

Witness Name: Gaynor Lewis

Statement No.WITN02368001

Dated: 15th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GAYNOR LEWIS

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12th December 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Gaynor Lewis, will say as follows:-

1. Introduction

1. My name is Gaynor Lewis. My date of birth and address are known to the Inquiry. I am the wife of Haydn William Lewis. Haydn was born on the GRO-C 1956 and tragically died on the 21 May

2010. We were married on 21 November 1975. We have two children; Steven and Paul, their respective dates of birth are **GRO-C** 1976 and **GRO-C** 1978.

2. Haydn suffered from haemophilia; he had a brother called Gareth who was also a haemophiliac. Neither of our sons suffers from the condition. I believe his condition was classed as mild.
3. Haydn's brother Gareth also suffered from being infected with HIV and Hepatitis C. Gareth also tragically died on 13th December 2010 just 6 months after Haydn passed away. Gareth had a stroke whilst on holiday visiting family in Spain.
4. Haydn was a Carpenter by trade. He left school at 16 and worked as a Carpenter until around 1992. He had his own business and was doing well.
5. Haydn was diagnosed as having haemophilia in 1958, when he was 2 years of age. I believe it was after he had bit his tongue and they could not stop his bleeding.
6. When Haydn was a young child, his haemophilia was treated in the normal way at that time. It was probably in the 1960's that he received Cryoprecipitators (Cryo). I believe he attended hospital on a few occasions as a young child when, for example, he would be showing a silent bleed or a bruise or whatever.
7. Haydn told me that on one occasion when he was about 11 or 12, he saw his medical notes and counted up how many times he had been in hospital. He said it was about 68 times.
8. Haydn attended hospitals in Cardiff which at that time, were the Cardiff Royal Infirmary (CRI) and Llandough Hospital.

9. Haydn could recall being treated by Professor Bloom. He originally looked up to him and regarded him as a 'father figure.' In later years he changed his mind and became critical of Professor Bloom.
10. When Haydn was little, he was living in the docks area of Cardiff and the local hospital for that area was Llandough and CRI housed the Haematology Centre, so Haydn started to attend there.
11. Haydn believed he was treated with Cryo up until around 1978. He was always treated in CRI, until he then started attending the University Hospital of Wales (UHW) which was built in the 1970's. Throughout that time, his Consultant seemed to be Professor Bloom. He switched to UHW in around 1972.
12. Haydn believed that he could trace the chain of treatment to beginning to use Factor VIII to around the time our second son was born which was in late 1978.
13. That year Haydn had a bleed in the leg. He did not respond to cryoprecipitate so Factor VIII concentrate was required.
14. Haydn developed an inhibitor to Factor VIII and received high doses treatment including imported concentrates.
15. In 1980 Haydn had an injury to his wrist. He did not respond to cryoprecipitate so Factor VIII concentrate was required.
16. Haydn by then began infusing at home. The factor concentrate was given to him by Professor Bloom primarily, but also other doctors were involved, such as Rd. Pete Collins, Dr. Dasani. I would pick up the Factor VIII from the Unit at UHW if Haydn was incapacitated. I kept it in the fridge at home.

17. The only exception was, on one occasion when Haydn had to go to hospital in Cornwall when he stubbed his toe when he was on holiday in Dartmouth.
18. The Factor VIII would be provided to Haydn in a box of factor concentrate. Inside the box would be individual vials
19. I understand from medical records he seroconverted sometime in 1979 -82.

2. How Infected

1. Haydn was told by Professor Bloom that he was infected with HIV in 1985. He told Haydn at the Haemophilia Unit at UHW.
2. I can recall us being at home and Haydn received a call from Professor Bloom to go to see him. He went on his own. When he came home he was in shock. He told me. We assumed it was a death sentence. In those days you heard regular reports of people dying from HIV/AIDS. I can remember him saying that he wanted to see the children playing as his time might be limited.
3. Haydn was told that he had maybe 3 to 5 years to live.
4. He continued to have the usual bleeds in the late 1980's but at a lesser frequency.
5. It was in the early 1990's that Haydn spoke to Dr. Dasani and asked him whether he had hepatitis C (HCV). Haydn had been suffering from a pain in his side. Dr Dasani confirmed this. I recall Haydn being told that he had Hep C by Dr Dasani in a matter of fact way.
6. On another occasion I can recall Dr Dasani matter of factly saying to Haydn that the Hep C 'will get you in the end.'

3. Other Infections

1. Haydn had Hep B which I believe he contracted in the 60's from blood products. We were led to believe that it was a harmless virus and would just give you a bit of jaundice.

4. Consent

1. Not sure on this. When bloods were being taken there would be lots of vials taken. They must have been doing tests without his knowledge as they used that to diagnose his HIV in 1985.

5. Impact

1. When Haydn was told by Professor Bloom that he was HIV positive, he was offered some counselling but nothing substantial. There was no real support networks in the 1980's for victims like Haydn. Along with fellow haemophiliacs from the Heath hospital they set up the Birchgrove group. The Birchgrove is a pub not far from the hospital. They would meet up as a source of mutual support.
2. I can recall a card about this group being put up in the Haemophilia Centre. It mentioned HIV. The card kept getting taken down, presumably by people still unhappy at being linked with those with HIV.
3. Haydn relied a lot on the social workers for support. Mary Dykes and Linda Ford were extremely helpful. They were more like counsellors. We were never given any formal counselling.
4. Haydn was never given any sort of written materials about how to live with HIV.

5. HIV came with a terrible stigma especially in the 1980's. We decided not to tell the boys. As they got older they suspected something but we didn't tell them until they were virtually grown up.
6. We told very close family. There were lots of stupid rumours about how easily it could be transferred to other people. Most of these were of course silly but it did make me worried about things such as making sure Haydn toothbrush was not shared. He was worried about hugging or kissing the children.
7. After Haydn was told he was HIV positive we never had sexual contact without protection.
8. Haydn became too ill due to the HIV and Hep C to carry on with his business. It was a gradual thing. He began to realise he wasn't physically strong enough to keep going. An example was that he took on one job but had to pull out after just a few days. He didn't want to let people down.
9. Before his illness we had been comfortably off. We were not well off but were financially quite stable. We lived on Welfare Benefits and meagre handouts from the pig's ear of a scheme, Macfarlane Trust (MFT).
10. I had worked in retail but by now, with Haydn ill and two young lads I could not work. Finances became very strained. It was very stressful.
11. Haydn began receiving treatment for HIV in 1992. The treatment was AZT. It was not pleasant. It made him ill. It was like having anaemia.
12. Haydn and I were physically attacked once around 1995. Haydn ended up with a broken nose which he had to have operated on and

various other bleeds. My sister spoke to the Police and had a statement taken as she was with us when it happened. She told the Police about the HIV. We had contact from the Police a few days later to say it was best not to prosecute as we may have been at fault as we didn't tell the assailant that we had HIV.

13. Haydn received treatment for hepatitis C (HCV) in early 2000, he was treated with Interferon and Ribavarin and Amantadine. The treatment lasted for about 6 months. It was horrible.

14. The Interferon treatment caused extreme fatigue, confusion, cramps, headaches, bad moods - the list could go on and on. It wasn't unusual for him to be in bed most of the day, doubled duvets at the ready to get warm. He was constantly feeling cold.

15. He was only on the Interferon for, I believe, 6 months when it should have been longer.

16. Unfortunately, 3 months after treatment the hep C virus was back.

17. It was like having a terrible dose of flu all the time. It also made him very angry and temperamental. He was difficult to live with. He was having lots of rows with the boys. It was a really stressful time.

18. He would look very jaundiced, yellow, at times.

19. He suffered from terrible cluster headaches. These were like severe migraines. I can recall him getting them when driving and having to pull over in the car and be physically sick. One such headache caused him to be hospitalised.

20. Throughout the time after his diagnosis, as he became ill he suffered mentally. He was not just physically injured by the contaminated blood but also mentally. He was frustrated and

anxious that he couldn't work, he couldn't properly support his family, that he didn't have the energy to engage fully with the boys.

21. At times something would boost his spirits. For example when the boys got houses he wanted to help them sort them out.

22. Haydn spent a lot of time on his computer researching the infected blood scandal. Many a night I would wake up and he would be up, on the computer.

23. Eventually he channelled his frustrations into his research into the contaminated blood scandal. This gave him a focus.

24. He began to have terrible pains in his side. He put a brave face on it but he knew something was seriously wrong.

25. He had scans and tests at the Heath Hospital (UHW). They revealed tumours in the liver. Things were getting worse and in December 2008 he went to QE hospital in Birmingham to be assessed for a liver transplant.

26. Haydn was put on the transplant list. You had to be always on standby for that phone call. You had to have a bag packed and be ready to leave for hospital right away.

27. The tumours were getting worse. He was in a lot of pain. His stomach was swelling up.

28. Eventually, in March 2009 we got the call. The operation in Birmingham was done by Simon Branhall. I can recall the surgeon saying before the operation that things would be fine and he would give Haydn his autograph. I thought that was an odd comment but a few years ago I was astonished to see Mr Branhall being fined £10,000 for writing his initials on peoples organs.

29. The operation went well. Haydn began to recover. He gave himself little goals like walking down to the local shop. At first that would take him an hour when it should just take 5 minutes.
30. Initially he was told the cancer had cleared but that was short lived. By September 2009 it was back and was aggressive.
31. Haydn underwent a procedure called Chemo-embolization. I believe it involves laser treatment to target the tumours. They are then filled in with a substance to stop any growth. This is the only operation that I recall Haydn regretting having. It was worse than the transplant.
32. Unfortunately, the donor liver that Haydn received was also hepatitis C (HCV) positive.
33. From the beginning of April 2010 Haydn was having palliative care at the Holme Towers Hospice. Nurses would come to the house sometimes and he occasionally stayed at the hospice.
34. Haydn knew he was dying. He made a video diary to try to tell his tale from beyond the grave.
35. Tragically Haydn declined and in his last week was in the hospice. He sadly passed away on the 21st May 2010.
36. His death was mentioned on the BBC programme 'Newsnight' as Haydn had appeared on it on a number of occasions.
37. When Haydn died I was told that his body could not be treated in the usual way because of him being contaminated. He couldn't wear the clothes that I wanted him to wear. The staff were not allowed to do it. I offered to dress him but was declined.

38. Haydn's funeral was on 2nd June 2010. I was informed that he was cremated. I wouldn't be at all surprised if one day I find out that Haydn wasn't cremated at all - what his body went through would be very interesting, especially regarding vCJD.

6. Treatment/Care Support

1. There were no real support networks in the 1980's for victims like Haydn. Along with fellow haemophiliacs from the Heath hospital they set up the Birchgrove group. The Birchgrove is a pub not far from the hospital. They would meet up as a source of mutual support. The pub had an old fashioned snug area where they could meet and discuss over a drink with a bit of privacy.
2. It gradually became a more formal organisation. I think it became a charity. Birchgrove went National in about '92. Fellow haemophiliacs from around the country set up self-help groups. There is a website that is looked after by GRO-B and Alan Burgess.
3. The group was a great mutual support but you also became aware that its members were dying. We were always going to funerals.
4. Haydn became a member of Tainted Blood in around 2006 - this website was set up by Andy Evans and Gareth Lewis as an online support network and for campaigning news. Haydn helped out as secretary.
5. Haydn and his friend, Andrew March worked together on compiling a Timeline of events to do with blood and blood products. They made sure everything was sourced that was uploaded. He spent hours and hours on this. It is still regarded as a definitive history of the scandal. He was always sending off FOI's.

6. There was a bit of tension between Haydn and Gareth, his brother, in that Haydn began to want the group to have a campaigning part to it. Gareth initially just wanted it to be a 'safe place.'
7. Haydn found it impossible to get life insurance or any mortgage insurance.

7. Financial Assistance

1. Hayden became involved in litigation in the UK in around 1987. His brother had told him there was a lawyer who was taking on haemophilia cases. Believe those are Hugh James in Merthyr.
2. The matter settled in 1991. There was a £20,000 payment in 1987 and a further £60,000 in around 1990.
3. Haydn received a payment of £20,000 from the Skipton Fund.
4. Haydn received a further payment of £25,000 from the Skipton Fund because he met the criteria of a second payment due to liver cancer.
5. The MFT were terrible to deal with. On one occasion we were doing adaptations to the house in around 1998 so it would be suitable for Haydn to live downstairs if (or when) he became too ill. We needed £5,000. The MFT did not want to know. They thought we were improving the house, that it was not a necessity. It was only when I was crying down the phone to them that they relented. Haydn always said people needed a hand up, not hand outs.

8. Other Issues

1. Haydn became involved with the Birchgrove Group. One of the patients' support groups. Haydn became involved in that at the time he was told he was HIV positive. Haydn was also involved in

Haemophilia Wales. Haydn was also a member of the Partnership Group of the McFarlane Trust. That meant he had meetings with the trustees of the McFarlane Trust a few times a year. This was from around 1990. He thought he could do good working within the organisation.

2. Haydn was concerned that the McFarlane Trust was not providing enough help and support. Haydn became very disillusioned with them. He said they were 'tightwads.' He saw how other victims were badly treated by the MFT, he was shocked and saddened. He saw high level people in the MFT decrying victims saying they were after 'a crock of gold.'
3. Haydn was involved in litigation against the government in the late 1980's. He instructed Hugh James solicitors in 1987.
4. The matter settled in 1991. There was a £20,000 payment in 1987 and a further £60,000 in around 1990.
5. Haydn was also involved in litigation in the USA with the law firm Loeff, Cabraser, Helmann & Bernstein acting for him.
6. All of this was stressful but we tried to do the best we could. Haydn was determined to get to the truth and to hold people to account.
7. Haydn gave evidence in the Archer Inquiry and was praised for his informed input.
8. In 2000 Haydn was told he had received blood from someone who had died from vCJD. This greatly upset Haydn. Haydn was informed that he was on the 'at risk' register as he had received blood from a donor that had died from vCJD by letter in the post... This greatly upset him.

9. What spurred Haydn and Gareth on was the tragic death of Little Colin Smith. Colin Smith was born in 1982 with haemophilia. He died at home from Aids at the age of 7 in 1990. Colin was treated by Prof Bloom at the UHW, Cardiff. Colin's parents were best mates with Haydn's brother Gareth. There was never an inquest into why a little boy died of AIDS.

10. Haydn fought to try to find the truth to his dying day. He did not die in ignorance.

Statement of Truth

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

Signed: GRO-C

Dated 15.2.19