

Witness Name: Joan Lewis  
Statement No: WITN2768001  
Exhibits: WITN2768002 - 003  
Dated: March 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JOAN LEWIS

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I, Joan Lewis, will say as follows:-

#### Section 1. Introduction

1. My name is Joan Lewis. I was born on GRO-C 1944 and I live at GRO-C  
GRO-C.
2. I make this statement on behalf of my late son, Damian Farley Lewis. He was born on GRO-C 1974 and died on GRO-C 1995 aged 20 years old as a result of AIDS.
3. I was a midwife. I retired early to care for Damian.
4. My son, Marcus Lewis, has also produced a witness statement, 'WITN2955001' for the Inquiry.
5. 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

6. Damian had medical problems since he was 3 years old. He started having seizures at age 3, caused by a subarachnoid cyst which was diagnosed later in childhood. He was misdiagnosed with epilepsy for which he started Tegretol medication which in large doses causes side effects such as bone marrow failure. He suffered from occasional seizures, and at age 8 started developing bruising and also complaining of fatigue. He was then taken to our local hospital in **GRO-C** and later transferred to Morriston hospital (MH) in Swansea, during then he was diagnosed with Aplastic Anaemia. Damian was kept in (MH) for a few weeks.
7. Prior to the bone marrow transplant (BMT), I remember Damian was given an experimental drug on trial, but it failed so his last hope was a BMT. I do not know what this drug was called. The transplant cured his Aplastic Anaemia.
8. Damian was transferred to the Haematology department at Hammersmith Hospital (HH) in London where he was being treated for his Aplastic Anaemia. His treating doctor was Professor Gordon Brown. Damian's bone marrow failure was so significant that on the 20 April 1983 he had to have a bone marrow transplant from Marcus. The transplant cured his Aplastic Anaemia.
9. Prior to the transplant and post transplant, he was given platelets, whole blood and plasma transfusions. A record of the whole blood batches that he received is exhibited at **'WITN2768002'**.
10. My husband and I were the main carers for Damian at the time as he was only about 8 years old. We were not provided with any information or advice beforehand about the risk of Damian being exposed to HIV through contaminated blood. We were also not provided with adequate information to understand and manage the HIV when he was diagnosed.

11. Damian was infected with HIV and I believe he was also infected with Hep C, but he was not told about it.

12. In or about 1987 I remember there was a lot of media coverage about HIV and how people contracted it. This prompted me to ask HH whether they had checked Damian for HIV and they said they had not. He was then tested and we received a telephone call from the doctor who confirmed that he tested positive for HIV. However, having reviewed his limited medical records, there is a letter dated 15 September 1987 to Dr Hewitt from Dr V Chowdhury who provided information that Damian was first tested on 23 February 1983, and then subsequently tested on the 17 March 1983 and 08 April 1983 (pre-bone marrow transplant (BMT)) and he tested negative. Another test was done on the 10 October 1983 (post-BMT), which confirms that he tested positive for HIV. However, we were not told until 1987 that he had HIV. A copy of this letter is exhibited at 'WITN2768003'.

13. I believe that information should have been provided earlier as soon as it was known to the doctors that Damian tested positive in 1983.

14. I do not think we were given any information about the infection when we were told about it. I was a midwife, health visitor and nurse manager at the time and so I had enough incline to know what HIV was. I was shocked to find out Damian was HIV positive at the time. It was only by chance that we found out that he had it.

15. We were not told about the risks of others being infected as a result of the HIV.

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

16. I do not believe Damian had any other infections other than what I stated above.

### **Section 4. Consent**

17. We consented to the bone marrow transplant which Damian had. However, we did not consent to him being tested for HIV in 1983. I believe he was also treated without being given adequate and full information.

18. I do not know whether he was tested for the purposes of research.

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

19. Damian suffered mental effects as a result of the infection. He was not stupid and there was a lot of stigma attached to HIV back in the 1980s. He did not want to have any sort of bodily contact with anyone. He was very careful and kept his hygiene things very close to him. His mood started to change. He became a very private person and became withdrawn.

20. Damian also suffered Physical effects as a result of the HIV, in the late 1980's, his general health started to deteriorate. He developed Boils on his Scalp, bottom and anus, as well as having psoriasis, all over his body. He also suffered from frequent infections, diarrhoea, thrush, pruritus, and malaise. He also suffered from hair and weight loss.

21. Damian was given Zidovudine (AZT) for the HIV which he started shortly after he was diagnosed. I believe he had a reaction to the treatment which was when things started to go downhill for him. He became recluse and withdrawn, and did not want to go out. We had to stay home and look after him. His psoriasis got worse and he looked very bad physically. He started to really deteriorate.

22. We had a small Study at the back of the House where he used to read a lot of books, play and watch TV. In the mid 1990's when Marcus and Damian were in the study, Damian started to stare into space and he could not talk properly and was dribbling. Marcus called me and I looked at him. I called Dr Ishmael who was a Haematologist and Damian was admitted into Singleton Hospital (SH). After a few weeks, he was transferred to MH and started to deteriorate rapidly.

He was then moved to an ICU and put on a ventilator and later died of AIDS. All of this happened in the space of 2-3 months.

23. I do not know what complications Damian had in obtaining treatment for the HIV. I do not know whether he ought to have been given any other treatment.

24. Damian's infected status had an impact on his private, family and social life. He was very withdrawn and he did not fulfil as a teenager. He did not do things that a normal teenager would do. He was in quite poor health. Following the BMT his health did improve for a short while but later started to deteriorate during the later stages of his life.

25. Marcus was also badly affected after Damian's death. Marcus did not know that Damian had HIV until after his death. Marcus found Damian's death extremely difficult because they were so close. As previously stated, Marcus has also produced a witness statement, which details how he has been impacted.

26. Damian's death devastated me and my family, and had a huge impact on me. I couldn't function with him not being with me anymore and I started drinking heavy. I was a heavy drinker for 11 years and it was my way of blocking out what had happened to Damian. After the funeral, I was absolutely shaken. What happened to Damian finished me and my husband. It was very tough. Life had been hard on Damian and Marcus. I was 32 years old when I got married. It seems a long time ago but when I think about the time that we found out that our boy was infected with HIV, it does not feel like it was that long ago. Marcus was the one that took care of us even though he was finding Damian's death difficult. He had to grow up fairly quick.

27. Damian's education was heavily impacted as a result of the HIV. Initially he went to a mainstream school but was then home-schooled from the age of 13. He did not achieve anything in school, but I believe that he could have had a good education not been for the infection.

28. I stopped working when I was 48 years old in order to care for Damian.

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

29. I do not believe Damian was ever given any support or care as a result of the infection. He also did not receive any counselling or psychological support.

30. I was not offered any counselling or psychological support, even after his death. I believe we should have been given counselling but instead I just left to cope on my own.

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

31. Damian was involved in the 1991 litigation and received roughly between £38,000 and £40,000.

32. In the mid 1990s, he received a disability living allowance of approximately £200 per month. In or about 1994, he also received a winter fuel allowance of £500 from the Eileen Trust.

33. After Damian died, I received a payment in the sum £1,000 from the Eileen trust, towards funeral expenses.

34. I am in the process of applying for a payment from the EIBSS. When I initially received the letter from them, I noticed that the payment would be made because it was possible that Damian was also infected with Hepatitis C (Hep C). I was shocked when I found out that there was possibility that Damian could have also been infected with Hep C. Nobody told us that he was infected with Hep C or that there was a possibility that he could also have Hep C. I only found out about it when the hospital told me that I could be entitled to this financial assistance. This application is still ongoing.

NOT RELEVANT

NOT RELEVANT

**Section 8. Other Issues**

35. I want to find out what happened and why, I want to know who if anybody was responsible and if this terrible tragedy could have been avoided. I want answers. I want to know why support was not given to people. What happened to Damian could have easily been avoided had the hospitals tested the blood beforehand.

36. Marcus has not had an easy life since Damian died. Not only did they ruin Damian's life, they ruined Marcus' life as well as mine and my husband's life.

**Anonymity, disclosure and redaction**

37. 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.

38. 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

29-3-2019.