider ought to have been made available to Trevor. Everything was new at the time but if there was any treatment that wasn't made available it should've been.
28. I don't know if Trevor suffered from any effects from the treatment that he received as a result of the infection/s as he was living with our parents at the time.
29. Trevor was treated the BRI for his teeth. As a child, he was sent to Manchester Children's Hospital (MCH) to have some teeth removed.
30. The infections had an impact on Trevor's private, family and social life. He had a lot of frustration. He had a girlfriend but they broke up. After that, anytime a girl showed any interest in him, he would push them away. He would've liked to have a family but he kept his distance and I believe it was because of the way the media portrayed the infection at the time. He didn't tell any of his friends about his infected status, probably because he was scared of their reaction. He would talk to people but that didn't constitute friendship in his case. He was weary about his surroundings. When he went to his local pub he had his own glass with his name on it as he was worried about the possibility of infecting anyone through, sharing a glass, kissing and touching. He wanted to avoid infecting anyone else at any cost. Previously, he was a very outgoing and bubbly person and had a lot of friends.
31. What happened to Trevor had an impact on me physically, mentally and emotionally on my private, family and social life. As it did my Sister. We had to keep it from our children although they were old enough to know that something was not right and that HIV was around. Watching my brother in

hospital, seeing him being a shadow of himself, it took me a long time to get over his death even though I was relieved that his pain was over. Six months after Trevor's death, my husband insisted that I go and see the doctors to try and get some psychological support. I received counselling as I went into a deep depression. The counselling really helped, but it is very hard losing a brother. He didn't die through an accident but through treatment that he received that was supposed to help him and make his life easier.

32. There was a stigma attached to the infection at the time which made everything harder for us. At my sons school, there was a boy who had HIV and the school sent out a message to all the parents informing them of this. A lot of parents withdrew their children from the school. When I spoke to the head teacher, I told her I was leaving not because of the child who had HIV but for other reasons. I said I wouldn't leave just because a child has HIV as my family members were also infected with it. The head teacher was very understanding. Sadly, that young boy died. Because Trevor moved to **GRO-C**, which was a new area, no one knew about his infected status and luckily he did not face the stigma there.

33. My parents were also massively affected by Trevor's infections and subsequent death. My parents lost one son already when he was a teenager and to lose another son was very difficult for them. My mother had also already lost 3 brothers by that point because of the contaminated blood products. I believe my father regretted the fact that Trevor didn't get married or have children. He really cried about it and he was knocked for six. I've never seen my father cry before or be so heartbroken.

34. However, one thing my family is good at is getting on with life which we did as there was nothing else any of us could have done. My father dealt with it the best way a he could. Keeping busy!

35. I don't remember Trevor ever getting a qualification. He went into a printing and binding job. He was isolated a little bit at work and did not have close contact with other people. He had to give up work about 5 years before he passed away.

36. I worked in a play group at the time and I believed it helped me deal with things that happened.

Section 6. Treatment/care/support

37. I don't think Trevor faced any difficulties or obstacles in obtaining treatment. He got treatment as and when he needed it. However, he didn't receive the right care and I don't know whether he had any support from the medical staff as a result of what happened.

38. As far as I'm aware, Trevor did not receive any counselling or psychological support when he was diagnosed and neither did my parents or my sister. I believe it would've helped all of us if it was offered at the time when Trevor was diagnosed.

Section 7. Financial Assistance

39. Trevor did receive some financial assistance but I don't know whether it was from the Skipton Fund or the Macfarlane Trust.

40. I did not receive any financial assistance.

Section 8: Other Issues

41. My mother wanted to see the outcome of the Inquiry, but unfortunately she passed away.

42. I have been watching the Inquiry online. I didn't realise, how many people were out there on the same boat, telling a very similar story as me. It's shocking what has happened.

43. There are a lot of people living off basic money given by the Government when it was the Government's fault that they were infected in the first place. The payment need to be reviewed.

Anonymity, disclosure and redaction

44. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry

45. I do not mind giving oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated

31. 8. 19