

Witness Name: Gaynor Lewis

Statement No.WITN2368002

Dated: 12<sup>th</sup> March 2019

## INFECTED BLOOD INQUIRY

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### SECOND WRITTEN STATEMENT OF GAYNOR LEWIS

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 12<sup>th</sup> 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 is GRO-C 1956 and my address is 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 21st May 2010. We were married on 21st November 1975. We have two children; Steven and Paul, their respective dates of birth are GRO-C 1976 and GRO-C 1978.
2. I met Haydn in 1973 but we grew up on the same street so we knew of each other before then and we were married in 1975.

3. 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.
4. Haydn was diagnosed as having haemophilia as a child.
5. Haydn believed that he was treated with Cryoprecipitate up until around 1978. He was always treated in Cardiff Royal Infirmary (CRI) until he then started attending the University Hospital of Wales (UHW) in Cardiff which was built in the 1970's. Throughout that time his Consultant seemed to be Professor Bloom. He switched to UHW in around 1972.
6. Haydn believed that he could trace the chain of treatment of beginning to use Factor VIII to around the time our second son was born, which was in late 1978.

## 2.How Infected

1. In 1980 we decided that our family was complete and I was sterilised. I needed two doctors to sign for the operation to go ahead. Professor Bloom and my GP at the time Dr Sadler signed off the operation. So from 1980 the doctors knew that we weren't using protection.
2. Haydn was told by Professor Bloom that he was infected with HIV in 1985.
3. I was diagnosed as having HIV in 1988. I had been ill for a lot of 1987 but we didn't think that it could be HIV. I'd had a HIV test in 1985 which had come back negative. In the 1980's the testing for HIV was not as reliable as it is now so although the test came back as negative in 1985 it is likely that it was a false negative. As soon as we were told that Haydn had HIV in 1985 we had used protection.
4. In 1988 we were on holiday in Spain and I wasn't well for the 2 weeks that we were away. When we came home I had a HIV retest which came back positive. The day I was told was an awful day. I think it was almost worse for

Haydn being told that I was positive than it was for me. The only way I can describe how I felt is that I stepped out of my body and watched myself being told. I spent my time at that appointment reassuring Haydn that everything would be fine as he looked as though he had been shot. It definitely didn't sink in for me straight away.

### **3.Other Infections**

1. I have no other infections that can be related to contaminated blood.

### **4.Consent**

1. I don't know if I was ever tested or treated without my consent. There is a possibility but nothing that I am aware of.
2. In regards to medical notes and attending doctors appointments regarding the HIV I doubt very much that there will be much mention of this in my actual notes. There was an attitude by some doctors of 'oh we won't write that' when referring to the HIV. This was just piling on the stigma of HIV in itself.

### **5.Impact**

1. This section of the statement has been difficult as I have never really thought about how being infected has impacted myself directly. I have always thought about the impact on others.
2. After my diagnosis of HIV I would have recurrent infections.
3. I would have regular HIV reviews most years. I took a regime of various drugs which have changed a number of times over the years. I started taking the drugs 30 years ago so I have trouble remembering the exact names of all the different drugs I have been on.

4. I started on AZT anti-viral's almost immediately following my diagnosis but definitely by 1989. It was trial and error with AZT in those days as they would trial the different doses.
5. I restarted treatment with Combivir and Neviraphoen in December 2000. I did give myself 'drug holidays' where I would stop taking all drugs two or three days before I would see my doctor. I was feeling so ill on some of the drugs and would feel better during these 'holidays'. I do know that I have to take my medication now but at the time it was partly to show the doctors how bad I was feeling on the various combinations of drugs.
6. I have been prescribed various drugs including Nevirapine, Darunavir/Ritonavir, AZT, Truvada, and Klvexa. In 1998 I developed debilitating migraines and I couldn't say if this was a side effect of one of the drugs I was taking or a part of the illness. At times I had little side effects but other times, like in 2016, I had terrible nausea and vomiting.
7. Around 2000, before Haydn's death, my care was transferred from Haematology to CRI.
8. I suffered from terrible depression about us both being infected. I tried alternative therapies such as massage and hypnotherapy. This has helped over the years as I do still use some of the techniques introduced in the various therapies to help even now.
9. Attending clinics was very stressful. I didn't have a lot of patience at the time and the clinics really didn't help with this. I would get stressed by the amount of time I would have to wait over my appointment time and sometimes end up walking out. I would often have to retell my story at each clinic as I wouldn't always see the same doctor for every appointment.
10. I was of course greatly upset by Haydn's decline and death. I was very angry and stressed that this terrible thing had happened to us.

11. I was prescribed anti-depressant drugs by my GP but there was never a 'how are you?' or a referral to a psychiatrist or counselling.
12. We were never given any support about how to live with HIV. Nobody, including the medical professionals, knew much about HIV at the time (30 years ago). We were just left to get on with it.
13. 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.
14. We told very close family but we were always careful who we spoke to. 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's toothbrush was not shared. He was worried about hugging or kissing the children.
15. 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.
16. After Haydn was told he was HIV positive we never had sexual contact without protection.
17. Haydn became too ill due to the HIV and hepatitis C (HCV) to carry on with his business. It was a gradual thing. Before his illness we had been comfortably off. We were not well off but were financially quite stable. After Haydn stopped working we had to live on Welfare Benefits and meagre hand-outs from the pig's ear of a scheme, Macfarlane Trust (MFT). 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.

18. I relied on my family whenever Haydn was incapacitated. My Mum, Dad and sisters in particular were so helpful. They would help Haydn and I out by looking after the boys and everything that entailed. I will always be grateful for all the help.

19. Haydn had a knee replacement in 1991 and he was out of it for 10 days. No one at the hospital would listen to me but he went crazy. I'm sure that the Heath Hospital (UHW) was using him as a guinea pig for the drug combination of fentanyl and morphine.

20. Haydn began to have terrible pains in his side in 2008. He put a brave face on it but he knew something was seriously wrong. He had scans and tests at the Heath Hospital. They revealed tumours in his liver. Things were getting worse and in December 2008 he went to QE (Queen Elizabeth) Hospital in Birmingham to be assessed for a liver transplant.

21. Eventually, in March 2009, we got the call for the transplant operation in Birmingham. The operation went well. Haydn began to recover. Initially he was told the cancer had cleared but that was short lived. By September 2009 it was back and was aggressive.

22. From the beginning of April 2010 Haydn was having palliative care at the Holme Towers Hospice in Penarth.

23. Tragically Haydn declined and his last week was in the hospice. He sadly passed away on the 21<sup>st</sup> May 2010.

## **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. It gradually became a more formal organisation.

2. I have not been offered any psychological support or counselling. Yes I could have asked for it but it has never been offered.

## 7. Financial Assistance

1. I had the 2<sup>nd</sup> payment in 1991 of £23,500 from the Macfarlane Trust (MFT). Haydn had a number of conversations with Martyn Harvey at the MFT that it was unfair that I was excluded from the 1<sup>st</sup> payment of £20,000 despite also being infected and that our sons were excluded from the Category G payment. Haydn was hoping to get it all sorted before he died but he didn't manage to do so.
2. The deed's of the agreement with the MFT were tweaked in regards to me only receiving the 2<sup>nd</sup> payment and a senior member of the MFT said it was to 'piss off the Lewis'. They seemed to almost be making things up as they went along.
3. It was always an uphill battle with obstacles in the way to receive any financial support. The Trustees of the MFT would say no and then there would be a lengthy appeals process. We requested £5000 to make adaptations to the downstairs of our home so if either myself or Haydn became too ill to go upstairs we would have facilities downstairs to enable us to stay in our home. We were refused and this was only overturned after I burst into tears on the phone to the MFT. It's wrong that I had to cry to get them to agree to our request.
4. When Haydn was on the sick from work I never had a carer's allowance. I was never told that I was entitled to anything. The Social Workers at the time that we were dealing with would have known what we were entitled to so why didn't they tell us. I worry where my pension will come from as I haven't worked for many years.

## 8. Other Issues

1. We became involved with the Birchgrove Group. The group was originally set up just for the men infected but once I found out that I was also infected I started attending the meetings and, gradually, other wives started to attend. I began helping with organising weekends away and self help weekends and I enjoyed this. In terms of funding for the Group we were constantly sending letters to different organisations for funding which almost felt like begging. The Haemophilia Society were the ones who upset us as they would often wait till the 11<sup>th</sup> hour to offer any funding.
2. I can remember breathing a sigh of relief when Haydn got to know Sue Threakall, the current co-Chairwoman of Tainted Blood, around 2006. He had met someone that was on the same wavelength and I think this was around the time that Tainted Blood was created.
3. We were also involved in litigation in the USA with the law firm Lieff, Cabraser, Helmann & Bernstein acting for us. We were made to look like idiots by the defence in the litigation. They fired off the different doctor's names that had treated Haydn over the years and Haydn couldn't account for every doctor. By the time he was 12 he had been in hospital 66 times it was an impossible task to remember the name of every doctor who had treated him. I didn't mind taking part in the litigation but it was very stressful and more like an interrogation.
4. I would also like to say that we all know how frustrating Brexit is for the UK at the moment but imagine living like that for 35 years!!



Statement of Truth

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

Signed

GRO-C

Dated... 12.3.19 .....